

COMMERCIAL VERSUS HEALTH INTERESTS

The Chemical Industry's Organized Denial of Toxic Injury and Multiple Chemical Sensitivity ("Environmental Illness"): A Portrait of Disinformation

Two Historical Documents

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- 1. Multiple Chemical Sensitivities Under Siege** - Ann McCampbell, MD
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- 2. Environmental Illness Briefing Paper**, reprinted from BEST of the Reactor, edited by Susan Molloy, 1990, pages 171 - 181. Discussed in *Illness and the Environment: A Reader in Contested Medicine*. Ed Steve Krohl-Smith, Phil Brown and Valerie J. Gunter New York University Press, New York (1997).¹ Pages 15-30

MULTIPLE CHEMICAL SENSITIVITIES UNDER SIEGE

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Movies like *Erin Brockovich* and *A Civil Action* depict the true stories of communities whose members became ill after drinking water contaminated with industrial waste. Their struggles clearly show how difficult it is for people to hold corporations responsible for the harm they have caused. Whether individuals are injured by exposures to contaminated air or water, silicone breast implants, cigarettes, or other chemicals, their quest for justice is usually a David versus Goliath battle that pits average citizens against giant corporations.

When confronted with the harm they have caused, corporations typically blame the victims, deny the problem, and try to avoid responsibility for the harm caused. The corporate response to people with multiple chemical sensitivities (MCS) has been no different. People with MCS are made sick from exposures to many common products, such as pesticides, paints, solvents, perfumes, carpets, building materials, and many cleaning and other products. But the manufacturers of these products would rather silence the messenger than acknowledge the message that their products are not safe.

To that end, the chemical manufacturing industry has launched an anti-MCS campaign designed to create the illusion of controversy about MCS and cast doubt on its existence. What has been said about the tobacco industry could easily apply to the chemical industry regarding MCS, that is, “the only diversity of opinion comes from the authors with ... industry affiliations (1).”

It is a credit to the chemical industry’s public relations efforts that we frequently hear that multiple chemical sensitivities (MCS) is “controversial” or find journalists who feel obligated to report “both sides” of the MCS story, or attempt to give equal weight to those who say MCS exists and those who say it does not. But this is very misleading, since there are not two legitimate views of MCS. Rather, there is a serious, chronic, and often disabling illness that is under attack by the chemical industry.

The manufacturers of pesticides, carpets, perfumes, and other products associated with the cause or exacerbation of chemical sensitivities adamantly want MCS to go away. Even though a significant and growing portion of the population report being chemically sensitive, chemical

² Ann McCampbell, MD, 'Multiple Chemical Sensitivities Under Siege,' *Townsend Letter for Doctors and Patients*, January 2001, Issue #210; reprinted with permission, www.townsendletter.com. For a wealth of information on MCS, chemicals and the chemical industry, see <http://annmccampbell.com/publicationwritings/publication-1/>

manufacturers appear to think that if they can just beat on the illness long enough, it will disappear. To that end, they have launched a multipronged attack on MCS that consists of labeling sufferers as “neurotic” and “lazy,” doctors who help them as “quacks,” scientific studies which support MCS as “flawed,” calls for more research as “unnecessary,” laboratory tests that document physiologic damage in people with MCS as “unreliable,” government assistance programs helping those with MCS as “abused,” and anyone sympathetic to people with MCS as “cruel” for reinforcing patients’ “beliefs” that they are sick. They also have been influential in blocking the admission of MCS testimony in lawsuits through their apparent influence on judges.

Like the tobacco industry, the chemical industry often uses non-profit front groups with pleasant sounding names, neutral-appearing third party spokespeople, and science-for-hire studies to try to convince others of the safety of their products. This helps promote the appearance of scientific objectivity, hide the biased and bottom-line driven agenda of the chemical industry, and create the illusion of scientific “controversy” regarding MCS. But whether anti-MCS statements are made by doctors, researchers, reporters, pest control operators, private organizations, or government officials, make no mistake about it – the anti-MCS movement is driven by chemical manufacturers. This is the real story of MCS.

CHEMICAL INDUSTRY

In 1990, the Chemical Manufacturers Association (now the American Chemistry Council) vowed to work to prevent the recognition of MCS out of concern for potential lost profits and increased liability if MCS were to become widely acknowledged (2). It specifically committed to work through physicians and medical associations to accomplish this, stating that it was critical to keep physicians from legitimizing MCS. Unfortunately, this plan has been relatively successful. The industry has enlisted the aid of vocal anti-MCS physicians who promote the myths that people with MCS are “hypochondriacs,” “hysterical,” “neurotic,” suffer from some other psychiatric disorder, belong to a “cult,” or just complain too much. Most of these physicians work for industry as high-paid expert witnesses although their financial ties are usually not disclosed in their journal articles, interviews, or speaking engagements. Therefore, many people, including those in the health care profession, are often led to believe that these physicians’ opinions reflect an honest appraisal of MCS rather than the chemical industry’s agenda. At least one industry expert witness has authored two anti-MCS position papers for prominent medical associations. It is easy to see why these papers are biased against MCS and how by helping to combat MCS in the courts, these position statements are quite lucrative for industry and expert witnesses alike.

PHARMACEUTICAL INDUSTRY

The pharmaceutical industry is also involved in the effort to suppress MCS. Drug companies, which usually work with the medical profession to try to help patients, are working to deny help for those with MCS. This is extraordinary, but can be explained by the fact that the

pharmaceutical industry is intimately linked to the chemical industry. That is, many companies that make medications also manufacture pesticides, the chemicals most implicated in causing MCS and triggering symptoms in people who are chemically sensitive. For example, Novartis (formerly Ciba-Geigy and Sandoz) is a pharmaceutical company that makes and sells the widely used herbicide atrazine (3). This helps explain why a Ciba-Geigy lobbyist submitted material to a New Mexico legislative committee in 1996 opposing all legislation related to MCS and declaring that the symptoms of people with MCS “have no physical origins” (4). The legislation being proposed would have, among other things, funded a prevalence study of MCS, an information and assistance program and “800” telephone number, hospital accommodation guidelines, and an investigation of housing needs of people with MCS (5).

Novartis is also a large manufacturer of the organophosphate insecticide diazinon (3), a neurotoxic pesticide currently being reviewed for its safety by the U.S. Environmental Protection Agency (6). The EPA recently banned a related organophosphate pesticide, chlorpyrifos (commonly sold as Dursban), from household uses because of concern about its toxicity, especially to children (7). The pharmaceutical company Eli Lilly used to be a part of DowElanco (now Dow Agroscience), the primary manufacturer of chlorpyrifos (8). Aventis (formerly Hoeschst and Rhone-Poulenc) manufactures the allergy medicine Allegra as well as the carbamate-containing insecticide Sevin (active ingredient carbaryl) (9). Monsanto, known for making Roundup and other herbicides, is a wholly owned subsidiary of a pharmaceutical company called Pharmacia (10, 11). Zeneca manufactures pesticides (12) and pharmaceuticals (AstraZeneca), including drugs to treat breast and prostate cancer, migraine headaches, and epilepsy (13) — illnesses whose cause or exacerbation have been linked to pesticide exposures.

Pfizer and Abbott Laboratories make both pharmaceuticals (14) and pesticides (15), while BASF makes pharmaceutical ingredients and pesticides (16). Even Bayer, famous for making aspirin, manufactures the popular neurotoxic pyrethroid insecticide Tempo (active ingredient cyfluthrin) (17). Novartis, Ciba, Dow, Eli Lilly, BASF, Aventis, Zeneca, and Bayer are all members of the American Chemical Council (formerly the Chemical Manufacturers Association), as are other pharmaceutical manufacturers, such as Dupont, Merck, Procter & Gamble, and Roche (18).

