9-30-1992

Interim Hearing on Multiple Chemical Sensitivity and Environmental Illness

Senate Subcommittee on the Rights of the Disabled

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CALIFORNIA LEGISLATURE

SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED

SENATOR MILTON MARKS
CHAIRMAN

INTERIM HEARING ON

MULTIPLE CHEMICAL SENSITIVITY AND ENVIRONMENTAL ILLNESS

SEPTEMBER 30, 1992

SAN FRANCISCO, CALIFORNIA

712-S

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California Legislature

Senate Subcommittee
on
The Rights of The Disabled

SENATOR MILTON MARKS
CHAIR

Interim Hearing

of the

SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED

in cooperation with

THE OFFICE OF THE MAYOR, SAN FRANCISCO

on

MULTIPLE CHEMICAL SENSITIVITY AND ENVIRONMENTAL ILLNESS

COMMITTEE MEMBERS

Milton Marks, Chairman

Ed Davis
Diane Watson

COMMITTEE CONSULTANT

Joan M. Ripple

MAYOR'S DISABILITY COORDINATOR

Paul Imperiale

September 30, 1992
Public Utilities Building
505 Van Ness Avenue
San Francisco CA

CALIFORNIA DECADE OF DISABLED PERSONS (1983-1992)
DESIGNATED BY S.C.R. 15 INTRODUCED BY SENATOR MILTON MARKS

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THE OFFICE OF THE MAYOR, SAN FRANCISCO
on
MULTIPLE CHEMICAL SENSITIVITY / ENVIRONMENTAL ILLNESS

Wednesday, September 30, 1992
10:00 a.m. - 1:00 p.m.
Public Utilities Building
505 Van Ness Avenue at McAllister Street
San Francisco

PLEASE DO NOT WEAR FRAGRANCES OR OTHER SCENTED PRODUCTS
SOME SEATING IS AVAILABLE NEAR OPEN DOORS
PLEASE DO NOT SMOKE OUTSIDE THE ENTRANCES TO THE AUDITORIUM

AGENDA

10:00 AM OPENING STATEMENT................SENATOR MILTON MARKS, CHAIR
Senate Judiciary Subcommittee on the Rights of the Disabled

10:05 AM OFFICE OF THE MAYOR, SAN FRANCISCO............PAUL IMPERIALE
Disability Coordinator

10:10 AM BACKGROUND & HEARING RULES........JOAN M. RIPPLE, CONSULTANT
Senate Judiciary Subcommittee on the Rights of the Disabled

SCHEDULED WITNESSES

10:15 AM Susan Molloy, Executive Director, Environmental Health Network and member, Mayor's Section 504 Task Force. An Overview.

10:25 AM James E. Cone, M.D., MPH - Assistant Clinical Professor, UCSF; former Chief, Occupational Health Clinic, San Francisco General Hospital; primary editor, problem buildings: Building-associated Illness and the Sick Building Syndrome; in private practice in Berkeley.

CALIFORNIA DECADE OF DISABLED PERSONS (1983-1992)
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Appendices

Written Testimony Submitted

CHAIRMAN MILTON MARKS: I am Senator Milton Marks, Chair of the Senate Subcommittee on the Rights of the Disabled. My colleagues, Senators Ed Davis and Diane Watson, the other members of the committee, are unable to be here today.

San Francisco is the first city in the nation to develop an access plan for Environmental Illness. I am pleased that this hearing is being held in cooperation with the Office of the Mayor of San Francisco. Paul Imperiale, the Disability Coordinator, is representing the Mayor's office. He's right here.

Environmental Illness (EI) or Multiple Chemical Sensitivity (MCS) is recognized as a potentially disabling condition by federal agencies such as the Environmental Protection Agency, Department of Housing and Urban Development, the Social Security Administration, the National Research Council, and others.

Further, the Americans With Disabilities Act (ADA) and state laws guarantee people with disabilities access to public facilities, housing, education, employment, and transportation and to reasonable accommodations.

The purpose of this hearing is to gather information on the impact of Multiple Chemical Sensitivity or Environmental Illness; the status of access for people with MCS or EI; the economic and social consequences both for the person with MCS or EI and the community; and problems in providing access.

The important questions are: Who has responsibility to decide how and when to make California facilities accessible to people with EI/MCS? And, what policy modifications, building and ventilation codes, and curtailment of the availability of toxic products for use by the general public are necessary to allow safe integration of people with EI/MCS into society? What steps are necessary to make hospitals, schools, publicly-funded housing, and other public and commercial facilities and programs accessible?

More than 10 state agencies implement regulations for facilities' access or reasonable accommodation to programs. Clearly, some coordination is vital.

This is not a new issue. My good friend, Margarete Connolly, on receiving the hearing notice, reminded me that 35 years ago when ARC-SF had its first wine tasting, the Napa Valley vintners gave them a list of suggestions. Among them was one that suggested that guests to the event refrain from using scent since the quality of the wine could not be appreciated if the aroma was affected by the scent of perfumes. At that time the question of asking guests to refrain from using scent was too much.

In December 1989, the Attorney General's Commission on Disability addressed this issue; in January 1991, it became an issue in a hearing I held on access of San Francisco buildings.

From a social event 35 years ago to the implementation of the Americans With Disabilities Act today, it's time to go forward. I personally feel that every effort must be made to enable people with disabilities to achieve the highest level of participation in society that they desire to have. I believe that it is our responsibility as legislators and as citizens to create laws and communities that enable disabled people to live their lives as independently as they wish.

Serving with me on the panel today are Paul Imperiale, Disability Coordinator, Office of the Mayor; and Joan Ripple, Consultant to the Subcommittee.

Mr. Imperiale, would you like to say a few words?

MR. PAUL IMPERIALE: Thank you, Senator Marks.

I'm Paul Imperiale, the Disability Program Coordinator for the City and County of San Francisco. I'm based out of the Mayor's office.

Two years back we created a proposed policy for the City and County of San Francisco. This wasn't a very popular policy but it's one that we're struggling to implement at this time. Per the Americans With Disabilities Act, we have an obligation to make sure that people with Multiple Chemical Sensitivity and Environmental Illness are able to deal with mainstream programs in San Francisco, and to that end, as I say, we're trying to implement a policy.

Today's hearing is going to be one where we are hoping to obtain information from you, the ultimate consumers who may have or may be prone to develop Multiple Chemical Sensitivity or Environmental Illness. As well, we'd like to hear from agencies concerned with policy that is guiding this state for the provision of programs, facilities, and services that will be accessible to people with Multiple Chemical Sensitivity or Environmental Illness.

We appreciate your attendance today, and let the hearing begin.

CHAIRMAN MARKS: Thank you very much.

Joan Ripple.

MS. JOAN RIPPLE: Senator Marks stated that several of the federal agencies have recognized EI/MCS as potentially disabling. Some of the specifics include the following.

EPA (Environmental Protection Agency) has determined that chemical sensitivity is one of two chronic health effects -- cancer is the other --

caused by chemical exposures in tight buildings.

The Social Security Administration, in its program "Operations Manual System", has a section on how to evaluate claims by people disabled by EI. HUD (Department of Housing and Urban Development), after legal action was taken on on-site use of chemical contaminants, will begin to provide direction to management and maintenance people of low-cost housing projects so the housing is accessible to people with EI.

HUD is also considering a demonstration project called "Ecology House" specifically designed for people who have multiple chemical sensitivities. If it's approved it will be built in the Bay Area.

The Board on Environmental Studies of the National Bureau of Research Council, which is the research arm of the National Academy of Sciences, has developed, with cooperation of 45 scientists and physicians, criteria for research on EI.

Congress is considering legislation which would direct the Environmental Protection Agency to establish a research program and provide financial and technical assistance to states, local governments, and public agencies and include several references on indoor air pollutants which pose a serious threat to public health, including cancer, respiratory illness, Multiple Chemical Sensitivity, skin and eye irritations. And, it's estimated that 20 percent of workers may be exposed to conditions manifested as the "Sick Building Syndrome".

The State Attorney General's Commission on Disabilities report stated that after two years, they said "the advent of Environmental Illness creates new challenges that have yet to be addressed," and they include drafting appropriate building code requirements, integrating chemically uncontaminated units into the design of public houses and apartment complexes, providing safe access to medical facilities. They're saying that new or newly remodeled hospital units need to use chemically inert construction materials and furnishings, avoid the use of carpets, eliminate pesticides and cleaners of toxic chemical origin.

And I apologize, because we just learned about a half an hour ago that the bathroom over here was cleaned. We have the door open, we hope it's airing out, and there are supposed to be chemically safe bathrooms in the cafeteria. However, I hope I stopped the cleaning there.

Anyhow, they're saying we have to use alternatives to synthetically scented products, employ adaptable vent filter systems, and the Attorney General's report goes on and on and on.

In the past six months the calls to Senator Marks' office have increased significantly from an occasional call to a regular spate of calls, often after a spill or accidental chemical release by industry. But what's happening now is people are aware of not only being made sick by the chemicals but the potential for long-range effects.

There are a few rules of the hearing in order to facilitate the proceedings. Although we had advised persons invited to give testimony that they could prepare for 10 minutes, we are asking that you summarize your remarks. The number of interested witnesses is greater than the time available. I think I did catch some people and say 3 to 5 minutes.

Individuals interested in providing testimony today who are not among the invited witnesses, but who would like to speak, are invited to sign the witness list in the back which will be brought to us at the end of the scheduled witnesses. Time permitting, we will hear speakers that aren't on the agenda in the order of sign-in. Therefore, we request that testimony of organizational representatives be limited to 5 minutes and individuals will be limited to 3 minutes. Speakers should state their name and any affiliation that they have.

If you wish to be on our mailing list for the Subcommittee on the Rights of the Disabled and you did not get a hearing notice directly from us, be sure that we also have your address. There are two sign-in sheets, one for those who wish to give testimony and an attendance sheet.

There were no requests for interpreters for the hearing impaired so there will not be signing. However, an assistive listening device -- where's Richard? Is it available? It's connected up right now, thank you. If you inadvertently are wearing perfume or aftershave, I'd like to ask you to please sit in this lower right-hand corner of the auditorium over here.

Written testimony will be accepted through October the 15th.

As I mentioned, there are bathrooms straight down the hall but they were cleaned about a half hour/45 minutes ago, and I hope I rescued the cafeteria bathrooms in time because they had not been cleaned yet and I requested that they not be cleaned chemically. Don't worry about the washing of the windows, it's plain soap and water.

The proceedings here today are being recorded.

CHAIRMAN MARKS: Thank you very much.

The first witness is Susan Molloy, Executive Director, Environmental Health Network and member of Mayor's Section 504 Task Force.

MS. SUSAN MOLLOY: Good morning, everyone. I'm so pleased to see you here, and thank you, Senator Marks.

The disabled status recently conferred on people with severe functional limitations due to environmental exposures has far-reaching consequences for our society. Safe access for people with EI/MCS will necessitate codification of design features and materials for less chemically contaminating construction, furnishing, and maintenance of public facilities. Synthetic chemical furnishings and poor air quality in modern energy efficient buildings effectively block access for someone with EI just as a flight of stairs blocks access for someone who uses a wheelchair.

For the people who've been struggling with chemical and other environmental sensitivities, the recent federal acknowledgment of our disability is welcome. The disabled status confers a dignity and civil and access rights to people with Environmental Illness and Multiple Chemical Sensitivity. But it's just fiction, it's just a legal fiction unless we get to work designing and implementing codes that can be enforced with the force of law in our state.

An important question is: Since this disability is now federally acknowledged, what policy modifications, building and ventilation codes, and curtailment in availability of toxic products for use by the general public are necessary to allow safe integration of people with EI/MCS into society? What steps must be accomplished to make hospitals, schools, publicly funded housing, and other public and commercial facilities and programs accessible?

Despite federal recognition of this disability, in California there is not one hospital room, not one classroom, not one apartment, no store, and no workplace built or maintained to be safely accessible to people with our disability.

There are several specific issues that are going to be coming up for us in the next couple of years which we're going to be addressing. At the present time, people with EI/MCS (we're going to call it EI/MCS until we settle on a name that's efficient) are being assisted on a case-by-case ad hoc basis by sympathetic individuals within certain California agencies without benefit of institutional provisions or considerations. Employers and agencies are committed in principle to facilitating access for people with disabilities, so a few have arranged modifications for individual employees or clients. But overall, any public and commercial facilities built or remodeled according to the state codes during recent years are inaccessible to people with EI/MCS due to synthetic furnishing materials and limited fresh air ventilation.

Exposures that currently preclude use of public facilities by people with this disability vary considerably but fall within these general categories: New carpets and flooring adhesive, environmental tobacco smoke, carbonless copy paper or NCR forms, perfumed personal care products, cosmetics, and fragrance emission devices affixed to the walls, paint, building maintenance products and cleansers, application of roof and street tar, thermal plastic, paint application to parking lots and streets, electromagnetic fields from heating ventilation and air conditioning systems, wires, industrial chemicals exhausted from factories, combustion products from vehicles and natural gas, and the occupant-introduced, indoor chemicals such as those found from photocopiers, felt pens, photo development chemicals, correction fluids, inks. You know what the list is. Mold and other biological contaminants are problematic for us, as are many of the energy efficient features which severely curtail intake of fresh outdoor air to modern structures' ventilation systems.

Being discussed currently within our own part of the subculture and those disability rights advocates who care about us, and quite a number of lawyers, are the following issues.

We need posted notification of remodeling chemicals. The Office of the State Architect's 1991-92 code revision is going to be followed by a supplement which will begin to codify certain architectural access features for people with EI/MCS. We hope that this supplement is going to correct some very overtly discriminatory language which is now included in the Office of the State Architect's working documents.

For example, we want removed language that says that certain minor construction projects such as those affecting air conditioning, heating, ventilation, re-roofing, and cosmetic work such as painting, carpeting, etc., are not considered substantial alteration projects and shall not be subject to the codes for access. That's not working for us. That's precisely the kind of exposure during remodels that's made a lot of us become disabled. We want it out.

We need housing safely accessible to people with Environmental Illness. That means that the Department of Housing and Community Development for the state is going to have to get a grip. They're going to have to realize this is a disability. They are being paid to codify provisions that will result in our access to safe housing. They've got to get a nudge, I hope from Senator Marks and from others in a legislative position, to go ahead and get busy on the projects that are going to mean access to housing for us.

Quite a number of people in the audience are going to be addressing some of these issues individually during their own testimony so I won't go into detail.

We need safe access to medical care. What this means is that the Office of Statewide Health Planning and Development department in Sacramento is going to have to get a grip. They've got to write codes that are going to protect our access to hospital care.

We don't expect anyone to treat our environmental sensitivities in a medical facility in California right now, but if we have a broken leg, we're having twins, we've had a heart attack, we've got to be able to get in the building even if the folks running the hospital don't know what to do to treat our environmental sensitivities.

We need protection from synthetic fragrance exposures. Ruth Fontana is going to go into that issue in detail during her testimony.

We're going to be requesting reasonable accommodation in the workplace. This means the Department of Rehabilitation and others are going to have to do some code writing to protect us. San Francisco's Human Rights Commission has drafted some new regulations for employment by contractors with the City and County. I don't know where their draft is going to go but it's worth a look.

We need access to educational facilities, improvements to ventilation. Safety measures and disaster preparedness don't address the kinds of disasters or preparedness for even natural disasters for people with environmental sensitivities.

We're going to need some economic work and some research done by the Department of Health Services. They're in complete denial at this point as to whether this disease exists or not, and unfortunately, quite a number of people with Environmental Illness are having to sue Department of Health Services to get their oxygen covered by Medi-Cal.

During this period, while the regulatory principles that we know are right are translated into specific codes, individuals with Environmental Illness need protection to obtain skills for independent living and vocational retraining when it's appropriate. A responsible policy, which I hope is going to be suggested, possibly in the form of a resolution in the future by the Senate and the State Assembly, is going to enable people with Environmental Illness to acquire degrees, attempt retraining, and join the California economy and public life using the same principles of disability access protection that are used by people with other disabilities.

An additional consideration is that measures which make facilities safely accessible to people with Environmental Illness will protect the health of other people who are not yet so obviously affected by exposures to the synthetic environment.

Thank you.

CHAIRMAN MARKS: Thank you very much. We appreciate your testimony.

Dr. James Cone, Assistant Clinical Professor, UCSF. Go ahead, Doctor.

DR. JAMES E. CONE: Yes, Senator Marks, and guests in the audience. I'm going to speak today on the subject of multiple chemical sensitivities and the Americans With Disabilities Act.

I'd like to start by making a statement regarding the long history of this problem. I'm going to quote from a book by Leon Pierre-Quint called "Marcel Proust: His Life and Work".

> "My dear friend," he would say, "I beg you: shall I be causing you much inconvenience if I ask you to take the handkerchief out of your jacket? You know I can't bear any perfume..."
>
> And he gave three rings on the bell, out of habit, as if at his parents' house.
>
> "Celeste, take the gentleman's handkerchief and put it in another room. My dear friend, the last time you were so good as to come and see me -- for nobody comes to see me anymore to see the wretched invalid that I am -- I was obliged to take the chair you sat in and keep it out in the courtyard for three days: It was impregnated with the scent."

This was 1925. This is an old problem we're dealing with and it impairs people who have tremendous abilities to contribute to society.

Multiple Chemical Sensitivity itself has been defined by Mark Cohen as "an acquired disorder", characterized by recurrent symptoms referable to multiple organ systems occurring in response to demonstrable exposure to many chemically unrelated compounds and doses far below those established in the general population that cause harmful effects.

Multiple chemical sensitivities, you've already heard, often results in long-term disability which is particularly severe due to the ubiquitous presence of solvents, pesticides, odorants, and products of combustion in present-day society.

Although this syndrome may develop out of a particular toxic exposure at work or in the environment, exposures which result in symptoms typically broaden in some cases at least, and then patients report they subsequently have their symptoms made worse by multiple exposures that we've heard about already. The usually safe havens of your home, doctor's office, hospital, or social service agencies may then become actual sources of potential aggravation of the symptoms, resulting in dramatic changes in lifestyle, habitat, social contact based on attempts to avoid exposure to potential irritants and toxicants, or odorant allergens and other chemicals.

The Americans With Disabilities Act provides that it's unlawful to discriminate against a qualified individual with a disability, and disability is defined as a "physical or mental impairment that substantially limits one or more major life activities." Secondly, a record of such impairment -- or being regarded as having such an impairment by, for example, an employer.

The question is, are persons with MCS, or Multiple Chemical Sensitivity, impaired? I think the patients that I've seen with Multiple Chemical Sensitivity clearly meet the definitions of the ADA. They have physiological disorders; they have as well mental or psychological disorders which clearly qualify them under the definition of impairment.

Although there is much heated debate about the cause and primary mechanism of multiple chemical sensitivities, whether it be physical or psychologically mediated, and its diagnosis and treatment methods, some which we'll hear about today, there's little disagreement that many persons with MCS are impaired in multiple organ systems.

Is the impairment serious enough to substantially limit (quote/unquote) "major life activity"? Certainly, the patients I see have severe difficulty in coping with their day-to-day life. They have difficulty with fatigue, they have trouble speaking at times, breathing, learning, and particularly working in our society.

The next step and the final step in the analysis, according to the ADA, is to make sure that the effect is so-called "substantial" on the major life activity. You must have permanent impact or long-term impact resulting from the impairment. In each case, the impairment must restrict performance of the activity compared to a so-called "average person" in the general population and must be made on a case-by-case basis.

Now, people with MCS are particularly limited in competing in the workplace at the present time, in my experience. The person under the ADA must show that they are otherwise qualified for the job and with reasonable accommodation they could function in the position.

Now, what is reasonable accommodation? If they're capable due to other than the fact they have MCS, are performing essential functions of a job and could perform such functions with provision of reasonable accommodation, he or she must be deemed qualified under the Act. A common example, and I've seen many cases of this problem, are persons who need to avoid perfume or odorant exposure in order to continue working. Many of them could continue their job at the University or private industry and be productive but for the uncontrolled perfume exposures which occur today at work. They become disabled as a result, totally preventable, an inhumane outcome for people who are highly talented, trained, otherwise could be productive in society. Basically they become lost in this disability morass and ultimately very impaired, not for any reason of their own but the fact that society refuses to adapt to their needs.

These patients must be reasonably accommodated in the future under the ADA. I think that's clear.

My conclusion is that many persons with multiple chemical sensitivities are clearly, clearly impaired in ways that qualify them as disabled under the ADA. They have significant impairments and multiple organ systems which substantially limit major life activities and is likely, in many cases, a long-term impact.

Thank you.

CHAIRMAN MARKS: Thank you very much. We appreciate your testimony.

Dr. Robert Dowell, Primary State Entomologist, California Department of Food and Agriculture.

DR. ROBERT DOWELL: Good morning, Senator. I'm Dr. Robert Dowell, California Department of Food and Agriculture. I'm the Primary State Entomologist. I'm here today to describe our notification system that we use in advance of our pest eradication programs. I've also been asked to discuss briefly what several of the insects that we are attempting to eradicate might do should they become established in California.

When the Director of the California Department of Food and Agriculture determines that we have an infestation of an exotic pest, we prepare a Proclamation of Eradication Project that is express mailed overnight to mayors of all affected cities, the boards of supervisors of all affected counties, the district offices of the local Assembly and Senate Members and the affected county agricultural commissioner. In addition, hand-carried copies of this proclamation are taken to the Capitol offices of affected Assembly and Senate Members and the various officials in the California Department of Food and Agriculture.

The proclamation is published in at least one or more newspapers of general circulation in the county where the eradication project is being held. We also contact the Governor's office if necessary, the Federal Aviation Administration if necessary. We also notify all residences within the proposed treatment area that are going to be subjected to pesticide applications 24 to 72 hours in advance. The notification is done either door-to-door by handout, notices being slipped on the doors or handed out to people, or through First Class mail. This is done prior to every pesticide application, whether applied from the ground or from the air, that's conducted by the California Department of Food and Agriculture.

All schools and day care centers within the treatment area are notified. The school lists are obtained through the Department of Education and the list of day care centers through the Department of Social Services. All hospitals, emergency medical care facilities, and physicians within the area are notified of our activities and appropriate information is provided to them.

We have copies of the notifications and the handouts and I'll be leaving those with you today for your perusal later.

All county and city governments are notified through the Proclamation of Eradication Project and through direct contact through our staff.

Again, we'll emphasize that all citizens within the treatment areas, those treatment areas are notified 24 to 72 hours in advance of any pesticide treatments that occur before every pesticide treatment.

MS. RIPPLE: Could you repeat that again? How many hours?

DR. DOWELL: 24 to 72 hours in advance.

MS. RIPPLE: To prepare for an evacuation?

DR. DOWELL: They are notified of our treatments to occur. So we notify them 24 to 72 hours before we come on their property to treat.

MR. IMPERIALE: Is there a general press advisory released on this as well?

DR. DOWELL: Yes.

MR. IMPERIALE: Okay. Through a news service?

DR. DOWELL: We get these out to people through the electronic and print media, in addition to notification of all the elected officials, in addition to the notification of the citizens in the area. And again, the press release information and the notification to the citizens occurs prior to every application whether by ground or by air.

That, in brief, is our system. And again, I have some handouts I'll leave with you.

The University of California has estimated that for at least for the Mediterranean Fruit Fly where the pest, as an example, has been established in California, increased grower costs would range anywhere from about $580 million in excess of $1 billion per year. More frighteningly is their estimates that increased pesticide use could increase by -- ranging from 1.6 to 3.6 million pounds of active material per year.

Department of Food and Ag has estimated that for fruit flies in general, urban pesticide use, that is home owner pesticide use, could increase from 69,000 to 346,000 pounds of active material per year. Putting this in a slightly different perspective, that would range from 215 to about 1.1 million pints of added malathion use per year.

And again, I'll leave these materials with you, and I thank you very much.

CHAIRMAN MARKS: Thank you very much.

MS. RIPPLE: (Inaudible.)

DR. DOWELL: (Inaudible.)

MR. IMPERIALE: Okay, the next person to testify, Emily Levy. Emily is with the City of Santa Cruz, Citizens' Advisory Committee on the Implementation of the Americans With Disabilities Act. Thank you, Emily.

MS. EMILY LEVY: Thank you.

I want to focus on things I think that other people are unlikely to say because there's so much and we're all likely to repeat each other a lot because the issues are important to all of us. Generally, my focus is a little bit on the ADA, the Americans With Disabilities Act, because that's what I'm working on in Santa Cruz.

I'm a person with Environmental Illness. Although the ADA clearly covers people disabled by Environmental Illness, the materials that have been provided by the federal government for entities including what I'm working on, which is government entities to work on compliance, don't really include anything that helps. In our case, city departments determine whether or not they're accessible and what the barriers are to access. And what we're doing in Santa Cruz is working on some additional materials to be used by the city government agencies in order to assess access for people with EI. And I would encourage the state to do the same and also other public and private entities.

Another thing that we're doing in Santa Cruz is that we've now had a decision by the city council that each agency of the city government will appoint an accessibility coordinator so that employees and members of the general public know who to talk to if they're having access problems, and I think that's a really important thing and would like to encourage the state to do the same.

Basically, I want to really urge you to take EI into consideration all the time when talking about access modifications, to become informed on the issues, to have consultants who are hopefully paid. I've found it ironic that I can't find an accessible paying job outside my home, but yet, the city can use my services for free to tell them how to become more accessible.

Another thing that's really important for many disabilities, and I think it's extremely important for EI/MCS access, is that not only does access have to be created but it has to be maintained, and that creating a building that's built with safe products doesn't really do us any good if the first time it needs paint it's just painted with your average toxic paint. And so, you know, the people who originally were involved quit and somebody else installs carpet and also things like cleaning materials. There has to be follow-up to make sure that access is maintained.

Then I want to talk about some things directly related to the state. We've talked a lot about need for there not to be any smoking in public places but we're always talking about buildings and indoor areas. People with Environmental Illness don't have access even to outdoor public places. People who are smoking, barbecues, things like that, deny us access to parks, both playgrounds and city parks and things like that but also state parks, campgrounds. Most of us, if we need to travel or want to travel can't stay in motels because even if we can afford it they're not accessible. An alternative that would seem to make sense would be to camp but we have lighter fluid from barbecues, we have cigarette smoking, and we have sometimes bug spray that people are spraying, and therefore we don't have access to the recreation areas. Just because we're outside doesn't mean that those things don't affect us.

I personally don't have full access to, as I said before, work, to recreation, to health care, to my own home, which I have the fortune of being able to have retrofitted, but neighbors smoking or houses nearby being tented for termite control, pollution in general, roads being tarred, the industrial area that's a mile away spraying of the fields that are a few miles away all impact my access to my own home.

I don't have access to education. I was trying to finish my college degree and was told in the last few years both by our local community college, Cabrillo College, and by the University of California at Santa Cruz by both disabled student services access that they simply could not provide access for me to their facilities.

Similarly, I recently went through the Department of Vocational Rehabilitation to try to get retrained and my initial worker closed my case after determining that I was not eligible for services because she had no idea what to do with me and I had to appeal that in order to get any services at all.

I don't have access to my child's school. An example of that is last week when it was "Back To School Night" and his first grade teacher had the students cleaning their desks with Windex, he said, "My mom's coming tonight and this will make her sick," and she said to him, "You have no right to tell me what I can clean with." He is five years old and he understands EI access and I would wager that everybody else is capable of understanding, too.

I want to talk about spraying of roads, which is another thing that decreases access to our homes. Because it's so prevalent and it's not only in, you know, one county or one city, we don't necessarily think about it as -- or know who to talk to about that, but it's something that -- especially for those of us who live in rural areas, which many of us do because of the pollution in cities, it's a major issue for us.

Emergency services were mentioned earlier. I'd like to include ambulances, 911 services. I know people with EI who are afraid that if they have a seizure and the ambulance comes that they'll end up being dead or much more severely disabled because of the chemicals being used in the ambulances and insensitive treatment by the paramedics.

We need to look at alternative forms of government services for disabled people who are not able to go into public offices to get their services, and even when we have the offices as accessible as possible there will be some of us who are not able to go in them and we have to have ways of services being performed by phone and by mail outside, etc.

We also need to look at people who are incarcerated either in jails or state prisons or state hospitals. They need access too, and including areas where there isn't smoking. Disinfectants are highly used in places like that. We need to stop doing that.

The population of people with EI is growing very quickly, and the burden on public agencies to respond to it is also growing. I want to point out that major at-risk populations for developing EI are low-income people and people of color. And two specific reasons for that are farm workers don't have very much health protection and need more, and another thing is people who live in industrial areas, which is generally low-income people of color, need to be considered. Locally, we can look at what's been happening in Richmond in the last few years, and I would wager there's a lot of undiagnosed cases of EI there now.

I want to close by saying that I find it very ironic that people with Environmental Illness are considered sick because we react to poison as if it were poison, and that people who react to poison as if it were air or water or food are considered healthy.

Thank you.

CHAIRMAN MARKS: Thank you very much. We appreciate your testimony.

Dr. Robert Harrison.

DR. ROBERT HARRISON: Thank you. I am an Associate Clinical Professor at UC Medical Center here in San Francisco. Over the last 8 or 9 years I've had the opportunity to evaluate dozens of individuals with EI and MCS.

I'd like to address myself to just one point, and that is the question of what is reasonable accommodation. I'm not an attorney but the way I read the Americans With Disabilities Act, that really is a key question in terms of how we set public policy to protect individuals with EI and MCS.

As Dr. Cone, I think, so ably described, I don't think there's much disagreement that EI/MCS is a cause of disability. However, there's tremendous disagreement in the scientific community as to the etiology of EI/MCS. And as we proceed in determining what is reasonable accommodation for individuals with this impairment, I think we're likely to run smack into the question of what criteria do we use to determine what is reasonable accommodation for these individuals.

When we set occupational and environmental standards to protect individuals from exposures, we generally use scientific evidence either from animal or human studies to provide the evaluation criteria for setting standards to protect people from exposure. If we look at what is reasonable accommodation for patients with EI and MCS, you will find, as I have when I've reviewed the literature, a real dearth of studies that would guide us to determine, for instance, what would be adequate ventilation standards for an individual with EI/MCS. What would be considered a toxic paint product. What would be considered a safe level of a pesticide that was used in a workplace.

And as we proceed, I would urge that there be very careful consideration of not only the existing scientific evidence that could guide that question of reasonable accommodation -- to which I would add that in reviewing the Disability Action Plan, what I think would be needed here would be some of that scientific documentation to accompany any material that's developed by the city, and I certainly would be one to be happy to help you do that -- but also to consider the research needs. And we need for additional funding to set those evaluation criteria for patients with EI and MCS. There have probably been a half a dozen studies. Of those, half have concluded that this illness is psychiatric and half have concluded that it's not. I mean, I'm being -- roughly, I think I could summarize the literature in that regard that the scientific community is terribly split. And if we develop criteria for reasonable accommodation under the ADA, there will be many who might argue that we're setting indoor air pollution standards for a psychiatric disorder. And unless we carefully document the need for reasonable accommodation and refer to an adequate scientific base, I think there's likely to be a tremendous controversy erupting over the setting of public policy.

This is really unique, in my experience, or maybe not so, but in any case, we are proceeding to set policy with a real dearth of scientific evidence concerning what criteria we use to set that policy. So I just urge the consideration of those kinds of issues, particularly with funding. I should just close by saying that I've sat on at least one federal agency panel. This one was funded by the Agency for Toxic Substances and Disease Registry. That's the ATSDR. A year ago 50 scientists came together and recommended a research direction for MCS. We've heard from the Environmental Protection Agency, the ATSDR, but there haven't been any research dollars coming to really further define this disorder that would help guide the questions of reasonable accommodation under the ADA.

Thank you.

CHAIRMAN MARKS: Thank you very much. We appreciate your being here.

Barbara Scott.

MS. BARBARA SCOTT: Thank you, Senator Marks, for having me.

I am from South Lake Tahoe. I've gotten Multiple Chemical Sensitivity because of being sprayed with pesticide without my knowledge for a whole year, of 1990, every other day. Unfortunately, my workplace denied it and I am...(microphone adjustment)

I'll start all over.

Thank you, Senator Marks, for having me here.

I came down from South Lake Tahoe to help with the impact on MCS, and hopefully other cities in California can follow with you in San Francisco in what you are trying to do. I think it's great. This is the first positive thing I've seen in two-and-a-half years of dealing with my impairments.

After the application was sprayed of pesticide in my workplace, it was denied by my workplace, and that hurt me more mentally than my physical impairments can ever hurt me, and it's still denied.

I am denied my place of work right now -- I have been fired -- and I am denied new training because I am sick and they will not train me to do any other job.

I'm facing two brick walls: One, my MCS, the handicaps, mental and physical; and the other, recognizing the illness and trying to get treatment. And, unfortunately, it is not recognized where I come from, so we cannot get treatment.

We just had a worker's comp hearing. First, it was at a low level of worker's comp; it was with a layman. We had physicians testifying for us that I've seen for two-and-a-half years, several top-notch doctors. Then I went to see my workplace doctor; I saw him for one hour. He also said I was disabled, and quote, "You are disabled. You have all the signs of toxic exposure. But guess what, we didn't spray that much." That's exactly what he stated.

We know the layman refused us worker's comp, me and 35 other people. At the time we got ill in our workplace and they had sprayed, 150 of us, dealers and other ones in my workplace literally went unconscious, passed out.

So we appealed it. We went to a higher level of the worker's comp. I believe it was the highest that we can go. I got a phone call three days ago. She denied us, and she's a layman. And here then again, the same thing: testimony after testimony of all the top-notch doctors.

I have medical evidence that my RBC cholinesterase dropped 3.0, which is low and proves I was exposed to pesticide. That's the same test that exterminators are given once a week to see if they're being exposed. They found it in my blood. I have the evidence. But yet, to the worker's comp layman, what the heck is RBC cholinesterase?! Okay, I had to learn all this too, myself. She could have read up.

Then I had one taken after. I do have a norm. My norm is 5.70. So it proves I was exposed to pesticide, but the denial is unbelievable.

The side effects -- I was very healthy before I started working. After that, my symptoms were, gosh, amongst lots others, loss of my eye sight, especially my left side. I'm sorry, I slur my speech sometime also. My left eye hangs. I've never worn glasses before in my life. I have 20 over 400 in my left eye. I am color blind. I have vasomotor reactions. I have seizures, headaches in the back of the neck. I am losing my motion functions in my hands and in my feet. I have black and blue marks that don't go away anymore. My white blood count cell is dropping in my blood.

I don't know what else to say. I came down here to try to help and the people in San Francisco to hopefully get it recognized, and I'm hoping that this shows a precedence that somehow it gets heard up where I come from and maybe this will help us someday.

Thank you very much.

MR. IMPERIALE: Thank you for your testimony, Barbara.

The next speaker, Richard Skaff, the Disability Access Coordinator for the City and County of San Francisco's Department of Public Works.

MR. RICHARD SKAFF: Thank you, Mr. Imperiale, and Senator Marks, and Joan.

I have been handed, and I would like to read first, a letter, testimony from a Ms. Maggie Dee Dowling. She was not able to stay and had to leave the room. I don't know why but I presume because of chemical sensitivity.

May I read this for her?

MR. IMPERIALE: Certainly.

