Multiple Chemical Sensitivity (MCS)

By Helke Ferrie

INTRODUCTION

The following is the written version of my oral presentation made on June 27, 2003, at the offices of Human Resources and Development Canada. I did so at the request of RAINET (*Research Advocacy and Information Network*) in support of that organization's efforts to have citizens with an MCS diagnosis treated equitably when applying for CPP or similar benefits. On April 10, 2003, RAINET had presented the Minister for Human Resources, the Hon. Jane Stewart, with files on applications for CPP which appeared to have met with bias because of the applicants' MCS diagnosis.

Senator Herb Sparrow was also present at the April 10th meeting with the Minister because he had been a witness to one such RAINET case at a Canada Pensions and Disability Review Tribunal hearing. Important technical aspects of this case also were (1) the fact that the applicant, who was too sick to attend in person, was not accommodated as required by the recent Supreme Court decision (May 2000) known as *Granovsky v. Canada,* and (2) the manner in which her MCS diagnosis was dealt with may not have followed the direction given in August 2001 by the Federal Court of Appeal's *Villani* decision, which defines the test for a disability's severity.

Following our meeting with the Minister, another meeting took place on June 27 with the Department of Human Resources' senior administrative and management staff. Our delegation was told at the outset that the fundamental legislative criterion guiding the Human Resources Department in assessing a disability application is a person's *observable, measurable and verifiable disability – rather than a generally accepted diagnosis*. This is so because diagnoses may change over time, different disease states with various diagnostic names can lead to one or more disabilities, a particular diagnosis can lead to serious disability in one person but not necessarily in another, a person can be clearly disabled but the diagnosis may take time to established (e.g. Multiple sclerosis), or an illness may not yet be understood but clearly leads to serious disabilities, such in the case of AIDS. Therefore, we were told, *objective disability is what matters and diagnosis is secondary*. As an example, we were given the case of AIDS. When AIDS patients first began to apply for CPP, they were *routinely accepted* until a better understanding of the disease led to treatments that reduced disabilities in many people, and an individualized approach to each applicant became more appropriate. The parallels between MCS and AIDS are, in my view, significant and will be dealt with at the end of this report.

Every application for CPP must, however, be based on some medical assessment which necessarily includes a diagnosis focusing on a disability's cause. Therefore, recognition of a disability is always somewhat dependent upon a diagnosis. A person would not even come to the attention of the Department unless a doctor identified some disabling condition, whatever the diagnosis. Not surprisingly, problems are to be expected, even if the granting or denial of a CPP application is primarily focused on whether this person is able to function. Therefore, our delegation was told, we could be helpful to the Department by *providing our analysis of how medical science views MCS at the present time; this information might assist the Department in the creation of guidelines appropriate for the assessment of MCS cases.*

ABOUT THE AUTHOR OF THIS PRESENTATION

I became ill with MCS myself, hence I am speaking with the authority of a patient. I studied environmental illness when I started to recover, and began to write about health and environment issues and especially medical politics. Eventually I became a publisher. Copies of my first publication, *Healing The Planet One Patient At A Time: A Primer In Environmental Medicine* by Dr. Jozef Krop were given to all who attended these two meetings. Currently, several books by environmental physicians specializing in asthma, infertility, endocrinology, holistic dentistry, and by a medical law attorney are in preparation for publication. My work enabled me to interview and meet at many medical conferences leading researchers in MCS and public health. It was through my articles that RAINET became aware of me and we began to work together on MCS issues.

In addition to my own illness, one of my sons (now 30 years old) developed MCS as seriously as I had, following two farm accidents in 1995 and 1996 while working on a summer job; both events involved being completely drenched in pesticides for a few hours. His T-cell count went down to the level of an AIDS patient. His immune, gastrointestinal, and nervous systems were all seriously affected and the struggle for his recovery began in 1996 when we finally understood what was wrong with him and we found a doctor trained in environmental medicine, namely Dr. Jozef Krop in Mississauga. By spring of this year, my son's T-cell count reached low normal and most of his symptoms are gone. He has returned to university and his doing his PhD in the philosophy of physics at McMaster University.

Like many MCS patients, we did not know that this condition had a name and that specialized treatments were available. Over time, I developed a full-blown "traditional" neurological disease generally thought of as "idiopathic", namely Myasthenia gravis, a neuro-muscular disorder. Other people with MCS may develop "traditional" illnesses such as asthma, Multiple sclerosis, chronic dermatitis, porphyria, Parkinson's or Alzheimer's disease, severe anemia, Lupus, or cancer - depending on the nature and duration of the chemical exposure they experienced and the vulnerability of the target systems. I was at the time in my PhD program (physical anthropology) at the University of Toronto, where I was also teaching. The underlying causes, as objective tests soon indicated, were decades of exposure to DDT while living in India, years of antibiotic

treatment for various tropical infections, and systematic poisoning of my immune system from mercury through dental amalgam (as later established through standard laboratory tests; for the mercury levels the World Health Organization's toxicity scale was used).

As can be readily surmised, the fact that MCS victims can and do often develop "traditional" chronic diseases has far-reaching implications for medical theory as a whole and challenges the concept of "idiopathic". It also sheds light on the epidemic rise of chronic idiopathic diseases. As for government policy, such as Medicare, Human Resources and Labor, MCS may prove to be as significant for medical history as the discovery of bacteria which launched public health and hygiene measures. Indeed, the discovery of bacteria changed the understanding of disease throughout the world; environmental toxins will do so, too. Researchers N. Ashford and C. Miller state in their classic book on MCS:

"We may be dealing with an emerging new mechanism or theory of disease. According to this theory, a two-step process occurs; (1) an initial salient exposure event(s) interacts with a susceptible individual, leading to loss of that person's natural prior tolerance for everyday, low-level chemical inhalants, as well as for specific foods, drugs, alcohol, and caffeine; (2) thereafter such common, formerly well-tolerated substances trigger symptoms, thus perpetuating illness." [1]

The technical name Ashford and Miller coined for this condition is **Toxicant-induced loss of tolerance** (TILT) – a symptom that is observed in MCS, its related illnesses such as Fibromyalgia, Chronic fatigue and Gulf War Syndrome as well as in conventional illnesses when various agents (toxic or otherwise) can also produce this response. Hence, a new theory of disease is a justified prediction.

However, the basic principle of scientific medicine, as first enunciated by Hippocrates 2,500 years ago, remains unchallenged, namely that an exterior agent, hostile to an organism's ability to function, may cause disease or systemic malfunction. Bacteria, organophosphates, viruses, solvents, radiation, transfatty acids in processed foods – they are all very similar, when seen in the light of this fundamental concept.

The subsequent treatment (for my son and me) consisted of detoxification treatments developed by nutritional and orthomolecular medicine following the removal of all "silver" dental fillings; my son had none, but the necessary removal of lipophilic pesticides in his body required installation and long-term use of a far infra-red sauna. Drastic environmental interventions were necessary also, such the replacement of gas cooking and water-heating appliances with electrical ones, a shift to a 100% organic diet, air-purifying equipment throughout the house, substitution of clothing requiring dry-cleaning with cotton garments, and removal of all cleaning materials of synthetic chemical nature as well as avoidance of all scented products etc.). I was unable to work or even manage my household unassisted from 1994 until approximately 1997; most of 1995 I could not drive a car and was unable for many months to handle a telephone or

[1] N.Ashford & C. Miller, *Chemical Exposures: Low Levels and High Stakes*, 2nd ed.,Van Nostrand, 1998, p. 172

read due to seriously blurred vision. Fortunately, I did not need the help of my government, as my husband, a physician, was able to take care of me and our son, and we could afford the treatments not covered by Medicare. The total, estimated cost of my recovery is about $ 20,000 and for my son about $ 26,000.

Today, I work fulltime out of my environmentally-safe home meeting monthly deadlines for articles published in Canada and the US and working with my prospective authors. I agree with the great Canadian psychiatrist and nutritional medicine physician, Dr. Abraham Hoffer's definition of health: according to him, people are healthy when they are *1. usually free of symptoms, 2. get along reasonably well with their families, 3. get along in their communities, and 4. pay taxes* [2]. I pay taxes and employ people, especially those who need accommodation, and make sure that my books are printed on fully recycled paper using vegetable inks free of scents and synthetic chemicals such as glues; that increases production costs, but chemically sensitive readers can safely read them.