The pharmaceutical industry has been able to spread misinformation about MCS and limit the amount of accurate information received by physicians and other health care providers through its financial influence over medical journals, conferences, and research. It is well known that magazines containing cigarette ads are less likely to publish anti-smoking articles. Similarly, because medical journals rely on pharmaceutical advertisements for funding, they are not likely to publish positive MCS articles. In fact, researchers supportive of MCS have long complained that it is very difficult to get their studies published in the medical literature. Pharmaceutical companies may also influence medical organizations such as the American Medical Association, whose funding relies in large part on the sales of drug advertisements in its journals (19), and the American Academy of Family Physicians, whose major donors are drug companies (20).

Corporate financing of medical conferences has also been shown to bias the information presented (21). Since continuing medical education is becoming increasingly reliant on corporate sponsorship, industry influence over physician education is a growing concern in the medical community (22). Other ways the pharmaceutical industry can influence physicians are also of concern. In a 2000 *Journal of the American Medical Association* article (23), the author states that “physicians have regular contact with the pharmaceutical industry and its sales representatives, who spend a large sum of money each year promoting to them by way of gifts, free meals, travel subsidies, sponsored teachings, and symposia” (p. 373). The study concludes that “the present extent of physician-industry interactions appears to affect prescribing and professional behavior and should be further addressed ...” (p. 373). This is especially true regarding the effect that the pharmaceutical and chemical industries have had on physicians’ professional behavior in response to MCS. Because they do not receive appropriate and accurate information on MCS during their training or from medical journals and continuing education courses, physicians have been largely unprepared to deal with chemically sensitive patients. As a result, their responses to MCS patients have tended to range from dismissive to blatantly hostile.

One example of the pharmaceutical industry’s direct attempt to present anti-MCS information at a medical conference was at the 1990 meeting of the American College of Allergy and Immunology. Sandoz (now Novartis) was scheduled to sponsor a one day workshop that characterized people with MCS as mentally ill (24). This company was a large manufacturer of pesticides and pharmaceuticals (25), including anti-psychotic, anti-depressant, and sedative medications (14). Therefore, Sandoz stood to benefit both from pesticides being exonerated as the cause of MCS and from people with MCS being treated with psychiatric drugs. As it turned out, people with MCS outraged by the workshop risked their health to protest the event and were able to shut it down (26).

The pharmaceutical industry also influences research on MCS. First and foremost, it is not pursuing research on MCS (other than to perhaps fund a few studies to try to discount it), despite being a major source of funding for medical research to help those with other diseases. Secondly, as was evident when the Ciba-Geigy lobbyist opposing funding for MCS research in New Mexico, the industry is not only refraining from doing research on MCS itself but is attempting to block research by others as well.

A recent editorial in the *New England Journal of Medicine* outlined a myriad of ways that financial ties with the pharmaceutical industry may influence physicians (27). “The ties between clinical researchers and industry include not only grant support, but also a host of other financial arrangements. Researchers serve as consultants to companies whose products they are studying, join advisory boards and speakers’ bureaus, enter into patent and royalty arrangements, agree to be the listed authors of articles ghost written by interested companies, promote drugs and devices at company-sponsored symposiums, and allow themselves to be plied with expensive gifts and trips to luxurious settings” (p. 1516). In fact, some industries, including the tobacco industry, have paid authors up to \$10,000 to publish letters in high-

profile scientific journals (28, 29). The author of another New England Journal of Medicine article wrote, “The practice of buying editorials reflects the growing influence of the pharmaceutical industry on medical care” (30). Since these conflicts of interest are increasingly encroaching on the medical profession in general, it is highly likely that some of them apply to physicians opposed to MCS as well.

ENVIRONMENTAL SENSITIVITIES RESEARCH INSTITUTE

Several nonprofit organizations and trade associations sponsored by the chemical industry are particularly active in opposing MCS. For example, lobbyists for RISE (Responsible Industry for a Sound Environment), a pesticide trade association, and the Cosmetic, Toiletry, and Fragrance Association testify against MCS each year in the New Mexico legislature. The Chemical Specialties Manufacturing Association, which represents companies who manufacture and distribute home, lawn and garden pesticides, antimicrobial and disinfectant products, automotive specialty products, waxes, floor finish products, and many types of cleaners and detergents, has also submitted anti-MCS comments to the NM legislature (31). And individuals from a lesser-known organization calling itself the Advancement of Sound Science Coalition published an opinion-editorial in two New Mexico newspapers several years ago that was critical of the positive steps being taken by the New Mexico legislature on MCS (32, 33).

The leading opponent of MCS, however, is unquestionably the Environmental Sensitivities Research Institute (ESRI). This corporate-financed nonprofit organization was founded in 1995 specifically to combat MCS. According to MCS Referral and Resources, ESRI was founded to “serve the needs of industries affected by MCS litigation” (34). But since ESRI tends to be secretive about its membership, board members, and activities, it is hard to know exactly who is involved with ESRI and what the organization does. However, it is known that ESRI is primarily supported by its member companies and trade associations, who pay \$5000 or \$10,000 a year in annual dues (35, 36). It is also known that the past board of directors have included representatives or employees of DowElanco, Monsanto, Procter and Gamble, RISE, the Cosmetic, Toiletry and Fragrance Association, and other chemical companies and trade associations (36).

Although ESRI has in the past claimed to be a scientific and educational organization dedicated to the open exchange of scientific information (37), this is belied by its decidedly anti-MCS views. ESRI’s bias against MCS is evident in its fact sheet that claims that MCS is a “phenomenon” that “defies classification as a disease” (38). It appears that this organization’s main work consists of disseminating anti-MCS literature, holding anti-MCS conferences, intervening in legal and government affairs, and otherwise trying to impede progress on MCS. And despite its name as a research institute, ESRI has only recently begun to award small MCS research grants. It will be a great surprise, however, if the majority of these studies do not support a psychological basis for MCS.

Besides lacking objectivity, some of ESRI's activities demonstrate questionable ethics. For example, ESRI published an "advertorial," advertisements made to look like legitimate news stories, in newspapers around the country that stated that MCS "exists only because a patient believes it does and because a doctor validates that belief." Then, according to Albert Donnay of MCS Referral in Resources, ESRI anonymously tried to get the American Academy of Family Physicians Foundation (AAFPF) to endorse its anti-MCS brochure (36). Fortunately, the AAFPFF withdrew its support for the brochure when ESRI would not put its name on it.

One of the more flagrant misrepresentations in the brochure (39) was the answer "No" to the question, "Is MCS listed as a disability under the Americans with Disabilities Act?" One might consider this an honest mistake if it were not for the fact that an article published at almost the same time by ESRI's then executive director clearly demonstrated he knew better. In the article, he states that "although not categorically noted to be a disability in the body of the law, the ADA [Americans with Disabilities Act] does allow for the consideration of MCS as a disability on a case-by-case analysis that is applied to all other physical and mental impairments" (40). And he also writes that "in 1991, the Department of Housing and Urban Development stated that people suffering from MCS can seek protection under federal housing discrimination laws." It appears that ESRI was attempting to mislead physicians and the public into believing that MCS is not a covered disability, while its executive director was warning an industry-oriented audience that MCS was a covered disability and offering suggestions for how to defend themselves against a claim.

