

By David Beach

Learning to deal with chemical sensitivity

ON SATURDAYS HELEN MOORE OF RALEIGH, N.C., drives along a portion of Interstate 40 as she heads to the grocery store. If state road crews spray herbicides along her route on Thursday, Friday or Saturday, she is warned by a Department of Transportation employee.

Moore has multiple chemical sensitivities (MCS)—a mystifying chronic health problem also known as chemical hypersensitivity, environmental illness or total allergy syndrome. When she is exposed to herbicides, pesticides or even common household products such as fabric softeners and air fresheners, she becomes weak and disoriented, suffering severe headaches, muscle pain and swelling of the skin.

She's had the problem for 15 years and isn't sure what caused it. She speculates that living in an apartment that had a leaky gas oven and was sprayed monthly to control pests may have affected her immune system.

When she requested notification of highway spraying, state officials not only refused, but also disputed whether the spraying could harm her. She won her point, however, by being polite and persistent.

"As a taxpaying citizen I have a right to use the highways without endangering my health," she says. "Sometimes you have to be a nuisance to protect yourself."

Since then, Moore, who now runs an ecology consulting firm that assists other chemically sensitive persons, has continued to bother state and local authorities. She is promoting a ban on herbicides along state roadways and is campaigning for a pesticide notification law requiring that signs be posted on lawns and in public buildings after spraying. When Raleigh was hit by a gypsy moth infestation several years ago, she organized community protests that prompted a switch from aerial spraying to non-toxic biological controls.

Across the country in the San Francisco Bay area, MCS sufferers have drafted a "Declaration of Rights for the Environmentally Hypersensitive." Susan Molloy, a local activist and editor of *The Reactor*, a newsletter for chemically sensitive people, says that MCS "is a disability, not an illness. People with chemical sensitivities have a right to reasonable accommodation in the workplace, public buildings, hospitals, schools and housing."

Molloy has also worked with the Independent Living Centers in California, an organization that receives state funds to assist the disabled and obtain services for MCS victims. She is trying to get a federal community development block grant to build an ecologically safe apartment complex. And she helped lead a drive against environmental hazards (such as gases from carpeting, adhesives and formaldehyde-laden building materials) in a new wing of a Marin County hospital. She says that the hospital has since tried to reduce indoor pollution and has developed training programs to make its staff aware of the special needs of chemically sensitive patients.

"If I have to go to the hospital, I want to be safe. I want access," Molloy adds. "Just like stairs are a barrier to people in wheelchairs, new carpeting is a chemical barrier to me."

Sick of being sick: Helen Moore and Susan Molloy are just two examples of a growing number of politically active people

with MCS. They believe that the modern chemical world is injuring more and more people in unexplained ways—perhaps by disrupting the body's immune system or nervous system.

At the grass roots, MCS activists are joining environmentalists and community groups to fight against pesticide spraying, indoor air pollution and toxic waste dumps—and to fight for chemical right-to-know laws, bans on cigarette smoking and stricter limits for chemical exposures in the workplace.

Such activity by the environmentally ill is a relatively new phenomenon, according to

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Earon Davis, an attorney with a master's degree in public health who edits the *Ecological Illness Law Report*. He says that for many years MCS sufferers were preoccupied with coping with the illness. Their organizations, such as the Human Ecology Action League (HEAL), focused on providing services such as local support groups, advice on where to obtain medical care from understanding doctors and information on creating a less toxic personal environment through changes in diet, clothing, home furnishings or cleaning products.

"Organizations of victims can't always be expected to be politically effective," Davis says. "Some are struggling to be healthy people and have no energy left for activism. Many don't even want to talk about their problems—they've been told they are crazy so many times that they don't want to stick their necks out. Also, they get sick going to the courthouse, or they can't read a newspaper to find out what's going on because of the chemicals in the paper and ink. It's easy to become isolated."