MR. SKAFF: "My name is Maggie Dee Dowling. I reside in Pittsburg, California. I have asthma. I am severely affected by blowing of industrial smoke stacks. I live five blocks away from PG&E Pittsburg Power Plant. When their stacks are cleared I must leave my home for several hours. This process is conducted at different times, morning, afternoon, evening and during the night. There is no notice to residents of the area. On a number of occasions, I have had to have emergency room personnel administer appropriate breathing aid medications with follow-up medications for weeks.

"I lived in a HUD 202 building where the carpeting was chemically treated to prevent cigarette burning. I broke out in large welts each time I used the floor to build and maintain my upper body strength through an exercise program that was medically necessary. In addition, I was frequently in the local community hospital's emergency room due to excessive breathing difficulties.

"I hold three employment positions: columnist, broadcaster, and Fax Reader Project through Smith Kettlewell Eye Research Institute of San Francisco.

"I was forced to relocate partly due to the chemicals at the HUD 202 building; toxics of the carpet and closed ventilation.

"Thank you for accepting my written comments. I have another obligation at 11:00 that I must attend." (There's the answer.) "Please send me a copy of the transcript.

"Maggie D. Dowling, September 30, 1992."

MR. IMPERIALE: Thank you for reading that for Maggie.

MR. SKAFF: I will leave this with you.

As you stated, Mr. Imperiale, my name is Richard Skaff. I'm the Disability Access Coordinator for the San Francisco Department of Public Works.

The San Francisco Department of Public Works recognizes its responsibility in providing accessibility in employment and programs to all persons with disabilities, including those with EI/MCS. The Department today is providing the sound enhancement system for this hearing as one of the ways we are attempting to provide access for persons with disabilities.

I am here today to inform you of the efforts of the San Francisco Department of Public Works and that we have taken steps to provide access to persons specifically with EI/MCS that are in need of reasonable accommodation required by the Americans With Disabilities Act.

First, the Department of Public Works has developed a policy, which I will provide you a copy, that states the bureau's policies on public meetings. This policy also requires that each bureau, when holding a public hearing or meeting, will display a sign indicating that the hearing must be, or is scent-free.

Secondly, the Department has developed bureau coordinators. We have 12 bureaus, we have a coordinator for each bureau, that act as a liaison between the Department and the employees in each of the bureaus. These bureau coordinators, access coordinators, are available to consult with employees regarding access issues, including those issues relative to EI/MCS.

The difficulty, presently, the Department has, and I believe the City in general, is the fact that there is a lack of specific codification of requirements describing our responsibility to provide people with EI/MCS appropriate access. We are presently attempting to provide minimal access, although I realize it isn't adequate in many cases. However, again, our hands are tied because we have no specific direction provided to us by the state: Office of the State Architect, Housing and Community Development, Office of Occupational Safety, or any other state agency that would define for us the direction we should be taking to provide correct access.

An example of the chemical problem that exists in our community, not just within the city bureaucracy but in our community generally, is described in an article I brought today, and I believe there are a few copies available. It was in yesterday's Chronicle and it describes a chemical spraying in San Francisco's schools and an evacuation that was required because the chemical spraying was done during school hours. I'll leave this with you also for your minutes.

Thank you.

MR. IMPERIALE: Thank you, Mr. Skaff. We appreciate your testimony.

Next speaker will be Wil Ussery, President of BART Board of Directors and he'll talk about BART's approach to the issue of EI/MCS.

MR. WIL USSERY: Good morning, Senator, Mr. Imperiale.

Thank you for the opportunity to appear before your committee today. As you have noted, the topic of Environmental Illness and Multiple Chemical Sensitivity is not an easy one to address. There is confusion which breeds resistance among many sectors of our community, including many businesses and large institutions. These groups fear unknown requirements, uncertain responsibilities, and costly constraints; and there is confusion among the general public which has been pulled from one side to the other by proponents from both ends of the issue.

Those of us in the public sector who indeed are required under federal law to accommodate all patrons are, in a sense, damned if we do and damned if we don't. We cannot ignore the concerns of those who say they have environmental illnesses that cause disabling conditions. That would violate not only federal law but our obligation to serve the public. Yet, some of our earliest discussions of policy options have been criticized in some quarters as frivolous. Suffice it to say that BART is experiencing both sides of the public debate. It's no wonder businesses are concerned and the public is confused.

BART first became aware of the Environmental Illness issue about a year ago. Since then we have appended a statement to our meeting notices asking people to refrain from wearing scented products. It's similar to the note on the announcement for this meeting.

We have also asked our staff to gather and evaluate information relevant to the environmental illnesses and to fold environmental illnesses into the agenda of BART's Accessibility Task Force.

BART is also working closely with the environmental products industry. We have discovered, for example, that complaints that our newest cars cause allergic reactions diminishes with time, much as a new car scent that is caused by certain chemicals and materials fades with time. So we will speak to our manufacturers about airing out the cars before they are delivered.

BART is also working with manufacturers to identify and select materials which have shown not to cause allergic reactions. BART recognizes that a public awareness campaign by public agencies could begin a sensitivity education process. This would not entail a ban on perfumes and aftershaves, as some media persons have characterized it, but an effort to remind the public that the heavy scents of perfumes and aftershaves are offensive to many people, also aggravate disabling conditions in others.

BART is committed to meeting the needs of its patrons, all of its patrons, in providing safe, comfortable, economic transportation in the Bay Area. We encourage your committee to continue the work with the medical community, the disabled community, and the products industry. We encourage your committee to take the next step and identify acceptable products and standards. BART and other public agencies could then use these standards to deliver our necessary services to the public.

Thank you, again, Senator, for giving me the opportunity to address your committee.

MR. IMPERIALE: Thank you, Mr. Ussery, for your testimony. We appreciate that.

Next speaker will be Sue Hodges, Program Director of Disability Education and Advocacy Resources, and Chair of the Oakland Mayor's Commission of Disabled Persons, specializing in employment issues.

MS. SUE HODGES: Good morning.

First of all, I want to commend you on holding these hearings, particularly with the variety of people you've had available to testify, or you found to testify.

My comments are directly related to the relationship between Environmental Illness and employment and the lack thereof.

People with Environmental Illness experience chronic and severe unemployment. There is a grinding oppression in the relationship between poverty and disability and the perpetuation of poverty by disabling conditions, and not just the conditions but the environment in which people with disabling conditions live.

I have to ask you to bear with me because there's perfume on the mike which I would really appreciate having removed and having another one put here. Somebody who's handled it has worn perfume.

MR. IMPERIALE: Why don't you just move over to the next mike, Ms. Hodges, please. Thank you.

MS. HODGES: Thank you. And also because even though you've taken steps to make this room safe, I am reacting to the environment in here. So if I'm not as coherent as I had planned to be when I arrived, bear with me.

Issues around employment have to do with access, safety, and civil rights. Starting with the application process, can the person who has EI even access the place where the applications are provided. Are those applications printed on NCR paper which is -- I can't handle it and I know many people with EI who cannot either. It's toxic.

In the interview process, first of all, access to the building, to the site where the interview is held is an issue. The people who are going to be conducting the interview are an issue. It's very likely they will be wearing scented products, chemical products. The room itself has probably been treated with chemical products. How does the person who is a prospective applicant prepare the people who are going to interview her to be safe, and prepare them to make the site where she's going to be interviewed safe.

I heard someone testify about accommodation a little bit ago. He termed it "reasonable accommodation". I think that the term would be more likely to be "unreasonable" in the terms of the testimony given.

What's reasonable is what it takes for the person to be accommodated. If the employer doesn't understand what reasonable accommodation is they should work with the person who is being accommodated to find out what's needed. Many people experience EI on an individual kind of level. People's immune systems react differently to different agents. What works for one person may not work for another. So that kind of individualization is necessary.

There is also the problem of transition from being a non-working person to a prospective working person. There is much in the way of preparation and cost that's incurred.

You will hear testimony that Medi-Cal does not pay for people who need oxygen. I've had a prescription for oxygen since 1989, which I have been unable to fill because Medi-Cal won't pay for it. It has been a profound barrier to my seeking employment; also to being able to enjoy daily life, just to live.

Also, in this interview process it's really helpful if, when the person with EI/MCS enters the room, the reaction is not "The Martians are Coming, The Martians are Coming!" because the person may have portable oxygen or wear a mask. People who are involved in that interview process need to be educated ahead of time on what to expect.

Another barrier to employment is the site where the employment is going to take place, and not only the site but the location of the person within that employment area. I cannot work in a sealed building; it is not accessible. I might as well be asked to work at the top of the Himalayas. It is not accessible. I have to have a building location where the doors and windows open, where the building is not sealed, where I am not daily exposed to the physical insults of chemicals that are trapped within that building.

Okay. The site is one of those. If the site can be made accessible that's terrific. However, is that the only site the person's going work in. Will they have to go to workshops. Will they have to, because of the nature of their employment, especially if they're in a management position and seeking advancement, have to go to different locations; the entity may have or go for advancement training, or whatever. The unpredictability of that site can also be characterized by the people who will be working there. Are they people who will be regular and steady? Is there going to be a turnover of temporary workers? Are there rotations involved? And also, it's not just the people that the person is working next to but the people who may be coming in and out on a regular or irregular basis.

Maintenance of the work site is a crucial issue. Chemical and synthetic contaminants are present in even the most carefully thought-out worksite, and some of those can be the ones that are the least predictable. Perhaps the contractor comes in who hasn't been prepared about the precautions that are enforced and uses an agent that has not been approved. Notification of the employee that maintenance is going to occur and having a site for the person to be relocated to if necessary is very important.

And employee awareness, both of permanent employees and temps and rotations. It's very important that the people who are going to be working with this person are educated in what EI/MCS is all about, especially if the person they're working for gets exposed and has a reaction and they look really bizarre. People have to know what to do and what steps to take to remove a person from a chance exposure, to remove them from a place of danger to a place of safety, and understand that reactions can be all over the scale. Reactions can be mental, can be emotional, can be physiological.

The cost of impairment-related work expenses is something else that's very much at issue. The person must bear the cost of her oxygen herself. Perhaps she uses acupuncture or homeopathy, something that Medi-Cal pays for only in the barest, barest minimum repayment. I'm not sure what happened, if those two got the ax in the latest budget cuts, but I think that's probably on Wilson's agenda for the fall election is to take what little remains out. I'd like to see Medi-Cal expanded to be able to cover a truly aggressive treatment program for people through the mitigation measures and acupuncture and homeopathy.

EI/MCS can also present tremendous barriers to advancement in the worksite. I mentioned already about workshops and trainings.

All right, so what is the alternative? Well, perhaps it's to work at home. I certainly don't feel that to not work at all is an alternative. However, I just contacted the Department of Rehabilitation and they were profoundly uninformed on the needs of people with EI/MCS for supported work and work at home.

People are becoming chemically injured at work. People are becoming newly disabled. This isn't just about people who already have EI/MCS. It's about all the people in the world who are going to get it. We need in the worksite mitigation for people currently experiencing and living with EI and MCS, and prevention to keep people from becoming disabled, and protection for those who most are at risk.

In closing, I'd like to draw your attention to an example that I frequently use in trying to help people who don't understand about EI/MCS.

Let's look at work injuries. When you're at work, okay, say you work in a loading dock and somebody runs you through with a fork-lift. You're injured. Nobody doubts that you're injured. You have a wound, you bleed, it's very spectacular. However, when you become chemically injured people don't understand what they're seeing. They see behavioral changes, they see what they think are psychological changes, and perhaps they are. They see mood changes, they see people being angry or out of control and they don't understand that that is a chemical injury. The body has been injured as profoundly as it would be injured being run through with a fork-lift.

MR. IMPERIALE: Sue, you need to wind this up.

MS. HODGES: Okay.

The last thing is, I don't think anybody here in this list of speakers is prepared to speak about the criminal justice system. I hope that you do have someone today doing that.

I will be submitting more comments in writing. I'm sorry they weren't in writing today but I was profoundly exposed to a variety of chemicals yesterday and I can't touch my electronic word processor for two or three days. It's not accessible to me.

Thank you.

MR. IMPERIALE: Thank you for your testimony, Sue.

We'd like to remind the speakers who will be next in line here that we're going to have to impose the time limit that we spoke about in the rules for this hearing. We appreciate everyone's testimony and want to remind you again also that we're going to be receiving written testimony from those of you who were not signed up or not scheduled to speak today. We will be taking that testimony until the 15th of October. That written testimony should be sent to Senator Milton Marks, 711 Van Ness Avenue, San Francisco, and we'll look forward to getting that written testimony.

The next person to speak will be Barbara Ruth, Disability Activist, and she'll speak about disaster preparedness, accessible shelters, Medi-Cal payment for oxygen, and directives to health care professionals.

Barbara, please try to keep your comments within our time frame, please.

MS. BARBARA RUTH: I'm not going to speak about all that given the time constraints.

MR. IMPERIALE: Fine, thank you.

MS. RUTH: Thank you, Mr. Imperiale, Ms. Ripple, Ms. Malloy.

I'm Barbara Ruth. This is a cannula. This is a portable liquid oxygen system. And I'm not wearing them to make a fashion statement. The tank is heavy and the nose hose is uncomfortable. Supplemental oxygen makes my brain work better in the presence of toxins. I have less headaches and nausea and am less likely to have a seizure. I absolutely needed the supplemental oxygen to get here and participate today.

For the past four years I've been fighting the oxygen wars. Medi-Cal doesn't want to pay for oxygen for me or my co-litigants, all of whom have Multiple Chemical Sensitivity. We all have prescriptions for oxygen from our doctors. Medi-Cal routinely pays for oxygen for people with such disabilities as emphysema and muscular dystrophy. Our lawyer argues that we are being discriminated against on the basis of diagnosis.

It seems to me symbolic that we're fighting the state for air. It's typical of the way folks with MCS are denied our civil rights, that the so-called evidence presented against us is couched in psychiatric terms. The lives of those of us with MCS are made a lot more difficult by doctors who are on the payrolls of worker's compensation boards, chemical manufacturers, etc. They want to prove that MCS is a psychiatric disorder or non-existent. This is clearly motivated by concern about the price tag of recognizing the real extent of chemical injury, both in product liability and employer responsibility. It doesn't make for good science or good public policy.

People with MCS need clean air. This means getting rid of toxic substances. Putting deodorizers in public bathrooms means we can't go in. Rather than saying they just want to make money, the manufacturers use so-called expert medical opinion which denies the existence of our disability. Because the statements are made by doctors they appear to be objective. Doctors' testimony is used to subvert our legal right to access of public facilities. Meanwhile, more people exposed to such atrocities as deodorizers develop MCS. It would be useful to have more scientific information about MCS. Certainly, we need to know about the effects of chemicals and biologics in our environment. We don't need the kind of science that values profits over people.

The tobacco industry regularly pays for studies which deny any association between cigarette smoke and cancer, emphysema or heart disease. Humans are not exposed to cigarette smoke, electromagnetic fields, formaldehyde, or volatile organic compounds in isolation. How is it possible to know the synergistic effect of all the toxins we are exposed to as part of daily life? It would seem to me more humane and more prudent to eliminate possibly harmful substances such as pesticides which are making people with MCS sick. Even if a given substance turned out not to be toxic to most people, getting rid of it would increase access for those of us with MCS.

What is access and how do we get it? Access means the removal of chemical, architectural and attitudinal barriers. I do not consider an event or place accessible if being there results in illness, diminished capacity, or pain. For most of us here today with MCS, this meeting is not accessible. Access needs to be planned from the beginning of an event or project. It's essential to solicit the expertise of people with access needs. Paying us for our work should be a high priority. If there's money to pay an architect to design public housing, there's money to pay a knowledgeable person with MCS to ensure safe building materials are used.

In closing, I want to talk about a series of catastrophes which happened to me due to lack of adequate regulation of toxins and lack of appropriate medical and emergency facilities. Given the current budget problems, and since I am a Medi-Cal and SSI recipient, I'm going to talk about these events in terms of their cost to society.

In July of 1991 my subsidized home was sprayed with pesticide without my notification or consent. I had to evacuate and abandon most of my possessions. I became gravely ill. If I had received 24 to 72 hours advance notice, this would still have been an emergency. I couldn't have gotten all my possessions out and found a safe place to live in that amount of time. Because I did not follow the Housing Authority's stipulation to give 30 days' notice before leaving, I lost my Section 8 subsidy. The state had to pay a legal aide attorney who worked on my behalf to have my housing subsidy reinstated.

I had many doctor appointments, mostly paid for by Medi-Cal. So are the various anti-convulsants prescribed to control my seizures which had been exacerbated by this pesticide exposure. My need for county-paid, In-Home Support Services increased. I stayed with friends in eight different places over the next five months. Eventually I ended up in Marin General Hospital where I stayed for three weeks at government expense.

Marin General is reputed to have the best accommodations of any hospital in the Bay Area and possibly the U.S. for patients with MCS. The physical structure and linens were fine. Yet, despite a prominent sign on my door saying not to enter if the person was wearing scented products, every single day I was there perfumed medical personnel treated me. I was also routinely dismissed and insulted by doctors unqualified to treat MCS.

MR. IMPERIALE: Barbara, we need to wind this up pretty soon, please.

MS. RUTH: Okay.

I'm convinced I could have recovered more quickly and less expensively if I had not had these daily chemical and verbal assaults. There is no environmentally accessible homeless shelter. If I had been in one I could have more effectively searched for my new housing once my Section 8 was reinstated. Part of why I stayed at Marin General so long is I didn't have any place to go.

My story is not unique. Those of us with MCS are all one bad exposure away from such a nightmare. Perhaps my uniqueness is in the generosity of my friends and my luck in finding another home as soon as I did.

By its nature, MCS is isolating. During my siege, I called on every one I knew and plenty of people I didn't. The hard fact is that if I had fewer friends and friends of friends willing to help me in any way they could, I might not be around to tell the story.

In a just society, one's survival shouldn't depend on having enough friends. The whole concept of social welfare rests on the premise that society should be responsive to people in need.

MR. IMPERIALE: Thank you for your testimony, Barbara.

Next speaker is Larry Guthrie, the Principal Architect, Chief of Seismic Program with the Office of the State Architect.

MR. LARRY GUTHRIE: Thank you, Mr. Imperiale.

I'm Larry Guthrie, Chief of the Seismic Program for the Office of the State Architect. I was just recently appointed as Chief of the Special Toxics Program for OSA which addresses asbestos, PCB's, and underground tanks.

I just recently became aware I was scheduled to speak here this morning so I did not have a prepared statement. What I'd like to say is though I'm here to learn and to answer or respond to any questions you may have, I have a couple of comments I'd like to make.

The Office of the State Architect is both a service and a regulatory office and we respond to the direction from the Legislature and from the Administration. As far as I know to this particular day, we have not received any direction, specific directions as to treating or working with chemical sensitivity as you've addressed here today. We have worked with paints and things like that but not to the extent being talked about here. This is one of the reasons I am here is to learn about this.

I am OSA's representative to the Indoor Air Quality Control group and from that group I am now becoming very aware of the degree of chemical sensitivity that people have encountered.

So with that, I'd like to close and just say that I am willing to learn and want to learn all about it.

MR. IMPERIALE: I have a feeling, Mr. Guthrie, that we'll probably have a lot of input from this audience to your office. We thank you very much for your testimony.

MR. GUTHRIE: That's why I'm there.

MR. IMPERIALE: Thank you.

The next speaker is Ruth Fontana, a person with MCS, and she will speak about fragrances in public places. And Ruth, if you can keep your comments, please, to five minutes. Thank you.

MR. RUTH FONTANA: I have shortened this quite a bit. All of it will be included in my written statement with the full quotes and citings.

Mr. Chairman and Members of this committee, my name is Ruth Fontana. I am a person with Environmental Illness/Multiple Chemical Sensitivity, and an active member of the Environmental Health Network. Thank you for giving me the opportunity to speak about fragrances in public facilities.

This use of fragrant fake scents shows a blatant disregard for the safety of people with EI/MCS. Meanwhile, the fragrance business is booming. Japan's leading fragrance maker is promoting mood enhancing chemicals for distribution by heating and ventilation systems in public facilities worldwide. A Wall Street Journal article states, "Japanese construction companies are installing these systems in public rest stops on Japanese highways and in their hotels in the United States and elsewhere." On June 21, 1992, an article in the San Francisco Examiner by Louis Trager points to the alarming phenomenon of aromas being used in stores to lure shoppers. An earlier Examiner article describes an office complex in Japan which has computer controlled fragrance systems that put artificial fragrances into the atrium and surrounding offices. The article has frightening detail.

Also in today's Japanese market are scent emitting alarm clocks, futons, and artificial potted trees for the purpose of putting in public buildings. London is in the process of scenting some of their subway cars.

Earlier this year, Channel 4 television (KRON) in San Francisco did a story called "The Smell Manipulators". In it they told of major companies who are searching for ways to use fake smells to capture the smell of emotion. Many of them have already contacted a smell researcher, Dr. Alan Hirsh, at the Smell and Taste Treatment and Research Foundation in Chicago. Dr. Hirsh is a psychologist and a neurologist. He says, "By the early 21st century, odors will be used as much or more than music and lighting today. It will be the Musak of the '90s." Dr. Hirsh is currently doing research to find out if smells can manipulate customer spending habits. Preliminary reports show they can, whether detected or subliminal. A contract has just been signed by a bread manufacturer to plant the artificial smell of baking bread into their wraps in the grocery stores to influence the brand we buy. This is truly frightening and unethical. In his research, Dr. Hirsh found that odors go directly to the limbic system, the emotional center of the brain. He quoted, "We're just at the tip of the iceberg of smell research."

Harry Snyder of the Consumers Union was appalled at this prospect, so appalled that he gave an example of the farmer who keeps the lights on in the hen house so the chickens will eat more corn and lay more eggs. He says, "The hens have more stress and they do die earlier, but they lay more eggs and it's more profitable." American companies are doing tests on this right now. Consumers Union is in favor of stopping these tests.

John Bailey of the FDA says that they haven't decided if regulation for these fake smells is needed. "These chemicals are approved as safe." But, of course, we know that these are industry studies with a vested interest. People with EI/MCS are not part of this equation. These fragrances must be tested and be reclassified according to their toxicity and irritation factors.

Herbert Gunter of the San Francisco based Public Media Center said, "This is worse than subliminal advertising. It causes a physical reaction. The smell of chocolate chip cookies, for example, causes you to salivate. We will certainly lobby hard that we know why we are buying something."

Also in the same Channel 4 report, Dr. Tom Linden said these smells can cause physical illness. "Smelling peanuts or fish can cause a life-threatening, physical reaction in some people. In others, severe irritation of the eyes and throat. As an example, a fake peppermint smell gave me a sore throat and headache. Avoidance is the best. Get out of the room if it causes irritation."

Anyone who has the EI/MCS knows well this advice, but if this is allowed to be implemented unregulated, even more of us will be confined to our homes. This will increase our need for supportive services such as in-home support where the state pays someone to do all of our errands. They have just cut that service 12 percent for all of those being served.

Herb Levine, of the San Francisco Independent Living Center, when speaking on the subject of Americans With Disabilities Act, cited examples of readily accessible barrier removal. They included shutting off the scent of deodorants in bathrooms, better yet their removal, and eliminating the use of fragrances that come through ventilation systems as in hotels. Mr. Levine said that he feels strongly that we must go further than posting warning signs when considering accessibility for the disabled. I personally have run into two medical offices in Contra Costa County that are currently using fragrances in the ventilation systems.

On a recent newscast from KPIX-TV 5, it was stated that American Airlines, Hallmark, General Motors, Quaker, Nike, and Montgomery Wards are among the companies currently looking into the use of these artificial scents.

There is no time to waste; we must look seriously at the ways to deal with this assault on our senses while the research is in its infancy. For those of us with compromised immune systems this is a matter of survival. We are already disabled by chemicals and personal fragrances on a daily basis. Please help us to stop this trend before it gets out of control.

CHAIRMAN MARKS: Thank you very much. We appreciate your testimony. Appreciate hearing from you.

Mike Henning.

MR. MIKE HENNING: Mr. Chairman and Members of the Subcommittee, I am Mike Henning, President of Aurora Modular Industries, a relocatable classroom manufacturer located in Southern California. I am speaking today as the Vice

Chairman of the School Facilities Manufacturers' Association.

School Facilities Manufacturers' Association is composed of six California manufacturers located throughout the state and their related suppliers. Our products are built to specifications developed by the individual school district architects or the State Office of Local Assistance Emergency Portable Program. These specifications are incorporated into detailed construction plans that are submitted to the Office of the State Architect along with structural calculations and energy calculations. Our relocatable classrooms are then built to these stamped and approved plans.

Both the factory and school sites are continuously inspected by independent third-party inspectors hired by the school district architects to ensure compliance with the Office of the State Architect approved plans.

As parents and as manufacturers of a product that we feel is an important part of solving the school facilities problem, we are very supportive of all efforts to house students and teachers in a safe and healthy environment.

It is important to understand that our product is not a trailer or motorhome designed to be towed or driven over the road; nor is our product a manufactured or mobile home designed as a dwelling; nor is our product a commercial coach which is built to the Department of Housing's standards. This is probably the most confusing area because these Department of Housing trailers look very much like our product. However, they generally are higher off the ground and are on a cement pad foundation. These DOH trailers encompass a range of products from construction trailers to temporary office trailers.

Our products are designed and built to a higher structural standard, the Field Act, which covers all kindergarten through junior college classroom construction. This standard is enforced by the Office of the State Architect. Our product does not utilize substandard materials such as particle board or paneling. We build with conventional materials such as dry wall and plywood, just as your home or office is constructed, with the only difference that our products are built in a factory environment rather than on site.

As with all buildings, our manufacturers have encountered various problems related to chemical sensitivity or indoor pollution. I will attempt to briefly outline some of these problems.

Number one, relocatable classrooms are built with raised floors with crawl spaces underneath; so subfloor ventilation and proper drainage to prevent moisture accumulation are very important. Additionally, classrooms cannot be placed on grass sites due to the possibility of methane gas build-up as the grass dies. The grass site must be cleared before the classroom is set, so the method of killing the grass is also important so that no type of toxic chemicals are present.

In tests supervised by Dr. Joseph Fedoruk, Doctor of Occupational Health Medicine at the University of California at Irvine, very little levels of formaldehyde and VOC's were found in relocatable classrooms. These levels are comparable to those found in a new home. However, school districts can add shelves, cabinets, desks, partitions that can emit higher levels of formaldehyde due to the materials used in their construction. Additionally, cleaning materials used by the school district maintenance department to clean carpet, walls, chalkboards, windows, etc., can positively contribute to these problems of chemical sensitivity.

(EMERGENCY BREAK)

MS. RIPPLE: If anyone has entered the room recently and has not been aware of the no fragrance, no scent rule for this hearing, please move to the front right-hand side of the room.

MR. HENNING: Proper ventilation and proper maintenance and operation of the air conditioning systems has proven to be the most critical element in the indoor pollution problems that we encounter in relocatable classrooms.

Relocatable classrooms are designed for 30 students and one teacher. Their air conditioner and the system is sized by a mechanical systems consultant or engineer to meet current California Energy Commission standards of 5 cubic feet per minute of outside air per occupant. However, if the fan, the conditioning equipment, or outside fresh air provided by doors or windows are not operated or provided for continuously during the use of the classroom problems can occur. The noise of operating the fan or the air conditioner frequently causes teachers to not properly utilize the ventilation systems designed for the building. Windows and doors are not utilized as a source of fresh air due to noise, dust, or other concerns about the environment outside the classroom. The California Energy Commission is considering raising the cubic feet per minute of fresh air per occupant to 10 or 15, and this should help the problem of air circulation, although at a potential cost of higher energy operating costs. Overcrowding of classrooms designed for 30 students and one teacher will obviously cause potential health problems but proper operation and maintenance of air circulation systems is still the most important factor we see as an industry.

Thank you for allowing the School Facilities Manufacturers' Association to testify. Let me reemphasize our industry's commitment to working with this committee, to continue to develop proper specifications for construction and operation of our products to provide a healthy school environment.

CHAIRMAN MARKS: We appreciate your testimony very much. Thank you very much, Mr. Henning.

Ramona Albright. Is Ramona Albright here? Margaret Verges. All right, we'll have to skip them.

Julia Kendall. Come forward, please.

MS. SUSAN SPRINGER: I'm Susan Springer. I'm the Director of Media Relations for the Environmental Health Network and I'll be speaking for Julia Kendall.

Thank you for having this precedent-setting hearing. San Francisco has been in the vanguard of recognizing people and providing services for people with immune system disregulation. That is, people with AIDS. We applaud these progressive policies but it is now time that we need to expand our awareness and implement new policies toward other people with chronic, life-threatening immune disregulation.

I am one of over 12 million people who have asthma. I acquired asthma through my occupation. I also have Reactive Airway disease and Multiple Chemical Sensitivity. I'm also legally disabled.

Perfumes and cigarette smoke are major barriers to my ever returning to the workplace. In fact, they're barriers to even going to a pulmonary specialist's office or a hospital where no policy is in place to assure my safe health.

There are many respected studies on asthma, cigarette smoke, and perfume, including one by Dr. Cone on the health effects of indoor odorants.

I want to read from a letter that our organization received. The Honorable Pete Stark from the House of Representatives wrote to the National Institute of Health concerning our organization's concerns for what was being done in regard to Multiple Chemical Sensitivity. This is from Bernadine Healy, the Director of NIH.

> "Dear Mr. Stark: Thank you for your letter of June 19th requesting information on research being conducted by the National Institute of Health on Multiple Chemical Sensitivity.
>
> "Within the NIH, the National Institute of Environmental Health Sciences is currently supporting research to demonstrate a causal relationship between the exposure to environmental substances and the subsequent adverse health effects.
>
> "Studies of the impact of disruptions in one's system and the effect it might have on the other systems are so promising for improving public health that NIEHS has made this subject one of the four highest priority areas in its current research program."

Of course, that doesn't mean that there is funding for that research.

I have another article that I want to quote from briefly, and it is from Lawrence Wallick, who is a Doctor of Public Health, teaching at the School of Public Health at the University of California, Berkeley.

> "Public Health faces an uphill battle because it tends to run counter to dominant economic interests. Historically, public health has met resistance from groups who benefit from conditions that give rise to and sustain disease. Public Health tries to turn the tables and move away from blaming the victim. Instead of harassing the smoker, for example, progressive public health approaches focus on the behavior of the producers and advertisers who profit from promoting a deadly product. The new wave in public health is to focus on the system. Involving the varied social, political, cultural, and economic sectors of cities is important to a comprehensive view of health. Health, rather than being seen as a collection of personal choices, that is whether to smoke, whether to exercise, is seen as a product of society's choices as evidenced through social and public policy decisions."

The rigorous debate about underlying values of public health is crucial to the future of health promotion because the prevailing world view will largely determine the form and content of strategies that are considered to be legitimate.

Thank you.

CHAIRMAN MARKS: Thank you very much. We appreciate your testimony.

John Cailleau.

MR. JOHN CAILLEAU: Thank you, Senator, and Joan Ripple for putting this thing together. It's long overdue and very much appreciated. And, Senator, for the pronunciation of my name, thank you. Very rarely is it ever pronounced correctly.

CHAIRMAN MARKS: I try.

MR. CAILLEAU: I will leave all of this stuff with you because it appears that we're running real short on time.

Three years ago, I had never heard of Environmental Illness and would have thought that most of the people in this room were pretty nuts until I developed it myself.

I moved into a brand new apartment and was fairly thrilled that I had this brand new place that smelled what I call, like, you know, a new apartment. It was during the winter so I closed the windows and turned on the heat, thereby baking out all the formaldehyde in the carpet and the solvents in the paint. Three months after living in that toxic suit, I began to notice all the symptoms of what I later claimed to call Environmental Illness, the hypersensitivity to perfumes and cleaning chemicals.

As such, my life has totally turned upside down, and to give you an idea of the hierarchy of disabilities, some six or seven years ago I learned I was

HIV-positive, and then in 1988, I suffered a stroke which left me with some deficits on one side of my body and caused me to close down a business that I had going. Both of those pale in comparison with the effects of Environmental Illness, which means I can't go to the theater or movies or ride most public transportation. And with the winter season coming up and all the clothing with mothballs coming out of the closets, I live in deadly fear of what that's going to be like.

Products oft considered safe by conventional standards make people with Environmental Illness very, very ill. Actually, one product like Lysol has been pulled from grocery shelves by the state already. But similar products using the chemical pinene are still in general use, including use by Caltrans to clean the trains. And in complaining one day about that, they just sort of brushed it off until I learned a few minutes later the conductor was getting sick from being in the same car where they were cleaning with this stuff. All of which points out that the standards that are being used for safety completely eliminate the sensitivities of 15 percent of the population, which, if we get down to actual numbers, is a very large number of people just in this city or the numbers of people riding any public transportation. There's a ton of us out there, and you can't tell unless we're running around with one of these stupid masks or an oxygen tank. This is not a political statement; this is just to keep my sanity.

And on the issue of sanity, let me talk a little bit about something that I call a rage reaction which is that there seems to be an interrelationship between the molecules in some of the cleaning chemicals and perfume that interact with the brain in such a way as to produce an almost automatic feeling of anger and rage which, in most cases, I have been able to control, but in some cases I have gotten into shouting matches with people who are much younger and stronger than I am and I have engaged in language and behavior that is not very flattering to me and is quite unusual for me. It could have gotten me killed real easy. I wonder how much of what we call street craziness in fact isn't people with undiagnosed EI reacting to exhaust fumes and perfumes on the street and thereby having these behavioral difficulties.

Even today, as much as you all have taken the efforts to make this a fragrance-free meeting, I still am reacting from some fragrance in the air which leaves me with what I call this "feeling stupid" effect.

For a person without EI, let me suggest that if you use caffeine or alcohol or tobacco or any of the so-called legal drugs, imagine for a minute that you had the effects or the benefits that you claim from using any of those substances, only you had them without knowing the introduction of any of those chemicals into your body system. It's like somebody feeling drunk without having had a drink and not having any control over that, but just because of walking by someone or riding on public transportation you suddenly have this feeling of intoxication and feeling dumb.

We are totally barred from going to theaters and any kind of public gathering because of the huge amount of perfume that's used at those occasions. Because it's a special occasion, going to the opera is a nightmare because of the amount of perfume that people load themselves up with.

I have the answer to a lot of this, I think, and that is throw a tax on perfume and use the revenue to do a public education campaign. (Applause.) I even have a sample of the piece with me, which I'll be happy to leave, which I hand out myself. When I notice somebody wearing a lot of perfume I say, "I notice you enjoy wearing fragrance; perhaps you'd be interested in this information," and then I give them my little flier. It's a lot easier and probably more productive than screaming at them, which is what I really feel like doing.

Least anyone think that this is a rare phenomena, I leave with you this cartoon from the December 1991 <u>New Yorker</u> showing a New York City street magazine stand showing scented and unscented magazines separated. So if things have gotten so common that they are the subject of a cartoon in the <u>New Yorker</u>, we know we have a major problem, and it's time to do something about this. I think the taxation on the perfume would not only increase the revenue for the state but it could be used...

CHAIRMAN MARKS: We can use extra revenues.