New Mexico has had direct experience with ESRI representatives and tactics. In 1996, ESRI mailed anti-MCS literature to a state disability agency that was developing a report to the legislature on MCS. Among other things, this material included advice on how to avoid accommodating chemically sensitive employees (41). Then, ESRI staff visited New Mexico in person. The ESRI manager attended a Town Hall Meeting on MCS at which she offered to help the state epidemiologists develop a prevalence study protocol. Shortly thereafter, however, she reportedly told another member of the prevalence study working group that MCS can't be studied because it doesn't exist. This circular reasoning, that you can't prove MCS exists without more study and you can't study it because it doesn't exist, is commonly used by industry lobbyists. A corollary to this is the lobbying strategy of calling for more research on MCS while attempting to block it at the same time.

ESRI's then executive director also visited Santa Fe in 1996. Among other things, he went to a Medicaid Advisory Committee meeting and urged that Medicaid benefits be denied for the diagnosis and treatment of chemical sensitivities, spoke against MCS at a continuing medical education (CME) conference for physicians where he failed to disclose his industry affiliations as required by CME guidelines, and berated the staff at an independent living center for providing a support group for people with MCS.

Another ESRI project involved paying a medical journal to publish the proceedings of an anti-MCS conference in its supplement (42). This conference was organized, in part, by a consulting

firm that was owned by ESRI's then executive director and supplied expert witnesses to testify against MCS. Later these papers were cited as references to support anti-MCS statements in material ESRI gave to the Ciba-Geigy lobbyist, which she submitted to the legislature. In keeping with its attempts to keep a low profile, however, ESRI did not put its name on the documents that were submitted.

A ROSE BY ANY OTHER NAME

Even though MCS has gone by that name for over a decade, industry associates would have you believe that it goes by a myriad of other names, so many that it must not be describing anything legitimate. In fact, if an article starts out with a long list of possible names for MCS, you can be almost positive it is going to be critical of MCS. Referring to MCS as a "phenomenon" rather than an illness and using the term "multiple chemical sensitivity syndrome" also tend to be code for "it doesn't really exist" or if it does, "it's all in people's heads." Articles using these names are usually accompanied by other myths and put-downs, such as MCS has no definition, no objective findings, and no known prevalence, and is "only symptom-based," a "belief system," or "chemophobia." People with MCS are also frequently dismissed as having an "unexplained illness," as if they, rather than their physicians, were to blame for not adequately "explaining" it.

Since 1996, however, the chemical industry has taken a bold new approach to the name for MCS. It has made a concerted effort to rename MCS "idiopathic environmental intolerances (IEI)." It is quite clear that its motivation is to get the word "chemical" out of the name. This would be analogous to the tobacco industry trying to change the name of "smokers cough" to "idiopathic respiratory paroxysms." Anything to try to distance the disease from its products.

But despite frequent claims to the contrary by its users, the term IEI has not replaced the name for MCS. Its use, however, has slowly increased over the years in anti-MCS journal articles, industry propaganda, and medical association position papers. Fortunately, the use of the term IEI is like a tracer dye that immediately alerts the reader, patient, or constituent that the person or organization using the term is biased against MCS. The most frequent users of the name IEI are doctors who work for industry as expert witnesses or allegedly "independent" medical examiners, industry-sponsored organizations, and allergy or occupational medicine organizations that have long been critical of environmental doctors who treat people with MCS. While there may be some individuals who innocently use the term IEI, the overwhelming majority who use it appear to be connected to industry in some way.

One of the more outrageous claims that the chemical industry and its associates make is that the World Health Organization (WHO) supports the name change from MCS to IEI. The WHO was one of the sponsors of an International Programme on Chemical Safety (IPSC) workshop on MCS held in Germany in February 1996. This workshop was dominated by industry-associated participants and had no representatives from environmental, labor, or consumer groups. Instead, the non-governmental participants were individuals employed by BASF, Bayer,

Monsanto, and Coca Cola (43). It was at this meeting that the decision was made to try to change the name of MCS to IEI.

Besides getting the word “chemical” out of the name, the workshop participants chose to add the term “idiopathic,” apparently because they thought it meant the illness was “all in someone’s head” rather than of unknown etiology (cause) (44). But lots of “real” illnesses are considered idiopathic, such as idiopathic epilepsy (i.e., epilepsy not resulting from trauma, surgery, infection, or other obvious cause). Still, implying that MCS has no known cause helps the industry. They do not want to be held responsible for their products causing MCS, or for that matter, triggering symptoms in people sensitized to them. It’s hard to understand, however, how IEI is much of an improvement over MCS, since the term MCS does not address the cause of the illness either. It is just a good description of the condition, that sufferers are sensitive to multiple chemicals, which is not that different from having multiple “environmental intolerances.”

In any case, the WHO issued a statement to the workshop participants after the meeting to try to put a stop to claims that WHO supported the name change from MCS to IEI. It stated that “A workshop report to WHO, with conclusions and recommendations, presents the opinions of the invited experts and does not necessarily represent the decision or the stated policy of WHO.” It goes on to say that “with respect to ‘MCS,’ WHO has neither adopted nor endorsed a policy or scientific opinion” (45). Despite this explicit disclaimer, claims that the World Health Organization supports IEI continue to be made by MCS opponents.

MCS IN COURT

Perhaps the area where the chemical industry is most aggressively fighting MCS is in the courts. This is not surprising considering the fact that ESRI was founded to assist industries involved in MCS litigation. MCS cases commonly involve workers compensation, social security, toxic tort, disability or health insurance, and disability accommodations. MCS can also arise in divorce proceedings, child custody battles, and landlord-tenant and other disputes. In lawsuits where chemical manufacturers are directly involved, for example, when they are being sued for harm caused by their products, it is clear that attacks on the plaintiff’s credibility and medical condition, including MCS, come from the manufacturers. It is often unrecognized, however, how much the chemical industry is also involved in suppressing MCS in other lawsuits, through filing of briefs, supplying “expert” witnesses, and distributing anti-MCS literature to attorneys and witnesses.

The chemical industry also seems to have been influential in convincing many judges that MCS testimony should not be allowed in court. They argue that MCS does not satisfy the Daubert criteria for the admission of scientific testimony established by the U.S. Supreme Court in 1993. This ruling eliminated the requirement that expert testimony be “generally accepted” in the scientific community to be admissible and replaced it with the requirement that the reasoning or methodology underlying any proposed testimony merely be scientifically reliable and

relevant (46). Thus, the intent of the ruling was to allow testimony on emergent theories of disease even if they had not yet been generally accepted by the medical community. But in the case of MCS, this has backfired. The Daubert ruling, which was intended to make it easier to admit scientific testimony in court, has increasingly been used to block testimony on MCS.

Some judges have ruled that MCS does not satisfy the Daubert criteria, despite the fact that it clearly satisfies at least three of the four factors specified in the Daubert ruling to assess proposed testimony. The Daubert ruling states that the following considerations will bear on admissibility of expert testimony: 1) whether the theory or technique in question can be (and has been) tested, 2) whether it has been subjected to peer review and publication, 3) whether the reasoning or methodology has a known or potential error rate, and 4) whether it has widespread acceptance within a relevant scientific community (46). According to these criteria, testimony on MCS should be admitted because, it “can” and “has” been tested (47), has been subjected to extensive peer review and publication (48), and is widely accepted in the environmental medicine community. The factor regarding potential error rates is largely irrelevant because MCS is a clinical diagnosis that does not rely on tests.