I am even able to attend – on a short term basis and not too frequently – events such as conferences and meetings held in environments that are commonly unsafe for MCS sufferers, such as the windowless Human Resources building which has wall-to-wall carpeting; but thankfully all participants were free of aftershave lotion and perfumes. It takes a day or two to recover after such an event, thereby reducing my work pace due to extreme fatigue and headaches, but so far I always recovered. My son and I were fortunate. Many such severe MCS cases do not recover. Looking over the past 5 years, it is clear that medical science is advancing in this area - both with regard to diagnosis as well as effective treatment and the recognition that prevention is key. Public and political appreciation of this condition is also progressing, especially in Canada, which pioneered much of the political and social integration of MCS.

HISTORY AND OVERVIEW OF MCS

MCS is a condition medical science began to recognize in the 1950's[3], when it was exceedingly rare and initially had no agreed-upon name. Its name implies the presence of synthetic chemicals. Today approximately 80,000 synthetic chemicals exist which had not yet been invented in 1950 when DDT, a biological warfare agent declassified for agricultural and garden pesticide use, was the most widely used toxic chemical. Since 1960, synthetic chemical production rose from approximately 10 *billion* pounds per year to the current estimated annual release of about 35 *billion* pounds into soil, air and water

[2] A. Hoffer, *Putting It All Together: The New Orthomolecular Nutrition*, Keats, 1996, p. 163

[3] T. G. Randolph, MD, *Environmental Medicine – Beginnings and Bibliographies of Clinical Ecology*, Clinical Ecology Publications 1987. Dr. Randolph, a professor of medicine at the University of Chicago in the 1940's and 50's is generally credited with being the first medical researcher to identify chemical-induced illness and to have initiated the research into that field. Later, both Rachel Carson and Linus Pauling built on his work. P. Radetsky, *Allergic to the Twentieth Century*, Little Brown & Co., 1997, is possibly the best history of environmental illness from the 1950's to the late 1990s for the general reader.

in the US alone. Of these only about 600 are *known* to be carcinogenic, neurotoxic and/or teratogenic because the rest have never been tested for safety [4].

By 1999 MCS was integrated into mainstream medical research and supported by animal and human experimental investigations, theoretical explanation, therapeutic interventions, and some statistical and epidemiological data. That same year the international consensus statement on MCS was published by the US National Institutes of Health [5]. It is based on observations going back to the 1950's and essentially systematizes those observations published by Dr. Theron Randolph. It states:

1. **The symptoms are reproducible with repeated chemical exposure.**
2. **The condition is chronic.**
3. **Low levels of exposure (lower than previously or commonly tolerated) result in manifestations of the syndrome.**
4. **The symptoms improve or are resolved when the incitants are removed.**
5. **Responses occur to multiple chemically unrelated substances.**
6. **Symptoms involve multiple organ systems.**

A list of the signs symptoms commonly observed with MCS

The main source for the list given below is the research done by the University of Toronto published in the *Archives of Environmental Health* , September 2001.

Central Nervous System

Increased sense of smell, problems with concentration, fatigue, confusion, headache, temporary memory loss, dizziness, sleep disorders (some people can't sleep, others sleep 14 hours every night), anxiety, hyperactivity, and generalized sense of disorientation and confusion (following exposure) known as "brainfag" (sometimes also called "brain fog"), a term coined by a famous MCS patient, the Chief Librarian of the United States Library of Congress (he was a patient of Dr. Randolph's), intolerance to bright light and to heat and cold.

Musculoskeletal Symptoms

Joint pain, backaches, muscle spasms, swollen joints or limbs, muscle twitching, and severe muscle weakness.

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[4] T. Kerns, *Environmentally Induced Illness: Ethics, Risk Assessment and Human Rights*, McFarland & Co., 2001, p. 13-15 summarizes EPA reports on chemical production, release and safety up to 1995, the last year for which data were available; it also contains international legal information on toxic chemicals.

[5] "Multiple Chemical Sensitivity: a 1999 consensus", in *Archives of Environmental Medicine*, Vol. 54 (3), 1999, pp. 147-49. This paper is part of RAINET's submission documents.

Respiratory System Symptoms
Frequent colds or bronchitis, asthma, heavy chest, shortness of breath.

Hematological System
High or low platelets (depending on status of immune function), easily bruised, anemia or leukemia.

Genitourinary Symptoms
Water retention, frequent urination and urgency, inability to void, chronic infections of urinary tract, enuresis, infertility.

Gastrointestinal Tract Symptoms
Nausea, diarrhea, bloating, constipation or all of these in rapid succession, often followed by vomiting.

Cardiovascular Symptoms
Rapid heart beat, irregular beat, hypertension, severe flushing of the face (sometimes involving the whole upper body) when exposed to an offending chemical or reduced oxygen supply), tingling in hands and feet.

Ear, Nose and Throat Symptoms
Chronic stuffiness and runny nose, earaches, frequent ear infections, watery and itchy eyes, frequent sinus infections, intolerance to noise.

Dermatological Symptoms
Rough skin, sores, generalized itching, intolerance to certain fabrics.

It is important to note that MCS patients may have many of these symptoms at the same time, not necessarily in the same order or combination, or progressing to the same severity level. This makes them such a challenge for doctors not trained in environmental medicine who attempt to treat all these many symptoms traditionally: one at a time, or refer the patient to a psychiatrist – the doctor of last resort. Of course, each of these symptoms could also, when presented in *isolation and without a history of chemical exposure* at home or at work, be responsive to standard medical intervention. In the final analysis, the **history** and the **multiplicity of symptoms** should alert the doctor to the possibility of environmental illness. [6]

A person severely ill MCS will virtually never be free of symptoms; only the severity will fluctuate. And consequently impaired functioning will vary also. Such a person *will have difficulty keeping appointments for a future* date because he or she may be totally unable to function (e.g. unable to predict if they may be able to drive a car, speak without a slur, as was the case with me, have breathing problems such that climbing a set of stairs would be out of the question, muscle spasms and joint pain making movement difficult etc.). Many *MCS patients become socially progressively more isolated*; their families often cannot understand what is happening, and making them understand is at first difficult: in my case, visiting family members may need to take a shower and wash their hair immediately upon arrival at our home and use borrowed fresh clothes free of scented detergent; the scents that cling to them from subway and bus rides can ruin the family gathering for my son and me, so my other sons and daughters readily comply.

On a fairly "good" day, when such a person is managing basic chores satisfactorily, a *single exposure* to aftershave lotion (often one of the worst incitants) on the mailman delivering a parcel, or driving behind a diesel-fueled truck in slow traffic may cause within minutes a migraine size "12 on the Richter scale" (the measurements used for earthquakes), as I used to describe the experience. Eating a dish of fresh strawberries (there are more pesticides on strawberries and peaches than any other fruit) can cause stomach cramps, convulsions, and muscle spasms within a few minutes. A Human Resources worker wearing hairspray or perfume who visits such a person and sees her doing dishes and vacuuming would perhaps find it hard to believe how totally disabled this person may be half an hour later due to exposure to the worker's perfumed products.

[6] To get an appreciation of what is involved in clinical practice, the British textbook on environmental medicine for doctors is highly recommended: H. Anthony et al, *Environmental Medicine In Clinical Practice*, BSAENM Publications 1997. The majority of the original basic science involved in MCS studies, which led to the 1999 Consensus Statement, is contained in one of the first US textbooks on the subject edited by A.B. Tarcher et al, *Principles and Practice of Environmental Medicine*, Plenum, 1992; its authors are primarily from the EPA, many US universities and several European medical schools. A current summary of what to look for in environmental illness in general is in the *Canadian Medical Association's Journal* (CMAJ) series from April 16 to June 25, 2002. The two international journals devoted to environmental medicine, including occupational medicine, are *Archives of Environmental Health* (published by the US National Institutes of Health) and *Environmental Health Perspectives* (published by the Harvard School of public Health).

Because of the unpredictability of a severe attack, MCS patients are often embarrassed by their condition. MCS can make you feel like a complete idiot and be frightening at the same time. One example: one day in 1993 I was teaching a class in an Anthropology 200 course at U of T (introduction to world prehistory), when in mid-sentence, while discussing a prehistoric human skull (of all things) my lower jaw and my tongue would not move. My arms felt heavy, and it required tremendous effort to breathe. My class looked at me in astonishment, waiting for me to continue speaking. I turned my back to the class and struggled through several slow, deep breaths and simply waited. Slowly, my tongue began to move and so did my jaw and I completed the class without further incident.

These are, of course, classic Myasthenia gravis symptoms – as I know now. The neurotransmitter responsible for muscle contraction was briefly blocked at the neuro-muscular junction. Today, I also know that neurotransmitters, hormones, as all known types of messenger molecules, are reduced in their numbers and ability to function because the organs that produce them (especially the thyroid, the thymus, the hypothalamus, the adrenal glands etc.) are primary targets of pesticides, solvents, and heavy metals - the chief chemicals involved in MCS.