MR. CAILLEAU: Yes. It might even reduce the amount of perfume in the air which is not going to do anybody any harm, including the people who like to use it.

CHAIRMAN MARKS: Thank you very much. We appreciate your being here.

MR. CAILLEAU: Thank you very much.

CHAIRMAN MARKS: Thank you.

MR. IMPERIALE: Thank you, John.

CHAIRMAN MARKS: Carol Kuczora. Did I pronounce that right, too?

MS. CAROL KUCZORA: Yes, you did. Thank you.

I have a written statement which is not going to fit into the space of time. Thank you for having this hearing for us.

The concerns that I bring to you today are dictated by my experience, and that has several aspects. First, there was the initial poisoning of my lungs and blood which started with sick building syndrome where I worked for 10 years, and then it was complicated by my recovering furniture three years ago. Then the disappointing contact with agencies of the State of California. Then ever since I got poisoned I have had to move every six months because I become sensitive to whatever is toxic in the air that I'm exposed to on a daily basis.

All these experiences have been shattering. First I lost my health, then my job, then my home, then my faith in the medical profession, then my faith in our government.

In order to obtain accommodation, we first must overcome the prejudice against our illnesses that can be traced to the entities that are causing them. The prejudice is traceable and the illnesses are both traceable to the chemical manufacturers. Something is rotten in California!

I'll skip that paragraph.

The problem is defining the population who needs help. Multiple Chemical Sensitivity isn't just one illness. It doesn't even point to a symptom or a syndrome; rather, it refers to a characteristic that many acquired disorders share in common. Whatever symptoms we get are triggered by exposure to toxic chemicals one after another. Earlier chronic or acute exposures have either caused our bodies to become hypersensitive to those and similar chemicals, or to have lost the defenses against whole categories of toxic chemicals that share metabolic pathways, everyone with any of the disorders that require pure air in order to function. I mean, I'm including systemic poisoning and lung injury and fibrosis and asthma and hypersensitivity pneumonitis and some lymphoprolipherative diseases including leukemia and hypersensitivity diseases that include allergies and autoimmune diseases. Even cancer chemotherapy with immune systems stimulant drugs can make you chemically hypersensitive. And the symptoms differ, too, and they depend on the characteristic effects of the toxic substances.

These things affect my heart and blood vessels and lungs and eyes and ears and memory and make my face and hands numb. We're not talking about sneezing. We react; we chemically hypersensitive people react to undetectable levels of toxic substances and to things we cannot smell. That's not surprising. The permissible exposure limit of a whole lot of toxic synthetic polymers, or monomers, is below the threshold for odor detection.

The history of hypersensitivity reactions goes back to the distillation of coal tar in the mid-19th century. They created dyes and fragrances and discovered all kinds of toxic effects from phenols and nitrobenzenes and anilines and polycyclics. So it's not like we didn't know about it. And in the

'70s we suddenly learned a whole lot about the mechanisms. But something funny happened in the '80s. A lot of funny things happened in the '80s and I don't want to go into too much detail because I'll use up all my time.

MR. IMPERIALE: Carol, if you can start to wind up, please.

MS. KUCZORA: Okay.

The Chemical Manufacturers Association disseminated a briefing paper in 1990 on Environmental Illness and it indicated that the illnesses associated with exposures to toxic chemicals should be diagnosed as psychiatric. The effect of that is character assassination and it sends the message, "Don't believe anything these people say." The effect of psychiatric diagnoses is to block economic recovery for injury or transfer the cost from the private sector to the public sector. It also intimidates and makes us feel very helpless.

We need all kinds of help. We need it in housing. We need a standard diagnostic protocol. We need a disease registry. We need to look at the California Department of Health Services as a creature of legislation in response to public demand. It warrants continuous legislative oversight. We have no assurance that it has recovered from the scandals that plagued it throughout the '80s. We need to look at the worker's compensation system. It isn't working. The California Occupational Safety Health Consulting Service is not available to employees, only to employers. It shouldn't be that way. The Occupational Health Clinic seems reluctant to diagnose these illnesses. There are no toxicologists available through most people's insurance companies. Kaiser doesn't even employ one. The medical boards should include toxicology and immunology and nutrition in their testing and curriculum. We need standardized labs and standardized test results.

And we ought to look all gift horses in the mouth when we have private sector funding of medical education and services.

Thank you.

MR. IMPERIALE: Thank you.

CHAIRMAN MARKS: Thank you very much.

MS. RIPPLE: Carol, can we have a copy of that? Thank you.

MR. IMPERIALE: Carol, do you also have a copy of the Chemical Manufacturers' paper?

CHAIRMAN MARKS: Okay. Michael Mankin.

MR. MICHAEL MANKIN: Thank you, Senator Marks, for inviting OSA Access Compliance to participate, and thanks to Joan of your staff for giving us a call.

I don't have too much to say here except just some highlights about what we've been up to at OSA.

In the mid-1970's OSA was given a mandate to write regulations to address the barriers to people with disabilities, and we drafted regulations in 1982 to provide for a barrier-free environment for Californians. And part of that mandate from the Legislature was also to amend the code on an ongoing basis to address new technologies and new issues that came up. And as part of that process we have recently received a lot of testimony from people with Multiple Chemical Sensitivity.

Approximately July 1990, the Americans With Disabilities Act was passed and that immediately seemed to pre-empt state building code requirements. We looked at those federal design standards for barrier-free design and determined that there were about 35 issues that were not covered in state code. But fortunately, most of Title 24 matched item for item all of the requirements in the federal standard, and we were lucky in that we were able to almost swallow hundreds of pages of federal access regulations that were new to many states, 49 other states that had almost no provisions for access. We were able to basically incorporate all of those provisions, and by adopting 35 new, more restrictive requirements bring our code up to an equivalent ADA standard of barrier-free design.

In the process of doing that, one of our mandates also is to begin with the model code, and almost at that same date in history the model code reformatted substantially and put all of the accessibility requirements that were literally throughout the code, relocated them all into one chapter.

So OSA had a job to do. We had all the ADA provisions to incorporate into the State Building Code, plus we had to relocate 435 sections of code into the new Chapter 31; and in that process we received a lot of testimony from people with Multiple Chemical Sensitivity.

I've worked with Susan somewhat and others in the community and I've also worked at OSA to try to get whatever we could in the issues into this last package, but we were limited in that the issue is somewhat new, there's a lot of diversity in reaching a consensus about what the design criteria would be. And because of the amount of work we had to do with such limited resources, we had decided that that package of changes, 435 sections of code, would just be mostly for two issues: one, to relocate the code into the new Chapter 31; and two, to address the deficiencies with the ADA. And we did not, at that time, entail taking on new territory or new provisions, new regulatory areas just simply because we did not have the resources.

But we were able to alter Exception 3 of Section 110, which I feel, and all of us do feel, was, in the way it was written, it seemed to indicate that access was not an issue as it related to heating and ventilating and air conditioning, and we rewrote that section to strike out the language that people with EI wanted struck, to the extent that that section now says that accessibility issues more or less include people's needs with EI difficulties. And I have the language of that section if Susan would be interested or if you want to check with my office.

It was a difficult task because, like I said, our office really wanted to only do the relocation of the code language and the ADA provisions, and this was an area that ADA did not touch with a 20-foot pole except in the area of readily achievable. So we felt that we were able to at least provide you with some indication that we could do whatever we could do under the circumstances, and beyond that, we'll continue to do what we can to address your concerns and to look at the issues that you have.

CHAIRMAN MARKS: Thank you very much. We appreciate your being here. Appreciate your interest.

MR. IMPERIALE: Michael, before you leave the mike, I know that many, many people with EI/MCS have been writing in to Judd Boyce, Pat McFarland, Barry Ryan, yourself. I'm asking about how one would go about entering things into code, or codifying issues that pertain to people with EI/MCS. I'm wondering, after about four years of watching people aggressively work the process and submitting suggestions for codification of items, I'm wondering what the status is at this time of those files. I know the files must be plentiful by now; there've been a lot of creative suggestions that have come forth from the community. I realize that we are in a budgetary crunch at this point and it looks as though it's insurmountable as far as bringing on new staff to deal with these issues. But again, I would like some insight into how we can possibly expedite the process with all of those full files on hand at this time.

MR. MANKIN: Well, I think we need to meet with industry and put the diversity in one room and have some contact directly between, you know, people with Multiple Chemical Sensitivity and people in the industry who might fear constraint of trade on whatever product they have, so that that dialogue is developed.

I know originally when access was required in hospitals, the doctors sat on one side of the room and they said, "We don't want any access here. The patient is to be taken care of by the staff and we do not want any accessibility in the hospitals." And people with disabilities sat on the other side of the room and they said, "Of all places, hospitals should be 100 percent accessible," and there was no meeting of the minds and it was finally settled that 2 percent of the rooms were to be accessible. And that has been the case for 10 years until the ADA came along and said, well, we'll increase that to 10 percent.

But on the issues here before us, I think there is quite a lot of diversity and a lot of concern on the part of the building industry that there'll be constraint of trade. And I think that what first has to happen is a direct interaction between people that have the need and people that have the product, so that everybody feels very comfortable about the direction of things.

Also, I'd like to say that the establishment of minimum criteria does not prevent anyone from doing whatever they can do, whatever they must do under the ADA to make sure that readily achievable accommodations are there to the extent that people with Multiple Chemical Sensitivity are not disenfranchised and not discriminated against. It's a provision of the ADA in readily achievable obligations that people with disabilities, cognitive disabilities or EI disabilities, whichever the case may be, disabilities not specifically spelled out in the ADA, all of those people, even people who may be in the slightest degree considered disabled, are protected under the ADA. And an entity is required to make readily achievable changes, to do whatever they must do to the extent that they do not have to incur significant costs, to make sure that they do not discriminate.

So I think we have some protection in ADA right now, and I would encourage things now to go more or less in the direction of communication, and I would like to see signage and people who have meetings such as this one do exactly as you have done; that is, notify the public in advance that perfumes are -- you know, people wearing perfumes are going to need to be ostracized or more or less sheltered into one area of the room. I think signs need to be put up that say this area is provided for people with chemical sensitivities. It doesn't have to be a requirement of law or of regulation for people to go beyond the pale and reasonably accommodate each other.

MR. IMPERIALE: Thank you, Michael.

CHAIRMAN MARKS: Thank you very much.

Milan Param.

MS. RIPPLE: Milan, I want to apologize; you were not on the printed agenda. I must have had a slip of the finger on the computer because you were in there yesterday.

MR. MILAN PARAM: Well, this isn't the first time I've been ignored, which you will find out.

I would like to thank Senator Marks and Paul Imperiale and staff for having this today.

I'd like to begin with a brief personal history. Three times in two decades I became ill or injured due to indoor occupational exposures to photographic chemicals, pesticides, solvents, and resins. In 1989 I became overtly chemically hypersensitive and felt close to death due to intense symptoms. I then sought a specialist who allegedly had a letter that denied formaldehyde sensitivities and prescribed psychotropic drugs even though he was not a psychiatrist. These drugs induced dramatic negative reactions and I discontinued use in spite of his encouragement to continue. Thirty months later I finally received test results verifying high concentrations of chemical toxins in my blood, high immune responses to various chemicals, immuno gamma globulin immune deficiencies, EEG testing irregularities, nutritional deficiencies and intestinal damage.

In understanding the Environmental Illness/Multiple Chemical Sensitivity, denial(?) crusade said it is important to acknowledge some of the diagnostic accusations, beliefs, and myths branding the environmentally ill patient. One theme is that chemical phobias are caused by sexual childhood abuses, not chemical exposures. Another is the presumption that patients lie or forget about their own case histories. Another popularized fear by the knife(?) seers of Environmental Illness is that M.D.s who practice environmental medicine possess such powers that they induce the belief of Environmental Illness and chemical phobias in the confused patient. And yet, another shared concept is that sick building syndrome is an example of mass hysteria. Hysteria, by the way, means wandering uterus, and I'm sure no discriminatory offense is directed to men in such buildings. This is all on record and I have documentation of their citing.

This unscientific presumption was also the case with most diseases, including Parkinson's, multiple sclerosis, and cancers before the physiology was broadly recognized. I might add that "mad as a hatter" is a term referring to hatmakers who suffered brain and neurological damage due to mercury toxicity and not because hatters are just a crazy group of workers.

However, it should be acknowledged that psychological factors are created for anyone who is ill from whatever cause. This holds especially true for the environmentally ill patient who may be in pain, not able to function normally, who may not be taken seriously by the medical, governmental, legal, or social systems that may determine their health and well-being.

Often now physical markers of Environmental Illness are being revealed in an ethical, scientific manner. The National Research Council's efforts, funded by the Environmental Protection Agency and the National Institute of Health, has presented excellent documentation of Multiple Chemical Sensitivity testing procedures and results, and I suggest that their publications be used as sources of validity for Environmental Illness and Multiple Chemical Sensitivity. This kind of reality check is long overdue.

Special disability needs for the environmentally ill include disability access, rehabilitation, job training, special housing, transportation, patient rights and proper care, and record registries that can accommodate and account for the chemically sensitive.

It should also be noted that people with MCS may also have immune disorders such as asthma, thyroiditis, multiple sclerosis, arthritis, lupus, and allergies that may need to be addressed. For example, according to a 1986 FDA study, 72 percent of all asthmatics had adverse reactions to chemical fragrances. That's 7 million people in the U.S. that have chemical sensitivity reactions to petroleum, synthetic colognes, perfumes, deodorizers, etc.

Education about Environmental Illness and Multiple Chemical Sensitivity is vitally needed in the public, private, industrial, and especially the medical sectors. The National Academy of Sciences has said most physicians are inadequately trained to recognize and treat illnesses that stem from unhealthy environments at home and work.

Also, disability access for the environmentally ill may include avoidance of pesticides, herbicides, synthetic petroleum, personal products, deodorizers, cigarette smoke, solvents, carpets, glues, particle boards in general. What is needed in buildings and transportation vehicles is unpolluted air.

In my opinion, there are three major factors that mold any public policy or law. They are first and foremost economics; second, politics; and the third is ethics, which would include disability rights and public health and safety.

In all frankness, special interests will lobby, for economic reasons, on many of these issues, creating a lobbyist democracy which is nothing short of an oxymoron.

There are tremendous social costs that are incurred when serving vested interest, or rather, vested ignorance. Until we as a society and a government assess the true and total cost of the long-term environmental impact on health and the environment, including property values, we are deluding ourselves. Many of the needs of the environmentally disabled, especially those involved in indoor air quality, will be of benefit to virtually everyone. As it stands now, hypersensitivity diseases in general are among the most common and costly health problems that afflict at least 35 million Americans. Also, immune suppression and autoimmunities are also of great concern of the U.S. Department of Health and Human Services and the National Institute of Health. This is from 1980. Those numbers have increased.

Also, studies by the World Health Organization in 1964 revealed that 75 percent of cancers were caused by carcinogens produced by humans. And I would add that according to the EPA indoor air pollution studies, it is many times as toxic -- indoor air is as many times as toxic as outdoor air pollutions that also include carcinogens and sensitizers.

MR. IMPERIALE: Milan, can we start to wind this one up, please.

MR. PARAM: Yes, okay.

So, the realization is that 35 percent of everyone will have cancers primarily due to carcinogens which are incurred indoors.

So how do we suggest that industries, including medical industries, look at the broader implications? It may be cost effective for interests such as government and the public and their economic paradigms. With meaningful resolutions to indoor air quality problems, work of productivity can increase. Retirement age and incentives to continue on can be increased. Toxic tort litigations would be minimized and so on. Worker's compensation costs will decrease.

Also, industries should know that new business and opportunities exist in the fields of natural building products and interior accessories that are favored in Germany and other countries. Integrated pest management, natural deodorizers, and ventilation and filtration systems are but a few of the additional growing industries. The alternative for major industries is to lose a market share in these new growth industries if they do not change.

Thank you.

CHAIRMAN MARKS: Thank you very much. We appreciate your being here. Appreciate your testimony.

Alan Levin.

DR. ALAN LEVIN: Thank you very much for inviting me to speak. I'll try to be as brief as possible.

I just want to say that this is a widespread problem; it's not involving simply a few hypersensitive individuals. It's involving a large segment of our population. It's also not a new problem. It's been around for a long time. The difficulty is that our genetic population is changing and our environment is changing. We have to recognize that there are many things in our environment that are affecting our health, if you look at the market of the people who are chemically sensitive -- you don't necessarily have to look into this room --

people who buy Rolaids, who buy Sominex, who buy Benadryl, who buy Anacin. I mean, these people are covering up environmental hypersensitivities. They just don't want to admit it because it's not politically correct.

Another very important issue is that the problem is growing. It not only affects females now but it also affects males; and indeed, it affects the Desert Storm veterans. Desert Storm veterans are coming back with serious environmental illnesses, and the Veterans Administration is beginning to recognize it. So it would be very politically wise for people to begin to understand that this affects a large segment of our population.

I think some of us in this room remember when we used to use x-ray fluoroscopy to see when our shoes fit. I used to zap my gonads to see if my Buster Brown's fit.

If we're successful around here about 5 or 10 years from now, I'm going to tell a 10-year-old boy that we used to spray pesticides from airplanes. That boy is going to say, "Nobody could be that stupid."

Anyway, these chemicals are extremely toxic; they're affecting a large segment of our population. This particular issue has been widely recognized in Europe and in Asia but has been suppressed in America. There have been special interest groups that have suppressed the reality within the American medical institutions. The drug companies don't particularly like this particular disease process and they are having a great deal of effect on the American medical establishment. I will tell you, however, that the American medical establishment is losing a great deal of power because the general public recognizes this is a problem.

I'm going to say something and it's not very pleasant but I'm going to say it anyway. I used to run around the country saying that trichloroethylene in the water causes birth defects and learning disabilities and childhood leukemia. Everybody said, well, Dr. Levin, that's irresponsible; we need more epidemiology, we need more studies. Then I started saying it causes wrinkles and impotence. It's now illegal.

We have to get to Joe-Six-Pack and make him recognize that these things are dangerous. Joe-Six-Pack now knows it and the politicians should also know.

Thanks.

MR. IMPERIALE: Thank you, Dr. Levin.

CHAIRMAN MARKS: This is one politician who's learning.

Katy Crecelius.

MS. RIPPLE: Katy's not here yet.

CHAIRMAN MARKS: All right, let's have the public comments. David

Gilmartin. We're not going to have too much time for this, about three minutes.

MR. DAVID GILMARTIN: I'm David Gilmartin. I am a Unitarian Universalist minister whose ministry is on behalf of people with disabilities.

Since 1987 I've worked at three Independent Living Centers. At one of those centers I was a Client Assistance Program Advocate, part of the program of the Department of Rehabilitation, to help people who are having any kind of problems or difficulties, complaints with the Department. In that connection, or in those connections I feel I want to make a couple comments with regard to the Department of Rehabilitation and the living centers.

Some of the problems in terms of serving people with Environmental Illness/Multiple Chemical Sensitivity that I experienced with the Department of Rehabilitation come together in the case of one man. He was formerly a newspaper reporter in the Central Valley. He moved out to Marin to escape some of the pesticide spraying of the valley. He went to the Department of Rehabilitation for assistance in finding employment. He was very much wanting to work.

First of all, he had many problems because he was misdiagnosed and his secondary diagnosis of mental illness was given the primary importance and the EI diagnosis was ignored for quite some time. The functional limitations that he had in a sense were secondary to the medical condition.

This is exactly backwards in my view. The federal definition of disability, and now the state definition, has to do with impairment of a person's functioning in various life activities. So the Department, at its outer door in determining who can be a client, is looking at a medical definition rather than a functional definition of disability, which I think significantly prejudices the availability of the Department of Rehabilitation services to people with this condition.

Second, this particular client requested some medical treatment to help determine what his optimal state of functioning would be. The Department denied this kind of treatment, even an extended evaluation procedure, because these treatments are experimental. They're not approved by Medi-Cal and the Department will only accept for this kind of procedure, those procedures which are accepted by Medi-Cal. So he was denied an opportunity basically to show his vocational capability to its maximum.

The third thing that happened with this individual had to do with the kind of job that he suggested that he could do, which was to do a job as a photographer. This was something that on the basis of his research and his abilities and what he knew about the environment was something that he felt he could probably do. The Department of Rehabilitation rejected the idea because there were so few jobs in that particular area that it didn't meet their requirement for there to be an adequate labor market. Again, the Department, with its requirements, was not accommodating the very particular and individual needs that this gentleman had with regard to employability.

Independent Living Centers, one would think would provide services to people with this kind of disability. After all, they were set up by the California Legislature a number of years ago to serve people with all kinds of disabilities. This has not, however, proven to be the case, and not just for people with Environmental Illness but other disabilities, too.

Independent Living Centers came into existence, I think, during a period when physical disabilities, mental disabilities were the primary model of disability. People with alcoholism are often not well served by Independent Living Centers, just to use one further example, because they don't fit the older model of what a disability was and what you treat and what kind of services are needed.

Two examples of this come to mind. One is when Susan Molloy was briefly employed by the Independent Living Center in Eureka, California. Within a month or two 100 additional clients for that agency were identified and became active. The Environmental Health Network, which in many respects is like an Independent Living Center, it has a board governed by a majority of people with disabilities, statewide probably serves 100 people a month on an all volunteer basis. They do not receive any funds from the state to provide these independent living services. So there is quite an unmet need by people with Environmental Illness that Independent Living Centers are not picking up on either.

There've been a number of points made about things that are needed to address the situation today. Accessibility audits have become a very big thing recently with the ADA but do not address Environmental Illness, and development, I think, of an accessibility audit process that would identify and target Environmental Illness would probably be very helpful for the long-range planning in dealing with these disabilities.

And funding for independent living services, specifically for people with Environmental Illness and Multiple Chemical Sensitivity, I think, is also very important in addition to what has been stated already.

Thank you.

CHAIRMAN MARKS: Thank you very much. Appreciate your being here.

Gary Stevens.

MR. IMPERIALE: I want to remind those individuals who are speaking under public comment that we have quite an extensive list of people who have signed up so we need to try to keep our comments within the three-minute time range, please.

MR. GARY STEVENS: Yes, sir. Thank you very much. Gary Stevens.

I would like to talk about attitudinal barriers for just a couple of moments. My wife is EI/MCS. She can't be here today.

We certainly know that there are attitudinal barriers with the general public. We know that there's attitudinal barriers that have got to be overcome in bureaucracy and so on. But on a more personal note, those of us who have spouses or people in immediate family who have EI/MCS have to deal with a different kind of attitudinal barrier. With family and friends, they typically go through a process that they're trying to be understanding and helpful until something like a family reunion comes along. All of a sudden the rules change. All of a sudden a person with the EI/MCS has now to undergo often what is disbelief. People really don't want to believe about the illness. All it takes is one health practitioner in the media, to have one article in which the person has made a mass diagnosis of depression for the family or friends to let you know about that article.

This is very, very difficult for the person, obviously. It adds to the anxiety. As a spouse, I can tell you, yes, it causes problems. There are constantly changing symptoms, the mood changes, the inability as a family or for my wife and me to do things that normally people would consider normal; they take a lot of time, a lot of preparation. I've often thought, considering what we've been through together, I'm almost looking forward to the so-called emotional changes coming with menopause. That's not meant to be chauvinistic. The point is, they can't be any more difficult.

It's been very difficult for our children. Happily, our children have adjusted fairly well, I think, considering.

I noticed anecdotally -- I have no part of this -- divorce rate is very high. Typically, because it's been related very closely to women, with of course more males coming out now with the illness, it's the male spouses that have difficulty. They really don't want to believe this.

I thought about the kind of phases that people go through and I think it's public as well as individual spousal response. First, I know speaking especially for myself, there's kind of disinterest at first: oh well, one of those things. Skepticism: What? Come on, come on. I mean, I'm a trained biologist; I know a little bit about this. I know about the limbic system, I know a little what the smell does, but come on. Denial. Defensiveness with others, with your immediate family, with your friends, trying to explain this when you really aren't sure about it yourself. Anger; anger with your wife, anger with others around you. And then spouses go through their own depression. They get depressed, too; like what the heck am I going to do? How much more of this? How long, oh Lord, how long? Finally, if things work well in a family, finally, maybe with counseling, whatever it takes, you get some kind of a reluctant acceptance. Then you get a little more curious; it's time to learn. This goes along with the acceptance. You get a little more curious, you start doing a little education, you start re-evaluating the presumptions, the assumptions that people make. You begin to question the experts, so-called experts. You develop a certain amount of sympathy, compassion. Finally, you really get into support.

This is a long process. This is not something -- that's why I'm very happy to see that you folks are doing this, and I hope that you have a long, long life and continue to do this, because thinking in terms of my personal life and what it has taken me to get to this point, for the public to get to this point it's going to demand a continued effort.

And I thank you.

CHAIRMAN MARKS: Thank you very much.

MR. IMPERIALE: Thank you for your comments.

CHAIRMAN MARKS: Chrysa Caulfield. Again, I have to remind you, we're suppose to adjourn this meeting at 1:00 but we're going to go for a few minutes longer.

MS. CHRYSA CAULFIELD: Senator Marks, ladies and gentlemen, thank you very much for the opportunity to talk with you today.

My name is Chrysa Caulfield. I am chemically sensitive.

The key points I would like to make are that Environmental Illness is costing society the loss of many talented people, it is not a psychosomatic illness, and that it is largely avoidable.

First I would like to briefly present my experience of EI. I became chemically sensitive in May of 1990 as a result of exposure to relatively new carpeting in a tight building at work. Within eight weeks I became almost completely incapacitated and had to leave work on full disability. My symptoms were incredible fatigue and exhaustion, difficulty breathing, severe hypoglycemia, and inability to concentrate, memory loss, and mental confusion. It felt as if my body was dying while I watched.

The first month off work I slept 18 to 20 hours a day. I was so exhausted I could hardly move. I wrote down what I did each day because otherwise I could not remember.

My condition slowly improved over the next six months but was always dependent upon avoiding chemical exposures. Even though I'm doing much better now, my condition deteriorates dramatically when I'm exposed to chemicals.

Environmental Illness has radically changed my ability to make a significant contribution in the workplace. I have over 10 years of high-tech experience in engineering, marketing, and sales. I have three Master's degrees from Stanford University: one in electrical engineering, one in business, and recently one in environmental engineering.

I just started a new job two weeks ago but I'm resigning because the building is making me very sick. Every day that I go to work I have difficulty breathing, my lymph glands swell, I become severely hypoglycemic, and am so fatigued that I cannot concentrate. Each day my condition deteriorates a little more. I find it rather frustrating to be removed from the marketplace simply because of poor indoor air quality.

I can tell you many more sad details of my experience, but let me move on to the psychosomatic label given to Environmental Illness.

EI is a relatively new disease without a medical cure. The symptoms are highly subjective, involve many different systems in the body, and may be delayed in time from the chemical exposure. Some doctors are baffled or frustrated by this situation and turn to a psychosomatic diagnosis. In addition, the majority of EI patients are female, which may be another contributing factor in the ease of dismissing the symptoms as psychosomatic.

I'm not sure what I can say to convince you of the physical cause of EI except to state that in my case my symptoms have correlated precisely with the level of chemicals present regardless of whether I knew the chemicals were there. To me, telling someone that EI is psychosomatic is like telling someone that fire burns them only because they believe it will. I strongly encourage you to fund unbiased research into the causes of Environmental Illness.

Finally, I would like to offer a few suggestions as to how EI can be avoided.

1) Reduce or eliminate the use of toxic chemicals, especially indoors. There are many non-toxic alternatives available and many more will become available as demand increases.
2) If chemicals must be used, then bake buildings and houses before occupying them. Baking greatly accelerates chemical outgassing and results in much lower residual chemical concentrations.

3) Regulate indoor air quality in the same way that we now regulate outdoor air quality. EPA studies show that many toxic chemicals found indoors are carcinogenic and are the same chemicals found at toxic Superfund sites.
4) Increase fresh air flow rates in tight buildings. If increased energy costs are of concern, use energy saving technology that does not lead to poor indoor air quality.

In closing, please let me repeat that Environmental Illness removes many highly skilled people from our workplace, that it is not a psychosomatic condition, and that many actions can be taken to eliminate or reduce the conditions that cause EI.

I sincerely hope that you will take my words to heart. Thank you, again, for the opportunity.

CHAIRMAN MARKS: Thank you very much for being here. We appreciate your testimony.

Krista Munson.

We're going to again have to limit you to about three minutes.

MS. KRISTA MUNSON: I would like to speak on the topic of housing and shelter needs.

Housing is one of the most critical problems for people with EI/MCS. We need both accessible permanent housing and accessible temporary shelters. Current housing and shelters, both public and private, contribute to making people sick and to keeping us sick.

We need housing that does not contain particle board, gas appliances, carpeting, fragrance or tobacco smoke permeating the walls, paint or caulking applied in the last several months, or pesticide applied ever. We need housing away from industrial and traffic exhaust. We need temporary shelters that meet the same criteria. And we need prevention of situations that cause us to flee our homes.

Some first steps towards meeting these needs include:

1) Restrictions on pesticide use, especially residential use; and education in integrated pest management for landlords, pest control businesses, public agencies, and the general public.
2) A registry of safe housing, and incentives for landlords to make housing safe and to keep it safe.
3) New building codes.
4) Programs for modifying existing housing.
5) Creation of special temporary shelters.
6) Education about the disability of EI/MCS for landlords, developers,

architects, contractors, hotels, and public agency employees.

7) A resolution that all state agencies must recognize the disability of EI/MCS and must provide us equal access. For example, when the Agricultural Board lists fragile populations who might be harmed by certain chemicals, EI/MCS must be included.

If these needs sound in any way strange to you, listen to the effect of chemicals on us.

People with EI/MCS struggle with chronic illness affecting multiple systems of the body; typically the immune, endocrine, neurological, digestive, and detoxification systems. Neurological effects include mood changes and so-called psychological disorders. When we are exposed to toxins, even in minute amounts, our chronic symptoms intensify. We also experience other acute symptoms. We lose functional abilities. As you can see, I have difficulty walking, talking, and thinking when I breathe fragrance, smoke, or other toxins. I was not having these difficulties when I arrived here this morning.

Because of both the chronic and the acute effects of toxic exposure, people with EI/MCS must work very hard to make our homes a safe haven from the ubiquitous toxin to the modern world. But there are times when a home is no longer a haven. Earthquake, fire, flood, and yes, toxic chemical spills can force anyone from their home. People with EI/MCS have additional causes for evacuation. Road paving, hot tar roofing, neighbors or landlords painting or using pesticides can force us to flee our homes for a day, a week, a couple of months, or permanently.

We need equal access to emergency shelters set up for natural disasters. We need equal access to permanently operating homeless shelters. Equal access is granted under the ADA but agencies are not prepared to provide it. Shelters are not accessible when residues of smoke or scented laundry products are in people's clothes, scented soaps are in the showers, volatile cleaning products are on the floors, or the food is laced with preservatives, coloring, artificial flavoring, fermentation, hormones, antibiotics, or pesticide residues.

Evacuations of the general public are infrequent, but people with EI/MCS have frequent need to evacuate for the local, more individual emergencies. In the 16 months since my first seizure I've had to evacuate 11 times; six of those on an immediate basis with no warning. On one occasion I could not ever go back to that apartment.

There is no safe place to go when one has to evacuate. It does not exist. I have had to depend upon friends and strangers to take me in and to modify their product choices or to let me sleep on their porch for a few days and then move on to someone else. At that, I'm lucky in having a wide network of friends. But friends get tired of coping with someone else's frequent emergencies. With the isolation of this disease, one's network shrinks, too. Heaven help those, or rather, the State of California must help those who have no friends who can take them in.

Ordinary homes aren't chemically safe anyway. Hotels aren't safe. Campgrounds aren't safe. The home of someone else who has EI/MCS would be safe but we're too overwhelmed with our own medical needs to be able to take in someone else. There is simply no safe place to go when one has to evacuate.

Because there are unpreventable disasters, the need for shelters will always exist, but the need to flee is often preventable. By minimizing the demand, prevention measures will minimize the cost for shelters. Availability of accessible permanent housing will reduce the length of shelter stays.

We need safe housing so that we can rebuild our health, to function well enough to take care of ourselves and to support ourselves. Without safe housing, we can't get there.

Thank you very much.

CHAIRMAN MARKS: Thank you very much. We appreciate your being here.

MS. RIPPLE: Krista, can we have a copy?

CHAIRMAN MARKS: Susan Nordmark.

MS. RIPPLE: If you have a paper that you've prepared, would you please summarize and hand the paper in and we'll make sure that your paper is included in the final report in toto.

MS. SUSAN NORDMARK: My name is Susan Nordmark. I want to address a few medical issues that have not yet been addressed so that I can be as concise as possible. So these will be apparently somewhat random or disorganized because I'm summarizing.

One of the points that I wish to make regarding the needs of MCS people in medical treatment is that universal health care must become a reality.

CHAIRMAN MARKS: I've voted for it several times.

MS. NORDMARK: The existing frame work, or one might say "honeycomb" of private insurance, Medicare and Medi-Cal fails miserably in serving the medical needs of the multiple chemically sensitive.

First, many persons with MCS have no insurance coverage whatsoever. It's easy to imagine that someone recognized some years ago that she really couldn't work in an office and she shifted to working at home and she bought a personal policy and then her premiums became too high. You know very well that many people are not covered at all. This critical fact must be kept in mind. Reform of existing programs is not enough because many, perhaps most, MCS persons fall between the cracks completely.

Second, most carriers fail to recognize the existence of MCS and nearly all carriers are notorious for stonewalling payment for the types of treatments which have been found clinically most useful in MCS. Thus, these individuals lucky enough to have some type of insurance coverage are frequently forced to couch their needs for treatment under other diagnoses if they are, one might say, lucky enough to have them. Diagnoses such as asthma, autoimmune disease, cluster headaches, Chronic Fatigue Immune Dysfunction Syndrome, or various types of allergies.

Medi-Cal is the worst program probably; it pays for practically nothing at all that is medically helpful. Medicare is little better; yet, private insurance companies are sometimes worse than Medicare in some respects. As you know, the laws probably protect persons who have private insurance less than anyone else because there's no incentive for insurance companies to pay. HMO's are very, very, very bad.

So in practice, a person may technically be insured, but practically speaking be without medical help. And in general, in my experience, that's the majority of people with MCS.

Board of Medical Quality Assurance targeting and harassment of physicians who treat MCS must end. In effect, these actions violate both consumers' rights to choose medical services they find most helpful, and anti-trust laws as well. Medical politics in California and in the United States as a whole involves a bitter tug-of-war for consumer health care dollars currently.

With burgeoning public interest in nutritional, non-invasive, non-drug, immunotherapeutic approaches to treatment of illness, and innovative physicians as well as non-physicians such as acupuncturists, who offer treatment which mainstream physicians aren't yet prepared to present to patients, traditional doctors are fighting to keep control of consumer spending in health care. One way they're doing this is by persecuting doctors who don't follow the party lines. These actions, as sanctioned by government, are anti-competitive, and are contrary to the rights of consumers to choose in a free market.

CHAIRMAN MARKS: How is government agreeing to this?