But whether an illness or theory satisfies the Daubert criteria is obviously in the eye of the beholder. A judge in New Mexico, for example, ruled there was not enough published literature on MCS to fulfill the Daubert criteria (49). Yet there are over 600 articles on MCS and related conditions in the published literature, the majority of which support a physiological rather than psychological basis for MCS in a ratio of two to one (48). The judge rejected testimony on MCS even though he thought there would be enough literature in 5 to 10 years for it to satisfy the Daubert requirements. But if a judge is convinced MCS will be well established in the future, then testimony on MCS is credible and ought to be admitted now. After all, the intent of the Daubert rule is to admit testimony on just such valid emerging theories of disease as this one. In addition, it is unclear how much this judge was swayed by the anti-MCS opinions of the defendant’s expert witness, who admitted she relied on material sent by ESRI for her testimony and did not know who funded the organization (50). It is, indeed, unfortunate that the subjective nature of the Daubert criteria has allowed judges to misinterpret them in favor of the chemical industry. This has resulted in many people with MCS being denied disability benefits, compensation for toxic injuries, and reasonable accommodations under the ADA, among other things.

A case in point is a recent ruling by the Massachusetts Supreme Court that rejected MCS testimony in a work-related injury case because the physician’s testimony was not based on “reliable methodology,” that is, because he did not use a test to diagnose MCS (51). This conclusion was reached even after stating that “a new theory or process might be so ‘logically reliable’ that it should be admissible, even though its novelty prevents it from having attained general acceptance in the relevant scientific community” and that “in many cases personal observation will be a reliable methodology to justify an expert’s conclusion.” This is another example of a biased interpretation of the law against MCS. And again we find the chemical industry involved. Though not a defendant in the case, the American Chemical Council

(formerly the Chemical Manufacturers Association) filed a “friend of the court” brief against the worker and expressed delight with the court’s anti-MCS decision (52).

Finally, there are growing attempts to get medical licensing boards to revoke the licenses of physicians who diagnose and treat chemically sensitive patients. One physician is in a legal battle with the California Medical Board to keep his license, in part, for this reason (53). In an anti-MCS booklet, an author who is known as an industry sympathist, has called for state licensing boards to “scrutinize” the activities of doctors who treat MCS patients. He also stated that he thought “most of them should be delicensed” (54). Trying to put physicians who treat MCS out of practice or harassing them until they quit on their own is an extremely insidious way of trying to get rid of MCS. It is also a threat to the independent practice of medicine by everyone.

IMPACTS OF MCS

The impact of MCS on individuals and society is huge, both in terms of its potential severity and the number of people affected. Many people with MCS have lost everything – including their health, homes, careers, savings, and families. They are chronically ill and struggle to obtain the basic necessities of life, such as food, water, clothing, housing, and automobiles that they can tolerate. Finding housing that does not make them sicker, that is, housing that is not contaminated with pesticides, perfume, cleaning products, cigarette smoke residues, new carpets or paint, and formaldehyde-containing building products, is especially difficult. Many people with MCS live in cars, tents, and porches at some time during the course of their illness. In addition, people with MCS usually have financial difficulties. One of the most unjust aspects of the anti-MCS movement is that many expert witnesses are paid \$500 per hour to testify against people disabled with MCS who are seeking that much money to live on per month.

The impact on society is no less severe. An increasing number of physicians, lawyers, teachers, computer consultants, nurses and other skilled workers who were once productive members of society can no longer support themselves or contribute their skills to society. Their loss of earning power also translates into less money spent in the marketplace and less tax revenues. Deputy state epidemiologist Ron Voorhees of New Mexico estimated in a letter to the governor that the state may be losing 15 million dollars a year in tax revenues due to the decreased earning capacity of those with MCS (55).

And this medical condition is not rare. Prevalence studies in California (56) and New Mexico (57) found that 16% of the respondents reported being chemically sensitive. Additionally, in New Mexico 2% of the respondents reported having been diagnosed with MCS — the more severe form of chemical sensitivities — and in California, 3.5% reported having been diagnosed with MCS and being chemically sensitive. Although women report being chemically sensitive twice as often as men, which contributes to its “hysteria” label, those reporting chemical sensitivities are otherwise evenly distributed with respect to age, education, income, and

geographic areas. Chemical sensitivities are also evenly reported among ethnic and racial groups, except for Native Americans, who reported a higher prevalence in both studies.

It should be of great concern to everyone that this devastating and potentially preventable illness is affecting an increasing percentage of the population and disabling a significant portion of the work force. It is affecting people in all walks of life throughout the country and around the world. It is vitally important, therefore, that MCS be squarely addressed and not swept under the rug as the chemical and pharmaceutical industries are trying to get the medical profession and government to do. But ignoring MCS is not only ill-advised, it is inhumane.

CONCLUSION

MCS is under siege by a well-funded and widespread disinformation campaign being waged by the chemical and pharmaceutical industries. Their goal is to create the illusion of controversy about MCS and cast doubt on its existence. These industries feel threatened by this illness, but rather than heed the message that their products may be harmful, they have chosen to go after the messenger instead. While corporations are only beholden to their stockholders, medicine and government need to be responsive to the needs of their patients and citizens. Unfortunately, industry has convinced many in the medical and legal professions, the government, the general public, and even loved ones of people with MCS, that this illness doesn't exist or is only a psychological problem. As a result, people whose lives have already been devastated by the illness itself frequently are denied appropriate health care, housing, employment opportunities, and disability benefits. On top of this, people with MCS often have to endure hostility and disrespect from the very agencies, professionals, and people who are supposed to help them.

For example, an elderly woman with MCS was forced out of public housing and became homeless when staff insisted on remodeling her apartment, even though she warned them ahead of time that the new carpet and cabinets would make her too sick to continue living there. The physician of a woman, hospitalized because she was having anaphylactic reactions to all foods, tried to transfer her to the psychiatric ward for "force feeding." A school district fired a chemically sensitive teacher for excessive absenteeism after it failed to provide her with the accommodations she had requested and needed in order to work. A former airline attendant had to camp in the desert and a mother and her small child had to live in their car because they could not find housing that did not make them severely ill. And a man disabled with MCS is unable to obtain vocational rehabilitation services even though he wants to work.

Countless others have failed to find tolerable housing, including a former marathon runner who has lived in her car for 7 years and struggles to fight off frostbite every winter. In another case, a chemically sensitive woman living in her trailer was forced to leave a state park when hostile staff insisted on spraying pesticides while she was there. The park supervisor said that he had seen a television show on MCS which convinced him that he did not have to make accommodations for people claiming to have MCS because it did not exist. The show had

featured ESRI's then executive director and portrayed people with MCS as freeloaders and misfits.

Despite the chemical industry's disinformation campaign, however, and its influence over doctors, lawyers, judges, and government, incremental progress is being made with respect to MCS. This is a testament to the strength, courage, dedication, and sheer numbers of people with MCS. In fact, there are so many people becoming chemically sensitive that attempts to ignore or silence them are ultimately doomed to fail. But even though it is just a matter of time before MCS gets the recognition it deserves, each day it is delayed prolongs the suffering of millions of people with MCS and puts millions more at risk of developing it. Therefore, it is essential that those in medicine, government, and society begin to see past the industry disinformation campaign in order to recognize the true nature of MCS and the urgent need to address this growing epidemic.

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12. Zeneca, <http://www.zeneca.com> (10/29/00).
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Environmental Illness Briefing Paper

Chemical Manufacturers Association Anti-MCS Campaign launched 1990

“Environmental illness patients generally lead troubled lives and have genuine problems in coping with family, work and life-style pressures. They often eagerly accept environmental illness as the explanation for their condition...”