But chemically sensitive people are becoming more active as they realize that toxic chemicals cause everybody problems, says Ed Randegger of Fort Collins, Colo., who co-edits *The Wary Canary* newsletter. (The name refers to the idea that people with

chemical sensitivities, like the canaries in coal mines, are early warning signs of environmental hazards.) A reader suffering from an exposure to chlordane insecticide and pentacresol wood preservative recently told Randegger: "Lay off that 'sensitive' crap! If your kid plays in the street and is run over by a truck, do you say, 'Poor thing, he's sensitive to Fords'? We're basically dealing with poisons, not frail health."

Uphill battle: Recognition of MCS by the medical establishment and government agencies remains a difficult challenge, however. People with MCS typically react to minute amounts of a wide assortment of the chemicals and products encountered in modern life—everything from polyester to detergent, from dry-cleaning solvents to perfume. They often are stricken with multiple symptoms related to the central nervous system (tension, memory loss, fatigue, headache, depression), gastrointestinal tract, joints and muscles, respiratory system, skin, ear, throat or sinuses. The bodily mechanisms by which people become hypersensitive are not understood, although chemicals such as solvents and formaldehyde are suspected sensitizers.

It's not known how many people are affected, but some researchers estimate that

Researchers estimate that 15 percent of Americans may be hypersensitive to common chemicals.

as much as 15 percent of the population experiences some hypersensitivity to common household products. The Environmental Health Center in Dallas, one of a handful of centers specializing in the care of MCS victims, has treated 17,000 patients in the past 12 years.

Until recently, the chemically sensitive

had few allies, even in the environmental movement. Jay Feldman, national coordinator of the National Coalition Against the Misuse of Pesticides (NCAMP), recalls that when a few environmentally ill people attended NCAMP's early forums in 1984-85 on the adverse health effects of pesticide exposure, they were regarded skeptically.

"They had no medically certified diagnosis of illness," he says. "NCAMP was focusing on the exposure of farmworkers, not long-term, low-level exposures in non-occupational settings. It took a while for us to realize that these people had a valid problem that the medical community was not addressing."

Complicating the quest for recognition are ties between the chemically sensitive and a group of physicians called clinical ecologists or specialists in environmental medicine. MCS patients typically spend years searching for doctors who can treat them, or at least lend a sympathetic ear. Ultimately, many gravitate to clinical ecologists, who seek to detect the triggers in the environment that are causing the patients' symptoms.

The clinical ecologists, however, have been ostracized by the mainstream medical community. Critics call their theories unorthodox and desensitization treatments unscientific. The controversy surrounding their practices casts doubts on chemical sensitivities in general, causing some MCS activists to distance themselves from the clinical ecologists in an effort to separate the two issues.

"It has become not just a situation of convincing people of a new illness but how to unconvince them of the stereotypes of clinical ecologists," says Davis, who has worked on the issue for 10 years. "There are people with a mission to discredit clinical ecologists. I draw the line when they say the illness doesn't exist."