MS. NORDMARK: Well, the Board of Medical Quality Assurance is, I believe, a state board and there are also local boards. Now, physicians hold positions on these boards. These boards have the power to target and go after and examine and harass legally physicians who provide treatments which the mainstream of doctors don't agree with. And a lot of doctors who provide treatment for

Multiple Chemical Sensitivity, which mainstream physicians won't even recognize exists, they therefore label these doctors as fringe doctors and doing fringe treatment and thus.

So, physicians with expertise in treating MCS must be allowed freedom to exercise judgment and knowledge subject to the review of colleagues in their medical specialty. Last year's bill, AB 704, sponsored by Jackie Speier, would have ensured this by mandating that physicians be reviewed by a panel of their professional peers rather than by doctors from competing specialties.

It then follows that as treatment is offered to persons with MCS it cannot involve restrictions on choice of physician. The HMO model will not and does not work for persons with MCS. Because of medical-political trends over the last several decades, very few physicians have chosen to learn to treat MCS. And so there currently are just a few physicians competent in the field and we must be able to consult those physicians whom we've found are the most knowledgeable about our condition.

More physicians are needed to specialize in the treatment of MCS and related illnesses. Medical students need to be taught about MCS as a cause of somatic illness and as a cause of apparently psychogenic illness. Research on the etiology and mechanisms of MCS is needed; yet, as has been discussed at length, it has barely begun. This is no accident.

What we need to look at, and I wish to speak to the comments of, I believe, Dr. Harrison much earlier this morning, when we look at the literature, we need to realize that the literature doesn't represent the universe of facts. Literature represents the result of very, very expensive research and we have to look at where does research dollars come from. Production and distribution of scientific information in this country occurs within a context shaped by corporate financial influence. It is not in the financial interest of many large corporations that information on MCS is documented.

So because of this follow-the-money link between funding sources and direction of research, research is largely directed towards drugs, chemotherapy -- this is true for cancer as well -- away from environmental causes of illness, nutritional approaches to treatment of illness, immunotherapies as opposed to drugs.

By the way, this bias is not nearly as apparent if you look at papers published by medical researchers in Europe and in other parts of the world. The corporate influence just isn't as obvious at all. A lot of the best immunotherapy papers that I see, the work is done in Europe.

MR. IMPERIALE: You're going to have to start winding up your comments, please.

MS. NORDMARK: All insurance carriers must pay for medical treatment for MCS. Because there's sparse literature at the present time, physicians' clinical experience, patients' clinical response must be relied on. That is data. You can do blood tests if you want, but patient response is data. It's recognized in other illnesses, it needs to be recognized with this illness.

The truth is, people with MCS want to work. We want to get back to work. We want to be living productive lives. But you can't damage our bodies with chemicals and then expect us to crawl up on our own. We need medical treatment just like everybody else.

I'll just briefly mention some of the medical treatments that have been useful to persons with MCS and all of them have been blockaded by most insurance carriers. Intravenous gamma globulin is immensely helpful to many people who have MCS related illness. Various immunotherapies. Transfer factor. The research for transfer factor, Dr. Levin, who spoke just earlier, has been a great deal involved in doing transfer factor. Ampligen. Various types of desensitization protocols. Intravenous nutritional factors, including Vitamin C, oxygen therapy, and various pharmaceuticals which, by the way, are often available in Canada and Europe but which are either in the FDA's very slow pipeline or will never be in the pipeline for financial reasons.

CHAIRMAN MARKS: Well, thank you very much. We appreciate your being here.

MS. NORDMARK: Thank you.

MR. IMPERIALE: May we have a copy of your testimony, if you have one, please? Thank you.

CHAIRMAN MARKS: Melissa Sarenac.

MS. MELISSA SARENAC: Thank you.

I came today and I signed up to speak because I understood that Dr. Aba Terr was going to be here presenting his position that there is no such thing as Environmental Illness or Multiple Chemical Sensitivity.

Just in case he is submitting a paper to you, I want to go on record, and this is going to be very brief, that my company sent me to see Dr. Aba Terr. He took a very detailed -- seemed to take a very detailed history about my case and then after a very brief physical examination said conversationally, "There's nothing wrong with you." And I was flabbergasted because I have been -- I've suffered fumes from an air conditioning system on four different occasions that seared my lungs. A couple of months after I was seen by Dr. Aba Terr, I had a test, a highly sophisticated test up at UC Medical Center. I was hooked up to a couple of computers for breathing and for EKG and I had a tube in my wrist for -- they took blood tests every two minutes. So two months after Aba Terr said there's nothing wrong with me, this highly sophisticated test showed that I had pulmonary vascular disease or early interstitial lung disease.

So I just wanted to go on record in case Aba Terr was submitting anything to you. This is a man who was in a documentary on television saying that there's nothing wrong with these people and sending them back to work, and as a result of being sent back to work, one man lost his life.

I have a copy of that program.

So that's all I want to say about that. But one of the things I do want to say also is that after that gentleman talked about putting out announcements of pesticide sprayings and that sort of thing, I asked him from over here on the floor if these announcements, if it was mandatory that the newspapers and TV and radio make these announcements for the general public, and he said, not to his knowledge. And so, I would urge you, Senator Marks, to be sure that it is mandatory for those announcements to be made to the public by means of all media available.

Thank you very much for having me today.

CHAIRMAN MARKS: Thank you very much. We appreciate your being here.

Sandra Ross. Again, we have to limit you because we're running out of time.

DR. SANDRA ROSS: Yes.

I'm Dr. Sandy Ross. I'm President of Health & Habitat, which is a conservation and holistic health organization. In fact, we're one of the people that took Krista in at one point, and I'm just horrified to see what this building has done to her. It makes me wonder what it does to the decision-makers upstairs.

We support Susan Molloy and her well-thought-out list, and I hope you will enact everything immediately.

I'd also like to emphasize the concept that these precautions will benefit millions of people who may avoid acquiring EI/MCS by not being exposed to these chemicals, and this would certainly save billions of dollars in the health care.

There are also thousands of people who are ill with this syndrome and they don't realize it, and they, of course, will benefit by it by having the chemicals removed.

I'd like to take just a minute and talk about the Medfly debacle. I happen to be familiar with an entomologist who may have lost his life exposing it. I'm told that these applications are made on private lands, not necessarily on farmers' lands who already do their own spraying. And other countries put up with the Medfly; we probably should also. It's my understanding that the main reason we don't is that we export a lot of our fruit to Japan which does not as yet have the fly but probably will in the near future just simply because our world is getting smaller in terms that the transportation is so rapid.

I think this is an example of the marketplace costing the state a lot of money and endangering many lives. It happens with perfume and other chemicals we've been talking about, too.

So I'd really like to thank you, Senator Marks, for originally creating this committee -- I'm sorry your colleagues aren't here today -- and for taking up the EI/MCS cause. I trust that you will create accommodations for people with these conditions all over the state.

Thank you.

CHAIRMAN MARKS: Thank you very much.

Joy Hahn. Kelli Valle.

MS. KELLI VALLE: Thank you for this opportunity to speak. My name is Kelli Valle, and I am the Director of Transportation for a paratransit system in Marin County named Whistlestop Wheels. It is a division of the Marin Senior Coordinating Council.

Our first exposure, if you let me use that term, to EI and the problems that exist with Environmental Illness was a series of meetings that resulted from our Paratransit Coordinating Council in the County. We met in ventilated rooms by opening our windows and doors, by turning off our fluorescent lighting, by sitting far away because we were not as yet educated to the effects of perfume and cosmetics and different chemicals on clothing or used to clean clothing, that sort of thing, and we tried our best to listen to the problems when it comes to transportation and the needs of people who suffer from this disorder.

We understood that accessible transportation was needed, and the reason our transportation service was not accessible was because the people who traditionally used the system were elderly people who had been using fragrances and different substances that are toxic for many, many years. We learned that education was very important. And we also learned that the materials that our vehicles are made out of were not appropriate to transport people with EI.

We decided we should do something. Even though we're a non-profit organization, we are funded a majority by county funds, and we also are eligible for a grant process through Caltrans. We decided that we would use that grant process, which is the UMTA 16-B-2 plan, to rehabilitate one of our vehicles. We did that. It was the first time anybody ever thought of doing this. No one ever thought it would ever work, and the first time we tried it it worked.

We are in the process now of using $10,000 that the state is affording us for this project; it is a pilot project, it is a model project. I don't think there's anything in the nation that has been created like this. But I'm here to tell you that if you have any kind of processes or procedures that you have access to to raise money to create things that might help people in other ways, in other things that affect people's lives besides transportation to try, even though it would be precedent setting. We are only months away from the pilot project, from having this vehicle available. It is only one vehicle.

We also have PG&E who has decided that they would help us by funding the project in the sense that they will help us convert the vehicle to have another type of fuel alternative, which is natural gas. We understand that the emissions from gasoline can affect people with EI, but also the emissions from natural gas can affect people with EI, but at least it will give us a flexible alternative for people who aren't affected by either/or. And we feel confident and we feel encouraged that PG&E wants to be part of this project, that they want to be educated. And hopefully, they will start a trend that other corporate organizations will try to undo some of the physical, emotional, and social destruction that they have created.

We need policies, we need procedures, and we need funding to implement the kind of things that are needed to help people with EI.

Thank you very much.

CHAIRMAN MARKS: Thank you very much.

Cathy Weitzner.

MS. CATHY WEITZNER: I just found out a couple of days ago you were having this hearing so I don't have anything written except scribbled notes, but I will write them up and send them to you for sure by October 15th.

I'm here on behalf of my sister who has EI and severe, severe chemical sensitivities, and on behalf of all those people who already have it as well and for all those people who will be getting it if we don't eliminate the toxic substances in the environment.

Specifically, I want to address the problem that we're having at this time. My sister lived with me for nine months, if you call it living. Her life is really either a little less or a lot more suffering from hour to hour and from day to day. She's totally isolated to her home. No friends can come because even if you tell them not to wear perfume they forget about hairspray, about soap, about shampoo, etc. So she is isolated from society at this time. She is a bright woman who was very productive in a university and was forced to leave and is on total disability.

The ironic part in terms of insurance that I want to address is the fact that my sister gets hundreds of dollars for Social Security, from the federal Social Security disability. She receives $250 from PERS, the Public Employees Retirement System. And yet, she is denied care through her insurance company. The government will continue to be spending money for nothing because my sister will never become productive again unless the insurance companies accept the fact that this is an illness and that it can be treated. Right now she's being denied all the appointments she had with a doctor who is a specialist in this field. She tried many, many, many doctors before this doctor. Unfortunately, none of them knew basically what she was talking about. They even told her, "You know more than we do." She sought doctor after doctor as well as I did for her. We finally found someone who was intelligent, who was sympathetic, compassionate, and aware and very, very, very knowledgeable. He is not a preferred provider and she has been totally denied any remuneration for the funds that she paid the doctor to help her. She discontinued treatment in February and has not been back since.

I would also like to add that it is becoming a very common problem. The people around me, my social environment, the people that I see on a regular basis are talking much more about they can't wear perfume anymore, they are reacting to smoke, they are reacting to the environment.

I think the most important thing is that people be educated. If the insurance companies were educated and the government was educated, perhaps people could be helped.

Thank you.

CHAIRMAN MARKS: Thank you very much.

Sally Cahill.

MS. SALLY CAHILL: This year my office was moved to a remodeled building where construction was still going on. Before the move, in answer to some very difficult questions I posed, management assured us that everything was perfectly safe. The building had new carpet, new paint, particle board work stations and partitions, glue containing toluene being used during working hours and a severely inadequate ventilating system.

On the third day I became very ill. Because I feared losing my job, I worked in this environment for three weeks, some days wearing a respirator. The next two weeks after that I spent lying on the couch barely able to leave the house to transport my kids to and from school.

The air testing I'd begged for from day one was done five weeks after the move. It showed a high formaldehyde level plus the presence of toluene, zylene, and other chemicals.

Contrary to a statement made by our risk manager that the H-VAC system had undergone "major improvements," it was noted that no one even knew where the intake shafts were. When the air intake shafts were found they were discovered to be clogged with leaves and dirt. Floor vents had not been cleaned, although recent asbestos work had been done in the building, and many were not even open.

I'm currently fighting to regain my health and I'm also trying to regain my sick leave and vacation time that my employer has stolen from me. My worker's comp claim has been denied because of a doctor who made statements attributing my symptoms to psychological problems. She made statements such as the fact that I subscribed in recent years to "clinical ecology concepts. This is a cult-like phenomenon wherein people believe they are experiencing symptoms from very low levels of chemicals in the environment." She also said, "I know of no health effects, theoretical or otherwise, attributed to laser printers." When I mentioned formaldehyde levels in the building, she said, "Well, you know there's formaldehyde in permanent press clothing," and I said, "Well, I don't wear permanent press clothing." She didn't want to listen to me and she basically said that I decided to get sick and I got sick.

After being a very healthy person for my whole life, and virtually not missing a day of work in 25 years, I knew that something was wrong when I couldn't function.

MR. IMPERIALE: I have a question for you. I'm wondering whether you work for a private sector employer or whether this was a public employer such as a local or state government.

MS. CAHILL: Public.

MR. IMPERIALE: Public. Thank you.

MS. CAHILL: I think air testing should be mandatory for all new and remodeled buildings. I think it's just very sad that people are still in that building.

The doctor also made a statement that I could work in the building, and I can barely tolerate the place for two hours because of the exposure that I had. I'm not a hypochondriac. I went to work when I was in labor with my last child. And the statements that this woman made were just slanderous, to say the least.

I'm very fortunate that I haven't become totally disabled but I do have problems; I'm definitely more chemically sensitive than I ever was. I never had any sensitivities before this exposure, and something really needs to be done to make people aware of this problem. Sending people to so-called experts who make ridiculous statements and just totally don't want to listen and don't believe that this problem exists should just not be allowed.

Thank you.

CHAIRMAN MARKS: Thank you very much.

Jane Jackson.

MS. JANE JACKSON: Good afternoon, Senator Marks.

I feel like a very old canary in this room. The Department of Rehabilitation denied me services in 1973. I, too, am glad the name Dr. Aba Terr has come up. I, too, had hoped to see him here because in the late '60s I was a patient of his and underwent a long series of shots for a variety of allergies. While I was in graduate school my school was remodeled and I was environmentally injured. I went back to Dr. Aba Terr and he decided that it was all in my mind. I've been avoiding public places, groups, new environments, public transportation for years in order to be able to maintain some semblance of sanity, of clear-headedness. I suffer from asthma. I am now trying oxygen to see what kind of relief we get from it. I, too, have been denied oxygen by Medi-Cal and my mother at the moment is paying for it as a demonstration project to see if we can reconvince Medi-Cal with documented proof that it works.

I just want to thank you very, very much for dealing with an issue that has grossly affected my life. When I asked the Department of Rehabilitation to be facilitated to run a half-way house for physically disabled people coming out of the criminal justice system, because that's what my academic training is in, they told me there was no demonstrated need. Such a facility still does not exist, I still am not employed, and I've been on the public dole for almost 20 years unnecessarily. I just wanted to share that with you.

CHAIRMAN MARKS: Thank you very much. We appreciate it.

Robert Murray.

MS. BARBARA SCOTT: I have his testimony. I'm going to summarize it rather than read it.

This statement is written by a person with Environmental Illness who -- well, she terms it as "chemical poisoning" because she is currently living underground because the government subsidies that she's on force her to stay in a very, very sick environment, so now she is staying with somebody else who is on government subsidies and they're not allowed to live together or share housing or anything, even in the emergencies when we must evacuate. So she is currently living underground. She's been looking for a new place to move to for four years. She finally had to leave because her landlord could not put off the painting. So she is on oxygen all the time and she's extremely ill. She feels like she's in such a dangerous situation at this point that she's afraid she might not live through it. She is a constant refugee running from what seems to be chemical warfare. She urges you to start the process which will not only benefit us but others as well; a nontoxic environment and a healthy life is everyone's right. And I will give you her testimony.

MS. RIPPLE: Excuse me, I have a question. I'm afraid I don't understand what rules there are that cause her to have to go underground.

MS. SCOTT: She is on Section 8 and on Section 8 you may not live with another human being because they might benefit from your Section 8 program.

MS. RIPPLE: I'm going to make an offer. Since I handle all of the calls on this, I wish someone would talk to me. I think she probably did give me a call at the office but I'd like her to call me again after this hearing.

MS. SCOTT: Very good. Thank you very much.

CHAIRMAN MARKS: Thank you very much.

MR. IMPERIALE: What county are we dealing with on this particular item? Is this out of San Francisco county?

MS. SCOTT: Her place of residence is in Contra Costa County and her place that she's living right now is San Francisco. So she can't even appeal her In-Home Support Services' loss of 12 percent because this would bring it up and they'd have to review it and she can't risk it.

MR. IMPERIALE: Okay. Thank you.

CHAIRMAN MARKS: Diana Nikkel.

MS. DIANA NIKKEL: Hi, I'm Diana Nikkel, and I have Multiple Chemical Sensitivity.

It seems like a lot of confusion exists about whether psychological factors play a part in Multiple Chemical Sensitivity. I think some very well spoken things were said earlier about the CMA not wanting -- well, it was well said earlier what she said about the CMA.

In the opinion of many experts, such as Dr. Bernie Siegel, author of "Love, Medicine, and Miracles", psychological factors play a part in all illnesses including cancer and heart disease, so I feel it's very unfair to single out Multiple Chemical Sensitivity's psychological factors playing a major cause. It's no different than any other illness.

I want to also focus on that people with MCS need to recover enough to return to productive life. In my own experience with my slow, but steady, recovery, housing has proven the most difficult obstacle for me so far. I've spent six months in the last two years looking for suitable housing. I've been discriminated against on several occasions and I have had to settle for living in a much less desirable place than I really need.

Also, another thing that could be affecting my recovery in the future will be the bills which are going to be limiting the availability of nutritional supplements. The California Senate and Assembly need to oppose Speier's bill 3439...

CHAIRMAN MARKS: What bill's that?

MS. NIKKEL: 3439, which will strengthen the FDA's ability to take away supplements that are on the open market right now that are being sold at reasonable prices. Current legislation in the federal government, the Nutritional Labeling and Education Act, the regulations written by the FDA, which will become final in two months, will give the FDA the authority to make all supplements available only by prescription.

Supplements have played a huge part in my recovery as well as organic foods. Five years ago I was hospitalized for four months before I knew I had Multiple Chemical Sensitivity. I also could not read for two years after that. I began an organic foods diet, pure water, avoidance of chemicals, and a supplement program which has greatly helped me. Within two years I could read again, which I can't tell you how much that meant to me.

It would take years for the FDA to prove many of the supplements which are now available on the open market, if they did become available by prescription only as the Nutritional Labeling and Education Act intends to do; the regulations for it, that is.

I also want to address financial aspects of MCS and related to SSI and other assistance programs. First of all, there is a resource limit for people who receive SSI of $2,000. This includes their car, which cars generally run about $1,000 so you can see it doesn't leave much left over. I feel that extra money that MCS as well as all disabled people need to pay for their medical treatments, and when I say medical treatments I'm referring to such alternative treatments as organic foods and supplements, air filters, safe housing, whatever is prescribed by a doctor, by their physician, money that they need for this, whether it be in savings, whether it be given to them by a friend, by relative, it needs not to be counted as resources in deciding their SSI benefits.

A landmark tax court decision in 1976, and I can get the -- I don't have the name of that decision; I have it in a book I have on file; I can get that for you, though -- ruled that organic foods, when prescribed by a physician, could be tax deductible one-half the cost of the organic foods. Based on this I feel that one-half the cost of organic foods for MCS sufferers needs to be regarded as a medical expense and any extra money needed to pay for this should not be counted as a resource or income.

Also, Social Security representatives need to be more active in explaining medical trusts and PASS plans and making the PASS plan more flexible. The PASS plan, by the way, is the Plan to Achieve Self-Support. I feel the PASS plan needs to be revised to allow the MCS sufferer to use money above the SSI payments for medical expenses, including organic foods and supplements, with the goal of achieving self-support, even if not going to school or working at the time, which currently the PASS plan requires them to be.

I also want to address external education programs for the home-bound. They very much need to be developed in this state through community colleges. In Long Island, a community college provides a computer on loan -- this is an example; I'm sure there are many more -- they provide a computer on loan and lessons are sent to the disabled people via telephone hook-ups to the classroom. California has no such programs, though we host the computer capital of the world in this state! I am just amazed that we don't have any of those programs here. This would decrease the isolation that MCS sufferers as well as other home-bound disabled people feel by allowing them to interact in a classroom experience.

Thank you very much for holding this.

CHAIRMAN MARKS: Thank you very much.

We've heard a very interesting exposition of the problems that people are suffering. Let me assure you that I'm going to do my very best to try to help in any way that I can.

(Inaudible comment by someone in the audience.)

MS. TERRI MEAD: I just said that one of the things which has not been addressed is the mutation; not possibility, it's almost certain. We know what the nuclear radiation does to unborn but we aren't sure what the chemicals are doing but we have a pretty good idea with United Farm Workers. They're born without arms and legs and all.

And there is an example of a house that has been made healthy and that the Audubon Society bought a building in New York City and they've made it now healthy to work in. It's one of the few in the country probably.

CHAIRMAN MARKS: Thank you very much.

We appreciate the fact that everybody's been here. Appreciate your interest because we are concerned with it and we'll do all we possibly can to help.

Thank you.

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APPENDICES

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THE NATIONAL CENTER FOR ENVIRONMENTAL HEALTH STRATEGIES

1100 Rural Avenue
Voorhees, New Jersey 08043
(609)429-5358

October 15, 1992

Senator Milton Marks, Chair
Senate Subcommittee on the Rights of the Disabled
711 Van Ness, Suite 310
San Francisco, California 94102

Dear Senator Marks:

Thank you for the opportunity to provide comments for the record regarding the public hearings held in San Francisco on September 30, 1992 on the rights of those disabled by chemical and environmental exposures.

The National Center for Environmental Health Strategies (NCEHS) is a national non-profit, tax exempt organization that provides clearinghouse, educational, research, support and advocacy services for the public and those with chemically induced or exacerbated illnesses. The Center received approximately 6000 requests for information from January to June 1992. The majority of these requests came from people experiencing mild to disabling symptoms triggered by everyday exposures. These hypersensitive individuals have limited access to public and commercial buildings, facilities and properties; they also have a difficult time finding suitable and affordable housing, employment and consumer products.

NCEHS has focused on policy issues in the area of disability rights and assisted in the implementation of these policies. This has included effecting and implementing a policy promulgated by the U.S. Department of Housing and Urban Development to accommodate people with multiple chemical sensitivity (MCS) in apartments and public housing. (Attachment A) We have also actively worked with the Architectural and Transportation Barriers Compliance Board, The Access Board, and the Department of Justice in developing regulations to implement the Americans with Disabilities Act (ADA) and in working with the Access Board to develop an MCS Agenda. ADA regulations on MCS and our most recent comments to the Architectural and Transportation Barriers Compliance Board dated 30 July 1992 appear as Attachment B.

Those who are hypersensitive must be guaranteed access. To this end NCEHS has prepared a list of recommendations that can be adopted by governmental entities. Many of the essential efforts necessary to accommodate and guarantee accessibility are inexpensive and cost effective. Most recommendations will benefit the health and well-being of all citizens.

It is critical that all states and federal agencies expand their definition of the term "barrier" to include physical, chemical, and environmental barriers. Chemical barriers may include but are certainly not limited to smoking; pesticides-indoor and out-; deodorizers; fragrances and fragranced products; carpeting and adhesives; some cleaning products including carpet shampoo, floor wax and disinfectants, which are indeed pesticides; building furnishings includings materials and products with formaldehyde; building equipment, etc.

NCEHS supports your efforts to embrace those disabled by chemical sensitivity and to bring these citizens back into the community. We also thank the Environmental HEalth Network for inviting our comments and for all of their important work in this area.

Please let me know if we can be of further assistance. I look forward to your recommendations.

Sincerely yours,

Mary

Mary Lamielle, President
National Center for
Environmental Health
Strategies
(609)429-5358

ENCLOSURES

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Thomas A. Sult, M.D.
Board Certified Family Practitioner
Preventive/Sports Medicine and Acupuncture

October 4, 1992

Senate Subcommittee on the Rights of the Disabled
711 Vaness Ave. #310
San Francisco, CA 94102

Attn: Senator Milton Marks

Dear Senator Marks,

I spoke with your assistant Joan last week regarding the hearing you are having on the rights of the disabled and specifically about multiple chemical sensitivity. I learned from her that you are not attempting to establish the existence of this disease but rather trying to get a handle on the degree of disability this entity can cause.

I have been treating a large number of individuals with multiple chemical sensitivity. Originally, I through happenstance began treating a large group of individuals from Harvey's Resort Hotel & Casino who are afflicted with multiple chemical sensitivity that I firmly believe and I also believe I have significant evidence to support the claim that this is an industrial injury despite the fact that they have recently lost an industrial hearing on that subject. I also have several bits of biochemical evidence to support the notion that this is a true physiological disease.

All of those points aside, these people are greatly disabled. I have several patients who have been displaced from their homes, lost their cars, and spend every dime they have on trying to get well. They have been refused compensation from the Workman's Compensation fund and in many cases, they have been refused all other areas of disability funding. Particularly for the past two years when their case has been in litigation, all funding sources have been pointing the finger at the other party and requiring that the patients wait until their litigation is complete. As you are well aware, while we probably have the finest system of justice in the world, it's wheels turn slow. Creditors, particularly landlords, are unwilling to wait years for a settlement. These people have been ill for in excess of two years. They have lost everything. They have lost all of their personal savings. They have lost their homes. They have lost their cars. They in many cases have lost their relationships because of the stress and strain of this disease. These people are devastated; it is a tragedy.

I have several scientific papers which illustrate the existence of this disease. It is erie and frightening that these people in general, particularly the ones at Harvey's were high functioning, top of the line employees. All of these people were high limit dealers. Most of them had an employment record of many years.

They were all exemplary in their employee files, yet they are afflicted with this disease and incapacitated and now nearly reduced to homeless.

I have been treating them by and large for free for the past two years once their insurance decided not to pay any longer. While I consider it my duty to continue medical care for these individuals that I have started with, I cannot afford to take on this financial burden ad infinitum.

I would suggest that a hearing is a very sterile, impersonal thing. To understand this disease, one needs to know and experience first hand it's symptoms. These people are desperate for help, desperate for treatment, and ready and willing to return to work. It is my sincere hope that these words will help you understand that this is a serious, serious issue which will become more and more prevalent as our society ignores the need of the human body for a clean, toxic free place to work.

Sincerely,

Thomas A. Sult, M.D.

TS/kc
D:10/5-T:10/6/92

October 14, 1992

Stephen A. McFadden
Independant Research Advocate
P.O. Box 3313
Pasco, WA 99302

Senator Milton Marks, Chairman
Committee on the Rights of Disabled Persons
711 Van Ness Avenue, Suite 310
San Francisco, CA 94102

Dear Senator Marks:

I appreciate, as a former resident of the State of California, the opportunity to comment on the needs of those individuals disabled by Multiple Chemical Sensitivity (MCS).

Multiple Chemical Sensitivity is a condition of dysfunction of the immunological, neurological, and/or xenobiotic detoxification enzyme systems. It has been in the past controversial (see cover story, Chemical & Engineering News, July 22, 1991). However, this topic was recently addressed in reports by the National Research Council, including 'Biologic Markers in Immunotoxicology', and its non-peer-reviewed Supplement A, 'Multiple Chemical Sensitivity'. (For those not familiar with the National Research Council, it is sort of the Academy Awards of Science, at the National level.)

A previous industry position paper, the 'Chemical Manufacturere Association 'Environmental Illness' Briefing Paper', held that EI (and be extention, MCS) was 'a misdiagnosis', and that there should be No Accomodation; Limited Treatment (to the patient's other diagnosies), and No Rehabilitation, a Denial-Of-Services position that is literally victim-izing in that it effectively terminates the career of the individual who develops MCS. (The CMA is an Industry lobbying group, representing the interests of chemical manufacturers who have approximately $250 Billion dollars in gross annual sales).

Further, this Denial-Of-Services position is counterproductive from a societal point of view, because, when forced by oppression to 'pass' as normal, and 'cover' (e.g. as eccentric), these individuals will work-till-they-drop, and never work again, due to the consequent destruction of their health, and consequent neurological damage. If the employer successfully evades liability for this condition, these costs are spread out upon the society at large, affecting overall societal lifestyle.

Even further, such denial of the existance of the problem results in coverup. With Hazardous Materials, a coverup usually results in a problem that expands in size as large as the 'rug' that covers it. In a society with declining availability of resources, one cannot deal with a hazardous waste issue without, at least the threat, of public scrutiny.

We have, in the last several years seen several major industrial disasters resulting in Multiple Chemical Sensitivities to a large number of people. You may wish to review thr 400 pages of hearings held by Senator Harry Ried of Nevada on disabilities in the Aerospace industry due to the use of composite materials, including (published figures) 160 dilabled at a Los Angeles aerospace manufacturer on the Stealth Fighter project, and at least 43 Seattle aerospace workers disabled when an epoxy process was converted to a Phenol-Formaldehyde process. The Stealth disabilities are interesting, because while little public information is available, evidence in regulatory and industry changes suggests that it involved an aromatic diamine epoxy hardener, probably Methylene Dianiline, a member of a class of compounds whose metabolism varies up to a factor of 9 in the population due to what is known as the N-Acetylation polymorphism, first discovered in the early 1950's as a problem with the early Sulfa drugs.

Additionally, in a well-publicized case, several hundred workers at a Washington, DC EPA Headquarters Building were sickened by new carpeting, and at least 47 have permanently sensitized; asked for, and been provided, alternative workspace.

The debates regarding denial-of-services for MCS have moved from arguing whether it exists, to arguing about 'the state of the science', and whether it is treatable and rehabilitatable and thus 'deserving' of the allocation of resources.

Descrimination Against Individuals with Chemical Sensitivity:

Individuals with Multiple Chemical Sensitivities face both overt and covert descrimination in a number of ways:

I. They face descrimination in employment.

A. Perceived hirability: One cannot ask for accomodation (e.g. regard-quality of indoor air) without 'stickering' oneself in the minds of of the employer as non-accomodatable, and a potential insurance and/or workman's compensation liability.

B. Personal appearance: Wearing cotton clothes, and avoiding makeup, hair treatment, and toiletries, may result in descrimination. In one case, an individual (who was 'passing', so as to avoid termination before their benefits package was fully in force) was told in writing that 'their future at the company was in doubt because of their personal appearance'--wearing non-permanant-pressed cotton clothes, that rinkled.

C. Denial of insurance coverage/ the 'lead parachute': In at least one case, an individual asked for preapproval of medical treatment from a clinic dealing with individuals with MCS; they were denied health insurance coverage, after which there group was offered an incentive to individuals who wished to leave the company. After taking the money (several months wages) they went to the clinic at their own expense, only to find documented evidence that they were unemployable (e.g. brain scans), and discovered that by leaving they had forfeited their disability insurance.

D. Linguistic fraud: Individuals with MCS face discrediting images offered by those who see them as threats to their vested interests, to explain their differences in a discrediting manner, to self-justify denial of services, descrimination, and use of force (e.g. firing):

--Antisocial behavior: Cheap, Not Presentable, Not Promotable, Not a 'Team Player', Not Deserving of Benefits, Not Upwardly Mobile;

--Secondary Gains: Fraud, Malingering, Expecting 'Special Treatment';

--The 'Psychiatric Libel': Hyperchrondriasis, Oversensitivity, Irrational Environmentalism, Phobia, Paranoia, 'a Nut Case';

--Threats to 'The Peace', 'Rights of Property', and to 'Authority': Rebeliousness, Insubordination, Malicousness, Vengefulness, Litigousness, Vandalism, Luddisim, and Sociopathy.

The point is, that the above linguistic categories may be offered as 'Spin Control' to justify existing pre-judgements (prejudice).

II. Individuals with Multiple Chemical Sensitivity, given descrimination in employment, face SECONDARY VICTIMIZATION. This may include:

A. Loss of Health and Disability insurance dependant upon employment.

B. Loss of access to medical treatment, either due to loss of medical coverage, or loss of income.

C. Loss of home (either due to financial hardship, or worsening sensitivities.

D. Forced relocation (e.g. due to the need to gain access to medical treatment, to avoid pollution, or pesticide exposure from farming or Medfly erradication programs).

E. Loss of Bankability (e.g. required to purchase a 'safe' home--which may be necessary for self-employment; or access to capital to fund self-employment) due to loss of employment, and financial hardship.

F. Barriers to education--e.g. lack of expected future income to pay for education, for instance, for MS Engineering degrees available from University of Idaho, or Master's in Business Administration, available from Colorado's Mind Extention University, by videotape.

G. Barriers to re-employment--e.g. health insurance dependant upon continued disability, and disability insurance policies that cease permanantly when the insured earns 'Dollar-One' for wage or profit in any job or profession.

H. Lack of Rehabilitation--e.g. the Computer Software Engineer who, sensitive to carpets, pesticides, and 'sick buildings', spent 5 years without access to a computer--more than twice the length of time it took to get his degree--due to lack of access to capital.

In summary, descrimination in employment, insurance, and other accomodation, coupled with the effects of SECONDARY VICTIMIZATION, leads to MEDICAL INDIGENCY, indigent status linked directly to medical condition and insurability. In such a situation, the individual may be:

1. Unemployable &/or Unhirable due to lack of accomodation/perceived non-accomodatability, health constraints, and descrimination based upon perceived insurance &/or benefits risk.

2. Uninsured &/or Uninsurable due to lack of employment, medical history (e.g. the diagnosis of MCS), and/or lack of income.

3. Untreated &/or Untreatable due to lack of insurance coverage, &/or lack of income.

This is the sort of situation described in the past by the term 'Catch 22'. It is a no-win vicous circle, whereby society extracts from the individual, in return for its assistance, exactly that price necessary for the individual to be successful. It matters not whether one is a Harvard Law student, has a MD or MS after their name, or has been a business success. Exposure is ubiquitous and involuntary, and the price of sensitization is unilateral destitution.

Sheldon Samuels of the AFL-CIO noted that the failure to consider sensitive subpopulations is SOCIAL as opposed to NATURAL selection against these individuals.

Actually, it would seem that failure to consider sensitives is GENOCIDE, by the norm, against ALL tails of the 'Bell Curve'. All tails, because the Olympic Athelete and Nobel Prize winner may be adversly impacted (e.g. by organophosphate neurotoxicity) as well as the less valued or less well represented.

It would seem that some segments of society (the vested interests) have forgotten, or choose to ignore, the true societal costs of these disabilities.

Let us look at a benchmark: The young 25 year old engineer permananently disabled; Costs will include wages, an additional 33% in benefits, 66% in nominal disability payments, and medical treatment. In the short run, this will run over 2-1/4 times the nominal salary of the individual. Over the time of a 40 year career, inflation will erode the nominal disability wage, but these costs must be otherwise borne by society--and not just until age 65; thus the societal cost of a 25 year old engineer starting in today's wages at 33,000 per year, is nominally about 3 Million in benefits and lost productivity.

Of course, that number could well be an underestimate; that engineer could have been the next Bill Gates--who in under 2 decades became worth (on paper, it is reputed) more that General Motors.