“Because environmental illness is a health issue, the only people who can legitimize it are physicians, and they have not. Should environmental illness arise as an issue, a coalition with the state medical association is absolutely necessary.”

Our society now has long experience with the intervention of commercial interests when the evidence of illness from their products threatens their profits. Whether the issue is smoking or pesticide use, or any number of other substances or practices that clearly have proven harmful to humans and fellow creatures, commercial interests have often intervened in ways geared to powerfully undermine the credibility of those who suffer from the products of their commercial practice. These battles are major and ongoing every day, fought by scientists and environmentalists against corporations with profits to lose.

ES/MCS (originally called ‘Environmental Illness’) has been no exception. The difficulty is that the commercial propaganda promoted by the then-Chemical Manufacturers’ Association, (now, American Chemistry Council) left a harmful lasting legacy - the myth that people with ES/MCS are emotionally troubled, not physically sick - while the vast majority of those who have adopted this belief have no notion of its origin. It is our opinion that by denying the harms suffered by ES/MCS ‘canaries’ - harms that, unlike the slow and hidden progression of hidden cancers, for example, are acute and immediate and excruciating - the chemical industry effectively succeeded in whitewashing many of the chemicals that today have either been banned, or are under siege by those fighting for the interests of future generations and the biosphere. Some of the most ubiquitous of those chemicals have been documented in popular

books such as *Slow Death by Rubber Duck* and *The Body Toxic*.³

For those interested in understanding how this has taken place in the ES/MCS case, we include this historic document.

In **1990** CMA lobbied for approximately 175 member companies, and supported twenty full-time lobbyists in Washington, DC. The CMA was in the process of establishing a Political Action Committee to enable contributions to the campaigns of political candidates. The paper below was circulated to physicians associations, insurers, governments and other businesses. Today, the CMA has a new name - the American Chemistry Council.

Executive Summary

Known variously by more than 20 names, among them, chemical hypersensitivity syndrome, total allergy syndrome and 20th century disease, "environmental illness" is a subject of controversy within the field of medicine and an object of considerable public attention. For many patients, environmental illness has become the explanation for a combination of symptoms for which they've found no other acceptable explanation.

According to a small group of clinicians from a medically unrecognized specialty called "clinical ecology" or "environmental medicine," millions of people in this country suffer from environmental illness. Practitioners of environmental medicine report that the medical cause of their patients' conditions is a depressed immune system. These clinicians attribute their patients' symptoms which typically include headaches, fatigue, depression, anxiety and digestive problems primarily to exposure to trace amounts of virtually all synthetic chemicals found in food, water, air, clothing and everyday surroundings. In short, environmental medicine specialists believe their patients are severely "allergic" to the world they live in to the extent that many of them cannot function in society.

There is no doubt that these patients are ill and deserving of compassion, understanding and expert medical care. However, nationally known experts in the fields of allergy, immunology and internal medicine say the assertion that environmental illness is a legitimate disease is unproven. Elaborate testing of the immune systems of these patients almost always indicates normal immune functions, and they rarely have increased infections.

And only rarely are their symptoms supported by physical findings or laboratory tests. In addition, review of both the methods of diagnosis and treatment used by environmental medicine specialists have shown no convincing evidence that their patients have unique, recognizable symptoms or that their treatment procedures are any more effective than placebo

3

treatment.

Environmental illness patients generally lead troubled lives and have genuine problems in coping with family, work and life-style pressures. They often eagerly accept environmental illness as the explanation for their condition and undertake the costly life-style changes including moving to new environments and eliminating all synthetic agents from their homes that are part of treatment.

Despite unsubstantiated evidence, environmental medicine specialists and their patients persistently advocate that environmental illness exists. What they have failed to prove in the scientific arena, they are attempting to legitimize in the media, in the legislature, and in the courts. The important elements of human interest stories, human suffering, controversy, testimonials, and novelty, have provided natural stories for the media.

Legislative initiatives have so far failed to legitimize environmental illness, but it would not be difficult for legislators to misperceive the goals of environmental medicine as medically legitimate. And lawsuits, of which several are currently pending, could multiply.

The label of environmental illness is a misdiagnosis and condemns these patients to the life of an outcast with little hope of cure. It is essential that their described symptoms be taken seriously. These patients deserve the best medical evaluation and treatment consistent with established medical principles.

It is not the legitimacy of the patients that is in question, but the alleged environmental cause. Failure to recognize this critical difference can result in enormous costs to the patient, to industry and to society.

"Environmental Illness" Background "Environmental illness" has no single, accepted definition. However it may be described as a diagnosis that ascribes a broad range of common substances in the environment. Proponents allege that these symptoms are triggered particularly by contact with trace amounts of chemicals in our food, water, air and daily surroundings.

Symptoms are typically multiple, subjective and unsupported by physical findings or laboratory tests. Headaches, fatigue, depression, anxiety and digestive problems are some of the common initial complaints.

Those physicians who diagnose environmental illness call themselves "environmental medicine specialists." (Formerly they called themselves "clinical ecologists.") Environmental medicine is very controversial. There is no residency training in environmental medicine and the certifying board for its practitioners is not recognized by the American Board of Medical Specialties.

Furthermore, the American Academy of Allergy and Immunology, the California Medical

Association and the American College of Physicians have taken the position that the tenets of environmental medicine are unproven (Refer to Appendix D).

Diagnosis and Treatment

Practitioners of environmental medicine generally diagnose environmental illness by performing "provocation testing," which consists of exposing subjects to various mixtures of test substances at progressively higher concentrations. The testing is variously done by inhalation, injection or placing the test solution under the patient's tongue. If any symptoms occur, the test is positive.

Subsequently, part of the subject's therapy consists of injection of the offending agents in lower concentrations. This "neutralization therapy" has no proven or even logical medical or scientific rationale to support it, according to the medical community. Provocation testing and symptom neutralization bear some superficial resemblance to skin testing for allergies and allergy shots for desensitization but are actually quite different. (Refer to section on Allergic Diseases, p. 9.) No reputable medical organization accepts provocation testing combined with neutralization therapy as having scientific meaning.

Independent "provocation testing" of environmental illness patients, for example, has resulted in equal numbers of positive tests from placebo solutions and from solutions of substances to which they allegedly were sensitive. [Terr, A. I., 1987. In *Allergy: Clinical Ecology. Insights in Allergy*. 2(5).]

Another part of an environmental illness patient's treatment is to avoid the common substances that purportedly make them ill. This could include living in environments totally free of modern synthetic materials, such as rooms or trailers with metal or porcelain surfaces; elaborate air filtration; and diets free of all additives, preservatives, or contaminants. This approach obviously renders the individual unemployable.

In short, there is no consensus on the proper diagnosis, treatment or even existence of environmental illness as a single, proven medical condition. The hypotheses of environmental medicine practitioners are medically unproven and have been rejected by professional medical organizations. In addition, the treatments, which are extremely expensive, have not verifiably helped patients any more than placebo therapy would.

"Environmental Illness" Impacts

Environmental medicine specialists and other advocates are well organized and effective at representing environmental illness as a recognized medical condition affecting millions of people in this country. These advocates are working hard to legitimize environmental illness. Environmental illness already affects the patients who accept it as a legitimate disease. Should

environmental illness advocates succeed in their efforts, it would also impact society and many industries.

For the patients, the unproven tests used to diagnose environmental illness may in fact lead to misdiagnosis of a true medical illness. Because environmental illness cannot be clearly diagnosed by clinical criteria, environmental illness specialists use the history of presumed environmental exposure as the basis for diagnosis.