Today, thankfully, such events happen very rarely and always to a much milder degree, but just as suddenly if, for example, I am exposed to dry-cleaning fumes, a room full of heavily scented people, confined places like elevators in sky-scrapers, and lawyers' conference rooms which usually are full of books, documents, plastic plants, photocopiers, computers and printers, wall-to-wall carpeting, and those real knock-out air-fresheners often found in the bathrooms of public buildings and offices - all releasing neurotoxic benzene, limonene, and many other chemicals hostile to organisms (most of which are, incidentally, also on the official EPA list of known carcinogens). I do my best to avoid such situations and request meetings in places I know to be safe for me.

While the wide range of symptoms in MCS are nothing new - they cover the spectrum of reactions an organism can have to an exterior stimulation - the fact that such a *range* of symptoms and *all major bodily systems* can be involved has presented a major challenge to medicine: *MCS does not fit the classic model of diagnosis because it appeared in a post-classical period.* As an anthropologist I would add, that since science knows, for example, when and how conditions favorable to infectious diseases evolved (over the past 20,000 years) and what environmental and social conditions are required before a chronic disease can arise, the appearance of a new diseases should not be totally surprising, indeed it should be expected. The anthropological community would fully support my prediction that we will have many more events in the future, such as we have recently had with AIDS, MCS, SARS.

MCS is unique because of the following characteristics:

1. The "*one cause - one disease" model* which guided medicine since the Roman physician Galen (130-200 AD) *cannot apply to MCS* because chemicals do not

come in isolation; we live in a veritable chemical soup the interactive effects of its huge number of component parts being virtually unknown to science. Different chemicals may effect different bodily systems and the interaction between these substances increases their power to effect body system. Classic medical theory, as guides most doctors today, is ill-equipped to understand such dynamic complexity. However, *MCS yields to pattern analysis*, as has Fibromyalgia (one of the forms of MCS) and enables formulation of diagnostic criteria. Doctors are trained to think in a Newtonian, linear fashion, which results in patients being sent from one specialist to another, a different specialist for each bodily system's complaints, with the result that the underlying cause is not even looked for, and Medicare costs go through the roof.

2. *MCS does not follow traditional models with respect to its expected course and prognosis*. The patient might remain "stable" by remaining sensitive to a lot of chemicals in the environment, from pesticides to perfume, or develop a traditional, well known illness, such as asthma, cancer, MS, chronic infections etc. Size and duration of the exposure, pre-existing health condition, and unknown factors, such as chemical interaction and DNA response all play a part.

3. Unlike traditional illnesses, such as infectious diseases, *pharmaceuticals usually do not help, but tend to make the patient sicker*. Most drugs used for chronic illnesses contain certain synthetic chemicals also found in those very chemicals that made the person sick in the first place (e.g. antibiotics are also hormone disruptors and carcinogens, other standard drugs further slow or inactivate the detoxification pathways of the liver or deplete detoxification substances such as glutathione, serum vitamin C levels etc.*)*. Standard drugs cannot control the symptoms of MCS because standard treatments were not designed to deal with a dynamic multi-systemic disease.

4. *Avoidance of the offending chemicals is the first line of defense, remains the main defense, and is one of the most important preventive measures,* even after the patient has become free of symptoms: in an MCS patient the immune system appears to remain on hyper-alert for life. Such people can function well and may need no medical care as long as they work in an environment free of those chemicals and gases that made them sick. Furthermore, traditional approaches like immunization are not likely to be possible: immunization is based on the assumption that the vaccine interacts with a potential *biological* invader which the human immune system is expected to recognize. In MCS the immune system is depleted or in a state of perpetual alarm because it is confronted with a synthetic invader which it does not know how to handle. This can result in the worst-case scenario in which an MCS victim's available defense mechanisms are altered forever and can never again be exposed to those chemicals that caused the illness. Furthermore, as is discussed in more detail later in the section presenting Albert Donnay's material, some of the most toxic substances act *as neurotransmitters* (e.g. carbon monoxide) and effectively disable the body's defence protocols.

5. *MCS has turned upside down the classic notions of toxicology* first formulated in the Middle Ages by Paracelsus who taught, "the dose makes the poison". Modern toxicology teaches that *small, frequent exposures* to a toxic chemical substance may cause MCS, certain cancers, birth defects, and infertility. (See the appended "ABCs of Modern Toxicology".)

However, *classical methods of investigation have proven so effective*, that the 1999 consensus statement was possible. The following can today be asserted with confidence (the sources for these items are provided and discussed in more detail later on):

a. MCS is reproducible in animals.
b. MCS yields clear results with *in vivo* tests such as PET scans and MRI, liver enzyme tests and many others.
c. The statistical number of occurrences of MCS is predictable across populations in relation to specific chemical agents.
d. Classic epidemiological and statistical analyses have proven very useful.
e. Now we even have hints that genetic markers for MCS susceptibility are identifiable, thereby helping to explain why some people become MCS victims and others, equally exposed, do not.
f. We have extensive data on what treatments work, and why they work when they do work, with entire medical organizations dedicated to this field (e.g. American Academy of Environmental Medicine, Pan American Allergy Society, several Canadian organizations, and organizations of the same kind in the UK, Australia, Japan, and Germany).
g. Most importantly, we know MCS is not a psychiatric illness, even though MCS patients may understandably also be depressed and some may also be suicidal.

A MEDLINE search showed that by 2001 there were 10,741 entries on MCS, all from mainstream medical journals. Of those approximately 20% related to solvent sensitivity, 14% to perfume sensitivity, and 50% to multiple chemical sensitivity. As recently as 1997 only 120 entries existed. In the late 1950's only 5 entries existed. (For details visit www.asehaqld.org.au/chemical-injury-issues-paper.htm.) The current edition of *Harrison's Principles of Internal Medicine* includes discussion on environmental causes of many illnesses and mentions the 1999 consensus statement on MCS as does the 2003 edition of the MERCK Manual.

As is the case with all new diseases, there is inevitably a political component to the recognition of the illness, but the task is to take care of the needs of such patients now. A new disease implies the identification of new causes, and these imply the need for prevention and treatment – all carrying an economic impact for those who will inevitably be "blamed" and those who will work to prevent or treat its victims. MCS presents a serious problem for the chemical industry, just as cancer proved to be a problem to the tobacco industry. Both brought their products to market before safety was established, and they both battle against recognition of evidence proving that these products are not safe. Similarly, the discovery of bacteria forced 19th century governments to undertake

immense public-works programs to provide clean water and sanitation to stop the great epidemics. Coal-fired industry brought us classic IgE mediated allergies, unknown until the early 19th century, as well as the recognition of the existence of carcinogens. The effort to make this industry responsible for causing asthma and other diseases is ongoing, as are the current battles between scientists and the public and toxin-producing industries[7].

The world's economy is, in the words of Cornell University's Sandra Steingraber, a Senior Advisor to the World Health Organization, "chemically addicted", and if our economy is not cured of it, experts on environment and health issues agree, the extinction of the human race is a real possibility. [8] While cancer is the recognized outcome of our chemically polluted environment (now the second leading cause of death – up from 5th in 1960[9]), MCS is an illness affecting far less people, but with the potential to affect many more over time - especially children in whom MCS often progresses to asthma or even leukemia.

Unlike cancer, MCS carries with it the possibility of a cure for many victims, if given time and proper treatment. Even in serious cases, accommodating MCS patients in various ways allows them to continue being meaningful and effective members of society and keeping their families in tact and paying taxes, as Dr. Hoffer would say. MCS victims can achieve that status, even if the remain sensitive to the chemicals that once made them sick and must continue to observe strict measures of avoidance to remain functional.

The financial impact of MCS is backed by interesting research done in Canada. The Ottawa-based *Environmental Illness Society of Canada* commissioned the first study on the socio-economic impact of MCS on Canadians and published it in 2001. The results showed the following:

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[7] D.L. Davis, *When Smoke Ran Like Water: Tales of Environmental Deception and the Battle Against Pollution*, Basic Books, 2002. Professor Devra Lee Davis, a Scholar in Residence at the US National Academy of Sciences, teaches at the Carnegie Mellon University and is a Senior Advisor to the World Resources Institute in Washington DC and the World Health Organization. She has been one of my most reliable sources for the research in MCS over the past 4 years, ever since I interviewed her in 1999.

[8] S. Steingraber, *Living Downstream – An Ecologist Looks at Cancer*, Wesley, 2nd ed., 1999

[9] See proceedings of "Everyday Carcinogens: Stopping cancer before it starts". Workshop on Primary Cancer Prevention 1999, McMaster University, Hamilton, Ontario, on www.stopcancer.org. The most current revised mortality statistics for cancer are in the *Journal of the American Cancer Institute*, No. 94, 2003: the over-all annual trend of increase is stated as being 2-4%, depending on the type of cancer.