In short, descrimination by the vested interests, is effectively looting, by those interests, the assets of society, while redistributing the costs of their actions onto the society in general. Amplification of this harm by Secondary Victimization results in a major cost to society in terms of lost lifestyle. Every individual either disabled, or socially categorized as non-abled by society, requires the profit of several individuals to support their existence, in addition to the direct loss in productivity. Every percent of disabled individuals, for whatever reason, reduces overall lifestyle by several percent, and lack of rehabilitation continues such costs.

In summary, Multiple Chemical Sensitivity is an increasingly recognized condition, though it has been controversial. Several industrial disasters have contributed to the speed of its recognition. Individuals with MCS face descrimination in employment for a number of reasons, and this descrimination results in SECONDARY VICTIMIZATION and MEDICAL INDEGENCY by a number of means. The avoidance by vested interests of costs associated with this diagnosis results in substantial costs to society, in terms of lifestyle. Accomodation for those with Multiple Chemical Sensitivity, and prevention of those toxic exposures that cause its development, are matters of Social and Environmental Equity.

October 14, 1992

Stephen A, McFadden
Independant Research Advocate
P.O. Box 3313
Pasco, WA 99302

Senator Milton Marks, Chairman
Committee on the Rights of Disabled Persons
711 Van Ness Avenue, Suite 310
San Francisco, CA 94102

R.E.: The Potential Relationships Between Multiple Chemical Sensitivities (MCS), Emergency Pest (Medfly) Erradication Programs, and Data Gaps in the Toxicology of the Organophosphate Insecticides.

Dear Senator Marks:

I. Several pieces of evidence suggest a link between pesticide use, and the development of the disabling condition of Multiple Chemical Sensitivity. These include:

Epidemiological Evidence:

--One self-selected survey of 6800 self-identified chemically sensitive indivuals included 'about half' whom correllated the beginning of their condition with a pesticide exposure.

--Immunological testing by Russell Jaffe, MD suggests that maybe 2% of the general population may have an immunological sensitivity to organophosphate insecticides.

--Broughton & Thrasher have a small case series of individuals who developed autoimmune disease after exposure to pesticides.

Theoretical Evidence:

--The immune system has achetylcholine receptors on the T-Cells that may be affected by organophosphate insecticide exposure.

--The organophosphate insecticides have a mechanism of action of species-differential neurotoxicity; and any long term neurotoxicity effect could potentially result in a direct OP insecticide-nervous system reaction response. Further, due to neurotoxic action, any long term changes could modulate the response to other chemical and environmental stimulus.

In any case, many individuals with MCS report sensitivity to OP insecticides, and, given their neuro and immunotoxicity, should not be exposed further.

II. Data Gaps in the Toxicology of the Organophosphate Insecticides:

Much research was done on the development of the Organophosphates during the late '40's and early '50's, after the discovery of their development as nerve gases by the Nazi's during World War II.

Those compounds with species-differential neurotoxicity were classified as insecticides. Parathion was developed somewhere around 1949, and Malathion, which is now used in Medfly erradication programs, was introduced into commercial use in 1952.

Until June, 1991, there was no battery of tests specified by the EPA to test for CNS neurotoxicity. (The OPDN 'hen test' is a PERIPHERAL neurotoxic effect!) Further, reregistration of pesticides already on the market as of 1984 will extend until 2002!

Thus, it would seem, that at least 4 decades, up to 5, and perhaps even longer, will elapse before a class of insecticides whose mechanism of action is known to be species differential neurotoxicity will be tested for CNS neurotoxicity, despite the fact that one organophosphate (DFP) was known at high doses to result in EEG changes in humans since 1947; that between 1975 and 1981 the nerve gas Sarin (GB) was documented in humans and monkeys to cause EEG changes that last for at least one year, and that epidemiological studies in organophosphate poisoned individuals (matched retrospective studies taken from hospital admissions, as compared to their peers) show lower IQ (4-1/4 points lower 9 years later, without EEG changes--Savage '88) and loss of focus of attention (2 years later--Rosenstock '91).

While I have found no US animal EEG data regarding the organothiophosphate insecticides, (apparantly complete data gap), one foreign study showed EEG changes in rats with several OP insecticides with as little of 10% of the Ld-50, spread out over 5 days. (no information on rate of return to recovery).

The usual response to the issue of these data gaps, is the statement that 'the clinical significance is unknown'.

This lame excuse denies significant potential societal risks, that must be considered potential consequences of the continued existence of these data gaps--for instance, the data gap regarding the demonstration of a threshold for these CNS neurotoxicity effects, and their time-to-recovery.

III. Potential Societal Risks of the Continued Existence of Data Gaps in the Toxicology of the Organophosphate Insecticides.

Let us consider some of the unsettling societal effects, that might be in some way related to use of organophosphate insecticides, that cannot be ruled out given the data gaps in their neurotoxicity.

Remember, when reading these, that 'the first effects of neurotoxins are seen in behavioral parameters', which occur long before clinical signs of toxicity.

--the time correllation between the banning of the organochlorines/introduction of the organophosphates, and the much-decried drop in SAT scores (with a proposed mechanism due to the use of OP's as fumigants in grain, with an exposure population of billions, on a lifetime basis.

--Attention deficit disorder: is this new--or newly recognized?

--Perception of the American Farmer as 'Brain Dead'. Is this self selection, or aquired due to chronic exposure to agricultural chemicals?

--The '81-'82 Bay Area Medfly spray program--and the apparant fact that 10 years later the Bay Area has what seems to be the most rabid involuntary-chemical-exposure movement in the country. Even a 1-in-a 1000 sensitive subpopulation, would, with an exposure population of 1.2 million, result in 'several hundred' 'formerly healthy' YUPPIES with an eye for change and an attitude commeasurate with their disenfranchisement!

--The apparant coincidence that Los Angeles RIOTED AND BURNED just 2 years after the '89-90 Medfly spray program. THE FIRST EFFECTS OF NEUROTOXINS ARE IN BEHAVIORAL PARAMETERS! LA became a 'third world country' complete with revolution, banditry and teapot tyrants, the threat of superpower invasion, relief efforts, and foreign aid!

The claim here is not that these possible associations are, in fact, causal relationships; rather, the claim is that they demonstrate the potential societal risks of using a pesticide technology whose safety with respect to neurotoxicity has not been demonstrated in over 4 decades of use!

Keep in mind, that 'The Fall of Rome' may have had something to do with the use of Plumbum (lead) in their Plumbing (hence the word), a fact that we are only now beginning to understand (e.g. that the loss of 5 points of IQ, such as is due to moderate amounts of developmental lead exposure, reduces the number of individuals with IQ over 130 by more than half).

IV. Summary:

In summary, the EPA registration of Malathion, and other organophosphate insecticides, makes NO GUARANTEE OF SAFETY with respect to NEUROTOXICITY or IMMUNOTOXICITY. THESE DATA GAPS HAVE BEEN EFFECTIVELY INSTITUTIONALIZED, AND MAY EXIST UNTIL THEY ARE REPLACED IN THE MARKET!

Secondly, given the data gaps, and circumstantial evidence, I believe that Urban Aerial Spray Programs are from a scientific point of view, EXTREEMELY MISGUIDED! (My words to describe the fatal space shuttle Challenger launch decision, described contemporaneously as a 'Management Decision', and loosely described by Nobel Prize winner Richard P Feynman as 'A Flawed Decision' based on 'A Failure to Communicate Risk from Engineer to Manager').

Thirdly, as noted in my comments to CDFA, a California State and Federal 'Erradication' program (and Environmental Impact Statements) are pending this summer ('93) that may propose aerial spraying.

Fourthly, as similarly noted, the State of California seems to be extreemly reluctant to discuss these issues, e.g. by failing to publish the Proceedings of the 1991 Urban Aerial Spray Symposium during the entire 1992 election year, under the guise of 'internal and external peer review', despite long stating that it would be ready in 'a month or two' (e.g. in February, 1992)

Fifth, as similarly noted, there is a trend by both the manufacturers of the OP insecticides, and the EPA, to reduce human exposure to the OP's, and to expedite the introduction of 'reduced risk' pesticides, leaving the State of California in a lonely and indefensible position advocating their use.

Finally, large scale neurotoxic exposures of the human population is an issue of National Security and Economic Competitiveness. To risk subtle Brain Damage to your population is to risk loosing the new international trade war, which would guarantee serfdom of the loosers to the winners. Let us now make an effort to get the lead out of our homes and our air, the neurotoxic insecticides out of at least the human environment, and develop and follow up with batteries of neurotoxicity tests that will control neurotoxins in our workplaces.

I thank you for the opportunity to comment on this important issue.

ATTached: 9/8/92 Comments To CDFA

Stephen A. McFadden
P.O. Box 3313
Pasco, WA 99302
September 8, 1992

Robin Reynolds
Division of Plant Industry
California Department of Food and Agriculture
1220 N. Street, P.O. Box 942871
Sacramento, California 94271-0001

R.E.: The Exotic Fruit Fly Erradication Program Utilizing Male Annihilation and Allied Methods: Draft Environmental Impact Report: July 1992

Dear Robin Reynolds:

My name is Stephen A. McFadden. A Westinghouse Science Talent Search Final in High School (the 9th from the State of Washington in 36 years), I have a MS degree and a background in Scientific Research.

I have a permanent interest in California Medfly Erradication Programs, including both those that use Aerial Spraying, and the Allied Methods used with Male Annihilation.

In 1981-2 I was a Graduate Student in Livermore, California, while interning at Lawrence Livermore National Laboratory, when I took a hit of Malathion from a Medfly Chopper. I heard the Choppers start up, and ran out to lock up my car. As I walked back to the house, the nearest chopper passed below 45 degrees off of the horizon, probably flying straight down East Avenue at 300 feet on their first run. I, having a BS degree in Physics, thought that I was safe at that distance, but my clothing was sprinkled with Malathion-Bait seconds after they flew by, as a result of the backwash vortex thrown down and out by the rotor blades.

I have taken an interest in the Medfly programs ever since that night. I ha come to believe that, given the current data gaps in the toxicology of the organophosphates, and the failure by public health officials to fund significant basic toxicology research and epidemiological followup on their safety, that there is a substantial probability that the organophosphates, as a class, are neurotoxic to children, graduate students, and other intelligent living beings.

The organophosphates, as currently used, are not going to kill you. They have been tested for acute lethality. Additionally, whether the probability of carcinogenesis is 1 in a million, or 6 in a million, is irrelevant, you will never know if they give you cancer. That still leaves the important biological endpoint of neurotoxicity (e.g. brain damage), and immunotoxicity (e.g. chemical sensitivit the uncharacterized potential of chronic effects from chronic exposure; and the possible uneven distribution of risk in the population.

Specifically, the current reliance on the "kill 'em and count 'em" approach t toxicology fails first to consider important biological endpoints (e.g. neurotoxic and immunotoxicity), second, fails to look at chronic exposure, and chronic effects and third, being based on averages, fails to consider polymorphism (genetic variation) in the population, and thus the impact upon sensitive subpopulations.

Rhetorically speaking:

"I have gone on a Quest seeking the Cloak of the Documentation of Safety of the New Emperor Organophosphate, and I can find No Evidence that his Majesty is not Absolutely Buck Necked, with respect to Central Nervous System Neurotoxicity."

No longer does intoxication by the OP insecticides enjoy the ironclad presumption of complete reversibility. This presumption was shattered by the paper "Chronic Central Nervous System Effects of Acute Organophosphate Pesticide Intoxication" (L. Rosenstock, et al; Lancet 338:223-227; August 1991).

At least with single exposures, at near-lethal levels, the conceptual toxicological model, upon which the ironclad presumption of the safety of the OP insecticides is based, is demonstrably flawed.

In those few studies available, in both humans and animals, with both insecticides (e.g. the parathions) and nerve gases (e.g. sarin), at high (near-lethal) exposure levels, long term CNS neurotoxicity has been demonstrated, even with single, or short term, exposures. The effects seen include 1) loss of focus of attention; 2) loss of IQ; and 3) elevated Beta frequencies on an EEG spectrum; and further; there is some indication that this brain damage is both permanant and cumulative.

Further, despite 5 decades of military research, and 3 decades of commercial use, there apparently remains complete data gap as to whether these effects seen in single, acute exposures extend down to low level, chronic exposures, or whether there exists some threshold below which these effects do not occur (e.g. a threshold, perhaps due to the binding up of OP's in the plasma by Serum Pseudocholinesterase).

As far as I know, reading papers by experts in the field, there is apparantly no animal study with the OP insecticides, where, using the biological endpoint of EEG changes, starting at single dose exposure near the LD-50, under constant total dose, and using different administration regimes, the experimental basis for an exposure threshold effect for the OP CNS neurotoxicity effects seen is documented; nor is there any data regarding the mean-time-to recovery of this effect.

In fact, as I understand it, before mid 1991, there was no requirement by the EPA for the testing of the OP insecticides with respect to CNS neurotoxicity, despite the fact that the mechanism of action of these insecticides is via species-differential neurotoxicity. (the 'hen test' for OP Delayed Peripheral Neurotoxicity is a peripheral motor nervous system effect, not a CNS effect!)

The OP insecticides were never intended, nor should they be used, on humans; such application is outside their design criteria.

In the best epidemiological followup study that I have seen on human OP insecticide exposure, a SINGLE poisoning by OP insecticides (mostly the Parathions) resulted NINE YEARS LATER in 4-1/4 points lower IQ. ("Chronic Neurological Sequelae of Acute Organophosphate Pesticide Poisoning"; E. Savage, et al; Arch. Env. Health 43(1)38-45; 1988). This was a matched retrospective study of 100 OP insecticide poisoned individuals, from hospital admissions, compared to their peers.

In fact, there is a plausable conceptual model that could explain this CNS neurotoxicity. The presumption of the reversibility of organophosphate intoxication is based on the presumption that new synaptic acetylcholinesterase will be synthesized within 7-14 days. However, no one consideres what becomes of the old, organophosphate-inhibited acetylcholinesterase. The statement that the conjugate has "a half-life of arount 2000 hours" is probably ill-substantiated. Were the old, organophosphate-inhibited acetylcholinesterase to build up in the synapses, one might expect that it would result in synaptic "nonlinearity" (e.g. 'hypersensitivity', or loss of sensitivity) of the individual synapses, which in aggregate, across 100 billion neurons, would result in loss of focus of attention, consequent loss of problem solving ability, consequent loss of IQ, and eventually permanantly altered EEG spectra.

This is exactly the sort of damage that is seen, both experimentally and epidemiologically, with single and short term organophosphate exposures at high levels. One might conceptualize the brain under organophosphate exposure as a computer with a low-voltage power supply; it keeps 'crashing' until it doesn't get any work done.

The scarey thing about this revised toxicological model, the Organophosphate Zero-Threshold Cumulative CNS Neurotoxicity (OCCN) model, is that it potentially allows permanant, cumulative CNS neurotoxicity as the result of chronic, low level (sub cholinesterase-inhibiting) exposures, beginning with a total cumulative exposure quantity (for all time) as some fraction or multiple of the acute LD-50, say, for the sake of argument, at between 1/10th and 10 times the LD-50.

The claim to safety of low level chronic organophosphate exposures would seem then to be based on some claim of a threshold effect, based on metabolism, that prevents these organophosphates from reaching the central nervous system.

This, however, has apparantly not been demonstrated experimentally. Even if there is an enzyme effect, serum pseudocholinesterase is polymorphous (variant) in the population, with reduced activity in between 1 in 1250 and 1 in 2000 in the caucasian population (e.g. on the order of thousands of people in the LA basin) (see E.J. Calabrese: "Ecogenetics: Genetic Variation in Susceptibility to Environmental Agents"; John Wiley, 1984); additionally, for the aryl organothiophosphates that have been oxidized to the oxon form, (e.g. parathion to paraoxon, but not malathion to malaoxon), paraoxonase (aryltriesterase) is polymorphous in the population, varying about a factor of 3 with a 10% fast, 50% slow distribution (see GS Omenn: "Genetic Variability in Susceptibility to Chemical Exposures" --Banbury 16; Cold Springs Harbor Laboratory; 1984); there has been some suggestion that the anti-ulcer drug Tagemet (a thioether), may impair organothiophosphate metabolism (perhaps by impairing esterase metabolism), thus ulcer patients may be a population with risk of drug interaction; and some xenobiotic (foreign chemical metabolism pathways may be polymorphous, e.g. variable sulfation based upon an apparant polymorphism in sulfoxidation.

The REAL issue of concern is that of the societal risk of CNS neurotoxicity. A 5 point drop in IQ, as is seen with a moderate level of developmental lead exposure, has the effect of reducing by half the number of 'gifted' individuals in society with an IQ over 130. (see OTA report on neurotoxicity).

It is becoming increasingly recognized that the first indications of neurotoxic exposure is seen in behavioral parameters--e.g. Mercury and tremor, Lead and developmental IQ loss, Manganese and Pseudo-Parkinson's, and Solvents and reaction time. (see B. Weiss, "Neurotoxic Risks in the Workplace"; Am J Indust Med 1990)

According to Weiss, the neurotoxin-exposed subpopulation slowly begins to shift out of the norm of the behavioral bell curve on these neurological-mediated parameters, long before the first overt symptoms of toxicity are seen.

Let us examine the potential societal risks of the data gaps in the toxicology of the organophosphates.

Consider that the organophosphates, which were brought into the market to to replace DDT and the organochlorine insecticides (which were taken off of the market after the publication of 'Silent Spring' in 1962), have been in use since about the mid-1960's. Thus, it is an amazing coincidence that SAT scores have been falling since the late-1960's.

Ask yourself: Where did all this Attention-Deficit-Disorder (ADD) come from? Is it new, or is it simply newly recognized? Is the reason that Johnny can't read, because of the use of neurotoxic insecticides in the classroom and in the schoolyard, and on the fields next door? According to the data of Rosenstock, loss of focus of attention seems to be a HALLMARK of early OP CNS neurotoxicity.

Ask yourself, is the reason that Americans hold the projected mental image of the american farmer as 'Brain Dead' more related to their continued exposure to agricultural chemicals, than self selection into that class?

Ask yourself, is the reason that the San Francisco Bay Area seems to be the 'hotbed' in the country of the 'anti-involuntary chemical exposure movement' related to the spraying of the homes of approximately 1.2 million people with Malathion during the 1981-2 Medfly program? Even a 1-in-a thousand sensitive subpopulation would leave 'several hundred' formerly healthy 'YUPPIES'(young urban professionals), with an eye for change, and an attitude commeasurate with their disenfranchisement.

Ask yourself, what is the societal cost of going head-to-head in an economic trade war with a country that relies upon a different or safer pest control technology? (Japan is said to have banned the aerial application of Malathion during the 1950's.) What is the societal cost of loosing such a trade war-- serfdom to the loosers?

I made many of these comments to US Public Health on approximately 4/1/92, in a commentary in which I decried the '89-90 Los Angeles Medfly Erradication Program, which sprayed the homes of 1.6 million people. That was over FOUR WEEKS BEFORE LA rioted and burned. THE FIRST EFFECTS OF NEUROTOXICITY ARE SEEN IN BEHAVIORAL PARAMETERS!

Consider that CNS neurotoxicity, that could result in loss of focus of attention to the point of a drop in IQ of a few points could result in loss of job individually, but, collectively, it could result in social caos. Ask yourself, did the '89-90 LA Medfly Erradication Program effectively turn Los Angeles all but into a third world country, complete with revolution, banditry and teapot tyrants, the threat of 'superpower' invasion, relief efforts, and 'foreign' aid?

I make no claim that these possible associations are in fact causal relationships and not simply coincidences. Rather, the claim is, that given the data gaps, there is no way to rule these possible links out; thus they are good indication of the magnitude of the potential societal risks of those same data gaps.

No longer is it sufficient to simply perform a literature search to look for safety data. There is no incentive for a manufacturer to perform safety research or epidemiological followup on products before the patents run out, and then only to limit competitors market share while introducing a replacement product. The Silicon Gel Breast Implants fiasco was a simple example of the failure to fund immunotoxicology research on a product; and after 3 decades the victims of autoimmune disease mounted a political effort to drive the product off the market, which took down a CEO and drove a market leader out of a market. Further, government funding of basic toxicology research has also suffered during the budget cutting of the 1980's.

Instead of looking at toxicology, let us look to trends in regulatory and industry activity.

In February, 1991, the California Department of Health Services published "Health Risk Assesment of Aerial Application of Malathion-Bait", enumerating the technical basis for the claim to safety of the '89-90 Medfly Erradication Program, that sprayed the homes of 1.6 million with Malathion.

The following month (Federal Register v56 n52 p11420 March 18, 1991), the manufacturers of malathion voluntarily requested the deletion of certain uses and directions for use of the registration of Malathion by the EPA, including 1) in contact with human or animal skin; 2) in food, including grain storage, food processing plants, eating establishments, and packaged cereals; 3) indoor use; 4) forestry use; and 5) tobacco use.

Thus, while the State of California was making the belated claim to safety of the use of Malathion in spraying urban areas up to twice a week for up to a dozen times, a decade after it began that practice, the manufacturers and registrants of Malathion were voluntarily restricting its registration, withdrawing sanction of its use on, in, or near humans and animals.

Further, it is notable that the new (October 1992) EPA regulations for the use of organophosphate insecticides requires a 48 hour reentry period for worker protection; 72 hours in arid climates with less than 25 inches of rain per year. (57 Fed Reg 38102-166 Aug 21, 1992) Thus, in addition to the manufacturers, the EPA has backed off the presumption of safety of the exposure of humans to organophosphate insecticides.

Thus, given data gaps in the toxicology of the organophosphates for which there is substantial potential for societal risk, it is appropriate that research be immediately funded so that an accurate safety assesment can be made.

Ultimately, the issue of these data gaps, once having been raised, must be addressed by the Scientific and Regulatory community: the National Research Council; US Public Health; the National Institute for Health; the National Toxicology Program; and the Environmental Protection Agency. These institutions must develop, fund, and perform new research on both the basic toxicology and epidemiological followup required to substantiate the safety of the organophosphates with respect to CNS neurotoxicity.

My judgement is that the issue of a threshold for these effects could be established for the OP insecticides with "a couple hundred" rats in 4-6 months, which could be done by the defence establishment, if not public health, rapidly, if it has not already been done.

The issue, then, is not the difficulty of doing the research, but the willingness to develop the data. In fact, the best animal experimentation, and best known human epidemiological followup data, comes out of third world countries. In fact, it has been demonstrated that exposure of rats to organophosphate insecticides at a level of 2% of the LD-50 per day, for 5 days, produces short term EEG changes. With sarin, EEG changes in monkeys last for at least a year. With the Parathions, human IQ loss appears to persist for at least 9 years. These insect neurotoxins are most definitely neurotoxic to both humans and animals.

In no way can the action of the organophosphate insecticides be compared to the actions of anesthetics, such as the neutral anesthetic gasses (e.g. nitrous oxide--laughing gas), as is done repeatedly in Appendix A of the Environmental Impact Assesment. The organophosphates are permanant, irreversible enzyme inhibit whose toxic effects takes days to be accomodated for. At least at high levels, they produce permanant, irreversible, and perhaps cumulative brain damage. To compare them to anesthetics is a scientific and technological fraud that semantically backs a conceptual toxicological model that has been demonstrated by US Government research to be flawed, at least at high levels, over 4 years ago.

Apparantly, the CDFA has high standards for the selection of scientific studies to be considered in its safety analysis. Apparantly its standards of selection are so high that it would rather rely upon complete data gap than to consider the available data, including data from the third world where the ironclad grip upon the funding of 'independant' research has not forced safety research decades behind that of developmental research.

Apparantly, the CDFA is unwilling to engage in free and forthright public debate of the scientific issues involved. The 'Urban Aerial Spray Symposium' was held in October, 1991. Since early this spring, the CDFA has been saying that the proceedings would be published 'in a month or two'; and that it was currently undergoing 'internal and external peer review'.

It is now September, 1992. The UASS proceedings has not yet been published (or else, they have failed to notify me as requested). We, the public, are asked to comment on another Environmental Impact Assesment involving the use of Malathion and other organophosphate insecticides to erradicate the Medfly.

A cynic might suggest, that given the controversial nature of the use of OP insecticides in urban aerial spray programs, there never will be scientific consensus; thus there will never be a resolution to the process of 'internal and external peer review'. A cynic might also suggest, given the propensity of Medfly Erradication Programs (at least urban aerial programs) to fall in odd (nonelection) years, that the claimed right of a government to perform 'internal and external peer review' on a matter of scientific controversy and public safety, would appear to have been used to 'jerk the Medfly controversy off of the political burner' for an entire election year.

Thus, it would appear that the public has been deprived of the opportunity for fair and forthright public debate on this technological issue; and further, we have been deprived of timely access to the best and newest scientific information available on the subject.

How can we possibly comment on this Medfly EIA, when we do not have access to scientific information discussed at the UASS? I know, for instance, that Dr. Kathleen Rogers spoke. I have pulled one of her papers, suggesting immunotoxicological effects of Malathion more than 3 orders of magnitude below the LD-50. How can I discuss the immunotoxicology of Malathion, as an Allied Method in the Male Annihilation Medfly Program, without knowing what she said?

It is for that reason that I request that comment on this Draft Environmental Impact Assesment be delayed until after the publication of the Urban Aerial Spray Symposium, which has now been apparantly been delayed for over 10 months. The public cannot possibly discuss these technological proposals without timely and accurate scientific data and analysis.

In my estimation, the State of California has maybe 9 to 21 months to either develop data to fill in the data gaps in the documentation of safety of the OP insecticides with respect to CNS neurotoxicity, or to find another way to kill medflies, such as by encouraging the invention, testing, registration, and production of a newer, safer genetically engineered microbial insecticide, such as an improved BT strain with an endotoxin modified to kill fruit flies.

In fact, the EPA is currently, through September 18, requesting comments regarding 'Incentives for Development and Registration of Reduced Risk Pesticides'. (57 Fed Reg 32140-145; July 20, 1992). The EPA may be willing to support an expedited testing and registration of such a newer, safer microbial fruit fly insecticide, if there can be demonstrated both an experimental and theoretical basis for human safety, coupled with epidemiological followup to document such safety.

At this time, the CDFA can choose to Lead, to Follow, or to Get Off the probverbial Road.

They can Lead, by joining with EPA and industry to encourage the invention, development, and registration of newer, safer reduced risk (e.g. microbial) insecticide to kill fruit flies (e.g. a modified BT strain).

They can Follow, by raising concerns regarding data gaps in the documentation of safety of the OP insecticides with the National Research Council, US Public Health, the National Institute of Health, the National Toxicology Program, and the EPA, so that new scientific studies of basic experimental research and epidemiological followup may be proposed, funded, and performed. In particular, experimental data must be generated to document a threshold effect for organophospha CNS neurotoxicity, and a critical analysis must be made regarding the development of an improved toxicological model for organophosphate CNS neurotoxicity, such as the Organophosphate Zero Threshold Cumulative CNS Neurotoxicity (OCCN) model proposed here. The text of this commentary, and the results of this research, together with a critical analysis of the issues raised, can be published with the Final Environmental Impact Assesment, published after further an extended comment period following the publication of the proceedings of the Urban Aerial Spray Symposium.

They can Get Off the Road, by developing some biological barriers that will reduce the explosive growth of fruit fly populations to that which can be controlled by other methods, such as by the use of trap crops.

Simply 'reflagging' the CDFA Medfly Erradication Program as a USDA Federal Program in an evasive juristiction maneuver to circumvent the political rights of the populace will simply transfer the Data Gaps Issue to that Federal program.

Should, however, the CDFA fail to make one of these choices, to Lead, to Follow, or to Get Off the Road, either by taking organophosphates out of the Fruit Fly Erradication Program, or by demonstrating the existence of the 'Cloak of Documentation of Safety' of the organophosphates, they may be broadsided by a wave of public concern, extending from San Diego to San Leandro, during an election year, regarding the documentation of safety of the proposed program, failure to appropropriately characterize the toxicological risks of neurotoxicity in the Environmental Impact Assesment, failure to provide for fair and forthright public debate on the technical aspects of the issues involved by failing to publish the Urban Aerial Spray Symposium proceedings in a timely manner, and failure to allow the use of that information in comments on this Environmental Impact Assesment.

Judicious action by the CDFA, such as by publishing this commentary, newly developed scientific data provided by US Public Health officials, together with a critical analysis of the issues raised, in an appendix to the Final Environmental Impact Statement, will allow the CDFA time to consult with the Scientific and Regulatory community in order to decide how to best address the concerns regarding data gaps in the documentation of safety of the organophosphates

I expect, within the next 5 years, the following trends will occur:

1) The organophosphate insecticides will have their registrations restricted for uses indoors, in food, and in direct contact with humans, and their market share will be taken over by other classes of insecticides, thus greatly reducing both the highest risk and total human exposure.

2) The organophosphate insecticides will continue to have a substantial market share in agriculture, though under more stringent safety guidelines (e.g. 48-72 hour reentry criteria.

3) There will be a trend, and incentives provided, for the development of newer, safer biological insecticides to be used in pest erradication programs, such as Medfly Erradication Programs and Mosquito Abatement Programs.

In other words, a substantial amount of human risk can be reduced through a societal decision to push the state of the art of the pesticide technology, with a minimum of financial hardship upon industry.

Please acknowlege my letter, and state your intentions regarding the addressing of these concerns (e.g. in an appendix to the Final Environmental Impact Assesment) within 10 days of the receipt of this letter.

OCT 15 REC

Emily Levy
137 Plateau Avenue
Santa Cruz, CA 95060
(408) 429-8946

October 12, 1992

Senator Milton Marks
711 Van Ness Avenue
San Francisco, CA 94102

Dear Senator Marks:

Please accept the following as additions to my testimony at the September 29, 1992 hearing on access for persons disabled by environmental illness/multiple chemical sensitivities (EI/MCS).

I have EI/MCS myself and serve on the City of Santa Cruz Access Committee, which is responsible for making recommendations to the City regarding its compliance with the Americans with Disabilities Act.

I want to mention a few access concerns that I think others may not mention; I will not cover all areas where access is a problem for those of us with EI/MCS, for they are far too extensive.

I am particularly concerned with the lack of access to outdoor places such as State Parks and Recreation Areas. Our access is prevented because of the use of chemical herbicides, pesticides, fertilizers, and the like. Additionally, smoking and barbecues impede our rights to use these public facilities. There is a common misconception that these chemical products are not a problem outdoors; this is completely untrue. Barbecues are especially a problem because of the use of "lighter fluid," which I note has already been banned in Los Angeles. Its use should be banned statewide. An inexpensive alternative is an aluminum cylinder in which charcoal is placed. Newspapers are burned in its lower chamber, heating the coals to start the fire. These chambers cost about $15 each retail, and could be chained to barbecues in public parks and recreation areas. Also, in every park the barbecue areas must be segregated from other picnic areas and recreational facilities, as even smoke that does not contain fumes from lighter fluid precludes access for some people with EI/MCS.

For full access, smoking must be prohibited in all indoor and outdoor areas including lobbies, rest rooms, public transportation and transportation terminals, public buildings and adjacent outdoor areas.

Spraying of roads with herbicides or similar chemicals must stop immediately and completely! It denies us access to travel and to our own homes!

Aerial spraying of agricultural areas must cease. Not only does it contaminate the food, but also the air and water. In addition, it is causing widespread EI/MCS and other illnesses among farmworkers. They must be protected.

I am also concerned about the chemicals used for fighting wildfires. I have become very ill from driving relatively near wildfires. In August I had to evacuate my home in the Santa Cruz mountains because of toxic smoke blowing my way from the Shasta fire several hundred miles away. Alternatives must be found and residents must be notified if these chemicals are to be used.

Emergency services such as 911 must be made accessible to people with EI/MCS. This includes special training of personnel. Evacuation plans and emergency shelters must also be made accessible.

Alternative methods of service must be developed, provided and publicized when government buildings are not completely accessible. These could include but should not be limited to service via telephone and by mail, service via intermediaries, and service in alternative locations that are environmentally safe

Health care must be available and accessible to all residents of California, including undocumented workers.

In the area of transportation, access modifications must be made on vehicles used for long-distance intrastate transit. Additionally, people with EI/MCS must be included in the eligibility requirements for disabled parking placards, and methods must be devised by which people with EI/MCS can take both written and practical driving tests without being exposed to materials which make us ill.

In employment: work-at-home programs should be encouraged. Cal OSHA inspectors should be trained in areas concerning people with EI/MCS. State workplaces must be made EI-safe.

In licensing: access for people with EI/MCS should be required of all facilities that require state licenses.

In education: many schools are not accessible for teachers, students, staff or family members who have EI/MCS. Care must be taken to create and maintain access in schools. Portable classrooms which have high levels of formaldehyde must not be used at all! School maintenance must not limit access to schools by people with EI/MCS. Pesticides and herbicides must be prohibited on school campuses. Special education needs of children with EI/MCS must be recognized and served.

In general, much must change. The good news is that, by making the State accessible to people who already have EI/MCS, we will be preventing thousands of future cases of the illness which would cost the State a great deal. People who have expertise in the field of EI/MCS, including those of us disabled by it, must be consulted as modifications are considered and applied. State personnel must be trained to recognize the needs of people with this misunderstood disability so that access can be provided, for our access is as often limited by ignorance and prejudice as it is by offending substances.

Thank you very much for your work on this issue.

Sincerely,

Emily Levy

Emily Levy

Chemical Spraying Forces S.F. School to Evacuate

By Jim Doyle
Chronicle Staff Writer

Hundreds of children were evacuated yesterday from a San Francisco elementary school after teachers and students were accidently exposed to a toxic fungicide in the school's ventilation system.

Some schoolchildren and teachers at the Dr. Charles R. Drew Alternative School in the Bayview neighborhood reported a burning sensation in their eyes, while others said they complained of raspy throats, itchy skin, numb and discolored lips and breathing problems.

It was unclear whether anyone received emergency medical care.

The incident occurred yesterday morning in the school, which has about 350 students ranging from pre-kindergarten through fifth grade. There is a day care center for toddlers on the site.

School officials said that a contractor had sprayed the fungicide — ammonium phenate with bromine — into the school's heating and ventilation ducts to try to eliminate any disease-causing mold, mildew and bacteria.

"It looks like it was a contractor's mistake," said Arlen Siert, the school district's chief of industrial hygiene, who is investigating the incident.

"They were told to do this on off hours and weekends when no people were present," he said.

The contractor — Health Aire of California Inc. — could not be reached for comment.

All the schoolchildren were evacuated at about 11 a.m., parents said, after teachers and school officials spent an undetermined amount of time trying to figure out the source of a particularly strong odor.

Some parents voiced concerns about how long it took to order an evacuation.

"We didn't get a straight answer on length of exposure of our kids," said parent Debbie Bailles d'Err. "From what I gather, the school district didn't know what was happening."

But school officials insisted that they reacted quickly to the incident. The school is expected to reopen this morning.

OCT 02 RE

Date: September 30, 1992
To: The Honorable Senator Milton Marks
From: Jmv Joy Hahn, 265 North Point, #411, San Francisco, CA 94133
Re: Interim Hearing of the Senate Subcommittee on the Rights of the Disabled

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Statements as follows:

I. My name is Joy Hahn. I am 36 years old and I live in San Francisco. I've probably had environmental illness all my life but I first noticed symptoms in 1974 when I enrolled in college and for the first time began living and working in "forced-air" ventilation buildings (in other words, buildings without natural ventilation).