This belief in itself can be psychologically crippling. Indeed, some patients view themselves in a hostile world, surrounded by chemicals that make them chronically ill and physicians who do not care. Often, their life becomes centered totally around their disease. Coping becomes stressful and living needs become costly as these individuals change their life-styles to avoid all chemicals. They are determined to consume only organic foods grown without insecticides, sprays and fertilizers.

They may use only items made of glass, porcelain, stainless steel and untreated animal or plant fabrics (cotton, linen, silk, wood and leather). Often, this results in social isolation, difficulty within the community and unemployability.

The primary impact on society would be the huge cost associated with the legitimization of environmental illness. Up to now, environmental illness and the associated testing and therapy have not been eligible for coverage under such programs as medical insurance plans, Social Security disability, Medicare and Workers' Compensation. But proponents of environmental illness are now trying to legislate the legitimacy of environmental illness.

Although they have not been successful, it would not be difficult for legislators to misperceive environmental illness as medically legitimate and fail to recognize the potentially enormous cost that could accrue. Environmental illness advocates believe they are entitled to a number of sources of financial support. Among them:

- monetary damage for increased illness resulting from exposure;
- monetary damages for existing fear of contracting future illness;
- disability benefits from private insurance policies and Social Security;
- reimbursement for medical costs;
- Workers' Compensation payments;
- a variety of workplace protections (from termination, demotion, pay cuts, etc.);
- rehabilitation services; and
- financial assistance for alteration of living space.

Environmental illness forces nearly succeeded in accomplishing their goal in Maryland in 1988.

They proposed legislation and it came close to being passed before informed health professionals became aware of it and managed to transform a bill legitimizing the diagnosis of environmental illness into a resolution to study the issue. The resulting study basically called environmental illness an unresolved issue; however, further actions by the legislature in Maryland on this issue seem unlikely in the near future.

Proponents of environmental illness have drafted "fill-in-the-blank" model legislation in an attempt to accomplish their aims. Such legislation could pop up in any state at any time. A carbon copy measure in California passed, but Governor Deukmejian vetoed it after the California Medical Association intervened.

The impact, however, would not be restricted to the chemical industry. Commonly used chemicals are found everywhere, in the home, the workplace, outdoors, shopping malls, and even hospitals. Potentially affected industries include the textiles, clothing, lawn care products, household cleaners, dry cleaners, paints and solvents, perfumes, hair treatment products, plastics, paper and many other consumer goods industries.

There is also the threat of lawsuits. Litigants seeking redress for personal injury allegedly resulting from exposure to toxic substances are numerous now. Should environmental illness be recognized by legal or judicial decree, these suits would only multiply. Toxic torts create special problems for the defendant in the best of circumstances. It is scientifically impossible to ever prove a negative, the nonexistence of something.

Plaintiffs typically allege effects at very low exposure levels that are only known to be caused at much higher exposure levels. Often, only the presence of nearby chemicals, rather than true exposure, is documented. Or they allege that health effects were caused by substances not known to cause those effects.

Suits involving environmental illness are further complicated by the lack of a definition of environmental illness. In the eyes of environmental medicine practitioners and their patients, almost any symptom could be caused by exposure to almost anything. But most physicians do not agree with the environmental illness advocates. For example, Dr. Abba Terr, an immunologist at Stanford University Medical School, summarizes environmental illness in a chapter of a recent book reviewing multiple chemical hypersensitivity:

The concept of multiple chemical hypersensitivities as a disease entity in which the patient experiences numerous symptoms from numerous chemicals and foods caused by a disturbance of the immune system lacks a scientific foundation. Published reports of such cases are anecdotal and without proper controls. There is no convincing evidence for any immunologic abnormality in these cases. Diagnostic methods have been shown to be unreliable. Diagnosis, treatment and theoretical concepts underlying the purported disease are not consistent with current immunologic knowledge and theory. As defined and presented by its proponents, multiple chemical hypersensitivities constitutes a belief and not a disease.

[Terr, A. I., 1987. Multiple Chemical Sensitivities: Immunologic Critique of Clinical Ecology Theories and Practices. In "Occupational Medicine State of the Art Reviews: Workers with Chemical Sensitivities", ed. M. R. Cullen, Vol. 2(4):693. Philadelphia, Hanley and Belfus.]

Supporting Material: Theories of Etiology

Proponents of "environmental illness" ascribe many symptoms to exposure to numerous common substances in the environment. Although these can include natural chemicals, more often the symptoms are attributed to low level chronic exposure to synthetic chemicals. Most recently, environmental illness proponents have postulated that exposure to such chemicals causes a malfunction of the immune system that results in sensitivities not only to the chemicals to which the patient has been exposed but also to chemicals he may encounter in the future.

In the eyes of its advocates, almost any symptom can be attributed to environmental illness. But laboratory tests on patients who believe they are suffering from environmental illness have shown normal or inconsistent results.

Some of the patients who believe they have environmental illness also have symptoms characteristic of psychosomatic illness. [Terr, A. I. 1986. Environmental Illness: A Clinical Review of 50 Cases. "Archives of Internal Medicine". 146:145- 149. Stewart, D. E. et. al. 1985. Psychiatric Assessment of Patients with "20th Century Disease" in "Canadian Medical Association Journal". 133:1001 - 1006.]

Others have a variety of symptoms that do not fit any known medical disease. These latter patients should be investigated further with well designed scientific studies rather than being stigmatized by unproven illness that might hinder further medical investigation.

Allergic Diseases

Environmental illness advocates have borrowed much of their terminology from the fields of allergy and immunology. This can be very confusing since there are legitimate allergic diseases that are well accepted and documented by the medical profession.

Environmental illness advocates claim that sensitization to one chemical may cause a spreading phenomenon in which the patient becomes allergic to many chemicals. True allergies do not behave this way. If a patient is sensitized to one chemical, they are sensitized only to that chemical and perhaps to a few other chemicals that are structurally almost identical. New sensitizations must occur before the patient will react to different chemicals.

Documented allergic diseases are caused when an individual develops an exaggerated IgE response to environmental, drug or microbial antigens. IgE is an immunoglobulin protein that

circulates in the blood and brings about allergic responses; other immunoglobins are involved less frequently. Typically, allergies do not affect everyone exposed to the substance. Minute amounts of the offending agent may cause symptoms in a person who is sensitized or allergic to the substance. But not all chemicals are capable of causing allergies.

Allergic individuals characteristically give rapid responses in skin testing, have high sum IgE levels and often have increased blood and tissue concentrations of eosinophilic leukocytes; an eosinophilic leukocyte is a specific type of white blood cell.

Symptoms are subjective changes perceived and described by the patients while signs are objective physical findings observed by the physician. Allergic symptoms typically involve the skin, the respiratory tract or the gastrointestinal tract. The following statements are generally true:

- Food allergies may cause vomiting, cramps and diarrhea.
- Skin reactions cause hives, which are large blisters or red, itchy rashes.
- Respiratory allergies are either of the hay fever type which involves the nose causing sneezing or nasal congestion, or the asthma type, which involves the lungs and the lower respiratory tract causing difficulty in breathing.
- A severe generalized allergic reaction known as anaphylactic shock may have symptoms of a drop in blood pressure and spasm of the larynx leading to shock and suffocation.