Approximately 4 million Canadians are affected by chemical sensitivity, half a million of whom are severe cases, with 5,000 being disabled by this condition; of those **annually 50-60 persons apply for CPP**. About 60% of the most severe cases also involve suicide attempts and about the same figure applies to family breakups (suicide attempts and family breakups overlap for obvious reasons.)

The impact of MCS victims on Canada's economy is estimated to be as follows:

$ 10 billion are lost in productivity, roughly $ 1 billion is lost in taxes, another $ 1 billion is used in avoidable health care costs, and about $ 1 billion in (avoidable disabilities) are paid.

These statistics are very similar to those obtained by the University of Toronto and in various areas of the USA through similar studies conducted by State governments and the EPA (see appendix to this report; April 9, 2003, letter by Dr. L. Marshall of the Environmental Health Clinic of Sunnybrook & Women's College Hospitals, Toronto.) A recent study by Philip Landrigan of the Department of Community and Preventive Medicine at Mount Sinai School of Medicine in New York, estimated the cost of environmentally mediated pediatric cancer to be as high as US $ 600 million a year; for neurological and behavioral illnesses of known environmental origin the cost was estimated as high as US $ 18 billion per year[10].

THE RECOGNITION OF MCS

MCS is today recognized to include a family of diseases. Recognition began with *Sick Building Syndrome* which followed the energy crisis in the 1970's and the efforts to conserve energy through improved insulation [11]. The other members of the MCS family

[10] *Environmental Health Perspectives* vol. 110 (7), July 2002

[11] French Canadian MCS researcher, Dr. Albert Donnay, who is the research coordinator of the Johns Hopkins Multi-Center Study of MCS Immunology, in personal conversation during a medical conference in 1998 in Baltimore, Maryland, told me that the first cases of Myasthenia gravis were described by the Romans about 2,000 years ago after the city of Rome built its first city-wide sanitation system using lead pipes, a potent neurotoxin, cytotoxin and endocrine disruptor. The illness was re-discovered in 19th century Baltimore, named Neurasthenia. Sir William Osler suspected that the cause was the newly introduced gas lighting and heating. Osler he did not know that it is the carbon monoxide and nitrous dioxide released in small, steady amounts that acts as a most potent neurotoxin. In the 1960's Dr. Theron Randolph reported some 800 cases of neurological illnesses cured through the simple removal of gas appliances. Osler advised one of his patients diagnosed with "neurasthenia", to leave Baltimore and live in her New England country estate instead, where she was free from all symptoms. This patient, Mary Garrett, was the fabulously wealthy daughter of a railroad baron. She provided all of the seed money for the building of Johns Hopkins hospital and medical school, attaching only the condition that women should be allowed to study medicine,

are *Chronic Fatigue Syndrome, Fibromyalgia, Gulf War Syndrome,* and *Cacosmia* (MCS involving primarily smell: inability to tolerate petrochemical products, perfumes, tobacco smoke etc. which may produce severe symptoms). Collectively, the whole family is also known as Environmental Illness (EI); and they share certain biomarkers and the hallmark EI characteristic of many organs and systems being involved simultaneously.

MCS was first recognized and described by Dr. Theron Randolph in 1951 who called the condition "environmental hypersensitivity". One of his patients with multi-system complaints became sick in a seasonal pattern which did not agree with classic allergy - Dr. Randolph's specialty. Through a painstakingly careful history extending over a few years, Dr. Randolph established that the cause was exposure to petrochemical products brought into the patient's area through seasonal wind-patterns. Avoidance caused the symptoms to disappear, and experimental exposure reproduced them. This was, at the time, a total revelation, even to him. To a specialist in allergy and immunology it was astounding that the body would produce allergic symptoms and even anaphylactic reactions in response to low-dose exposures to petrochemicals. Randolph devoted the rest of his life to the study and treatment of environmentally induced illness and called this new area of medicine "clinical ecology". The *American Academy for Environmental Medicine* was founded in the 1965. Later, through his collaboration with Linus Pauling and Dr. Abraham Hoffer, Dr. Randolph went beyond mere avoidance measures and the AAEM developed the treatment methods used today.

The AAEM trains environmental doctors to this day; some graduates work in Canada.[12] It works cooperatively with the *Pan American Allergy Society* and some international medical organizations as well as some departments of occupational medicine that are university-based. The AAEM's annual courses and training seminars are recognized for continuing education by the Canadian, British, Australian, American, Japanese and German Medical Associations, and some of their members are professors at medical schools throughout the world, including Canada. Their research is published in standard peer-reviewed medical journals and textbooks. Some of the treatments and tests were originally developed at Johns Hopkins Medical School and the Harvard School of Public Health, the two medical schools of primary importance to MCS research. The World Health Organization now endorses some of those treatments as the treatment of choice [13] In the USA, research in MCS is supported by the Departments of Defence and Veterans Affairs, the CDC's Agency for Toxic Substances and Disease Registry, the EPA, the National Institutes of health, the National Academy of Sciences, and many universities.

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a condition vigorously supported by Dr. Osler. See, M. Bright, *Sir William Osler – A Life in Medicine,* Toronto, 1999, pp.199-205,.

[12] T. Randolph, 1987, pp. 73-6. During the 1998 AAEM international conference I asked about 300 of the attending doctors why they became environmental physicians. The answer in <u>each and every case</u> was the same: he or she or a spouse had become ill with MCS and their medical training left them unprepared to deal with MCS; so they sought training in this field

[13] One example of WHO endorsement is found in a summary report published in *Scientific American,* April 2002, in an article entitled "Drink Your Shots".

The 1960's brought the research of Rachel Carson to international attention and introduced a new concept into toxicology, namely that low and frequent exposures carry the high risk of often irreversible damage. (However, both high and low exposures can cause MCS.) The phenomenon of "sick buildings" brought about major changes in architectural protocols in which Canada led the way in 1984 by establishing building guidelines for chemically sensitive people under the auspices of the *Canada Mortgage and Housing Corporation*. Indeed, the recognition of MCS in both Canada (first) and the USA (later) was facilitated through the housing departments of both countries. In 1985 the Ontario Government sponsored the *Thomson Report* on environmental hypersensitivity disorders, making 30 recommendations covering research, clinical practice, and Medicare issues. Thus, Canada was the first country to examine MCS for purposes of medical research, development of therapies, and recommended its inclusion in the public support system.

In the USA, recognition of MCS was forced upon the government and the medical community through an event that occurred in 1987 in the headquarters of the Environmental Protection Agency (EPA). When 27,000 square feet of new carpeting was installed, hundreds of employees became seriously ill from the (now known to be neuro-toxic) glue fumes. Of these 75 individuals never recovered fully and are, to this day, working out of their homes [14]. This event led to the first serious medical investigation in the USA by Cullen (Cullen 1987) [15], and the criteria he developed for the recognition of MCS were eventually accepted internationally in 1999. A similar disaster took place from 1988 to 1993 in the Camp Hill Medical Centre in Nova Scotia where hundreds of people became disabled due to an error in the installation of the air ducts resulting in formaldehyde and other toxic substances being pumped into the building at low, steady levels. [16] One of the doctors there, Dr. Roy Fox, became ill with MCS himself. Eventually, in 1994, he became the director of Canada's first environmental health clinic (funded federally and provincially) in Nova Scotia. He also taught environmental medicine at Dalhousie University.

Subsequent workshops and research projects sponsored by the US National Academy of Sciences (1987) and the 1989 EPA report to the US Congress on MCS led to a full investigation of chemical neuro-toxicity by the Office of Technology Assessment in

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[14] MCS precipitated by neurotoxic substances of the solvent variety is generally irreversible and causes the most serious damage; those victims are the most likely ones to apply for assistance to this Department.

[15] M. Cullen, "The Worker with Multiple Chemical Sensitivities: An Overview" in M. Cullen (ed.), *Occupational Medicine: State of the Art Reviews*, Hanley & Belfus, 1987

[16] The hundreds of individuals who eventually were forced to seek WCB, a process that lasted until 2002, were subject to the most vicious campaign by industry lobbyists to discredit their MCS diagnosis (made in many cases at Johns Hopkins Medical School and based on internationally recognized test). However, MCS expert Albert Donnay organized an information campaign for the WCB panelists who threw out the insurance industry "experts reports", investigated and judged as false their alleged "scientific" material and the applications were handled properly.