II. SYMPTOMS

A. Physical symptoms which I can live with: ears plug up and throat tightens.

B. Central Nervous System (CNS) symptoms, which are disabling. Can't express thoughts, can't retain what is being said to me, loss of short-term memory, can't think or carry a thought. These are the functions that normally distinguish human life from other animal life.

III. WHAT BRINGS ON SYMPTOMS

A. Things that I can see or smell that bring on symptoms are cigarette smoke, either fresh or stuck on people's clothing and bodies.

B. Things that I can't see and identify relate to forced-air ventilated buildings. I generally cannot tolerate the "effluent" from supply vents, especially when the air is being cooled or the fans are on high.

IV. HOW DO I COPE?

A. It is very difficult having a part-time, unscheduled disability--if the A/C is off, I can cope but when it comes on, I don't make sense. Try telling this to an employer.

B. I basically "fake it," i.e. that I'm getting work done.

C. I try to avoid conversation--don't make or accept calls since I can't express myself or remember what is being said to me.

D. I work after the A/C has gone off, usually around 6 or 7:00 at night. Or, I'll go in on weekends to catchup but this gets tiresome.

E. Go to the office late at night when no one is there and tape over the vents with duct tape.

IV. HOW DO I COPE? - cont.

F. I do have good days though and they are wonderful. I love analytical work and communicating with others.

V. TREATMENT I'VE RECEIVED FROM EMPLOYERS AND MEDICAL PROFESSION

A. I was told to just get well and it was implied that I have more sex. This was told to me by a Partner at an international "Big-6" accounting firm, Deloitte Touche.

B. At Pacific Telesis, their medical department said that my symptoms didn't exist and that there was no one space that could accomodate me. This from an employer with probably 17,000 employees and 17,000 workspaces but they wouldn't let me identify one that would work!

C. Industrial Indemnity wouldn't let me work in the spaces that were available and would accomodate me. (I should add that if I can tape over the vents and even close the door, I can sometimes survive even though it gets warm.) The State Department of Fair Employment and Housing lacked the staff to investigate my claim.

D. A well-known spokesperson on the subject, Dr. Abba Terr of San Francisco, suggested that I try bike riding; also, perhaps working near the beach in Hawaii--this is malpractice since he doesn't have a cure for EI!

E. Another doctor at UCSF said I should read a book on coping with the personal "losses" in my life--he was going through a divorce and he said the book was helping him!

F. Oh, and the doctor who had graduated from UC Berkeley who told me that I should go to more football games!

G. While a lot of this is a result of the extreme sexism existing in the medical practice and the corporate community, as well, it also describes the treatment received by persons with EI.

VI. CONCLUSION

Thank you for helping to bring this issue to light. The illness does exist and we need accomodation.

OCT 05 REC'D

Raymond Mongeluzo
P.O. Box 3193
San Rafael, Ca.
94912

10/1/92

Joan Ripple
C/O Senator Milton Marks
711 Van Ness Ave.
Suite 310
San Fransico, Ca. 94102

Dear Ms. Ripple

I would like the goverment to recognize my EI/MCS disability and have resonable accomadation made for access. Furthermore I have become impoverished because insurance companies have denied me benefits for disability coverage.

Please help.

Sincerly
Raymond Mongeluzo

TESTIMONY BEFORE THE SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED

September 30, 1992

My name is David Gilmartin. I am a Unitarian Universalist Minister who works on behalf of people with disabilities.

Since 1987, I have worked at three different independent living centers. During this time, I have counseled with and advocated on behalf of persons who are handicapped by environmental conditions which substantially limit their ability to participate in normal life activities. At the Center for Independent Living, widely regarded as the starting place of the independent living movement and the first such center, I was for two years a Client Assistance Program advocate, and my responsibilities were to assist Department of Rehabilitation clients in resolving disputes with the Department.

My remarks today focus on some problems persons with environmental illness or multiple chemical sensitivities face in obtaining services from the Department of Rehabilitation or independent living centers.

With regard to the Department of Rehabilitation, I will describe aspects of the case of one man with EI/MCS which illustrates several problems.

This man had formerly been a newspaper reporter in the Central Valley. When he developed EI/MCS, he learned that the spraying of agricultural pesticides put chemicals into the air which severely affected his health. He moved to a coastal community in Marin County to have the cleanest possible air. Clean air and other therapies led to significant improvements in his health. He wanted to return to work, and applied to the Department for assistance.

His first difficulty was establishing eligibility with an appropriate medical diagnosis. Some physicians who evaluated him saw his altered mental functioning as his primary disability rather than as a consequence of EI/MCS, and diagnosed a psychiatric condition. Besides pointing to the problems which come as a consequence of lack of knowledge in the medical profession, I think there may be another problem with establishing eligibility based on a medical evaluation. The Americans with Disabilities Act, the Rehabilitation Act of 1973 as amended, and California law have all adopted a functional rather than a medical definition of disability. As I understand it, the law says a person is considered disabled if one or more major life activities is significantly limited. I would raise this question: Does an eligibility determination procedure which relies on a medical rather than a functional determination that a disability exists systematically discriminate against persons whose disabilities clearly impair functioning though they are not clearly understood medically?

The man whose case I am using to illustrate was accepted as a client of the Department of Rehabilitation. He next encountered difficulty in his attempts to demonstrate the level of functioning of which he was capable. The Department of Rehabilitation permits the use of an extended evaluation period in this situation, but would not approve payment for his prescribed medical regimen. The reason for this is that the Department will only do this for medical treatments which are approved by MediCal. It appears to me that once again he was victimized by policies that are based in a clear and generally accepted medical understanding of a disability, but not suited to impairments about which the medical profession has not yet formed a consensus of opinion.

This same man ran into one other roadblock which I think is related to this class of disabilities. After considering his health needs, his vocational skills, his interests and abilities, and, after having received some indications of interest from potential employers, he proposed a vocational goal to his counselor which was rejected on the basis that there were insufficient jobs in that line of work for the counselor to make a determination that a labor market existed for that kind of work.

It is ironic, as another person testified today, that persons who get sick from poisons in the air, water, or buildings we use daily are considered abnormal, and persons who do not get sick from these exposures are considered healthy. In today's urban environment, a person with EI/MCS is dealing with hostile environment, as much if not more inaccessible to him or her than buildings and vehicles and sidewalks were to wheelchair users twenty years ago.

In this situation, the usual guidelines for determining an adequate labor market exists for placement purposes may be entirely inappropriate, and using such guidelines may be another form of systematic discrimination against persons for whom society has developed accessibility to a much lesser degree than others.

One would expect that independent living centers, to which the State provides funds to provide services to persons with all kinds of disabilities, would at least be one place in the service delivery system that adequately provides services to persons with EI/MCS. This is not the case.

Independent Living Centers are slow to develop new capacities and new clientele. People with EI/MCS are not the only class of disabled persons who have found it difficult to find or develop appropriate services or resources in ILCs. Persons with mental disabilities, alcoholism, or drug addictions are others for whom the response is often slow and the service often inadequate.

One demonstration of this occurred a couple of years ago, when Susan Molloy was hired by the independent living center in Eureka. Within a short period of time, the center was serving a hundred new clients with environmental disabilities that it had never served before.

Another indication of the inadequacy is the ongoing work of the Environmental Health Network. This organization is much like ILCs in that it has a Board of Directors the majority of whom are persons with disabilities. Not receiving any state funding, and staffed entirely by volunteers, this organization provides services to approximately a hundred persons a month who have EI/MCS.

Yet another indicator is the extent to which independent living centers are inaccessible to persons with EI/MCS.

In the past six year I have worked in three independent living centers. All three have had problems with the quality of indoor air. In two, there was moldiness; in two there were volatile organic compounds from carpets and carpet glues; in one there was a problem of spraying for bugs without always giving adequate warning to staff or clients; in two there was use of scented products in the restrooms.

The situation reminds me of the—slightly sick—joke about the manager of an inaccessible restaurant who insisted the restaurant had no problems with disabled people because none ever came there. Clearly, services cannot be provided in a facility inaccessible to persons needing those services, and my experience suggests that there are widespread limits to accessibility for persons with EI/MCS, even in independent living centers, which is one place we would most expect to find complete accessibility for all, regardless of disability.

Clearly we are engaged in the early stages of efforts to extend the protections and provisions of the laws for social access and equal opportunity to people who, with unusual kinds of disability, do not fit the current models of disability or accommodation.

State building, health and safety, hazardous materials and air quality regulations, when compared to the needs of persons with environmentally imposed disabilities, are currently insufficient to protect the lives of these citizens.

Air flow and fresh air ventilation requirements are inadequate; safety levels for hazardous materials and airborne pollutants are set at too high a level; the requirements for provision of warning signs, detours, and alternative paths of travel are totally inadequate.

I believe that, if time were not an issue, the justice system would gradually develop a body of case law that would require the desired changes. Time is of the essence, however, because the lives and livelihoods of many people are at stake.

I urge you, therefore, to develop the legislative initiatives that will lead to the regulatory reforms necessary to assure accessibility in employment, public accommodations, and transportation for persons with this class of disabilities.

I would suggest two immediate measures, which I think can clarify the needs, suggest ways to meet those needs, and bring forth the advocacy and debate which can lead to formulation of public policy. One would be for the state of California to authorize a study of this whole area. The second would be for the State to authorize and appropriate funds to the Department of Rehabilitation to fund community-based organizations, analogous to independent living centers, which specifically provide independent living services to and advocacy on behalf of citizens with environmental disabilities. Such an appropriation could also include provision of technical assistance to independent living centers, to rectify their deficiencies in this area. I believe these two initiatives would have an immediate beneficial impact on the provision of services, and on the broader public policy debate on these matters in the years ahead.

Thank you for this opportunity to testify and share my views.

The Medical Needs of Chemically-Sensitive Citizens

by Susan Nordmark

EXECUTIVE SUMMARY

This paper addresses some of the medical needs of persons with multiple chemical sensitivities (MCS), and suggests guidelines for governmental response. MCS is a growing public health problem that demands action in terms of both prevention and treatment. Action is needed to keep people from getting sick in the first place. We also need medical treatment and in-home support services, to help people recover their health and get back to productive lives. Universal health care access must be a central focus of any effective treatment plan.

Prevention

Any medical policy on MCS must address two critical areas: prevention and treatment. Multiple chemical sensitivity is a growing public health problem. It is not a rare, isolated, individual phenomenon; on the contrary, it is common and it is on the increase. Thus, as for any public health issue, prevention is key. Any policy on EI must incorporate prevention of further illness as a core objective. It's simple and obvious: stop making people sick.

How to do this? How does MCS arise? Multiple chemical sensitivity, as well as chronic fatigue immune dysfunction syndrome, many autoimmune diseases (lupus, rheumatoid arthritis, thyroiditis), asthma, other respiratory illness, and allergy, as well as certain cancers, are increasing in the general population. There is ample evidence that frequent, everyday exposure to toxic chemicals during the last several decades is a significant precipitating factor in the onset of all these illnesses.

Estimating the true costs of MCS---in lost productivity for business, medical treatment, disability payments, and increased living costs for special living environments, foods, and personal belongings---is difficult. But the American Academy for the Advancement of Science has estimated that at least 15% of the general population of the United States is hypersensitive to, and adversely affected by, the chemicals in our everyday modern environments. That means that 15% of the people around us are not as productive as they could be and would like to be, and they are consuming medical services and running up medical costs.

I will not spend time enumerating issues which other persons are likely to mention in their testimony here today. However, I will simply mention that the leading causes of MCS, and triggers for continued illness symptoms, are pesticides; indoor air pollutants from synthetic carpets, furnishings, office and other electronic equipment; solvents and heavy metals from industrial and occupational sources; solvent-based and/or chemically fragranced personal and cleaning products; tobacco smoke; outdoor air pollutants such as vehicle exhaust, industrial emissions, woodburning stoves and fireplaces, and barbeques.

All of these sources of chemical emissions are subject to, or potentially subject to, government regulation. So government has the power to eliminate this illness. Government has the power to eliminate the misery, the waste of human lives, and the staggering expense of litigation and all the medical and non-medical costs of this disabling and growing illness--an illness which becomes more common as our environment becomes more chemically polluted.

It would surely be cynical to suggest that the elimination of human misery is lower on the priorities of state legislators than is salvage of state monies. Nevertheless, I would simply remind the legislators that they can save substancial state money now spent on Medi-cal payments, Workmen's Compensation-related costs, state disability payments, and In-Home Support Services costs in an innovative way: not by cutting off services and support payments in the short run, but by providing effective medical treatment for existing cases and preventing new MCS cases in the long run. And they can do this by implementing governmental curbs on indoor and outdoor chemical pollution.

This means that "preventative medicine", as it applies to MCS, means something different from the mainstream model of prevention. An effective social policy on MCS--like that for any other widespread public health issue--requires a fundamental change in the social, economic, and political conditions which give rise to the illness as a widespread phenomenon. It goes beyond low-fat diets, exercise, not smoking, or yoga. In particular, prevention of MCS goes beyond the focus on individual behavior emphasized by President Bush's administration. This means that when a citizen develops MCS, we can't blame the victim. We can't look to past individual behavior as the cause of this person's illness, as much as we must look to industrial behavior and government policy on toxic use and pollution.

Prevention of MCS must incorporate public policy precisely in those areas where industry lobbying against regulation has been most energetic:

---stricter building standards for ventilation (such as those recommended by the American Society of Heating, Refrigeration and Air-Conditioning Engineers/ASHRAE)

---indoor pollutant source reduction

---air pollution reduction through a much stronger focus on mass transit development and alternatives to private vehicles; stricter regulation and greater enforcement of regulations against industrial polluters; and regulations on private, as well as industrial, toxic emissions, such as from woodburning, barbeques, and large-scale solvent use

---extremely strict pesticide/herbicide access regulation, including private as well as professional applicators, and the mandated use of integrated pest management techniques as an alternative to toxics

---education about the negative health effects of chemical fragrances and discouragement of their use in workplaces and other public places

---much stronger laws against any smoking in public places

Treatment

Treatment for any illness is an illusion if few persons with the illness have access to it--and this includes not only strictly legal, but also financial and political access. This fundamental point underlies everything I have to say about treatment for MCS.

(1) The bottom line is that universal health care must become a reality. The existing framework of private insurance, Medicare, and Medi-cal fails miserably in serving the medical needs of people with MCS. First, many persons with MCS have no insurance coverage whatsoever. This critical fact must be kept in mind: reform of existing programs is not enough, because many--perhaps even most--MCS persons fall between the cracks completely. Second, most insurance carriers fail to recognize the existence of MCS. And nearly all carriers are notorious for stonewalling payment for the types of treatments which have been found clinically most useful for this illness.

Thus, those individuals lucky enough to have some type of insurance coverage are frequently forced to couch their needs for treatment under other diagnoses, if they are "lucky" enough to have them (asthma, autoimmune diseases of various sorts, cluster headaches, chronic fatigue immune dysfunction syndrome, or allergy). Medi-Cal is the worst: it pays for practically nothing at all that is medically helpful for persons with environmental sensitivity. Medicare is little better, yet private insurance companies are sometimes worse than Medicare in some respects. HMOs are certainly worse. So in practice, a person may technically be insured, but practically speaking be without medical help.

(2) Board of Medical Quality Assurance targeting and harassment of physicians who treat MCS must end. In effect, these actions violate both consumers' rights to choose the medical services they find most helpful, and antitrust laws as well.

A little background may clarify this odd situation. Currently, medical politics in California and the United States as a whole involves a bitter tug-of-war for consumer health-care dollars. Public interest is burgeoning in nutritional, noninvasive, nondrug, immunotherapeutic approaches to the treatment of illness. Innovative physicians (as well as nonphysician professionals, such as acupuncturists) are responding, offering treatment modes of the latter sort, which mainstream physicians aren't prepared to present to patients. Faced with loss of business, traditional doctors are fighting to keep control of consumer spending in health care. One way they're doing this is by persecuting doctors who don't follow the party line. And the State Board of Medical Quality Assurance has become a tool for cliques of mainstream doctors to target innovative physicians.

These actions, as sanctioned by government, are anticompetitive and contrary to the rights of consumers to choose in a free market. Physicians with expertise with MCS must be allowed the freedom to exercise their judgment and knowledge, subject to the review of their colleagues in this medical specialty. Last year's bill, A.B. 704, sponsored by Jackie Speier, would have ensured this by mandating that physicians be reviewed by a panel of their professional peers, rather than by doctors from competing specialties.

(3) It then follows that as treatment is offered to persons with MCS, it cannot involve restrictions on choice of physician. The HMO model will not and does not work for persons with MCS. Because of medical-political trends over the last several decades, very few physicians chose to learn to treat MCS, and so there currently are just a few physicians competent in this field. We must be able to consult those physicians whom we have found are the most knowledgeable about our conditions, and who have proved themselves most useful in helping us find effective treatment.

(4) More physicians are needed to specialize in the treatment of MCS and related illnesses. Medical students need to be taught about MCS as a cause of somatic, apparently "psychogenic", and cognitive difficulties in their patients.

(5) Research on the etiology and mechanisms of MCS is needed. Yet it has barely begun, and this is no accident. Chemical and pharmaceutical companies contribute the bulk of corporate support for medical research in the United States. Because of this "follow the money" link between funding source and the direction of research, that research is largely oriented toward drugs/chemotherapy and away from environmental causes of illness/nutritional approaches/immunotherapy. (This bias is not as apparent in medical research done elsewhere in the world, by the way.) Government "cooperation" with private industries' interests in research simply magnifies the bias. This trend must change.

(6) All insurance carriers must pay for medical treatment for MCS. Currently, both public and private carriers often refuse payment using the "experimental" label; but after all, there can be no officially "experimental" treatments for MCS: since the medical establishment won't even recognize the existence of MCS, it won't recognize any treatments for it either! Yet there ARE treatments which MCS-specialist physicians have found over and over to be clinically effective. (Published data is scarce, for several reasons. MCS has not been studied enough yet, so there isn't a huge published literature on effective treatments. In addition, serious articles on effective treatment for MCS have been censored from mainstream medical journals, which are largely supported financially by drug-company ads and drug-company-supported research.) Thus physicians' clinical experience and patients' clinical response must be relied on: patients ARE the data.

In addition, new treatments for MCS-related illness must be encouraged, and the cost must be covered so that persons with MCS can get well as fast as possible. The fact is that new treatments for illnesses of all sorts, based on new medical discoveries and fine-tuning of established treatments, are always called "experimental", and this rubric is just a ploy by the insurance industry to lower their costs by excluding as many medical treatments as they possibly can. This puts profits above people. Exclusion of "experimental" treatments from cost coverage must end.

(7) The truth about the medical needs of persons with MCS is this: persons with MCS want to get well and go back to work. We don't want to remain on disability forever; we want to go back to active, productive, gainfully employed---tax-paying---lives. We deserve treatment and support to make that happen.

And we can SAVE money---for society, for government, for individuals---in the long run, by providing ongoing supportive treatment that works. It's cheaper to keep people employed, and keep them physically functioning well, than to pay for expensive emergency-room visits and IHSS and disability payments. Insurance carriers, including Medi-Cal, must cover treatment so that people can continue to function; if people don't get treatment, their health declines further. People WANT to get well and want to work; they want to be productive and self-supporting, but you can't expect them to do it without treatment.

Some of the medical treatments that have been most helpful to persons with MCS are:

---various immunotherapies and other biological response modulators, such as intravenous gamma globulin, transfer factor, ampligen, various types of desensitization protocols (support and regulate immune function)

---intravenous minerals, vitamin C, and other nutritional factors (bypasses the nonfunctioning gut, to provide nutrients critical for detoxification and other metabolic processes)

---oxygen therapy

---various pharmaceuticals which are available in Canada and Europe, but which are in the slow FDA pipeline---or worse, are not likely ever to be FDA-approved because for various reasons it is not in the pharmaceutical maker's financial interest to invest the huge amount of money needed to push a drug through the FDA approval process.

These medical treatments are being used successfully by Californians with MCS and, combined with reduced-toxic home and work environments, they can enable many persons with MCS to return to employed, productive lives. It's time that the State of California sees the handwriting on the wall and implements regulations to make access and treatment available for persons with MCS now.

OCT 15 REC'D

Senator Milton Marks
711 Van Ness Avenue
San Francisco, CA., 94102

October 1, 1992

Dear Senator Marks,

I would like to thank you for taking the time to hold the hearing on September 30, 1992 on Multiple Chemical Sensitivities/Environmental Illness. It was eye opening for me, and I am a person with EI/MCS! I think that we just need to inform the general public, and they will hear the message.

There is a bill that, I feel could help persons with EI/MCS. It is HR 3401. It would establish a program for the prevention of disabilities and the prevention of secondary conditions resulting from disabilities. It was introduced by U.S. Rep. Henry A. Waxman. EI/MCS is a classic example of an illness that can be prevented, but not treated, as yet, anyway.

I look forward to seeing the transcript from the hearing. Please keep up the marvelous work. I will pray that there is more to come.

Sincerely,

Ruth Fontana

Ruth Fontana
3000 The Alameda #B
Concord, CA , 94519
510-680-1410

CALIFORNIA STATE SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED

SENATOR MILTON MARKS

CHAIR

INTERIM HEARING OF THE SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED

IN COOPERATION WITH

THE OFFICE OF THE MAYOR, SAN FRANCISCO

ON

MULTIPLE CHEMICAL SENSITIVITY/ENVIRONMENTAL ILLNESS

SEPTEMBER 30, 1992

Testimony by

Ruth Fontana
3000 The Alameda #B
Concord CA 94519

Mr. Chairman and members of the Committee, my name is Ruth Fontana. I am a person disabled by environmental illness/multiple chemical sensativities (EI/MCS). Thank you for giving me the opportunity tp speak to you today.

I would like to tell you about a little-known practice of using synthetic fragrances in public facilities. Installation of fragrance systems, commonly used in businesses, are now being added to many different areas that most people are unaware of. This shows a blatant disregard for the safety of people with EI/MCS. Meanwhile, the fragrance business is booming: Takasago International, Inc., Japan's leading flavor and fragrance maker, is promoting 'mood-enhancing' chemicals for distribution by facilities' heating and ventilation systems, worldwide. According to October 13, 1988 Wall Street Journal article entitled 'Search Is On For Emotion-eliciting Scents', Takasago and the Shimizu Construction Company are installing systems in public rest stops on Japanese highways, and in Shimizu's hotels in the United States, and elsewhere.

The San Francisco Examiner's article, by Louis Trager, pointed to the alarming phenomenon of aromas being used in stores to lure shoppers. This June 21, 1992 article is only the latest in several over the years.

In an earlier San Francisco Examiner article, April 24, 1990, titled "The Sweet Smell of Corporate Japan', by Hajime Yokota describes Kajima Construction Company's three-structure complex in the Akasaka District of Tokyo which has a 'fragrance control' system, jointly developed with the cosmetics firm, Shiseido. "In a basement computer room, three bottles of liquid are attached to air-conditioned blowers. A microprocessor automatically controls the spray emission, releasing at 10-minute intervals and varying the amount in accordance with temperature, humidity and external air flow. The scents go through the atrium and up to the surrounding offices." Now, also on the market in Japan, are scent-emitting alarm clocks, scent-emiting futons, and scent-emitting artificial potted trees for public foyers. Not to be outdone, a pilot project is in progress in London: scenting of London's underground subway cars on the East London line, which carries 6 million people each year, between Whitechappel and New Cross Gate under the Thames River and through 6.1 miles of tunnels.

Here in the United States, there is ongoing research being done to determine how smells affect us. As stated in the artical by Mr. Trager and a KRON TV series called 'The Smell Manipulators', in February 1992, **major** companies are searching for ways to use these fake smells to capture the smell of emotion. Many of them have already contacted a smell researcher, Dr. Alan Hirsh, at the Smell and Taste Treatment and Research Foundation in Chicago. Dr. Hirsh is a psychologist and a neurologist. He says, "By 2010 odors will be used as much, or more, than we see music or lighting used today. It will be the musak of the 90's".

Dr. Hirsh is currantly doing research to find out if a consumer will buy more when they are exposed to a floral fragrance, for example. Preliminary results show, that the consumer will buy more, and also be willing to spend more money for the product, according to Dr. Hirsh. This is also the case when the scent is only subliminal.

These fake smells are currantly being used to lure the consumer into certain resturants and shops. A contract has been signed by a bread company, to plant the artificial smell of baking bread into their bread racks in grocery stores, to influence the brand we buy.

In his research, Dr. Hirsh found that odors go directly to the limbic system, the emotional center of the brain. He says, "We're just at the tip of the iceberg of smell, and there are areas that we have no knowledge, as far as the sense of smell and olfaction."

Harry Snyder of the Consumers Union, commented on the use of peppermint or lemony smells that are used in Japan to increase worker productivity, by giving the example of the farmers who keep the lights on in the henhouses so that the chickens will eat more corn and lay more eggs. He said, "The hens have more stress and they do die earlier, but, they do lay more eggs and it's more profitable." American companies are doing tests on this, right now. Snyder's group wants the testing stopped.

Consumers in Brittan are currantly receiving their bills, scented with the smell of 'fear' to make them pay faster. Charles Wysaki, a researcher in Philadelphia, says that this is the smell of a mating pig.

These fake fragrances are not regulated. John Bailey, of the Food and Drug Administration says that they haven't decided if regulation is needed. "These chemicals are approved as safe", said Bailey. But, of coarse, we know that these are industry studies, with a vested interest, and not making persons with EI/MCS a part of the equation.

Herbert Chau Gunter, of the San Francisco based Public Media Center, was surprised and had not heard of this until the reporter for KRON TV, Tia O'Brien, came to him for his impressions. Gunter stated, "This is worse than subliminal advertising. It causes a physical reaction. The smell of chocolate chip cookies, for example, causes you to salivate. We will certainly lobby hard that we know why we are buying something. A sign, right on the door, 'smells that you experience when you walk in are not necessarily the real smells or natural odors', for example."

Also in the KRON report, Dr. Tom Linden said that these smells can cause physical illness. After smelling the samples of fake smells, Dr. Linden said, "Smelling peanuts or fish can cause a life threatening physical reaction in some people. In others, severe irritation of the eyes and throat might occur. In my case, the peppermint tile gave me a sore throat and a headache. Avoidance is the best. Get out of the room, if it causes irritation." Certainly, everyone who has EI/MCS knows well this advice. But, if this is allowed to be implemented, into the public, unregulated, even more of us will be confined to our homes. This will increase our need for supportive services, such as In Home Support, where the state pays someone to do your errands. This has just been cut by 12%, accross the board, thus, the already homebound would be at risk of being put into nursing home care.

Herb Levine, of the San Francisco Independant Living Center, when speaking on the subject of the Americans with Disabilities Act, cited examples of readily achievable barrier removal. These would be of little or no cost to anyone. They include shutting off the scented deoderants in the bathrooms (or removing them completely), and eliminating the use of artificial fragrances that come through ventilation systems, as in some hotels. Mr. Levine said that he feels strongly, that we must go further than just the posting of warning signs, when considering accessibility for those disabled by EI/MCS. I, personally, have run into two medical offices in Contra Costa County, that are using fragrances in the ventillation system. This use of fake smells, affectively eliminates any possibility of use by me, or even my friends with asthma.

On a recent newscast from KPIX TV 5, it was stated that American Airlines, Hallmark, General Motors, Quaker, Nike and Montgomery Wards are among the companies currently looking into the use of these fake scents. THERE IS NO TIME TO WASTE!! We must look, seriously, at ways to deal with this assault on our senses, while the research is still in it's infantcy! For those of us with compromised immune systems, this is a matter of <u>survival</u>. We are already disabled by chemicals and personal fragrances, on a daily basis. We must have your help to stop this trend before it gets out of control. It is much easier to do it NOW, rather than to clean it up after companies have spent a lot of money in implementation and research.. Thank you.

Articles Attached.

SUBMITTED BY RUTH FONTANA

PROOF of Story '#4805' Requested by SLAGER ($LSRV) on 10/06/92 12:18:42

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Copyright (c) 1992, The Hearst Corp.
DATE/DAY: June 21, 1992, Sunday LENGTH: LONG -- (1313)
EDITION: FIFTH SECTION: NEWS (A) PAGE: A- 1
HEADLINE: Business scents

BYLINE: Louis Trager
SOURCE: OF THE EXAMINER STAFF

<A1><ep> More and more people are sticking their business in your nose.<ep>

Retailers are pumping out manufactured scents to make customers linger, and so more likely to buy. Employers are doing it, seeking alert, accurate workers. Institutions are trying to relax stressed-out professionals and clients.<ep>

Researchers and consultants say mood enhancement is a whiff of the future, a whiff already caught by some trendsetters. Employees at San Francisco-based Jessica McClintock fashion shops wear a house scent that pervades the stores. A Seattle bagel bakery wants to install dispensers of garlic and bread aroma near its product at grocery stores.<ep>

""By the year 2000, odors will be as prevalent in stores as Muzak is,'' says Dr. Alan Hirsch of Chicago's Smell and Taste Treatment and Research Foundation.<ep>

He did a landmark experiment in which 10 percent of subjects paid an average $10.33 more for a pair of Nike shoes from a room with a mixed floral scent than from an odor-free room. Hirsch has received odor engineering inquiries from Hallmark, American Airlines, Crabtree & Evelyn, Dunkin Donuts, Omaha Steaks and others.<ep>

J'Amy Owens of Retail Planning Associates in Seattle says 25 of 40 projects she is working on call for scents. They include a Tiburon pet store, a national fast-food drive-through, and 10 shops for a new park at Florida's Walt Disney World.<ep>

""We're developing a concept for an ATM machine that will actually dispense aroma when you get your cash,'' Owens says.<ep>

Experiments are under way with combinations of spice, floral and fruit scents to help men make male strangers more trusting. Used-car salesmen, Owens notes, could use the aroma to seem more honest.<ql>
<ql>
<A7>AH: Subliminal scents<ep>

<A1> Businesses get most excited about subliminal smells -- aromas meant to work mood-altering magic without being noticed.<ep>

""They don't see that it's any more unethical than using yellowing in the lighting at a jewelry store to make the diamonds look more white,'' Hirsch says. He and other industry figures denounce the practice, but development continues.<ep>

The Knot Shop tie chain recently tested a subliminal tobacco, oak and leather blend meant to remind women customers of their dream man. The Chicago-based company gave up when customers showed no preference for the ambience.<ep>

Aroma engineers say they're just making the world a nicer place, but critics say the whole idea stinks.<ep>

""It's just another way business lies,'' sniffs Paul Hawken, business author and founder of Mill Valley retailer Smith & Hawken Ltd. ""It fits in with the ethos of the modern American corporation. . . . "We're going to mold this wallet disguised as a human being in our image.' ''<ql>

<ql>

<A7>AH: The chemically sensitive worry<ep>

<A1> Advocates for the chemically sensitive worry they will be stricken and excluded by products perhaps not even noticeable by smell.<ep>

""What is pleasant to you may exacerbate my asthma,'' says Susan Springer of the Bay Area's Environmental Health Network. Berkeley disability-rights lawyer Diane Lipton says state and federal laws provide grounds for fighting aroma engineering.<ep>

Ingredients are cleared by the U.S. Food and Drug Administration, the industry replies, and the products are no different in theory from room deodorizers and from the longstanding manipulation of colors, sounds and textures.<ep>

If you can't stand the smell, get out of the store or office, says President Arnold Zlotnik of Air Scent International, Braddock, Pa., maker of ""environmental mood therapy'' products.<ep>

""Start your own business,'' he says. ""When you're around people, you go with the majority. Like they say, when in Rome do as the Romans.''<ql>

<ql>

<A7>AH: Aromatherapy<ep>

<A1> The stink didn't come up sooner because the sense of smell was long neglected, though it may have huge potential. Smell alone bypasses the thought process and acts directly on the brain section that controls emotions, says researcher Hirsch, a neurologist and psychiatrist.<ep>

He says aromas can work commercially in three ways: triggering a conditioned response, like salivating from food smells; inducing fond memories, as with fresh-cut grass; or acting like a drug, the way lavender relaxes.<ep>

Long ago, bakeries and popcorn sellers found smell could be their strongest advertising. Food sellers vented aromas onto sidewalks and into malls.<ep>

Many shops started selling cachets and potpourris in the '80s, partly for store atmospherics. Limited Inc.'s lingerie chain, Victoria's Secret, integrated floral goods with music and decor to create a unified mood of romance for its mainly female clientele. Now a few J.C. Penney stores spray wisteria mist through their lingerie departments.<ep>

Sellers of food made off-premises, like the popcorn at many theaters, needed to buy smells that sell from firms like Air Scent and New York's International Flavors & Fragrances. Consumers can buy food scents for their homes and new-car smell for their cars.<ep>

The new boom is inspired by the explosion of personal aromatherapy -- the use of scents to alter moods -- and by reports from Japan on odor manipulation of employee moods.<ep>

This makes scent engineering an odd marriage of the glamorous fragrance world, providing the juice, and the industrial odor-control business, providing distribution networks and dispensers.<ql>

<ql>

<A7>AH: "Essence of tranquility'<ep>

<A1> Laundry and janitorial supplier Prinova Co. of South San Francisco has a hit with a 6-week-old addition to its line: Kalm, from Chicago's Technical Concepts, labeled ""the essence of tranquility'' because it is supposed to relieve stress. Prinova has 40 Bay Area customers, including a convalescent hospital, a hotel, bowling alleys, a country club and a city government.<ep>

Richard Strock, who manages a Palo Alto office building, bought Kalm because he liked the mild aroma and timed dispenser. He's less upset that he didn't know about the relaxation qualities than he is amused by the claim.<ep>

He was concerned, though, about the objections of a Cystic Fibrosis Research Institute tenant with breathing problems. Strock yanked the dispenser from the closest bathroom.<ep>

Bay Area entrepreneurs, usually innovative, are far from the vanguard on this issue.<ep>

Oakland's Cost Plus Inc. will start taking advantage of its aromatic merchandise -- from coffees and candles to incense and soap -- through strategic placement of the departments as ""scent zones,'' says visual-merchandising director Dan Sykes.<ep>

But San Francisco Music Box Co. of Emeryville found an artificial scent too powerful for its small stores. And unlike traditional department stores, with their perfume-drenched cosmetics counters, Hayward-based Mervyn's takes a hard line against scent.<ep>

""We make an effort to keep the numbers of testers on our counters to a minimum, to prevent scents from getting too strong in the cosmetics area,'' says spokeswoman Kathy Blackburn. ""We think that fragrance is a personal choice for our customers.''<ql>

<ql>

<A7>HD: Business<ql>

scents<ql>

<A5>AH: Aromas being<ql>

used in stores<ql>

to lure shoppers<ql>

<A7>BY: Louis Trager<ql>

<A5>SO: OF THE EXAMINER STAFF<ql>

<A7>GR: COLOR DRAWING<ql>

<A5>GS: EXAMINER / CHRIS MORRIS<ql>

<A7>CP: (HMMMMMNNNN SMELLS GOOD)<ql>

<A5>AT: SHOPPING; PERFUME; EMOTIONS<ql>

<A7>NO: SEE SIDEBAR (FOLLOW YOUR NOSE)<ql>

PROOF of Story '#4810' Requested by SLAGER ($LSRV) on 10/06/92 12:19:08

SAN FRANCISCO EXAMINER LIBRARY

DATE/DAY: April 24, 1990, Tuesday LENGTH: MEDIUM -- (724)
EDITION: FOURTH SECTION: NEWS (A) PAGE: A- 23
HEADLINE: The sweet smell of corporate Japan

BYLINE: HAJIME YOKOTA
SOURCE: Reporter with the newspa

LN# TEXT

<A1><ep> SWEET FRAGRANCES fill the Tokyo air: Scented pantyhose and alarm clocks, bath salts that evoke famous hot springs, ""smart'' buildings whose artificial flowers give off a delicate aroma. From stressful offices to suburban households, perfumed space is the latest in interior design.<ep>

8:30 a.m.: Soft sunshine from the atrium's skylight suffuses a fountain and a little brook. Sixty trees -- coconut, Polynesian cryptomeria and coffee -- 25 species in all, waft a faint citrus odor to employees who arrive early.<ep>

The place is Kajima Construction Co.'s KI building, a three-structure complex in the Akasaka district. Completed in March 1989, it has a fragrance control system jointly developed with Shiseido, the giant cosmetics firm.<ep>

In a basement computer room, three bottles of liquid are attached to air-conditioner blowers. A microprocessor automatically controls the spray emission, releasing it at 10-minute intervals and varying the amount in accordance with temperature, humidity and external air flow. The scents go through the atrium and up to the surrounding offices.<ep>

At 9:30 a.m., when the hectic workday is under way, the system switches from citrus to a sweet floral odor that counters stress. This fragrance is intended to enhance concentration and performance.<ep>

Then from 11:30 a.m. to 1:00 p.m. a cypress-like aroma refreshes everyone during the lunch break. The three faint scents, barely noticeble to most people, are repeated in the afternoon until 5:30.<ql>
<ql>

<ep> AN AUXILIARY system in the 400-seat conference room sprays jasmine when a meeting gets boring and rose when the discussion is intense. The odors are twice as strong as in the atrium.<ep>

""After a while, you are only aware of the scents occasionally,'' said Hiroko Kishimoto of the equipment design department. "It feels healthy, like being in a forest glen.''<ep>

Design manager Fumihiko Toyoda said: ""My sense of smell is poor, so unfortunately I don't notice any difference. But the rustling of the trees in the atrium at lunchtime is very pleasant. Visiting foreign architects really like the green space. They say it's a great place to relax and chat.''<ep>

Hiroichi Nakanishi, assistant manager for project planning, said: ""When you have been out and return to the building, it's very refreshing. The changing scents create a kind of daily rhythm.''<ep>

Not everyone agrees. One employee, who requested anonymity, said: ""We're forced to breathe the stuff. I feel like a guinea pig being given a nasal stimulus to work harder.''<ep>

But Takamichi Suzuki, deputy director for building design, is proud of Kajima's innovative method for dealing with techno-stress. ""Architects usually design offices as utilitarian work areas. Employers have never tired to create a pleasant environment.''<ep>

A questionnaire answered by 337 Kajima employees found only a small minority opposed the fragrance system: Some 3.2 percent said the odors were annoying and 3 percent said they hated the smell.<ep>

But nearly a third felt refreshed or thought the scents eliminated offensive odors such as cigarette smoke. Many called the fragrances relaxing.<ep>

In recent years, a host of new products have been aimed at the olfactory nerve, including an alarm clock with a built-in fan that spreads a forest aroma before ringing, a futon drier that gives quilts a floral freshness, and lavender-treated stockings for kimono-clad women.<ep>

Pantyhose containing microcapsules processed with rose and other scents appeared on the market in February 1988. Monthly production has soared from 30,000 pairs to 1 million. A delighted spokesman for Kanebo, the manufacturer, said: ""We plan to export the hose to North America and Europe this year.''<ql>

<ql>
<A7>HD: The sweet smell<ql>
of corporate Japan<ql>
<A5>BY: HAJIME YOKOTA<ql>
<A7>SO: Reporter with the newspaper Mainichi Shimbun.
Translated by The Asia Foundation.<ql>
<A5>DL: Tokyo<ql>
<A7>CO: HAJIME YOKOTA<ql>
<A5>GR: DRAWING<ql>
<A7>GS: EXAMINER / VAL B. MINA<ql>
<A5>CP: (MAN WITH BIG NOSE SURROUNDED BY FLOWERS)<ql>
<A7>TY: OP-ED<ql>

I wish to submit the following testimony to Senator Milton Marks for the committee hearings relating to environmental illness/multiple chemical sensitivity syndrome (MCS.)