The location and type of symptoms most often depends on the type of contact with the agent to which the patient is sensitized. For example, contact with poison oak or with poison ivy usually involves the skin and results in a red, itchy rash with small blisters. Firefighters who are exposed to smoke from burning oak or ivy, however, inhale and ingest the smoke and may have symptoms in the lungs, nose and gastrointestinal tract as well. [Hood, L. E. ed. 1984, Immunology, 2d. ed. 460-462. California: Benjamin/Cummings.]

In contrast to environmental illness, the symptoms of allergic reactions are reproducible. Usually a person who is allergic to an agent has the same type of contact and the same symptoms on each subsequent contact.

Problems with Medical Testing

The specialty of immunology is one of the newest and most rapidly changing medical specialties. Laboratory tests used to measure a person's immune system function are also relatively new and still evolving. Some of the laboratory tests proponents of environmental illness use to support their position are well established in the medical repertoire. Other tests are new and not accepted by the general medical profession. A few, such as cytotoxic testing, have been declared invalid by federal agencies [Fed. Reg. Vol. 48, No. 162, August 19, 1983-

Notices.] which will not reimburse for performance of these tests.

Environmental medicine specialists often do a large number of screening tests on their patients. Inevitably, one or two tests are abnormal. Individual laboratory results are often compared with ranges of numbers rather than one absolute number. By chance alone, five percent of people tested with no clinical disease will have either "abnormally" high or low laboratory values.

The more tests that are done, the more often the result will be abnormal, simply because of the mathematics involved. Proponents of environmental illness use these abnormal tests as proof that the patient has environmental illness.

The nonstandard test most often conducted by environmental medicine specialists is provocation with neutralization. In provocation testing, subjects are exposed to concentrations of suspected substances either by inhalation, injection under the skin, or placement under the tongue. The occurrences of any symptoms within a short period of time are noted; any symptom is interpreted as a positive test.

Lower concentrations are then given until no symptoms occur. The concentration resulting in no symptoms is termed the "neutralizing dose." Provocation testing is not an accepted practice within the medical community.

Any patient has the right to expect that a qualified person is managing the laboratory in which tests of immune function are being conducted. The patient also has the right to expect that the physician interpreting the test results is qualified. Both the American Board of Pathology and the American Board of Internal Medicine, in conjunction with the American Board of Pediatrics and the American Board of Allergy and Immunology, now have examinations to assess the competence of clinical pathologists, internists and pediatricians conducting diagnostic immunologic tests.

"This certification process was developed to ensure that clinical immunology laboratories are directed by the persons who know the most about conducting such tests, properly applying them in diagnosis, and interpreting the results." [1988. Certification in Diagnostic Laboratory Immunology, "Annals of Internal Medicine". 108: 458-459.]

Why "Environmental Illness" is Not Science or Medicine

"Environmental illness" lacks credible medical specificity. The symptoms, which are changes perceived by the patients, reported are neither substantiated by clinical signs, which are objective physical indications of illness, nor by laboratory testing of a wide array of body functions. The breadth of isolated symptoms is exceeded only by the number of purported chemical and environmental causes.

Indeed, there is no medical precedence to suggest that any syndrome or disease can be brought on by numerous separate and distinct agents.

Proponents of environmental illness assert that environmental illness exists because they have repeatedly observed patients with multiple, non specific symptoms, conceivably arising after a variety of exposures to numerous chemical substances. The heart of the problem lies in their reasoning process and the validity of the data they use to support a causal link.

The basic fallacy in their reasoning is that the observed symptoms may be induced by many other causes. An equivalent example of such erroneous reasoning is that if a rooster crows every morning before sunrise, then the sun rises because roosters crow.

Because a case of environmental illness cannot be defined objectively, control individuals (those without both the "disease" and exposure to the "agent") cannot be defined in order to perform traditional scientific studies. This fact is confirmed by the current scant medical literature on the subject, which only emphasizes collections of cases. Such case studies without controls cannot prove the valid existence of environmental illness but can only assert its existence.

Such hypotheses by environmental medicine practitioners are unfocused and scientifically unfounded, and have been rejected by main-stream professional medical organizations.

The data used by the proponents of environmental illness is largely invalid. [California Medical Association Scientific Board Task Force on Clinical Ecology. 1986. Clinical Ecology - A Critical Appraisal. "Western Journal of Medicine", 144:239-245.] Their principle data consists of uncontrolled and unblinded observations of alleged patients improving after therapy. Simply stated, they have not considered classical placebo effect, whereby a small percent of treated individuals will always improve regardless of whether effective therapy was used or not (the good effects of sugar tablets have been known for 2000 years).

Other problems with their information are that appropriate epidemiology cannot be applied, their patient history questionnaires are overly simplistic and biased, and high quality psychological testing of patients is generally avoided.

The scientific dilemma is that well conducted studies (with controls) cannot prove the nonexistence of the "disease" because true science can not prove a negative. Advocates can only assert the existence of a theoretical condition while assailing traditional clinicians and scientists for not having the ability to disprove their theory.

People who have received the label of environmental illness clearly merit the compassion and understanding of the medical and social communities. Emphasis should be placed on proper psychological diagnosis and treatment rather than upon false labels and therapy that can

ultimately prolong their impairment.

Because the role of true science is inherently limited, it is the responsibility of reputable scientists and clinicians to emphasize that environmental illness has not been proven to exist.

Responding to the Media

Because environmental illness is a health issue, its debate is best left primarily to physicians; the chemical industry, for example, should not get overly involved in such debates. Nonetheless, a ready response for media queries is a prudent precaution. Should reporters, editors, news directors or other media question industry about environmental illness, it would be appropriate to respond in a limited way. Steps best taken are:

Monitor media coverage of the issue.

Gather relevant background and reference material.

Identify medical personnel familiar with environmental illness who can speak as experts.

Informally offer guidance and background materials to reporters, based on their degree of knowledge.

Workers' Compensation Trends

Legislation already introduced by environmental illness support groups is designed to legitimize environmental illness for disability purposes. Given this thrust, more and more workers' compensation claims are expected. Presently, no state recognizes environmental illness on its list of workers' compensation diagnoses.

Each case would be considered on an individual basis. Since proponents of environmental illness advocate that patients suffering from environmental illness avoid all contact with synthetic chemicals, a diagnosis of active environmental illness could preclude return to work in many jobs.

Cost Impact

Once workers' compensation claims are settled, the plaintiff often files a toxic tort claim based on product liability theory. At the present time, it is estimated that to defend an average case of this type through a jury trial costs in excess of \$200,000 to \$300,000. No figures are available on the number of environmental illness cases filed nationwide.

Expert Testimony

Proof of causation varies greatly from jurisdiction to jurisdiction. For this reason it is impossible to give a short definition that would be accepted by most jurisdictions. However, in each case the plaintiff bears the burden of proof on the issue. Often the plaintiff needs a person accepted by the court as an expert who will testify that there is a cause and effect relationship to a reasonable degree of medical certainty.

The qualifications for being an expert vary from jurisdiction to jurisdiction and even from judge to judge, as does the meaning of "reasonable degree of medical certainty." While there have been a few exceptions, in most cases environmental illness proponents have not been excluded from giving expert testimony.

State Legislative Summary: History of Legislative Initiatives in Environmental Illness

California: Legislative activity in California began with a bill (AB 3587) introduced in 1981 to primarily set up a "chemical hypersensitivity syndrome advisory committee." It also made provisions for educating those who believed they were environmentally ill about treatment and life-style changes, public education for prevention, and workshops to facilitate exchange between researchers and proponents of environmental illness. The bill passed in both Houses of the California Assembly but was vetoed by Governor Deukmejian.