1990. The Dallas, Texas, Environmental Health Clinic, founded, in the 1960's, to this day trains doctors from all over the world. In 1990 Health Canada was the sponsor of the first government-initiated international medical conference on MCS in Ottawa, and that same year the US department of Housing and Urban Development (HUD) recognized MCS as a condition requiring special accommodation. That year also the landmark book on the subject was published: *Chemical Exposures: Low Levels and High Stakes* by Nicholas Ashford and Claudia Miller of the Massachusetts Institute of Technology and the National Institutes of Health respectively. It was based on a report commissioned by the New Jersey State Department of Public Health; for that effort the World Health Organization awarded New Jersey a prize.

In 1991 the EPA and the National Academy of Sciences recommended that MCS be integrated into medical research and clinical practice. The US Justice Department included MCS sufferers in their Disabilities Act Guidelines, and by 1992 the US Social Security Administration included MCS for coverage. That same year environmental health clinics were started in Australia, Germany, China and the UK. In 1994 the Ontario government started the environmental health clinic at Women's College Hospital which is affiliated with the University of Toronto (see letter by the clinic's director, Dr. L. Marshall of April 9 to the Hon. J. Stewart). In 1996 the Ontario Human Rights Commission made several rulings in favor of MCS victims.[17]

The 1999 consensus statement discussed above was based on research by several renowned experts in occupational medicine and toxicology, the most important being K. Kilburn, one of the world's most famous toxicologists and neurologists (current editor of the National Institutes of Health journal *Archives of Environmental Health).*[18] Kilburn's research into the neurotoxicity of substances relevant to MCS and the changes observable in the brain are key in MCS research[19].

Two carefully designed research projects set out to prove that MCS was a psychological or psychiatric condition - one by Ryan in 1988 and the other by Davidoff in the early 1990's[20]. Both failed to prove the psychological basis of the illness and, instead, reached

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[17] A detailed history of the understanding of MCS is in N . Ashford and C. Miller, *Chemical Exposures: Low Levels and High Risks*, Van Nostrand & Reinhold, 2nd ed. 1998, chapter 7.

[18] Kilburn proved that asbestos *causes* lung cancer, the first cancer thus proven to be caused by an agent in the environment, which opened up the research into carcinogens; today 96% of all cancers are accepted as being environmentally based, and only 4% are considered genetically anchored; see S. Steingraber, *Living Downstream: An Ecologist Looks At Cancer*, 2nd ed., Wiley, 1999. The most recent landmark study involving 90,000 identical twins, showed that the polluted environment is the principal cause of cancer: *New England Journal of Medicine*, July 13, 2000.

[19] K. Kilburn, "Measuring the effects of chemicals on the brain", *Archives of Environmental Health*, No. 54 (3), p. 150 ff

[20] C.M. Ryan et al, "Cacosmia and neurobehavioral dysfunction associated with occupational exposure to mixtures of organic solvents", *American Journal of Psychiatry* No. 145: 11, Nov. 1988, pp. 1442-1445

the inescapable conclusion that MCS is biological in nature and mediated by toxins in the environment. Subsequent investigations involving positron emission tomography or PET scans showed that MCS sufferers have *temporal lobe* impairment, while schizophrenics and other psychiatric patients have frontal lobe damage. [21] With single photon emission computed tomography (SPECT) central nervous system function has been investigated in MCS victims and shown clear deficits consistent with known neuro-toxic chemical damage.

In May 2000 the Canadian government issued a report entitled, *Pesticides: Making the Right Choice for the Protection of Health and the Environment*. Its primary aim was to reform the antiquated national pesticide legislation, which was done. Its recommendations included specifically the recognition of MCS and that its treatment be funded by Medicare (p. 55f), which has not yet been addressed.

In 2002 the *Canadian Medical Association* published a series of six articles (see appendix to this report) designed to teach doctors how to diagnose and treat patients presenting with symptoms of environmental illness. In October of this year the *Ontario College of Family Physicians* is holding its first medical conference on environmental illness in Toronto. The conference is supported by the *Ontario Medical Association* which granted the appropriate study credits. Earlier this year the *Ontario Human Rights Commission* specifically directed the Ontario Ministry of Health to protect and accommodate citizens with chemical sensitivity in case of pesticide spraying for West Nile Virus. (See appendix to this report).

A full list (up to the year 2000) of government agencies and medical organizations which have recognized MCS, and a representative list of legal cases won in favor of MCS sufferers, are found in the appendix to this report.

THE DENIAL OF MCS

An overview, even as brief as this one, of MCS in modern medicine would be seriously flawed if it didn't mention the fact that doctors practicing environmental medicine have been seriously persecuted, especially in the US, Canada and the UK, by the pesticide, pharmaceutical, and insurance industries, primarily through the industries' involvement with medical licensing authorities. This observation is supported by the findings published in the *Journal of the American Medical Association* (vol. 287, p. 612-17, 2002) showing that 87% of all physicians responsible for creating practice guidelines have financial ties to the pharmaceutical industry; 59% of these doctors recommend the products of those companies in the guidelines they authored. All of those relationships

[21] The PET and SPECT research results were presented by N. Ashford and G. Heuser at a conference held in Ottawa, May 2001, hosted by the *Environmental Illness Society of Canada*. Heuser's research is published in G. Heuser and J.C. Wu, "Deep Subcortical (including limbic) Hypermetabolism in Patients with Chemical Intolerance: Human PET Studies", *Annals of the New York Academy of Sciences*, vol. 933, 2001

were in place when those physicians were selected for the committees charged with drawing up practice guidelines. The pharmaceutical industry also produces all of the pesticides and most of the chemicals implicated in MCS. [22] In Canada, for example, until last year most of the 30 council members of the *College of Physicians and Surgeons of Ontario* (CPSO), the provincial medical licensing authority, were directly or indirectly connected with the chemical industry (e.g. pesticides, pharmaceuticals and insurance industries), as evidenced on their publicly available CV information.

For purposes of this report, it is important to point out that there are blatantly biased physicians whose "expert" opinions are sometimes part of files submitted to the Department of Human Resources; these physicians are not only directly connected to the insurance industry in most cases, but are openly hostile to anything involving MCS or chemical injury. RAINET has ample documentation to prove this statement with respect to specific doctors. The most prominent of them all is Dr. Arthur. Leznoff in Toronto whose reports assisted materially in the rejection of applications by seriously disabled Canadians. The appendix to this report includes a transcript from a disciplinary trial in which a sworn statement was submitted by Dr. Gerald Ross, the first director of the Nova Scotia Environmental Health Clinic and co-director of the training clinic in Dallas, Texas. This statement speaks for itself and deserves the serious attention of the Department of Human Resources. Of special interest is the fact that Dr. Leznoff is **not** trained in occupational medicine, nor is he trained in environmental medicine, but describes himself on his letterhead as an expert in environmental sensitivities. In a report written by him *this year* (available from RAINET) he claims, in clear contradiction to his official CV, to be an expert in those fields and makes the following astounding assertion:

"The major medical societies in the United States and Britain have published position papers on the disorder called Environmental Sensitivity or Multiple Chemical Sensitivity. These position papers all declare that there is no acceptable published evidence that, in these cases, it is the chemical, scent or food that is the direct cause of the patient's symptoms… this symptomatology can all be explained as manifestations of anxiety, panic or other psychological reactions."

This statement is unsupported by any references and, of course, ignores the international consensus on MCS. In the 1980's such position papers did exist, but all are superceded

[22] Among some of the best sources for this type of information on systemic conflicts of interest see Dr. Theron Randolph's history of clinical ecology, the already noted chapter 7 of Ashford & Miller's famous book), Linus Pauling in *How To Live Longer and Feel Better*, Avon, 1986, Dr. James P. Carter, *Racketeering in Medicine*, Hampton Roads Press, 1993, US Congressman D. Haley (US Congressman), *Politics in Healing*, Potomac Valley Press, 2000, J. Lisa, *The Assault on Medical Freedom*, Hampton Roads Publishing Co., 1997, the Globe & Mail report of February 6, 2002, the editorial in the *Canadian Medical Association Journal*, Feb. 19, 2002, the Canadian Association of University Teachers' *Olivieri Report*, Toronto, 2002, and my own website which contains the *Glasnost Report* prepared by 3 medical organizations (including some OMA Sections) and several patient advocacy groups (including RAINET) www.collegeofphysicianswatchdog.com. A book on this subject by me, entitled *Malice in Medicine*, is in preparation for publication next year.

by subsequent research as well as new position papers – a fact conveniently ignored by Dr. Leznoff. He merely appended, in support of this assertion, to this 2003 opinion on a serious MCS case, two articles: one by him from 1997 (pre-consensus) and the other from 2000 co-authored with others, which curiously gives no references past the mid-1990's - when the explosion in MCS research began (see above p. 10). It is as if the whole of international research on MCS simply does not exist for Dr. Leznoff – yet, his blatantly bias opinion has ruined many perfectly legitimate applications.