I Introduction

My name is Elna Widdell. I am 59 years old. For the past ten years, I have been forced to live in isolation because I suffer from MCS. I am acutely sensitive to foods, chemicals and molds. I react both to smells and to touch. There are very few things that I can safely touch without feeling some low level reaction in my body. Consequently, I am pretty much confined to one stripped down room containing only white cottons and glass.

Prior to becoming ill with MCS, I led an active life and was engaged for many years in education. I taught elementary school and also served as a college instructor in education. When I became ill, I lost my active life, friends and acquaintances, the ability to read books, to write, to use paper, to enjoy TV, and had to adapt to a very confined existance.

I am now completely homebound and dependant upon others to bring to me the necessities of life and to take care of me. When I am exposed to chemical fumes, molds or eat foods which contain pesticides, I suffer reactions which affect my central nervous system, such as poor coordination so that it is impossible to walk in a straight line, slurred speech, loss of mental clarity so that I can't remember what I'm doing, tremoring and shaking. If I have a strong exposure I will sob uncontrollably or need to scream.

II. Basic Survival Routine

The state IHSS program enables me to hire attendants to shop, do laundry and household chores and assist me with bathing and other personal care. I am extremely grateful for this program which enables me to live at home, since it would be impossible for me to enter a nursing home. The chemical exposures in such an institution would cause such severe reactions I would be unable to remain there. My attendants shop for organic, pesticide-free foods. They do ten or twelve baskets of laundry each week at the laundromat taking special precautions to avoid contaminating my clothes with the heavily perfumed cleansers used by others. They also work to maintain a very high level of cleanliness in my home. They assist me with frequent bathing. If I am unable to bathe frequently and change into clean clothing the level of microbes on my skin build up to where I have allergic reactions and want to scream. The workers at the welfare department have been for the most part sympathetic to my special needs but the IHSS program simply does not provide for some of the special services needed by MCS patients such as extra bathing or responding to chemical emergencies, so there is never enough money to cover all the attendant help I need.

What financial resources and savings I had at the beginning of this illness were rapidly depleted in trying to deal with the exigencies of medical help and safe housing. For the 10 years I have lived in isolation, my only income now is from SSI and I have no other resources. This amount of income has been so financially restricting that it has been impossible for me to seek medical treatments or theraputic remedies which might make me well. Medi-Cal will not pay for them. It is also impossible on an SSI income to pay the costs of relocating to a cleaner environment which I have no doubt would contribute significantly to my improvement.

I am essentially running a convalescence home for one person (myself). It is a full-time job to hire and fire attendants, research sources of organic foods, deal with bureaucracies, and supervise the ongoing household work of attendants. Chronic fatigue is part of this illness so that the best I can hope for is two hours of mental clarity each day, in the morning hours. After I eat my lunch I can expect allergic reactions to my food and am also tired, so that I am much less effective in supervising my afternoon helpers. My day ends at 4:30 pm at which time I am totally exhausted, my voice reduced to a whisper. When I am exposed to chemicals or mold, the nature of my reactions which I described earlier undercuts my efforts to be an affective manager of my own convelescence home. I fear I might reach the point where I can no longer manage my household. It is atotally exhausting job and because of this, I never have time or opportunity to be the patient and actually try remedies which might help me get better. I don't know what I will do if I can no longer run my own household and I cannot enter a nursing home.

III. What would make my Situation more tolerable?

1. Being able to hire a managerial person to run my household should the need arise. This person would need to recieve more than minimum wage. If the state were to pay for such a managerial person it would still probably cost less than the cost of institutionalization.

2. Education of the general public and especcially of neigbors regarding the nature of MCS. Many times my symptoms and reactions are increased and my health impaired due to the use of chemicals by others. Because the illness has not been legitimized in the eyes of the public, my neigbors tend to view my appeals for consideration with skepticism and disbelief. Here are four examples among dozens of typical events or problems with neigbors which have occured in the last few years.

   a. A neighbor two houses away sprayed weed killer on his lawn. The spray itself had an acetone-like base. It drifted in clouds around and into my house. I shut all doors and windows as soon as I noticed it, but my movements became spastic and jerky. I started shaking and sobbing and I spent three or four days in bed totally depleted recovering from the exposure. I had to ask my attendants to come for extra emergency hours to scrub the walls inside the house.

   b. Another day I suffered symptoms similar to those I described with the weed killer, but I did not smell anything. I did not know what was causing the reaction. I had to ask my attendant to come over on an emergency basis to take care of me. My attendant believed she smelled pesticide. She asked the next door neighbors if they had been using pesticide spray. They said yes, they had just sprayed the roses with malathion. I had to pay for extra attendant time to scrub the inside of the house.

c. One day I noticed roofers stripping the roof of a house up-wind of me. I sent my attendant around to ask what work was going to be done. The roofer replied, a hot tar job lasting two days. After closing all the windows and sealing them shut with tape my attendant and I went into full gear and prepared and cooked two days worth of food for me. My attendant helped me bathe and prepare for two days of confinement. After she left I stuffed towels around the edge of the entrance door and remained inside for the two days of the hot tar job. Fumes did seep through despite our best efforts so that I lay in bed shaking and tremoring but thanks to noticing the roofers and preparing in time I came through the ordeal without a major setback.

d. On a daily basis, I am subject to chemical exposures from a family who's apartment adjoins mine in the duplex where I live. Our front doors are four feet apart. They burn incense with their front door open. Their car is parked in the drivewaynear my front door and they spend some time revving the engine each time they start the car, sending clouds of exhaust my way. When outside my windows, he often smokes and she wears perfume. Once a week the highly perfumed diaper pail is set out for the pickup service, on the porch we share. I have allergic reactions to all of these exposures similar to the kinds mentions earlier. It requires a great deal of vigilance to close windows and doors in time to avoid these chemical exposures.

In all of the above examples, I have appealed to the neighbors through letters and by sending my attendants as emissaries to ask them to do me the favor of giving me advance warning when they will be using strong chemicals and in addition I tried to suggest alternative, less toxic chemicals. In almost every case, they experience this request as an encroachment upon the privacy of their home and property and activities. They have not heard of the illness. They are not inclined to be cooperative.

3. When neighborhood diplomacy fails, as described in number 2, some form of legal protection from toxic chemical fumes outside the windows seems essential for the basic survival of MCS patients living at home. Since that air is shared by all the neighbors, if an MCS patient is living in the vicinity mandatory advance warning would be the very least we might expect.

4. A change in IHSS provisions to allow for extra attendant care for emergencies within the home of an MCS victim such as I have needed when it is essential to seal the doors and windows shut and to scrub down the walls. The law guarantees us as disabled persons access to safe and healthful housing. For my housing to be safe and healthful, I require these attendant services at the time of these emergency chemical exposures. I believe equal access to safe and healthful housing must include these services.

5. Safe housing specifically constructed or set aside for MCS victims and maintained free of pesticides, chimney smoke, tobacco smoke, construction chemicals, scented products or perfumes, etc. (I have been searching for safe housing for seven years and have yet to find safe housing).

6. Access to basic health care for homebound MCS patients. This would mean home visits by doctors, dentists, optomitrists and others as needed. Those of us who cannot tolerate doctors offices are left without access to health care. In addition, we need Medi-Cal coverage for therapies which work to alleviate the symptoms of MCS but are now adjudged to be experimental by the Medi-Cal authorities and therefore not covered.

7. MEDICAL RESEARCH is desperately needed. There are numerous political and social forces at work to prevent this from happening. To make the illness and those who suffer from it invisible may be a short term solution for chemical companies and the insurance industry but in the long run our whole society needs to confront and understand this very serious condition which might well threaten the well-being of future generations living in a chemically saturated society.

On a more personal note, I want to thank Senator Marks and his committee for looking into this problem. Ten years of living in solitary confinement has been a terribly lonely existance. Morale is continually being undercut when there is no ready assistance or support and the attitude of family, friends and the general public is to blame the victim. I want very much to reclaim my life, to relocate to an environment which has cleaner air, to be able to once again walk outside under the sky and once again become a functional person and a productive member of society. Knowing that this senate committee is looking into this problem and more people are becoming aware of EI/MCS, helps me keep my spirits up and keep struggling with this illness in this terribly difficult situation. My thanks to all the members of the committee.

Sincerely,

Elna Widdell nem

Elna Widdell/nem
1536 Comstock ~~Place~~ Court
Berkeley, CA 94703

p.s. In order to give this testimony, I paid for three hours of assistance from a friend who agreed to have me dictate over the phone while she typed in into her computer. This has been very costly in many ways. I have done it because it means a great deal to me to have this information known to the members of the committee.

OCT 15 REC'D

544 Central Avenue,
#223
Alameda, CA 94501
510/521-7135
October 14, 1992

Senator Milton Marks
711 Van Ness Avenue, #310
San Francisco, CA 94102

Attn: Joan Ripple

Re: Public Hearing, September 30, 1992
Senate Subcommittee on the Rights of the Disabled
Environmental Illness & Multiple Chemical Sensitivity

Dear Senator Marks:

I regret that I was unable to be present at the above hearing and therefore request that the contents of this letter be entered into the official record.

PERSONAL HISTORY:

I am a 52-year old caucasian woman diagnosed with the above (environmental illness and multiple chemical sensitivity), including a thyroid disease (Hashimoto's thyroiditis), in 1988.

I test positive to trees, grasses, weeds, sagebrush, dogs, cats, dust, dust mites, feathers, numerous molds, 20 food items, ethanol, phenol, natural gas, chlorine, glycerin -- virtually everything for which I have been tested. I am also allergic to my own progesterone and thyroid.

My symptoms include the sense of losing consciousness or going into a coma-like altered state of mental and physical lethargy, migraine headaches (as an immediate reaction to certain inhalants), difficulty in breathing (that I can't get enough air), confusion and disorientation, deep fatigue, irritability, pressure in my chest, hoarseness, feeling cold, inability to support my head, feeling like my bones have melted and can no longer support my body, so that I become floppy - like a rag doll, bloating, short-term memory loss, inability to think, remember, learn, or participate in conversations at times.

I had most of these symptoms for at least a decade before I was diagnosed and treated. My illness has greatly impacted every area of my life, especially relationships and livelihood, as follows:

DIAGNOSIS & TREATMENT:

I was initially diagnosed in 1988 by Phyllis Saifer, M.D., herself a 'universal reactor' (an extremely environmentally sensitive and allergic person), who was at that time under treatment by Alan Levin, M.D. She died of breast cancer in 1989.

At her recommendation and urging, I moved from my apartment with gas heat and stove to different apartment with electric heat and stove, installed a water filter, purchased an air filter for my bedroom, got rid of everything in my home that was scented or contained toxic chemicals, and began to eat mostly organic food.
I also began two medications for thyroid disease, as I am also allergic to my own thyroid and progesterone, namely, Levothroid and Cytomel. In addition, I learned how to inject myself with antigens. I was given eleven infusions of gamma globulin, and many infusions of selenium and zinc. All of this helped, although very slowly over a period of three years, until I felt considerable improvement.

FORCED TO QUIT JOB:

I was forced to quit my job in January 1992 because the insurance company where I was employed for two years announced it was moving to a new office space in downtown Oakland which was freshly painted and in which they installed 4,000 sq. ft. of new carpeting. In addition, the windows in the new space don't open at all. There is no way I could spend any time in that environment.

HAZARDS DURING JOB INTERVIEWS:

While interviewing for a new job, I got migraine headaches in two different offices, one in downtown San Francisco and another in downtown Oakland, before the interviews were concluded. Both were in musty older buildings with poor ventilation.

PROBLEMS WITH PUBLIC TRANSPORTATION:

I am unable to use public transporation because I can't be that close to people whose clothing smells of cigarette smoke, perfumes or scented personal products, and because of the exhaust fumes. I did commute from Oakland to San Francisco by bus in 1987 (before I knew what was wrong with me and how to protect myself) and remember feeling ill while waiting in the bus terminal amidst many nearby buses with motors idling.

RENTAL CARS/NEW CARS:

I rented a car in the past year with a sharp odor that gave me a headache. I returned it to the rental car agency and exchanged it for another.

Several years ago I rented a car at the Phoenix airport. Because an article in Newsweek had mentioned that it was possible to request a car that had not been previously rented to a smoker, I did that. What they gave me was a brand new car with 70 miles on it. I knew it would offgas petrochemicals for months to come --that 'new car smell' that some people find appealing. I should have turned around when my headache began and returned the car, but I was anxious to see my son in Flagstaff so I kept going. I was unable to use the car while in Flagstaff even driving with the windows open. (This was December so it was a little brisk.) A kind travel agent in Flagstaff actually drove the car to the Phoenix airport for me and I booked a flight for myself from Flagstaff to Phoenix.

CIGARETTE SMOKE:

Cigarette smoke is the single most toxic substance I encounter and produces an immediate and violent reaction. (I lived with a cigarette smoker for sixteen years and was myself a smoker for seven years after that.) For the past eight years I have been so sensitive that if I get even a slight whiff of cigarette smoke, the pain in my sinuses and face is unbearable. I become totally brain-dead, unable to function, and go home to bed for usually 36 hours.

If I am even within several feet of someone who is not actually smoking but whose clothing smells of cigarette smoke, I feel immediate prickles of pain in my sinuses.

AIR QUALITY:

I am acutely uncomfortable in warm, poorly ventilated rooms. I can't get enough air. I can no longer attend operas or ballets at the Opera House because of the air quality.

Even outdoor events can become problematic if there are a lot of smokers.

The air quality at San Francisco Airport affects me much more than Oakland Airport. Although smoking has been considerably restricted at both, I still smell an underlying odor of cigarette smoke at San Francisco Airport and almost always get a migraine from being there.

Laundromats used to be a nightmare. The last time I used a public laundromat, I had to ask eight people to NOT smoke until I my laundry was finished and I could leave.

Restaurants are less of a problem than they used to be because of the fairly recent non-smoking ordinances.

NCR PAPER:

I consider myself fortunate that I don't react to electromagnetic fields and am able to use computers, but I do react to NCR paper with an instant migraine. There is no way to adequately describe the pain and the misery of those headaches.

CLEANING HAZARDS:

In 1986 I worked in an office near Pine and Stockton where the aged carpet was cleaned frequently with chemical solutions after the work day. I would open up in the morning, walk into that smell, open windows and doors to ventilate, but begin my work day sitting in the fumes.

EXHAUST FUMES:

While employed at the same office described above, the downtown traffic began heading up the hill on Pine Street beginning mid-afternoon each day. By 4:00 p.m. every day I was brain-dead from the exhaust fumes -- writing incorrect numbers on Federal Express forms -- barely able to sit upright at my desk or to talk coherently.

PESTICIDE SPRAYING:

I have spent the last three weeks barely able to function and feeling extremely lethargic both mentally and physically, with a constant dull sinus headache that leaves me feeling stupid and groggy. I learned only a few days ago that, without my knowing, a pesticide company sprayed the shrubbery immediately below my living room balcony about three weeks ago.

FAMILY HISTORY:

My father and his sister also experienced the same sensitivities and symptoms. I remember my father moving to a hotel whenever our Chicago apartment was painted until the fumes dissipated. He got migraines from certain foods and inhalants. He was always chilled and spent most of my childhood and adulthood in bed Page 5, "feeling lousy".

My mother has always reacted to scents, including flowers, and especially scented household products, as well as foods. Her allergies manifest in skin eruptions while mine do not.

URGENT NEED: SAFE HOUSING

In terms of living space, I need an apartment in a building free from molds, that has not been previously occupied by a smoker, and that is not above, below, or next door to a smoker. The apartment must have an electric stove and steam or electric heat.
It would be preferable to have hardwood or even tile floors rather than carpeting because of the molds, dust, and bacteria found in any carpeting even after it offgasses chemically.

However, a newly refinished hardwood floor or newly installed tile or linoleum floor would be a problem unless non-toxic materials, floor finishing products, and adhesives were used.

Fresh paint is impossible, or new laminated particleboard furniture or cabinetry. Nor could I live on a busy street or near a freeway.

It is extremely difficult to find an apartment without gas. I've called at least a hundred places in the past four years. Most newspaper listings don't indicate whether the unit is gas or electric, and most apartment finder companies and property management firms don't list that information either.

Obviously, management and maintenance of a living space with a tenant with EI/MCS requires special consideration.

Pest control, repairs, and yardwork are all likely to necessitate locating alternate quarters for someone with my disabilities unless the materials are chosen very cautiously and would not be toxic for me.

Fortunately, when I rented my present apartment the manager agreed to NOT replace the bathroom flooring and to NOT paint the walls with fresh paint. She also has allergies too, and had became sick herself when her own apartment was newly painted and carpeted.

CONCLUSION:

It is very difficult to deal with all of this on a daily basis. I am presently unemployed, and went to the YWCA in Berkeley today to use their career library and to look at job listings. I smelled a strange odor similar to exhaust fumes and became unable to think or to remember what I had just read. As lethargy began to overwhelm me, I made it to my car and carefully drove home. I headed for my bed and 'passed out' for several hours, unable to function.

On Friday I have an interview with the coordinator of an HIV Program located at a methadone clinic in Oakland. (I just completed the state training for certification as an HIV Pre- & Post Test Counselor.) There is a part-time position available for HIV Education & Outreach which I would love to do. However, I was told that the windows don't open since it's a methadone clinic, and I will need to determine if the air quality is acceptable.

I strongly urge the Senate Subcommittee on the Rights of the Disabled to include Environmental Illness and Multiple Chemical Sensitivity as a serious disability and to accommodate our needs in the workplace, in building codes, and in housing codes. This disability has affected me for more than ten years and continues to affect every moment of my life. I look like a 'normal' person. I 'pass' for normal in most situations, but I am most definitely not. I only wish I were.

Please feel free to call me if you have any questions or require additional information.

Sincerely,

Marilyn J. Hayes

Marilyn J. Hayes

cc: Environmental Health Network - Susan Molloy
Sam Atwood, San Bernardino Sun

OCT 15 R

Christian Counseling Associates
144 E. Foothill Blvd., Suite 101, Arcadia, CA 91006 • (818) 359-8308

October 12, 1992

State Senator Milton Marx
Chairman of the Committee on the Rights of Disabled Persons
711 Van Ness Avenue, Suite 310
San Francisco, CA 94102

Dear Senator Marx:

I am writing to express my gratitude to you for the work you are doing to explore the needs the chemically sensitive.

I am an educational therapist (working with learning disabled children and adults) and college instructor, and my husband is a licensed psychotherapist. Our two daughters, after more than five years of puzzling intermittent illness, were diagnosed by the head of pediatric immunology at Cedars Sinai Hospital in L.A. in 1978 as having immune system damage. But the cause and cure were unknown until in 1983 a San Francisco immunologist augmented the diagnosis of them (and me) as damage from chemical exposure.

Because of our having saved all my earnings against the day that we would finally know how to help our daughters, because my husband is unusually capable at both construction projects and at recruiting assistance for reaching his goals, and because about 250 people at our church volunteered to help us in one capacity or another, we had the resources to move the girls and me into an isolated mountain cabin for 3 years. My husband's fullest earning power was in his well-established practice, so he had to remain here, bringing the added pain of separation to all of us. But we were able to effect the life-style changes necessary and to obtain all the medical help that was available (in San Francisco and we were in Santa Barbara!).

Because medical care and isolation from chemicals in air, food, and water are such expensive commodities, we eventually obtained for the girls generous college scholarship funding from UCSB, State Rehabilitation funds for some of the expenses of their schooling, and a little Social Security Disability funding (after 2 years' of paperwork, a hearing before a trial judge, and a humiliating somataform diagnosis).

Since those years, my daughters have never been able to remain at the home we left here in Aracadia, but they have gone on to marry and to reach the final stages of their PH.D. degrees in schools in other parts of the country. They will be able to work by controlling their own environments, teaching in college classrooms for one and practicing as a clinical psychologist for the other. My husband and I agonize over the risks of my continued exposure to smog and our need to have our retirement funds replaced to an adequate level before we leave here for the clean air and reduced earning potentials of Colorado.

IN SHORT, WE ARE THE FORTUNATE FEW.

Marriage, Family and Individual Counseling

But, the four of us have counseled, kept in our cabin and home, supported, befriended, wept over, testified in Social Security hearings for, provided our doctor with office space in Southern California to treat patients, etc., in behalf of actual hundreds of environmental patients in this ten years. THESE ARE THE UNFORUNATE MANY with these illnesses. (I also periodically teach a series of classes on chemical sensitivity and allergy for the parents of my students, as there is a high correlation between learning disabilities and sensitivities.)

On top of loss of their vocations and avocations, loss of credibility with their families and colleagues, these sick and suffering people have to be their own advocates, educators, and activists to obtain the understanding necessary for public services to apply to them. Overwhelmed with fatigue, brain symptoms such as short-term memory loss and disorientation, and the humiliation of appearing in public with their symptoms and with masks and equipment over their safe cotton clothing and cosmetic-free face and hair, many retreat from any hope of the kind of recovery we have had because of lack of finances and isolation from the very community resources which should provide a temporary safety net for them.

For instance, the Centers for Independent Living passed a resolution recognizing EI some years ago, and the one in Santa Barbara supplied a wonderful staff member to accompany me on my first trip to the Social Security Office in Santa Barbara because at the time I was too ill to function adequately when exposed to the cigarette smoke, chemical cleaning agents, and pesticides of a public office. The advocate from the Center for Independent Living and I together were able to set it up for the S.S. people to come interview my daughters in the cabin as they were too ill at the time to make the trip into the city, and after that first visit, I managed the rest of the process by phone and mail. But I could not have initiated those applications without his assistance. I ONLY USED I.L.C. ONCE, although the daughter who lived in Santa Barbara did consult them a time or two subsequently, I believe. But in the larger cities in this area, I have found none of those Centers interested in assisting environmental patients, few State Rehabilitation offices sympathetic, and no Social Security people who would make home calls, etc.

Psychological studies of environmental patients being done in several research centers in the country show that the victims who are diagnosed are people who have been well-educated, highly productive, well-employed, and emotionally well-adjusted. Assistance and understanding during the crisis years can return them to productive life. Hence, I applaud your efforts to remove the prejudice, ignorance, and controversy that instead raise virtually insurmountable barriers to their recovery.

Please let me know if there is any way I can be of further assistance to your efforts.

Gratefully yours,

Martha E. Riecken

(Mrs.) Martha E. Riecken

cc: Molly Joel Coye, M.D., M.P.H.
    Mr. Robin Reynolds, CDFA

OCT 13 RE

I became sick with Environmental Illness (aka Multiple Chemical Sensitivity) when I was 28 years old. I got sick in May of 1989. I took two months off in the Fall. I went back to work part time, but soon realized that I was too sick. I left work and applied for state disability.

I went to the Department of Rehab to try to get job counseling. They were very uncooperative. They refused to meet me outside their building. The building was not accessible to me due to the carpet and ventilation. Every time that I went to their office I became quite ill. My counselor implied that I was too mentally unstable to work as I usually began crying after being in the building, usually waiting for him for as long as an hour as he was always late to our appointments. I explained that the building made me ill and that I cry when in a great deal of pain. The only "counseling" the Dept. of Rehab had for me was to state that I would never be able to have another job in my life.

I am still furious at the Dept. of Rehab for knowing so little about E.I.

My counselor at the Dept. of Rehab also told me that they do not recommend self-employment. He did not state that there was a standard policy and procedure for self-employment. He did not tell me about the SSI P.A.S.S. program. I feel that he lied to me in order to make his job easier.

I have since tried to take several courses at community colleges to retrain myself to be able to be self employed. I have had numerous problems that the colleges are often not accessible to me. Many of the computer classes are in rooms that are not accessible to me because of the ventilation. Another of my problems has been with my fellow students rather than the schoolroom. I become more dyslexic when exposed to perfumes; this can be a real problem in a language class such as medical terminology.

Emily Earhart

Emily Earhart
133 Alhambra Ave.
Santa Cruz, CA 95062

OCT 15 REC'D

October 12, 1992
P.O.Box 9714
San Rafael, CA
94912

Senator Milton Marks
711 Van Ness Avenue
San Francisco, CA 94102

Testimony on Mulitiple Chemical Sensitivity/Envirnomental Illness

Dear Senator Marks;

My MCI/EI stems from two trades I have worked in for a combination of 15 years. In both trades, Offset Printing/Photography and Book Restoration,I was employed by the State of California. I've had skin contract and have inhaled such chemicals as formaldehde, benzene, ethly acetate and ethly alcohol. There were no signs posted or any verbal notice to wear gloves or masks, and the ventilation in the three departments that I worked in were very poor. I had become ill with such symptoms as fatigue, memory loss, depression, sleepiness and rashes to my face. I left both these fields because I felt it had something to do with the work envirnment. I did not take any legal actions.

Most of my symptoms seem to clear themselves up after a few months away from the chemicals and poor working conditions. I decided to go back to school, get another degree and then start my own business. I enrolled at Marin College with twelve units, then found a job, surveying maps for a telecommunications company. I've had work loads like this before without much trouble. After a week of starting both these schedules, my concentration was becoming a problem. I'd be at the job and I'd feel confusion on what I was doing. Other symptoms started to cause further problems like muscle spasms and pain in my arms and shoulders, shortness of breath and headaches. I would drop one class at a time, thinking my schedule was too loaded. Finally, as I noticed all my old symptoms coming back like I had working at the State. I left the College and started talking to a few of the employees and employer on these health problems. We are a small company of about ten in one large room. The ventilation was a problem, only that the windows were shut because of the air conditioning. So, we left two windows opened. But the major problem we found was one worker would wear perfume, quite strongly. We put a ban on perfumes and other strong scented products. And we had the cleaning crew stop their use of strong cleaners to just using water.

My symptoms are now under control. They acted up only when I'm around prefumes/scented products and cleaners. This of course works for my working envirnoment since we do not usually have customer at the office. When there is a new employee to our office that still forgets the policy of no perfume, and I feel symptoms reappearing, I have the right to leave the area and not worry about being payed. I do have problems in the social world with perfume wearers and very smelly restrooms from clearers. I now have to be careful and avoid peolple as much as possible.

I hope my testimony helps in showing that with understanding of envirnoment problems in the work place, employers will take on the responsiblity to improve conditions and work with their employees on these problems. As we that stuffer with MCS/EI educate the medical and science communities, we also turn to politicans, such as yourself Senator Marks, to also educate your collegues and the public on the hazards, the reality of MCS/EI.

Thank you,

Kate Sky

Kate Sky

OCT 15 RECD

41 SUTTER, #1787
SAN FRANCISCO CA
94104

OCTOBER 10, 1992

SENATOR MILTON MARKS
711 VAN NESS AVE.
SUITE 310
SAN FRANCISCO, CA 94102

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DEAR SENATOR MARKS:

THANK YOU FOR HOLDING A HEARING ON ENVIRONMENTAL ILLNESS.

IN ME, ENVIRONMENTAL ILLNESS MANIFESTS AS APICH (AUTOIMMUNE POLYENDOCRINOPATHY IMMUNE DYSREGULATION CANDIDA HYPERSENSITIVITY). MY IMMUNE SYSTEM IS DESTROYING MY THYROID GLAND, OTHER GLANDS HAVE BEEN AFFECTED, AND I DO NOT MAKE ENOUGH ANTIBODIES TO FIGHT VIRUSES WITHOUT PAINFUL TREATMENTS. I AM VULNERABLE TO OVERGROWTHS OF CANDIDA ALBICANS, A MICRO-ORGANISM OCCURRING NATURALLY IN THE BODY, BUT PROBLEMATIC IN EXCESS. I HAVE ALLERGIES AND MULTIPLE CHEMICAL SENSITIVITIES, OFTEN MANIFESTING

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October 1989) .

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between autoimmune thyroiditis and environmental toxins and irritants, with c
that they trigger the disease by impairing the T lymphocyte cells of the im:

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2. DIGESTIVE UPSET, ASTHMA,
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I GOT E.I FROM A COMBINATION
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LIVING WITH EI HAS MEANT
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STRIDE. IT MEANS HAVING TO

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CLOSE WINDOWS ON A HOT DAY TO AVOID CAR OR LAUNDRY FUMES, HAVING TO FOREGO READING A LIBRARY BOOK AS A PREVIOUS READER HAD LEFT IT HEAVILY PERFUMED, AND STAYING AT HOME MOST OF THE TIME TO AVOID TOXIC EXPOSURES. IT MEANS NOT HAVING CREDIBILITY WITH MANY PEOPLE AS MY REACTIONS MOSTLY DO NOT OCCUR IMMEDIATELY WITH EXPOSURES BUT ARE DELAYED OR CUMULATIVE (I.E. RESULTING FROM EXPOSURES OVER TIME.) FINALLY, IT HAS MEANT LOSS – LOSS OF MY JOB, CAREER, SALARY, CERTAIN ORGANS AND PHYSICAL CAPABILITIES.

SINCERELY
Mary Ann Handzus
MARY ANN HANDZUS

ENCLOSURES
FRAGRANCE FACTS
DETAILS OF 1989 PERFUME EXPOSURE

October 1989) .

With an autoimmune disease, the immune system produces ant tissue of one's own body, such as the thyroid gland. There is an extreme between autoimmune thyroiditis and environmental toxins and irritants, w that they trigger the disease by impairing the T lymphocyte cells of the

* ALL FILM DEVELOPMENT WAS DONE)

July 6, 1991

I have severe asthma and autoimmune thyroiditis (Hashimoto's disease). In January of 1989, a person moved into an apartment in my building and began spraying perfume there. Because a large fan facing the hall was in use almost constantly and the door was open for hours at a time (the apartment was used as a photography studio), the fumes were very very strong in the hall and even entered my apartment.

Both my asthma and Hashimoto's disease worsened dramatically:

Asthma

December 1988	Moderate difficulty in breathing	2 - 3 doses of bronchodilator medication per day
August 1989	Much greater difficulty in breathing	4 - 6 doses of bronchodilator medication per day

Autoimmune Thyroiditis (Hashimoto's disease)
(Units/ml = antithyroid microsomal antibodies per milliliter of blood)
(Normal range: 25 U/ml or less)

June 1988		440 U/ml
December 1988 (after 6 months of treatment)	Improvement of symptoms most notably dry skin and fatigue	172 U/ml
August 1989	Worsening of symptoms	3550 U/ml
October 1990 (after moving, October 1989)	Improvement of symptoms particularly fatigue	269 U/ml

With an autoimmune disease, the immune system produces antibodies that attack tissue of one's own body, such as the thyroid gland. There is an extremely high correlation between autoimmune thyroiditis and environmental toxins and irritants, with every indication that they trigger the disease by impairing the T lymphocyte cells of the immune system.