A second bill (SB 1177) was introduced in 1985. It requested funding for a pilot project to identify those allegedly affected by this syndrome, to develop a clearinghouse for information and advocacy, to provide legal, financial, medical and support services and to conduct and coordinate interdisciplinary conference and research activities on environmental illness. This bill was also defeated.

Connecticut: A public health committee House bill (5191) was defeated in Connecticut in 1987. It would have established a program to study and treat environmental illness at the University of Connecticut Health Center in Farmington.

Maryland: The Maryland Senate drafted and both chambers passed Joint Resolution 32 (1988), which directed the Maryland Department of Environment to conduct a study on the alleged "chemical hypersensitivity syndrome." [Bascom, R., M.D., M.P.H. 1986. "Chemical Hypersensitivity Syndrome Study." University of Maryland School of Medicine.] While there is no single definition of environmental illness or the problems it is alleged to pose, the study group's mission was to determine if people could be classified as suffering from allergic reactions.

When the study was finished, Maryland's Secretary of the Department of Environment, Martin Walsh, sent an advisory letter to Governor William Donald Schaeffer. In his closing summary of the environmental illness study, Walsh dictated that "...a great deal more research is needed before there will even be a consensus on a definition of chemical hypersensitivity. It is, in my

view, premature to classify environmental illness as a purely environmental problem in the classic sense." (Refer to Appendix E.)

A copy of the Maryland Department of Environment's Report on chemical hypersensitivity syndrome can be ordered from the Maryland Department of the Environment, 2500 Broening Highway, Baltimore, MD 21224 (Fee: \$25).

Florida: In 1989, Florida passed a bill creating a registry of people believing they have multiple chemical sensitivities. Creation of such a registry implies that the disease listed is accepted as proven. In this case, this is not true.

Because environmental illness lacks clear definition, the issue could be considered in various state legislative committees. Depending upon the intent of an environmental illness bill, it could be forwarded to Health and Welfare, Labor, Judicial, or Environmental committees. If the proposal focused on alleged allergic reactions, it would be considered by Health related committees; if the purpose of the bill were to review workers' compensation claims rising out of alleged environmental complications, it would be reviewed in Labor or Judicial committees; and, if the proposal asserts environmental concerns then the bill would be sent to Environmental committees.

Legislators and respective staff should be wary of legislation attempting to review and redress the issue of environmental illness or related themes. (The topic is not easily recognizable as it is not consistently addressed by the popular names of environmental illness or chemical hypersensitivity syndrome.) Environmental illness bills should be thoroughly critiqued by members of the medical and legal community prior to legislative action. When considering a bill, legislators should remember that environmental illness is a grey area, one which has not proven its existence in the medical arena and one which has no precedence in state statutes.

Legislative and Social Goals

Dr. Linda Lee Davidoff, representing the Environmental Illness Support Group, stated in her testimony to the Environmental Affairs Committee of the Maryland Senate, on May 8, 1988, that if Senate Joint Resolution 32, titled "Chemical Hypersensitivity Syndrome" was enacted, "chemically sensitive" people would benefit from:

- access to insurance coverage;
- social services;
- financial assistance;
- vocational rehabilitation; and
- alternate housing.

E.J. Davis, J.D., M.P.H., editor of "Ecological Illness Law Report", Vol. 2(6): p. 3, revealed several specific legal goals of his agenda, several of which follow:

- preventing "improper" employee dismissals and demotions;
- securing and maintaining a "safe" work environment;
- securing financial assistance for the rehabilitation of living space;
- securing coverage under Medicaid or Medicare and various state and federal assistance programs;
- securing workers' compensation payments;
- securing assistance under federal and state protections for disabled;
- securing compensation from companies and individuals responsible for chemical exposures that cause disabling illness;
- securing proper income tax deductions for expenses associated with ecological illness, especially excess costs of remodeling or changing heating systems and organic foods; and
- securing safe environments and food in prisons, mental hospitals, hospitals, and other public and private institutions.

Overlap With Indoor Air Pollution

Indoor air pollution or "tight building syndrome" is currently a major topic in several regulatory agencies and environmental advocacy groups. Symptoms often resemble those attributed to environmental illness. Among them: headaches, dizziness, drowsiness, nausea, irritations of the skin and upper respiratory tract, anxiety, irritability and other nervous system disorders.

Insufficient provision of fresh air in a building's heating, ventilation and air conditioning system, resulting in a buildup of air contaminants, formaldehyde, pesticides, cleaning materials and others, most often is cited as the cause. However, rarely is a specific agent indicated.

Environmental illness advocates would like society to believe that "sufferers" in indoor air pollution have a form of environmental illness because this would significantly increase the victim population and further legitimize their cause.

Forming Coalition

Because it has the potential to impact many segments of society, many groups have an interest in placing environmental illness in its proper perspective. Among them:

- medical associations;
- manufacturers and applicators of agricultural and pesticide products;
- personnel, labor relations, etc.;

- food dealers;
- restaurants;
- insurance companies;
- self-insurers;
- soap and detergent manufacturers;
- chambers of commerce;
- lawn care services;
- homebuilders;
- aerospace industry;
- retailers; and
- automobile manufacturers.

Because environmental illness is a health issue, the only people who can legitimize it are physicians, and they have not. Should environmental illness arise as an issue, a coalition with the state medical association is absolutely necessary.

Appendix A Synonyms for Environmental Illness Allergic Toxemia, Cerebral Allergy, Chemical AIDS, Chemical Hypersensitivity Syndrome, Chemical Induced Immune Dysregulation, Complex Allergy, Ecological Illness, Environmental Hypersensitivity Disorder, Environmentally induced Illness, Immune System Dysregulation, Multiple Chemical Hypersensitivity, Total Allergy Syndrome, Twentieth Century Disease.

Appendix B Environmental Illness Organizations American Academy of Environmental Medicine The American Academy of Environmental Medicine (AAEM) was founded in 1965 as an international association of physicians interested in clinical aspects of environmental medicine. Prior to 1984, they were called the Society for Clinical Ecology (Environmental Medicine). This group changed its name after 1984. The position paper of the Society for Clinical Ecology states that the organization is made up of physicians, who are board certified in a clinical specialty and interested in newer concepts utilizing diagnostic and treatment modalities in treating environmental illness. The 1988 position statement of the AAEM is included in Appendix D of this paper. [AAEM, 10 E. Randolph St., New Hope, PA 18933 (215) 862-4544 or Fax (250) 862-2418]

American Board of Environmental Medicine, Inc. Formal residency training is required for board certification. The board, however, is not recognized by the American Board of Medical Specialties, which is the umbrella organization overseeing specialty board certification of medical doctors in the United States. The American Board of Environmental Medicine, founded in 1988, offers its own examination in the field of environmental medicine. Executive director: Dr. Clifton R. Brooks, M.D., M.P.H., 2114 Martingale Dr., Noran, OK 73072; phone (405) 329-

8437

Appendix C Editorial Statement "Clinical Ecology: Environmental Medicine or Unsubstantiated Theory?" Reproduced with permission from the Annals of International Medicine, Kahn, Ephraim; Letz, Gideon, 1989 July; 11 1(2): 104-106).

Appendix D Position Statements: California Medical Association Scientific Task Force on Clinical Ecology, Clinical Ecology -- A Critical Appraisal [Information], reproduced with permission from the "Western Journal of Medicine", 1986 Feb.; 144:239-245)

American Academy of Allergy and Immunology (<http://www.aaaai.org/>)

American College of Physicians (<http://www.acponline.org/>)

American Academy of Environmental Medicine (<http://www.aaem.com/>)