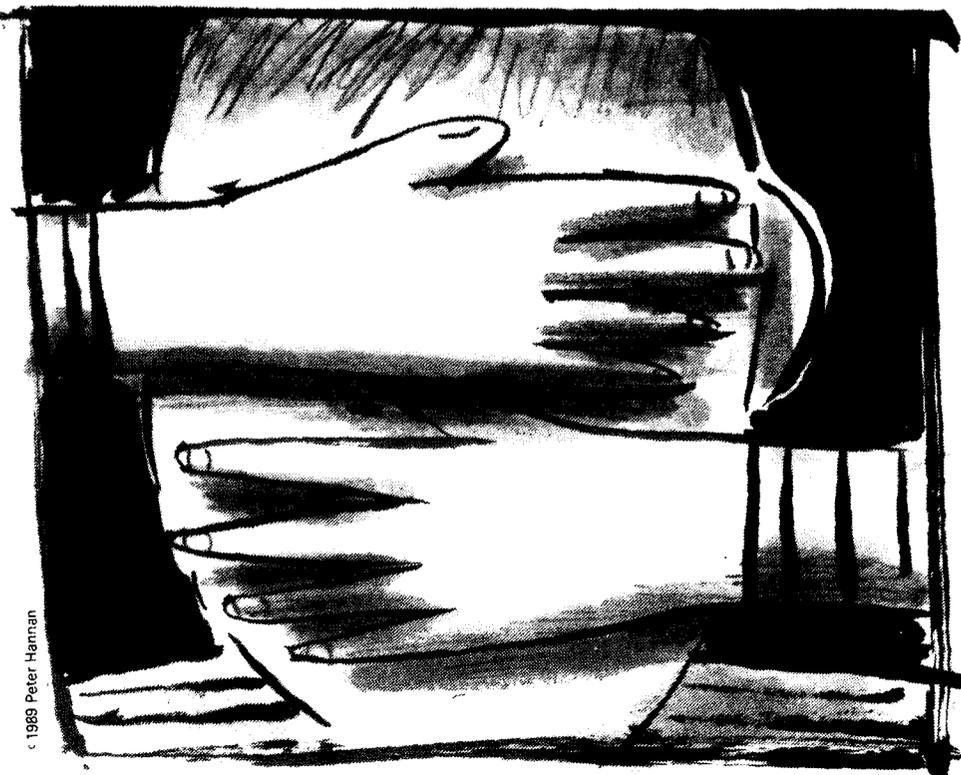
"Grandma makes me sneeze": Despite such difficulties, there is increasing awareness to MCS, Davis says. Much publicity has been generated by TV shows and tabloid stories ("I'm allergic to my family!") that focus on the most severe cases, the individuals who were forced from family, home and job to live like hermits in the wilderness.

"They're freak shows, but they get the word out," Davis adds. "That leads to other things. For example, researchers at the National Institute of Health realize they know people who seem to be chemically sensitive. They start wondering about it, start asking questions. We take advantage of that and press for studies."

Since 1985, recognition of MCS by medical and government officials has indeed been growing. The first major U.S. medical publication on MCS, a recent volume in the series *Occupational Medicine: State of the Art Reviews*, surveyed the medical community's diverse views on MCS. The volume's editor, Dr. Mark R. Cullen of the Yale University School of Medicine, concluded that "MCS patients suffer from a real and serious chronic disorder" and that expanded epidemiological and physiological studies are required for a better understanding of the condition.

• A major study on indoor air pollution completed in 1985 for the Environmental Protection Agency (EPA) mentioned chemical sensitivity as a major consequence of chronic exposures to toxic substances indoors. The study's author, Lance Wallace, now an environmental scientist with the EPA, says, "We gave them [activists working on the issue] the first solid information they'd

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had on how chemical levels are greater indoors than outdoors. It's what they've been saying for years."

- Amendments to the Indoor Air Quality Act, introduced in the Senate in 1988, also identified MCS as a health consequence of indoor pollution.

- The states of New Jersey and Maryland commissioned studies to evaluate the needs of chemically sensitive people. Pennsylvania has established a voluntary registry for chemically sensitive people at risk from pesticides.

Becoming sensitive to MCS: Activists trumpet each new supportive statement as fresh vindication, another part of the gradually emerging recognition of MCS. Mary Lamielle, a leading activist in New Jersey, says, "I have been involved in the issue at the state and national levels since 1986, and during that time public officials' reactions have gone from, 'What are you talking about?' to the point now where it's rare that someone won't know what environmental illness is. Now government officials are calling me for more information."

Lamielle has been chemically sensitive for 10 years. She believes she was made ill by fumes from a nearby trucking company and township sewage treatment plant. Once 4,000 gallons of gasoline spilled into the creek behind her property. Gasoline vapors entered her house, and she had to be rushed to a hospital emergency room. Not only did the doctor there have difficulty grasping her problem, but he made her symptoms worse by smoking in her presence.

She says, "I was always interested in environmental issues, but I became active when suddenly I had no options—I was getting sicker and sicker. But while I have desperate needs, I also see everybody else out there at risk, too."