Perfume, as an irritant, aggravates asthma. Further, irritated tissue is less able to fight infection than normal tissue. This is not an anomaly. You or someone you know may have noticed how, with a cold or a flu, something like fresh paint may intensify the soreness of a sore throat.

Living with an immune system under such assault means that I have to rely on drastic measures, such as gamma globulin injections, to prevent serious respiratory infections. Not only are chemicals, such as the petrochemicals in some perfumes, a problem to my immune system, it also cannot handle normally harmless substances such as mold, dust mites, and pollen, having been weakened by environmental toxins.

Finally, there are other serious aspects of assault on my immune system. Lymphocytes are in the first line of defense against cancer. Also, I am only one of many individuls with autoimmune thyroiditis, the incidence of which has increased sharply in recent years, according to many endocrinologists and immunologists.

Environmental toxins are factors in other health problems also,such as difficulty with concentration, memory problems, and some cases of arthritis, to name only a few. Although it seems that only a small number of people are affected at present, many endocrinologists and immunologists believe that many, many more people are affected but have not yet made the connection between their symptoms and environmental toxins.

Mary Ann Handzus

Mary Ann Handzus
41 SUTTER, #1757
SAN FRANCISCO, CA 94104

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FRAGRANCE FACTS

out 4,000 different chemicals are used in fragrances. These nclude: phenyl ethyl alcohol, methyl ethyl ketone, benzyl acetate, cyclohexanol, linalool, galaxolide, hedione, benzyl salicylate, methyl ionone gamma, hexyl cinnamic aldehyde, amyl salicylate and iso bornylacetate. (Potential Health Hazards of Cosmetic Products - 1989. Serial # 99-68) (Hearings before U.S.House of Representatives Subcommittee on Regulation and Business Opportunities, July 14, September 15, 1988)

** A recent government report targeted fragrance raw materials as one of six types of chemicals that should be given high priority for neurotoxicity testing along with heavy metals, solvents, insecticides, food additives and certain air pollutants. (Neurotoxins, 1986).

** Perfume is cited as an indoor irritant and pollutant in several major studies including: the EPA's TEAM Study (The Total Exposure Assessment Methodology Study, June 1987) and "Chemical Sensitivity: A Report to the New Jersey State Department of Health," by Nicholas Ashford, PhD, and Claudia S. Miller, MD, December 1989.

** 72% of the asthma patients in a study had adverse reactions to perfume, i.e. pulmonary function tests dropping anywhere between 18% and 58% below baseline. ("Affects of Odors in Asthma," Chang Shim, MD, and M. Henry Williams, MD, American Journal of Medicine, January 1986, Vol. 80)

** Symptoms provoked by fragrances include: watery eyes, double vision, sneezing, sinusitis, tinnitus, ear pain, dizziness, coughing, difficulty breathing, asthma, anaphylaxis, headache, migraine, seizures, fatigue, disorientation, incoherence, short-term memory loss, inability to concentrate, lethargy, anxiety, irritability, depression, mood swings, restlessness, rashes, flushing, muscle and joint pain, muscle weakness, irregular heartbeat, and more. (Candida Research and Information Foundation, Perfume Survey, Winter 1989-90)

** On April 30, 1984, Deborah Martorano was hospitalized with "respiratory distress and close to death," three days after a salesperson at New York's Bloomingdale's department store spritzed her with perfume. Ms. Martorano has filed and won a $75,000 settlement for her assault lawsuit.

** Jacobson's Department Stores (a chain of 24 with branches in Michigan, Ohio, Florida and Indiana) have discontinued fragrance inserts in their credit card statements. No involuntary spritzing of customers (for marketing purposes) is allowed. These actions were prompted by customer complaints.

** Macy's now flags customer accounts, on request, so that monthly statements can be mailed SANS SCENTS, to hypersensitive people.

Irene Wilkenfeld
President
H.E.A.L. of MICHIANA (The Human Ecology Action League)
52145 Farmington Square Road
Granger, IN 46530
(219) 271-8990
9/19/91

OCT 13 RECT

October 7, 1992

Dear Joan,

There have been so many circumstances in which I have needed notification in sufficient time and current accountability from county and state agencies of street maintenance and pesticiding, from the private pest control companies of pesticiding, from neighbors of home maintenance projects and pesticiding and from landlord.

To this day, U.S HUD has been the only program designed to protect my rights and they are unable to handle emergencies.

I have not found any other agency which has the jurisdiction to enforce the protection of my welfare and rights as a disabled person; and I have spoken to many county, state and federal government representatives.

I am enthusiastic about the hearings to encourage the government to give support and protection to EI/MCSs.

I sincerely appreciate the hard working efforts of you and the countless number of others in raising the political and social awareness in this matter.

In deep appreciation,

Marelee Kerns

MARILEE KERNIS October 1992

Thirteen years ago during the spring of 1979, I was exposed to leaking toxic house gas or natural gas and my entire life changed radically bringing me to the worse nightmare that I had ever known. At that time, I lived in a large house in Marin county. The natural gas had been leaking for three of four weeks into my bedroom through the wall before it was discovered. After several days, it became gradually more difficult for me to get out of bed in the mornings. I would feel heavily drugged, disoriented, mentally confused, and lethargic. Never did I suspect that I was being poisoned by natural gas. I could not smell the gas while I was in the room nor could I smell the gas when I left and later returned. Each morning I would drag myself upstairs and out on the patio and with difficulty jump on my trampoline and breathe deeply, until finally after thirty minutes or so I would feel better.

I shared my symptoms with other people, but we all assumed that it was overwork. I was building a successful career as a professional Holistic Health Educator and Body work practitioner in the San Francisco-Bay area. My background in traditional and humanistic psychological disciplines and progressive nutritional approaches added richly to my practice. This was a rewarding time in my life and I was very satisfied with how circumstances were unfolding.

Then one day I decided to go away for the weekend. I inadvertently closed my bedroom door. This allowed the gas to concentrate in the bedroom. When I returned and opened the door to the bedroom, the power of the gas literally pierced through my heart like a sword and forced me to fall backwards off my feet. Then I knew immediately what struck me and that I had been breathing toxic natural gas.

Immediately, I called the gas company, Pacific Gas and Electric Co. By then I could detect a subtle odor and could determine what part of the wall that it was coming through.

The gas company sent two heavy-set football type built men to investigate and repair the leak. For four days they came trying to locate the leak. Never did they break into the wall where I indicated the leak was coming through or did they apply pressure upon the pipes which later proved to be the method to uncover the leak. Finally they gave up with an assuring note to me..." Do not worry; our gas is not toxic and will not harm you " --a dangerous propaganda statement, one a person may easily believe!

Then, I went to my landlady who lived on the property in a back house and reported the situation. Her response to the problem perplexed me. She said that if I didn't like living here that I could move out. Finally, I persuaded her into hiring a private plumbing company. They came out and did what the PG&E gas company should have done right away, that is, to apply pressure on the gas pipe. What they found was a serious leak and repaired it promptly. When I went back to PG&E to question their ineptness, they excused their oversight by placating me. There never was an admission of incompetence. Their skewed sense of righteous justification seems to be common place.

Since then I have discovered and sadly so that there exists considerable incompetency and a great lack of accountability to the public and in particular to the disabled group of persons with Environmental Illness and Multiple Chemical Sensitivities.

At that time, I asked PG&E as to what treatment I could use to recover from these numerous symptoms of confusion, lethargy, and so forth, as well as consulting with both a conventional medical doctor and a holistic medical doctor. Not one seemed concerned about any complications and not one gave me any suggestions for therapeutic treatment. Obviously, I asked the wrong people.

Within two weeks, I collapsed. I had to be carried to the emergency room at Marin General Hospital. There the doctor suggested that I had a low grade fever brought on by a flu which was causing the various pains in my body. He completely disregarded my concerns about natural gas poisoning. I became gradually worse by the end of the year. By that time I was diagnosed as having Environmental Illness and was considered a universal reactor, that is I was unable to tolerate innumerable odorous and odorless out-gassings of vapors from all kinds of common and uncommon products. These chemical gasses like formaldehyde, hydrocarbons, petrochemicals, smoke, pollens, molds, mildew gas, and so many others were ubiquitous in the environment and caused me serious physical and psychological reactions and complications. I no longer had any quality of life.

My profession crumbled and my friends deserted me in disbelief with several rare exceptions. My symptoms were very numerous effecting my neurological, cardiac, respiratory, cerebral, gastro-intestinal systems. I was always in uncomfortable muscle, joint , and neural pain; sleeping twelve to fifteen hours a day—falling asleep or passing out often; constantly feeling extremely fatigued; frequently being unable to connect words together, to communicate or understand; having a poor memory, poor neural-motor coordination, extreme shortness of breath, multiple viral infections like EBV(Ebstein Barr Virus) and CMV(Cytomeglovirus) and reacting to almost anything that I breathed and ate. It was a nightmare and it was just beginning.

There was very little understanding of the EI/MCS disability and even less cooperation or support by government agencies and the private business sector. This is true even today—thirteen years later! We are ridiculed, disbelieved, placated, challenged as to credibility, reacted hostilely to, ignored, excluded or treated in a life- threatening way. There are those few who do try to give support or service, but most often they can not provide the type or quality of support and service that we may need.

Here are some examples of the difficulties that I have encountered in trying to get service and accountability.

1. Since 1986, I have been dealing with one of the local pest control companies—Pestmasters in Bishop, California. I requested of the owner, Mr. Jeff Van Diepen, that I would be notified when there would be a spraying of residences in my surrounding area. This is a continual, antagonistic problem as far as feeling the communication and support [illegible] there. I always live in a fear of being exposed because of bad communication. And, this did happen last May. The owner has never re-assured me of his full cooperation.

People have their homes sprayed from once every month to a quarterly application. After I am notified, I need sufficient time to make plans to find safe housing at my expense and to be away for seven days from the date of application. If I return any sooner, then I have reactions to the pesticide, such as I have difficulty breathing, shortness of breath, dizziness, confusion, slurred speech, blurring of vision, neural seizures and muscular spasming. Furthermore, I need to interrupt any projects that I am working on, let people know that I will be away for this period of time, and close up my apartment. When I go for an appointment to my medical doctor, I need sufficient time to schedule an appointment and to make special arrangements with the hotel to prepare my room since they need to follow very specific guidelines. At times finding safe housing has been difficult and I have had to park in a wilderness area and camp for the week.

At the beginning, I did not find the owner at all receptive to my request. He insisted that the pesticide products were safe and that I would not have any problems. He would not or could not hear me even after I sent him a very thick packet of information on EI/ MCS and a cover letter from my medical doctor saying that exposure to pesticides could cause a life-threatening situation for me. He stated that he and his staff were too busy to notify me; so I should arrange this with the neighbors. I felt that notification should be his responsibility.

So, I discussed the issue over with the Commissioner at the Inyo County Department of Agriculture and requested that he ask the pest control company to comply with my request--after all I was not asking him not to spray, but only to be properly notified. The commissioner was very sympathetic, but said that he could not enforce compliance since it was not within his jurisdiction; but he did offer to talk to the owner and supported my health claim. The owner slightly shifted positions; although he still denied any liability--even up to the present, he did agree to contact me, reluctantly.

Then, I called the chemical manufacturer, DOW Chemical Company, and was connected with a receptive techician who called the pest control owner. He agreed to encourage that the owner cooperate with notifying me. This he did.

I also called the Inyo County Department of Health. The directing physician told me that this was not a county issue and he could not be of help.

I was told that I could not take him to court because no harm had occurred. Besides, it would be a health problem for me to go into the court building.

My solution was to befriend the applicator who turned out to be a very sympathetic and deeply concerned man. For two years he fully cooperated with me. When he left, a woman took over. There were problems ,at first, to get her to cooperate. Again, I called the owner. Instead of his saying that he would resolve the problem right away, he always leaves me feeling that I am a sore that he wishes to get rid of right away. Finally she and I worked out a better communication. Then she quit and no one informed the new person of me. I discovered the change by chance when a neighbor told me, days after that she had called the pest control company to come to spray on the next day. I immediately tried to leave a message for the new applicator since the owner was out of town. He never received it. However, I called on the next day and left another one to let me know which day he sprayed because I had to be away for seven days from the date that he sprayed. I also left a message that he needs to notify me whenever he will be spraying any other residences in the surrounding area.

Something went wrong. When I returned and by the time I had walked the thirty feet from my car to my apartment, I started shaking ,getting disoriented, confused, piercing pains in my heart and head. I entered my apartment quickly and knew by the way I was reacting that someone had sprayed pesticides recently.

I called one of my neighbors in the apartment building and discovered that the pest control company had sprayed the house next door to my apartment the day before. Those neighbors have refused to cooperate by letting me know of any spraying.

I immediately called the pest control company, spoke to the owner and told him that I was reacting to an uninformed spraying and was having minor seizures and pain. I said our communication has broken down and I need to be informed and that I was leaving town after we hung up. So what he says is "I have no liability".

I had to be driven out of town since I couldnot manage on my own.

Who can help me, what agency can require that those of us who are more sensitive are informed and are related to with accountability?

2. American Airlines denied me special accommodations for my disability.

When I fly, I always take a specially made charcoal filter mask. I try to fly at off-hours so the planes will not be so full and I can more easily sit away from someone who is wearing perfume, colognes or hairsprays. Otherwise I am forced to wear a rather uncomfortable charcoal mask difficult to breathe through except by mouth. I am unable to remove my mask even for a few minutes so I can eat and drink unless I can have special seating. This flight was practically full and with the help of the flight attendant we tried tofind a seat a safe distance from any scent wearers. This was not possible except in the first-class section. So, I asked to be seated in first class , but the head ground flight attendant ,Clarke Blackwell, rudely denied my request even after I told him that my disability was recognized under the Americans with Disability Act. He abruptly told me that he was not about to provide first class seating for me under any circumstances. He said that he would put me on a later flight, but I told him that I was being picked up at the airport and the people had to drive two and a half hours to the airport. He still refused to accommodate my special circmstances and as a result, I was forced to fly under very uncomfortable conditions.

3. Hotels/Motels

Many hotels and motels have turned me down for they were not willing to accommodate my special requests in preparing a room. These are no new carpeting,at least three years old; no chemical cleaning of the room--the room must be water wiped including furniture and pictures; no lysol ever used in the room; no carpet shampooing for one month, no pesticides inside the room for two months; no pesticides outside the room or in common areas for ten days; no gas heat; no air fresheners; preferably a non-connecting room--otherwise I use masking tape to seal the connecting door and the room door; non-smoking room if possible; no painting for three months; no new furniture for one year; no furniture polish at any time; no restaurant smoke blowing to my room; a room with an opening window; an upper floor room on the quiet side.

Of the few that have been willing to accommodate, only a very few of those have been able to provide safe accommodations. Many times I have had to sleep in my car. One motel in Los Angeles listenened to my list of requests and claimed their rooms to be ideal. So I drove four hours to my appointment of several hours and afterwards exhaustedly I went to the motel only to discover that the room had been painted two weeks before and new furniture had been placed. When I reported my problem to the owner, he told me that I belong in a hospital and not in a motel.

The hotel that has consistently given me good service is the Frontier Hotel in Las Vegas where I stay eight to ten times a year when I have a medical doctor"s appointment.

4. Denied assistance by the EPA out of San Francisco.

I needed the EPA to help me enforce cooperation and accountability from Inyo County pest control department and the private pest control company. But EPA said that it was not within their job description. They denied my request to write a letter acknowledging that I spoke with them concerning my health problems, refused documents from my medical doctor attesting to the legitimacy of my health disability, refused to indicate that some pest control products can be harmful to a small group of the population who are sensitive to lower levels of the pesticides than the average person, and would not reccommend to the county and private pest control company to consider my request of cooperation.

5. Denied cooperation from the Inyo County Public Works Department.

I had difficulty getting cooperation from the Inyo County Department of Public Works concerning notificaion of road work in town. The head supervisor told me if the head physician supports my request and claims of disability then he would notify me. He would not accept any documentation from my medical physician. I contacted Inyo County Department of Public Health and spoke to the head physician about my problem and related what the Public Works supervisor told me. I had already suffered an exposure from some vapors from road work causing me to go into convulsions and pass out. The head physician of the county said that he had never heard of my particular problem and could do nothing to help me. He refused to support my requests.

How this worked itself out was in the interim I had contacted Cal Trans, the state of California's road department and received their receptive support. (To this day Cal Trans provides highly reliable notification.) So, I recontacted Inyo County Public Works and this time the supervisor was not there. So, I was transferred to an assistant supervisor who after hearing my problem and that Cal Trans was working cooperatively with me also agreed to notify me. Since there were several uninformed situations, I have to keep on top of them.

6. Denied any assistance from the Great Basin Unified Air Pollution Control District.

The first incident was when my neighbors directly to the south of me refused to inform me when they would pesticide spray. I asked the GBAPCD if they could intervene and request my neighbors to cooperate. I explained that the neighbors sprayed pesticides and that they could not keep the spray on their property, but it would drift over to my housing which could cause harmful effects to me. I said that I had a letter from my medical doctor and other pertinent information on the harmful effects of drifting pesticides. GBAPCD told me that they could do nothing to help me as an individual and that if I were able to get 9 other complainants that they would intervene. I was able to get 4 others, but the department would not give me any assistance.*

The second incident was when the current building that I live in was being sold and the building was to be pesticided with a toxic fumigant sulfuric fluoride gas, Vikane. I asked GBAPCD if I provided them with a letter from my medical doctor as to my problems with pesticide exposure and some information that this product has not been tested on the more vulnerable segment of the population such as the elderly, those with respiratory problems, those with immune system deficiency illnesses like EI/MCS and the very young from the manufacturer--Dow Illanco--would they intervene and state by letter that this fumigant gas could harm my health and others and suggest that the prospective owners and the current owners should look into the available, safer alternative termite methods. But they would not do this. They only offerred to monitor outer ambient air.

* see addendum

7. EPA

A similar request was made of an industrial hygenist from EPA. Although unfamiliar with my EI disability, he did agree to check into the ~~data~~ test data gap. He expressed concern for me, but never was anything put into writing.

8. Denied services by medical doctors.

They are the most resistant to provide services that accommodate Environmentally Ill. For three years I have been attempting to find a doctor who will accommodate me so I can have a pap smear. Doctors are notorious in refusing to not wear scented products or asking their staff not to wear scented products on the day that I come. Also they often refuse to use an acceptable alternative disinfectant like Zephiran or Borax or n one at all in the room that I will be seen. I can not go to an office that has been recently painted with paint toxic to me or with carpets newer than three years old or recently shampooed. They often use air fresheners and other toxic cleaning products.

6. Denied accommodating service at a hospital.

This situation is particularly unusual. Several years ago, I was having difficulty breathing. So I went to the emergency room of the local, rural hospital for oxygen. At the outside door, I explained my EI disability, gave information on my medical doctor and explained that I had been exposed to some unknown gases and was having reactions-chills, neurological shaking, pains, left side chest pains, and turning white. The nurse said that she would put me on oxygen, but could not do it next to an open door or window--for I had told her that the disinfectants, cleaning products, perfumes and so forth could cause me additional problems. She assured me none of the attending staff wore perfume, colognes or scented products.

I agreed to come in and she put me on oxygen immediately. About five minutes later the doctor came in. He was very unfamiliar with my EI disability and would have hardly believed me if it wasn't for my medical doctor's letter explaining my health problems. He tried to contact my medical doctor but was unable to since it was a weekend. I told him that I was very familiar with my symptoms and oxygen was the most sufficient treatment that he could provide me. I told him that my heart was fine, but he urged me to agree to an EKG. The EKG technician arrived and quickly hooked me to the equipment. In a few minutes after she arrived something began to agitate my nervous system slightly. I questioned her for perfume,etc. But she had nothing on. Then I realized that I was reacting to the vapors from her cough drop. I told this to the doctor who asked her to dispose of it. She refused and within minutes I started to get extreme pains in my stomach, pancreas, and heart and my body began spasming. I quickly got off the table and moved toward the emergency room outside door and collapsed while spasming on the floor. The nurse and the doctor put me in a wheelchair and took me outside. Now I had additional problems than the ones I came with.

7. Restaurants

Restaurants have failed to establish safe indoor and outdoor dining areas for the chemically sensitive. It is rare that I can eat at a restaurant and only outdoors and then it must be away from smoke, and often times restaurants will not agree to seat their smoking guests at the opposite end of the patio. It is difficult to be served by a serviceperson who does not wear perfume or scents and to find a restaurant that uses alternative pest control methods or find safe days to go.

8. Government agencies--and their buildings--and private businesses--and their buildings--are most often limitly available or non-accessible to an EI/MCS because of the toxic methods and materials used. This ia a partial list of problems: 1) cleaning chemicals and disinfectant products toxic to a EI/MCS 2) permiting smoking 3) allowing the staff to wear heavily scented products 4) having decorated or redecorated with toxic paints, installing new carpeting and furniture 5) shampooing the carpets with toxic shampoo 6) pesticiding with no warning posted 7) heating with natural or propane gas. I could not go into my bank for one year after they redecorated without my mask .

EI/MCS is a very expensive disability requiring extensive medical care, special products and organic food. Even though my health has slowly been improving over the past thirteen years because of my medical doctor's treatments, I still remain vulnerable to many chemicals, gases, smoke, pesticides, etc. and must be informed accountably or I may suffer a serious set-back which possibly could be life-threatening.

We, EI/MCS's, have the right not to be victimized by the system, but to be recognized and respected as the vulnerable segment of the population which is highly sensitive to the out-pouring of toxic materials and gases. We are indicators that safer, less toxic alternatives need to be rapidly developed and where they already are available to be used without delays.

We need to have better accessibility to safer goods and services and the environment and not to be run-off by the actions of an inconsiderate business or neighbor. We have the right to co-exist.

Marilee Kernis

Marilee Kernis
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ADDENDUM

I made the same request of Inyo County Department of Environmental Health. They said it was not within their jurisdiction, but agreed to talk to the neighbor. The agent told the neighbor that there was nothing in the law to enforce complianceand they did not need to cooperate, but it would be "nice".

I made the same request of Inyo County legal aid. if they could assist me. The attorney said that my case and status did not fit the directives of services. He did listen to what I had done and encouraged me to continue.

Share, Care and Prayer, Inc.

October 12, 1992

Senator Milton Marks
Chairman
Committee on the Rights of Disabled Persons
711 Van Ness Avenue, Suite 310
San Francisco, California 94102

Dear Senator Marks:

Thank you for this opportunity to comment on the needs of those who suffer with Environmentness Illness, a painful, debilitating, disabling and, most often, isolating disease. Our nonprofit organization serves over 2,400 individuals and families across the nation who have multiple chemical sensitivity (MCS). Major areas of need are as follows:

I. Education of State Employees and General Public to Existence of Disease.

A lot of time is spent explaining the disease, with the disabled patient often being rejected for assistance because of ignorance of the employee.

II. Safer Public Buildings for Equal Access

Buildings should be constructed and decorated with less toxic materials, not only to allow equal access, but to prevent further cases of MCS. Pests should be eradicated with non-chemical means such as Integrated Pest Control.

III. Safer Residential Housing for Chemically Disabled in Urban Areas

A. Apartment/motel type housing built and decorated with less toxic materials and with all electric utilities. Prohibition of commercial insecticide/herbicide use on the property, indoors or outdoors, and limitations on cleaners and laundry products used by tenants.

B. As above, safe refuges for short term housing for those with chemical sensitivities who visit the area for medical treatment, or for those who have to evacuate their residences due to chemical contamination—for example, use of pesticide (landlord, neighbors, Caltrans, aerial spraying), repaving of streets, fires causing smoke, adjacent apartments being painted, etc.

905 N. First Avenue, Arcadia, California 91006
(818) 446-2609

(During the aerial spraying of malathion over So. California, I arranged with the Red Cross to set up shelters for our members to avoid the spray. However, we did not follow through because all the normal shelter buildings were already contaminated by routine pesticiding and had gas heat. For these same reasons, the chemically sensitive cannot stay with relatives or friends, or in regular hotel rooms in emergency situations. They must have safe refuges to avoid chemical exposures.

I am acquainted with many chemically disabled people who are homeless because they cannot locate a place to rent or purchase because of previous use of pesticide and fragranced products which do not readily dissipate over time.

More and more people are selling their pesticide or new carpet chemically-contaminated homes and offices which made them sick and are moving out. I have a great concern for the health of the new buyers. And, many of our members became sick after moving into a used home and did not know why the home made them sick. One chiropracter in a small town treated a patient until she sold her home and moved on. When the new resident of that home began coming to him for treatment for the same symptoms, he wondered if there was a connection. Then the new patient's two children and, finally, her husband came down with the same symptoms. The second family has since moved from that house and are doing much better. But what about the next residents?)

IV. Perfume-Free Government Facilities

As with cigarette smoke, the chemically sensitive also react adversely to perfume. (Those employees who wear perfume generally become masked to the fragrance and use more and stronger scents. With more and more employees chronically ill, there is a possibility that curbing perfume would increase worker productivity.)

V. Safer Hospitals

There is a great need for emergency rooms and private rooms that can be tolerated by those with chemical sensitivities. Hospitals increasingly are putting in more carpet. They also use very strong cleansers and laundry products.

(Education of paramedics and emergency room personnel to the unique needs of the chemically sensitive is also greatly needed. In cases of emergency, the MCS patient frequently cannot physically communicate, or is not believed, when they try to convey to those helping them that they are, or will be, made sicker following normal procedures.)

VI. Medical and Insurance Companies Recognition of the Illness

Oxygen and neutralization shots are helpful to many patients but are not covered.

VII. Safer Schools

Many children react to the chemicals used in and out of the buildings, such as pesticide, art and cleaning products, and carpeting. The incidence of asthma has sky rocketed amongst young people. Less chemically contaminated schools would help prevent illness and increase productivity.

VIII. Discontinuance of Aerial Pesticide Spray Over Urban Areas

Those with MCS go to great lengths everyday to avoid exposure to pesticide. The recent aerial spraying of pesticide over parts of California contaminated their properties and the air around them for miles. It created a living nightmare for them. Not only were their symptoms exacerbated, but many have remained more sensitive to chemicals than prior to the spray. Certainly this is cruel and unusual treatment of those diabled by chemicals.

* * * * * * *

For your information on a little different tack, and looking ahead to the future, we have grave concern for the outcome of research being done on using mood alternating scents in public places (see recent <u>Los Angeles Times</u> article). Previous articles have reported businesses are considering using mood altering scents, subliminally, in subways, department stores and classrooms. This type of contamination of air in public buildings would have tragic results for those with MCS, and may cause more people to become sensitive or cause other diseases.

And, we are concerned about plans to market genetically engineered food. Most people disabled with MCS have multiple food-sensitivities as well. The FDA admits it has no way of knowing if an allergen from one food would pass to another when genetically combined, or if they would create a new allergen. And, there would be no way to label, for example, genetically combined food, such as wheat with corn or flounder with tomato, from the field or a can into a meal. Life threatening, or severe, long lasting reactions could result from someone unknowingly ingesting something to which they are allergic.

* * * * * * *

Senator Marks, once again we thank you for taking the time to hold a hearing and to read our letter on this subject. We look forward to good things coming from your interest and concern in those with environmentally caused disabilities.

Please let me know if we may of any further service, or answer any questions you may have regarding this matter.

Sincerely,

Janet Dauble

Janet Dauble
Executive Director

P.S. We have enclosed our brochure and a Church Concern Packet for your further information.

cc: Molly Joel Coye, M.D.
Robin Reynolds

941 Laburnum Dr.
Sunnyvale, CA 94086
Oct. 7/92

Senator Milton Marks
D-San Francisco District
State Senate, State Capitol
Congress of State of Calif.
Sacramento, Calif. 95814

Reference: Introduction of Legislation
that addresses concerns of
People Afflicted by
Environmental Illness

Dear Senator Milton Marks,

I am writing to you to cast my support for your activities in introducing legislation (that addresses the concerns of people afflicted by Environmental Illness,).

I feel there is indeed a need to protect the rights of us so inflicted to access public places; especially if not anywhere else, at least to medical clinics, hospitals, and dental offices.

I was an electrical engineer (who spent a whole life time acquiring two BSEE degrees, MSEE, and an MBA degree). I took classes towards a PHD degree while working at an Electronics Co. in the San Francisco Bay Area, only to end up inflicted with MCS. I was healthy up to, and until, Aug/90 (57 years old at the time). It was then I became afflicted with Multiple Chemical Sensitivity, (due to exposure of excessive fiber glass dust at work.) As a result, I no longer can tolarate the slightest hint of chemical odors or chemical emissions from carpets, and related materials. It is this phenomena that prevents me from going indoors of many shopping centers, convention centers, offices, manufacturing plants, public buildings, etc..

The irony of this is, that at my last job, I was charged with tracking the events by manufacturers, that were leading to the "slowing of the process of introduction of legislation" (that would otherwise protect the public from unregulated disposal of batteries) (in our public disposal sites). In this respect, I am both a perpetrator of activities leading to inhibit regulation protecting our health; as well as now; a victim of the same.

In view of the foregoing, I now fully support legislation that will permit victims such as myself to have access to "sealed buildings" and to tighten up the quality of air in public buildings, and work places.

On behalf of all collegues at HEAL (Human Ecology Action League), and other environmental groups, we applaud you Sir. We want to urge you to continue your fine work. You have our votes Sir. Good luck with your proposed "Bill".

My best regards,

Bill Shewage

(Ex Electrical Engineer)

File: Senate

Encl: San Francisco Chronicle

Article Oct. 1/92 (Attachment A)

(2) Dr John Wakefield MD Medical Report. (Attachment B)

ATTACHMENT A

Paul:
FYI

A20 San Francisco Chronicle ☆☆☆☆☆ OCT. 1, 1992

BAY AREA REPORT

■ SAN FRANCISCO

Help Sought By Victims of Baffling Illness

Wearing surgical masks, respirators and occasionally breathing from oxygen bottles, more than a dozen victims of a mysterious and controversial syndrome known as environmental illness yesterday called for laws to protect their access to public places.

Witnesses suffering from a baffling hypersensitivity to perfumes, paints, deodorants and cleaning products told a state Senate hearing in San Francisco that their rights should be protected like those of other disabled people.

The hearing was called by state Senator Milton Marks, D-San Francisco, who said he intends to introduce legislation in January that would address concerns of people afflicted by environmental illness.

Some scientists, however, dismiss the syndrome as a psychological disorder.

The witnesses testified that their suffering is real and that the cause is environmental. "I cannot work in a sealed building. It is inaccessible. I might as well be asked to work on top of the Himalayas," said Sue Hodges, chair of the Oakland mayor's Commission of Disabled Persons.

Advocates want rule changes that would take the disorder into account in building codes, workplace regulations and public housing standards. They want public meetings posted to discourage the wearing of perfumes and aftershaves.

ATTACHMENT D

JOHN WAKEFIELD MD.
Remington Health Center
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Suite #23
Sunnyvale, CA 94087-1155
PH (408) 732-3037

6 January 1992

Roy W. Krickeberg
Commerce Bank Building, Suite 650
111 West St. John Street
San Jose. California 95113

Re: William Shewaga

Dear Mr. Krickeberg

This is the report that you requested concerning the above William Shewaga. Mr. Shewaga was seen by me on 17 January 1991. He had scheduled a consultation to discuss his medical history since July 1990. Since that time I have seen Mr. Shewaga a number of times, taken a detailed and extensive history, and reviewed a variety of medical records.

HISTORY

Mr. Shegawa has enjoyed excellent health until 3 August 1990. Over the previous two or three days he had been reviewing a batch of old documents which had been covered with dust and fiberglass particles since the earthquake of 17 October 1989. On 3 August he broke into a sweat, became nauseated, vomited a thin, clear mucus and felt he as though he might loose consciousness. He saw the Occupational Health nurse at Hewlett Packard, Margaret Rankin, who referred him to Dr. Kanter at Sunnyvale Medical Clinic. He was advised to stay off work for a few days, which he did. After a week he was feeling much better and returned to work. He again developed sweating, nausea and vomiting and again was forced to stay away from work for a few days.

During the months of August, September, October and November of 1990, Mr. Shewaga was off work on Sick Leave a significant amount of time. There were a number of episodes in which he returned to work only to have the symptoms recur. He was back on the job in December 1990 and the first part of January 1991 until January 14. On that day he had developed dizziness and incoordination upon entering building 20 at his worksite following the installation of new carpeting. Over the next two days he felt nauseated, his face became red and swollen and the skin of his face and of his scrotum began to itch intolerably. His eyes swelled shut, he felt disoriented and developed flu-like symptoms. He again went of sick leave and ultimately on long term disability. Each time he returned to work and suffered some exposure, the became ill more rapidly and finally resigned on 30 April 1991 because of his health. He has continued to suffer the same range of symptoms whenever he is exposed to many of the chemical moieties commonly found in the ambient air.

DIAGNOSIS

Multiple Chemical Sensitivity

DISCUSSION

Mr. Shawaga has a history of excellent health until his exposure at work to heavy dust which had resulted from the October 1989 earthquake. He had no history of allergies or of respiratory disorders. His present medical problems all had their inception during and following the work exposures to dust, including fiberglass fibers. Initially he would improve rapidly when away from the work exposure, then deteriorate when he returned to the area. As time went by and he suffered repeated and frequent exposures, the range of identifiable substances to which he experienced adverse reactions broadened. He began reacting not only to substances found in the workplace but also to chemicals normally found in the society at large.

Physicians who knew Mr. Shegawa and saw him during this initial period diagnosed him as having reactions to exposures in the workplace. His personal physician, Dr. Brosterhaus, diagnosed him as suffering from Multiple Chemical Sensitivity, Dr. Kanter stated that Mr. Shegawa had a hypersensitive, irritative airway, and Dr. Rubinstein described him as having work-induced upper respiratory symptomalogy. Dr. Garb indicated that she thought Mr. Shegawa's condition was precipitated by stress and unusually dusty conditions at work.

Multiple Chemical Sensitivity is pathological condition the existence of which has now been widely recognized but the biologic mechanisms of which are not known. There is a growing body of literature which describes and attempts to deal with the questions surrounding this condition. A few references include:

'Workers With Multiple Chemical Sensitivities' OCCUPATIONAL MEDICINE: State of the Art Reviews, edited by ark R. Cullen, M.D., 1987, Hanley & Belfus, Inc.

'Multiple Chemical Sensitivity', Chemical and Engineering News, Bette Hileman, July 22, 1991

'Multiple Chemical Sensitivity: Treatment and Follow-up: Avoidance and Control of Chemical Exposures", a paper by Grace Ziem, M.D., Dr. P.H., presented at the 'Multiple Chemical Sensitivity Workshop' sponsored by the Association of Occupational and Environmental Clinics, Washington DC , September 1

21, 1991.

CONCLUSION

In my opinion, Mr. Shegawa suffers from Multiple Chemical Sensitivity brought on by his exposure at his workplace. My experience with a large number of these patients over a twelve to fifteen year period indicates that this condition is permanent and that he will never again be able to tolerate the same kinds of exposures that he has experienced in the past with impunity. If he practices very strict avoidance, the likelyhood is that he will improve slowly, and will be able to work in an environment in which he suffers no exposure to substances to which he is reactive. However, minimal exposure will result in his return of symptoms and his loss of work time. For all practical purposes, his disability is total as well as permanent.

Sincerely

John Wakefield, M.D.

JW:hs