Today, after the May 2003 Supreme Court decision which defines experts and expert testimony, the Department will need to re-examine the qualifications of doctors offering opinions on MCS cases. In *C.U.P.E. v. Ontario (Minister of Labour) 2003,* the Supreme Court defines an expert as somebody who is seen to be an expert by people in that same field of work, has a track record in that specific area, and has the qualities of independence, neutrality and proven expertise.

In this connection it is interesting to note that the organizations currently known to oppose the recognition of MCS are the *American Academy of Allergy* and immunology (of which Dr. Leznoff is a member) and the *Environmental Sensitivities Research Institute* (ESRI) established in 1995; it accepts *only* corporate members and its board of directors includes representatives from DowElanco, Monsanto, Proctor & Gamble, and the Cosmetics, Toiletry and Fragrance Association; its chairman is the CEO of the pesticide industry association RISE. [23]

In 1990 the *Chemical Manufacturing Association*, a US-based lobby group, submitted to various government agencies in the US and Canada a "position paper" which has since been made public by the *Environmental Illness Society of Canada*. To get a feeling for the importance of the timing of this publication, compare the list of events for that year given above. At that time, MCS was becoming part of mainstream scientific research and was being recognized in law and by government policy; research supporting MCS was coming especially from publicly funded medical schools. This position paper objected to MCS being recognized and states as follows:

"The primary impact on society would be the huge cost associated with the legitimization of environmental illness. Should the environmental illness advocates succeed in their efforts it would also impact on society and on many industries. Potentially affected industries include textiles, clothing, lawn care products, household cleaners, dry cleaners, paints and solvents [manufacturers], perfumes, hair treatment products, plastics, paper and many other consumer goods industries."

This position paper concludes with the following strategic advice: "*Should environmental illness arise as an issue, a coalition with the state [and provincial] medical associations is absolutely necessary*." And from that "coalition" the persecutions of environmental medicine practitioners arose in large numbers, as documented in the Glasnost Report (see my web site: www.collegeofphysicianswatchdog.com) and my forthcoming book.

[23] This information is based on RAINET files, the web site of Albert Donnay, and my own attempt to become a member of ESRI: I was turned down because I was not a corporation.

While the politics of medicine can indeed be astounding in its maliciousness against patients and the doctors who want to and can help them, this sort of struggle isn't exactly new to the history of medicine or any other human enterprise. The chemical industry – including gasoline, perfume, pesticides, various toxic synthetic drugs and endocrine disruptors – is for very good reason fighting hard for its survival. Indeed, the industry's anxiety about the economic impact of the eventual and certain end of the use of toxic substances is perfectly rational. However, one can take comfort from the fact that humanity has been through this sort of crisis many times before and society emerged much improved. The last and most brutal example being the end of slavery which was an equally unavoidable economic earthquake for society.

THE CURRENT DIRECTION OF MEDICAL RESEARCH IN MCS

The appearance of MCS has effectively set medicine on a new course. Just how important the MCS issue has become is illustrated by the editorial of the 2003 "Grand Rounds" issue of the National Institutes of Health journal *Environmental Health Perspectives.* Its editor, Dr. H. Wu of the Harvard School of Public Health and Medicine summarizes in the introduction to this issue how central environmental medicine has become to all medical research. It is a masterly analysis of the issues; a copy is attached in the appendix to this report.

Canadians who apply for CPP, because they have become disabled, are faced with having to prove that they are indeed disabled, and the investigation process requires some kind of biological support or verification of the person's disability. That brings up the question of *biomarkers and objective tests.*

The view is often expressed that there are no real biomarkers or definitive tests to establish MCS (discussed in next section below). Even if that were true - which it most certainly is not - one should remember that many well-established and fully recognized diseases face the same problem, such as Multiple Sclerosis, Alzheimer's, clinical depression, schizophrenia, to name just a few. All *eventually* provide clear-cut biological evidence permitting a correct classification, but generally by that time the disease has already progressed very far. Unlike these traditional diseases, MCS provides powerful clues about its identity at an early stage (see especially the material by Albert Donnay in the appendix). In short: the reality of MCS should not be subject to a double-standard when it comes to scientific proof; what is considered an acceptable work-in-progress approach with other illnesses, should also apply to the evolution of MCS research.

In common with traditionally hard-to-diagnose illnesses, experts in environmental illness agree, MCS is most effectively diagnosed on the basis of an *exhaustive history*, and its characteristic feature, the large number of "*symptoms which involve multiple organ systems*", as the 1999 Consensus Statement asserts. However, definitive biomarkers do

exist. The appendix to this report includes information on biomarkers and the appropriate tests from the medical literature.

THE LATEST INFORMATION ON MCS

It might be helpful to present the latest research on MCS. This is important because it points to what public policy will soon have to deal with. Four items are presented below which show the direction this research is taking. Each has relevance to your Department's concerns.

The **first** of these is the work of Martin L. Pall of Washington State University. This university issued a press release on January 4 this year announcing the publication of an article entitled "NMDA Sensitization and Stimulation by Peroxynitrite, Nitric Acid, and Organic Solvents as the Mechanism of Chemical Sensitivity in Multiple Chemical Sensitivity" in the prestigious journal FASEB (Federation of American Societies for Experimental Biology, 2002, vol. 16, pp. 1407-1417).

Pall suggests that MCS (including Fibromyalgia, Chronic Fatigue Syndrome, Gulf War Syndrome), as well as the psychological condition known as Post Traumatic Stress Disorder (PTSD), have a common biological mechanism which he describes as "*a vicious chemical cycle"*. In this case, "chemical" is interpreted as being stress-induced through toxic chemicals within the body (such as stress hormones) as well as foreign toxic substances. PTSD is accompanied by an overproduction of stress hormones during an emotionally highly traumatic experience, but the subsequent chronic condition is not understood. Similarly, MCS is usually precipitated by an exterior chemical injury, but the subsequent chronic condition is also in need of explanation. The common area of investigation for Pall became the way in which the organism processes the internal or external chemical influx so as to wind up with a chronic condition.

The press release stated, "In the United States about 10 million people are afflicted with multiple chemical sensitivity … the onset of the condition can usually be traced back to an exposure to certain chemicals, but why the initial exposure results in an often life-long, incurable condition has been a mystery." Describing Pall's work, the press release summarizes, "Pall's new theory is [based on the observation that MCS involves] excessive levels of two chemicals in the body – nitric oxide and its oxidant product peroxynitrite. He suggests certain mechanisms act to keep levels of the two compounds elevated, thus producing chronic [organic] changes." Pall also suggests that this explanation complements an earlier theory proposed by environmental physician and researcher Dr. Iris Bell of the University of Arizona, namely that "neural sensitization in the brain" produces the chronic effect after initial exposure.[24]

[24] It occurred to me that this proposed explanation provides a parallel to the already well-known and biologically well-understood phenomenon of "bio-magnification" which occurs when a toxic substance becomes even more toxic by being passed on through the food-chain. An excellent discussion of this phenomenon and its health impacts on Canada's population is found in the Canadian government report, *Pesticides: Making The Right Choice for the Protection of Health and the Environment,* Report of the Standing committee on Environment and Sustainable Development, May 2000

Pall said, "What my article reports is that if you assume both theories are correct, you come up with a fusion that explains all the most puzzling features of MCS. It explains why MCS is induced by a previous chemical exposure and why MCS sufferers show such a high level of sensitivity to a wide range of chemicals." Pall discusses the research which shows how hypersensitivity in the brain is created following initial exposure, the subsequent production of these two chemicals, and how they increase hypersensitivity even further.

"Ordinarily these activities are highly regulated," Pall observed. "acting only on specific synapses in the brain where they are involved with learning and memory. The MCS response is produced when chemical exposure produces excessive responses over large regions of the brain. In this way normal and important mechanisms may act to generate this chronic illness. Thus, not only is the brain constantly inundated by chemicals to which it is normally somewhat sensitive, but the brain of a person suffering from MCS becomes abnormally sensitive to the chemicals – from 100 to 1,000 times more sensitive than in an unaffected person." Pall discusses two other known mechanisms which facilitate the accumulation of these toxic chemicals to much higher levels in the brains of MCS victims.