One of the first things Lamielle did was to persuade her state senator to sponsor an "environmental illness" bill to provide services for MCS victims. The legislation, which is still pending, calls for a \$250,000, three-year demonstration program that would identify chemically sensitive persons and document their needs; establish a statewide clearinghouse for information, referrals and advocacy; help people obtain legal, financial and medical services, as well as housing, grants and long-term support; and promote the study of MCS by providing research, organizing conferences and developing educational material.

Lamielle also began educating state health officials about the issue. In 1987 the New Jersey Department of Health commissioned MIT professor Nicholas Ashford to review the current research on MCS and recommend how the state can assist victims. The Ashford report will be out this summer, and Lamielle hopes it will make a strong statement on the needs of the chemically sensitive.

Recently, she founded a new organization, the National Center for Environmental Health Strategies, which will link chemically sensitive people with physicians, researchers, legislators, attorneys, unions, environmentalists and the general public. By building a database and networks among groups, she hopes the center will further raise awareness of MCS and environmental hazards.

Last May, Maryland became the first state

to enact legislation on behalf of chemically sensitive individuals. The bill, which funded a modest \$7,000 study of MCS, was strongly opposed by the chemical industry.

"They lobbied harder on our issue than on anything else," says Linda Davidoff, a Baltimore-area psychologist and MCS sufferer who initiated the effort. "They were afraid of the precedent of a state legislature recognizing MCS and saying something ought to be done."

Davidoff also has interested scientists at the University of Maryland and Johns Hopkins University in developing research programs on MCS. Jeff Paull, program manager for toxicology and risk assessment for the state of Maryland, says that Davidoff has motivated him to do his Ph.D. thesis on MCS at the Johns Hopkins School of Hygiene and Public Health. He will study health policy issues, such as what services are available to MCS victims, which services are helping and how much MCS patients pay out-of-pocket for care. Davidoff, Lamielle and Davis also have helped persuade the American Public Health Association (APHA) to take up the issue.

"Buildings make me sick": Specialists in occupational health are frequently confronted with chemically sensitive patients who defy medical categorization and are a challenge to treat, says Judie Guerriero, chair of the APHA Occupational Health Section. Such patients raise questions about how ultra-low levels of exposure cause such problems, or, in the case of "sick building syndrome," why some people do not get better [after the pollution is controlled]. In "sick building syndrome," indoor air quality problems cause sickness among people in the building.

"We are trying to establish a diagnostic definition of the problem so we can study it," Guerriero says. "Of course, the people involved want answers today, and I can't blame them."

Activists do feel a sense of urgency. Each year they see hundreds of new chemicals added to the more than 60,000 already in common use, and only a small percentage are adequately tested for their long-term impact on human health. As with problems like acid rain, it defies common sense to wait for definitive proof of causation before acting.

"Chemical sensitivity is a sign that our system for protecting people from chemicals has failed," says Davis. In a recent article in his newsletter he writes that one reason this happened was that the environmental movement, as it evolved in the '60s and early '70s, embraced conservation at the expense of public health concerns.

"We were so upset about about the endangerment of the bald eagle due to DDT that we didn't bother to read the rest of Rachel Carson's book—the chapters about human health effects. We didn't bother to network with occupational health professionals and industrial hygienists. We had lost touch with the orientation and the people of public health."

"In order to tackle the immense social, economic and political challenges posed by toxic chemicals, it is necessary to reintegrate the environmental and public health movements," he adds. "It is the public health sector, along with political clout, that empowers the local activists, cutting through all the procedures and standards and coming down to this important question: is someone being killed or injured by toxic chemicals?" □

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Washington's free ride for corporate polluters at Superfund cleanups

By William K. Burke

A KEY SEGMENT OF THE FEDERAL SUPERFUND toxic waste cleanup effort has become another Reagan-Bush era environmental boondoggle. The forum for this scam is the natural resource damage assessment portion of Superfund—the federal program intended to clean up the country's worst toxic waste sites. The victims are wetlands, trees, wildlife and land—all the ecosystems contaminated by the estimated 2,000 sites that will eventually need to be cleaned up under Superfund.

The Environmental Protection Agency (EPA) has done little to protect non-human parts of the environment under Superfund. The EPA has consistently interpreted the original 1980 Superfund law to require only "cost effective" cleanups that meet EPA standards for protecting human health.

In most cases this has meant the EPA simply capped the worst areas of toxic contamination and built fences around sites to keep people away. Such solutions can leave water supplies and valuable wetlands—ecologists call them the kidneys of the water cycle because they purify waterways—laced with toxics, sometimes forever.

The natural resource damage assessment program was meant to prevent this type of abuse. It originates in the common law concept that the government is the custodian of the nation's natural resources. It allows federal agencies, usually the Department of the Interior or the National Oceanic and Atmospheric Administration (NOAA), and state governments to be appointed as "natural resource trustees." These trustees have legal standing to sue polluters on behalf of land, air, water, plants and animals damaged by toxic waste or oil spills.

Stumbling blocks: The 1986 Superfund Amendment and Reauthorization Act strengthened the damage assessment program, at least on paper. But three problems have crippled federal implementation of the program. All three of them stem from the unwillingness of Reagan-Bush agencies to translate congressional anti-pollution laws into effective actions.

- The Department of the Interior, the most important federal natural resource trustee, has avoided conducting full-scale natural resource damage assessments that could eventually bring the government millions of dollars in damages from polluters. Instead, the department has chosen to conduct a series of quick, easy and superficial surveys that generally free polluters from the costs of destroying ecosystems.

- The 1986 Superfund amendments instructed the EPA to actively involve natural resource trustees in every stage of its Superfund cleanups, but a section inserted into the law just before it passed Congress forbids the EPA from providing any Superfund money to conduct natural resource damage assessments.

- According to critics, the rules that the

Interior Department wrote for doing natural resource damage assessments seriously undervalue the costs polluters would have to pay for restoring those resources.

Erik Olson, an attorney with the National Wildlife Fund, says that if Congress doesn't act quickly to correct these problems, Superfund's statute of limitations for natural resource damages at many sites will expire in the next year. In May, Olson told the House subcommittee of fisheries and wildlife conservation that the EPA has treated the possibility of natural resource damage claims as a "stumbling block" and a "bargaining chip" in negotiations with polluters.

Theoretically, an effective natural resource damage assessment program could guarantee that Superfund cleanups completely restore damaged ecosystems. The natural resource trustees can sue polluters

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for damages to the environment while the EPA can sue polluters to force a cleanup to protect human health. If trustees and the EPA cooperated to press both types of claims at each Superfund site, polluters would be forced to pay for permanent cleanups that actually removed toxics from the environment.

But the natural resource damage assessments needed to press damage claims require wildlife experts, economists, geologists and other expensive technical staff members. A single site's assessment might take years to complete and cost millions of dollars. Environmentalists argue that money spent on assessments at Superfund sites would be paid back many times over when trustees file claims against polluters. But no one really knows, because the Department of the Interior has never actually attempted a full-scale damage assessment at a Superfund site.

Site unseen: Instead, Interior, at the EPA's request, created so-called Preliminary Natural Resource Surveys (PNRS). For an average cost of \$2,000, Interior conducts a PNRS to determine whether or not a Superfund site has sustained natural resource damages. The surveyor is allowed, *but not required*, to actually drive past or walk around the site he or she is surveying.

Olson says the latest available figures show the Interior Department had done 400 of the quickie surveys by January 1, 1988, without following up a PNRS with a full-scale natural resource damage assessment. He told the congressional subcommittee that an Interior official said the surveys often consisted only of a "few phone calls."

"It's a whitewash," comments Will Steele, an aide to Rep. Gerry Studds (D-MA). Steele and others say the PNRS program seems to be a cheap and easy way for the Interior Department and the EPA to discharge its obligation to include natural resource trustees in Superfund cleanups—without causing trouble for corporate polluters. Since there are no experts on the ground at the Super-