In PTSD virtually identical chemical activity has been observed following severe emotional trauma, and Pall suggests, "The notion that a biochemical vicious cycle may underlie [both] … suggests that this is a major new paradigm of human disease."[25]

Further research will expand on these observations, but it is clear that public policy will be powerfully influenced by this finding, if proven. The effect could be as powerful as the science that finally explained what smoking and exposure to second-hand smoke does to people's health. The parallel to smoking is helpful, as in both populations (MCS and smokers) there is a percentage of individuals who do not get cancer or other tobacco-induced illnesses. Even so, protecting the public interest demands that the consequences for the people who do get sick take precedence when formulating legislation. As far as the mandate of this department is concerned, the fact that this research is happening will hopefully help in evaluating MCS victims' applications; no matter how things turn out in detail, the science behind MCS has embarked on a road that will lead to further proof, not disproof of the condition's reality.

The **second** item of current research concerns genetic predisposition. On April 16 this year, the National Institutes of Health in Bethesda, Maryland, held a press conference during which it was announced that their Environmental Genome Project has sequenced "200 environmentally responsive genes [which] included links to vascular disease and leukemia." [26]

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[25] Sources: wsunews@wsu.edu and phmartin@xtra.co.nz

[26] Source: www.apps.niehs.nih.gov/odconfer/gxe/home.htm This research is in press.

The implication of this research is that with MCS we are again dealing with a phenomenon like tobacco-induced diseases for which the genetic basis of the causes are well understood. It is known which cancer-protective genetic mechanisms are disabled by the toxicity of tobacco products, thereby allowing faulty cell reproduction to take off unchecked.[27]. Furthermore, the research into oncogenes has shown that predispositions for cancer exist in everybody, as apparently may also be the case with MCS. However, neither predisposition need be expressed, unless a chemical assault takes place. For both MCS and cancer the observation of oncologist Dr. Susan Love applies who famously said, "We start out with a perfectly good body until some chemical comes along and screws it up."[28]

An interesting parallel for this genetic basis of predisposition exists in the field of chronic pain research. In a recent interview with pain expert Dr. Ellen Thompson of Ottawa I learned that research has shown that about 17% of people have genetic markers which are known to predispose a person to developing chronic pain if injured seriously. Of course, not all 17% of the potential chronic pain population does get injured. Her remarks were in connection with the ongoing battles pain experts have with insurance companies and with other agencies that fill disability claims. Dr. Thompson pointed out that only a certain number of people would ever come into this system and that the fear of a stampede of chronic pain victims depleting the coffers of such agencies (or the government's) is totally unfounded. However, unfortunately, with MCS the potential for disability is much larger and, additionally, there is the danger of new epidemics evolving for which we appear not to be prepared at all.

The **third** and final research item worth mentioning concerns the research by Dr. G. Nicholson at the Institute of Molecular Medicine in California. Dr. Nicholson is probably the world's foremost expert on Gulf War Syndrome. He addressed the Canadian Defense Department at a 2001 conference initiated by that Department. His research investigated the *infectious potential* of Gulf War Syndrome and other forms of environmental illness.

One of the most characteristics of MCS which is especially alarming is the fact that it *can sometimes become an infectious disease*, primarily due to an impaired immune system which provides the opportunity for infectious organism to develop about which medical science knew nothing until about a decade ago. Dr. Nicholson studied 60 families where one member developed MCS and the rest of the family, not exposed to toxic chemicals, also became ill with the same characteristic set of symptoms and subsequent hypersensitivities to chemicals they had never been exposed to. The result of the last 10 years of his research has been the discovery of *mycoplasma* which, like other less frequently encountered bacteria (e.g. clamidia etc.) in an MCS victim become unusually

[27] See chapter 10 in R.N. Proctor, *Cancer Wars*, Basic Books, 1995, for the story of this research.

[28] In the documentary film "*Exposure: Environmental Links to Breast Cancer*" produced by Women's Healthy Environments Network (WHEN) available worldwide in seven languages. It won Best Health Documentary at the International Independent Film Festival in 2001 and its producer, Dorothy Goldin Rosenberg was awarded the Governor General's Award of Canada. Contact when@web.ca or visit www.whenvironments.ca.

virulent and develop opportunistically due to the chemically-induced impaired immune function of the host. Further research showed the presence of these mycoplasma in other chronic diseases, generally known as auto-immune diseases such as arthritis, Multiple Sclerosis, Lou Gehrig's disease (ALS), and Lupus, generally in about 40% of cases. When treated with certain antibiotic cocktails in combination with therapeutic doses of certain vitamins, enzymes and minerals, most of the victims of MCS and the other traditional illnesses recovered fully so as to be able to go back to work. Most of the cases Dr. Nicholson's research team treated were US armed forces personnel who can only return to work if they are in perfect health.

The chief characteristic of mycoplasma appears to be that they reside in intracellular space where they attack the mitochondria, thereby impairing the Krebs cycle and disturbing the energy production of the body. They feed on the lipids inside the cell and thus reduce the ability of the body to detoxify toxic chemicals, a process done primarily by lipids.

These findings are so solid, that an editorial in the *Journal of the American Medical Association* as far back as 1997 by Cassell (vol. 278 p. 2051ff) opined that it is nothing less than malpractice not to look for these infections in such patients. [29]

The implications of these findings are very disturbing: here is the very real possibility of a new epidemic – another AIDS or SARS, only fed continuously by chemicals found in the environment everywhere. Containment through old, tried and true methods of quarantine or the promotion of safe sex habits would be quite useless as more and more people become hypersensitized to a chemicalized environment. Transmission of the mycoplasma-mediated environmental illness could take place through anything from a blood transfusion to traditional exchange of body fluids or be transmitted to a fetus through its mother. MCS in all its forms is not readily controllable through behavior modifications such as ceasing to smoke or using condoms. MCS in all its forms will only stop when the environment in which we live is restored to a state in which an organism, with an immune system evolved over some 100 million years can actually survive.

The **fourth** item was not presented by me at our meeting and is here added because of its profound relevance to all considerations about MCS and its family of illnesses. Following my attendance at your department I had the opportunity to interview Dr. Albert Donnay and speak to him about my meeting with you in Ottawa. His position as research coordinator of the *Johns Hopkins Multi-Centre Study of MCS Immunology* places him in the position of having access to the latest information on MCS issues. The appendix attached to this report contains the information pertaining to the newly recognized fact that "9 out of 10 MCS cases are actually carbon monoxide poisoning

[29] For Dr. Nicholson's research visit the rather enormous web site www.immed.org
Only two of his many publications are suggested reading for the purposes of this report: G. L. Nicholson, "Diagnosis and Treatment of Mycoplasmal Infections in Persian Gulf War Illness – CFIDS Patients" in *International Journal of Occupational Medicine, Immunology and Toxicology* vol. 5, no. 1, 1996. G. L. Nicholson, "Considerations when undergoing treatment for Gulf War Illness/CFS/FMS/Rheumatoid Arthritis" in *International Journal of Medicine* 1998 Vol. 1 p. 123 ff .

cases", as Donnay put it. The entire subsequently observed cascade of symptoms develops out of that. When asked what the trigger for the remaining one out of ten cases would be, he said, "Mostly solvents." The interesting point is that carbon monoxide poisoning is a well-understood traditional problem with a new symptomatology. Thus, a simple, traditional test which involves comparing the blood gases in a person as found in venous and arterial blood establishes with certainty whether an oxygen deficit exists. The implications for diagnosis and therapy are equally important, as early intervention is possible, treatment is relatively cheap, rehabilitation is highly likely, and a huge saving of money and suffering is within reach.

The sources of low-level carbon monoxide poisoning are many indeed in our society which totally relies upon fossil fuels and natural gas products. The mechanism of poisoning is also well-understood: carbon monoxide acts as a facilitating neurotransmitter in the body. Indeed, this interview prompted my husband to quip : "The solution clearly is to return to the horse and buggy since horse manure is healthier than gasoline." The serious fact behind the joking remark is, of course, the historical fact, that the industrial age has brought about exposures to steady concentrations of substances for which our biological evolution did not prepare us.

In conclusion, it can be said that medical science is learning that new patterns of disease do evolve, formerly harmless bacteria are able to become nasty when given new opportunities, and old poisons can create new responses. All of which pose new demands for social assistance upon governments and the helping professions.

SUGGESTIONS TO THE DEPARTMENT OF HUMAN RESOURCES

MCS is a disease caused by chemicals toxic to many organs and bodily systems. It has been researched by medical science with increasing intensity since the mid-1990's. MCS and its related, or overlapping illnesses, Chronic Fatigue Syndrome, Fibromyalgia and Gulf War Syndrome afflicts *severely* some 10 million people in the United States and about 1 million in Canada. The information currently available indicates that in Canada about 50 to 60 individuals annually seek some assistance because they are *seriously* disabled. The most immediate concern for the Department is to develop assessment criteria when a Canadian citizen presents with a diagnosis that specifically identifies MCS as the cause of the disability.

Below is a list of sources which contain *diagnostic criteria* developed by experts in the treatment of MCS. As I am a medical science writer and not a practicing doctor, it is not appropriate for me to inform you how to diagnose MCS. Nor can I authoritatively suggest to you which biomarkers you ought to look for in an applicant's file and which tests you can trust as definitive. Given the fact that you wish to develop assessment criteria, your Department and the Canadian public are best served if doctors trained in this area are consulted. The best source would be Dr. L. Marshall whose letter to the

Minister is included in this appendix. Also helpful might be the following whose material is also included in the appendix: [30]

1. Dr. A. Lieberman of the *American Academy of Environmental Medicine* presented at the 1999 annual international conference of that organization a summary of diagnostic and tools including tests that identify specific biomarkers.

2. The *Canadian Medical Association*'s recent series on health and environment issues commenced with an article entitled "Identifying and managing adverse environmental health effects: 1. Taking an exposure history." The authors of this series work at various Canadian universities and would no doubt be helpful to your Department.

3. Dr. G. Heuser summarized in an article published in 2000 in the *International Perspectives in Public Health*, vol. 13, the diagnostic protocol for MCS in its various forms.

4. Dr. Albert Donnay's material included in the appendix is invaluable, as it provides the latest information available with regard to biomarkers and applicable tests.

5. A helpful published source for both diagnostic and therapeutic procedures is the *Laboratory Evaluations in Molecular Medicine: Nutrients, Toxicants and Cell Regulators*, by J. A. Bralley and R.S. Lord, published by the Institute for Advances in Molecular medicine, 2001

My suggestion for the Department are as follows:

- To consider calling a meeting with Canadian doctors trained in environmental medicine who work with MCS patients on a regular basis by consulting Dr. L. Marshall whose position as research director for the environmental health clinic at Sunnybrook and Women's College Hospital in Toronto allows for access to whatever information the Department would be seeking. Furthermore, Ottawa happens to have an unusual concentration of doctors trained in this field. To my knowledge, all are graduates of the AAEM: Dr.

[30] Our meeting in June ended with a delightful and informal brain-storming during which I was asked what I would do to assess MCS applicants. I replied that the government should avoid expensive confirmatory tests; there is no need for MRIs, SPECT's and PET scans as these are among the universally recognized tools used in *research*. The reliable and most helpful tests that were cost-effective (done in excellent Canadian laboratories) in my own and my son's case were a set of *standard blood, urine, hormone, saliva, and intracellular tests* as well as *hair analysis* and *screening tests for chemical intolerances* with which all environmental physicians are familiar. As Albert Donnay has pointed out, the blood gas tests are probably essential, as carbon monoxide poisoning is involved in 9 out of 10 MCS cases. All these are also employed in standard medicine where the doctor orders the lab to look for different markers. In an MCS patient, these tests usually confirm the history and make sense of the specific reported disability for the simple reason, that toxicology is generally accepted as an *exact* science.

Jenny Armstrong, Dr. John Molot, Dr. Ross Michealson are all located in downtown Ottawa. Dr. J. Krop in Mississauga, whose primer in environmental medicine I published and gave you copies of, is a Fellow of the AAEM and annually teaches courses on diagnosis and treatment of MCS. He is one of the researchers and clinicians who signed the 1999 international consensus statement on MCS. His input would undoubtedly be most valuable to this exercise.

- A consultation with representatives of patient advocacy groups, such as you have now had with RAINET already, would probably also be most helpful. The Ottawa-based *Environmental Illness Society of Canada* comes to mind, of course, as does the *Environmental Hypersensitivity Association of Ontario*.

- Forming a committee, or working through an existing one, with Health Canada for the purpose of following up on the recommendation made in May 2000 by the Standing Committee on Environment and Sustainable Development: ***"The Committee recommends that Health Canada take the necessary steps to bring about legal recognition of multiple chemical sensitivity syndrome."*** (p.55) The object of this interdepartmental discussion would be the recognition of MCS, the coverage of its treatment by Medicare, and the initiation of a program for MCS patients that provide them with financial assistance while helping them to get cured (if possible) or to recover sufficiently to become functional and financially independent in a safe environment. MCS is more than a disease: it is an education.

MCS is a disability unlike any other. While it is the duty of your department to assist those Canadian citizens who are usually permanently disabled, a pro-active interface with Health Canada and, if at all possible, with the Ministry of Industry and Technology, would be most urgently indicated. People afflicted with MCS acts as the proverbial canaries in the mine. An economically viable technology, a wealth-creating industry, and a healthy population are not only possible but more likely if the lessons learned from MCS are incorporated into government policy. No country can afford a growing population of chronically ill people, nor can we afford more epidemics like AIDS or outbreaks like SARS. In conclusion, it is instructive to consider the experience of other, industrialized nation 's with MCS:

The German government funded a pilot project in 1994 and opened a hospital exclusively for environmental illness patients in the North near the Danish border in the town of Bredstett. The clinical director, Dr. Eberhard Schwarz, trained at the Environmental Health Clinic in Dallas, Texas. After the first 5 years the medical school of the University of Leibzig was asked to do an evaluation of the project measuring such scores as cost of treatments compared to conventional symptom-control oriented interventions, ability to return to work and stay in the work force, money saved on disability payments, impact on the integrity of the family, etc. The results were so impressive, the German government announced in 1999 it would open

four more such hospitals throughout the country. Also, between 1990 and 2000 all German medical schools funded chairs for environmental medicine.

In the UK a similar project was undertaken at Breakespear Hospital in Hamel Hampstead. The endorsement of the Royal Family was of great help to the project. However, the fact that the Countess of Mar of the House of Lords was cured of MCS (developed through chronic exposure to sheep-dip on her sheep farm), which had disabled her completely and had become life-threatening, resulted in a tremendous impetus to research, legal reforms and increased medical acceptance.

The impressive results obtained by Dr. Garth Nicholson, mentioned earlier, should be emphasized again. His unique combination of traditional medicine (e.g. antibiotics and the classic knowledge of infectious disease etiology) with the new insights into toxicology has resulted in helping people with the most severely disabling traditional diseases (Multiple sclerosis, Amyotrophic lateral sclerosis, Systemic lupus erythematosus etc.) as well as MCS victims back to work. Encouraging are especially the positive implications for reduced costs involving health care and disability and increased economic productivity.

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APPENDIX

1. The article reporting on the research done by the University of Toronto to establish the symptoms of MCS: G.E.McKeown-Eyssen et al, *Archives of Environmental Health*, 2001

2. Information on the *Canadian Medical Association Journal's* series on environmental health issues, 2002

3. "ABCs of Toxicology" from *Journal of Pesticide Reform*, Winter 2001

4. Abstract: S. Caress & A. Steinmann, "A Review of a Two-Phase population Study of Multiple Chemical Sensitivities", *Environmental Health Perspect*ives, Sept. 2003

5. Letter from Dr. L. Marshall to the Hon. Jane Stewart, Minister of Human Resources, April 9, 2003

6. Letter from the Ontario Human Rights Commission to the Hon. T. Clement, Minister of health for Ontario, April 16, 2003

7. Transcript excerpt from Vol. 7 of CPSO & Dr. J. Krop, 1995; letter by Dr. G. Ross of the Environmental Health Centre, Dallas, Texas, April 17, 1991, to CPSO

8. H. Hu & A. Woolf, "Environmental Medicine as an Emerging Discipline" in *Grand Rounds in Environmental Medicine: Environmental Health Perspectives*, National Institutes of Health, 2002

9. M. L. Pall, "NMDA sensitization and stimulation by peroxynitrite, nitric oxide, and organix solvents as the mechanism of chemical sensitivity in multiple chemical sensitivity", FASEB journal, 16:1407-1417, 2002

10. G. L. Nicholson & N.L. Nicholson, "Diagnosis and Treatment of Mycoplasmal Infections in Persian Gulf War Illness – CFIDS Patients, *International Journal of occupational Medicine, Immunology and Toxicology*, vol. 5 (1), 1996

11. A. D. Lieberman, "New Important Tools and Resources to Enhance the recognition and management of Chemically Injured Patients", presentation at the 1998 international conference of the *American Academy of Environmental Medicine, Baltimore*, Maryland.

12. G. Heuser et al. "Defining Chemical Injury: A Diagnostic Protocol and Profile for Chemically Injured, Industrial Workers and Gulf War Veterans" in *International Perspectives in Public Health*, vol. 13, 2000

13. Information and sample questionaires provided by Dr. Albert Donnay

14. Copy of the pamphlet entitled "Multiple Chemical Sensitivity" published by *The Environmental Hypersensitivity Association of Ontario;* attached is an EPA sample list of neurotoxins commonly found in fragrances

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