

#4304



Canadä"

SURVEY OF THE MEDICAL IMPACT ON ENVIRONMENTALLY HYPERSENSITIVE PEOPLE OF A CHANGE IN HABITAT

Prepared for

the Research Division

Canada Mortgage and Housing Corporation

by

Stephen. R. Barron M.D., C.C.F.P.

2275 Leigh Square Port Coquitlam, B.C., V3C 3B9

30 April 1990

CMHC - Project Manager Peter Russell P. Eng. Further copies of this and other CMHC Research Reports may be obtained without charge from:

CHIC - (Canadian Housing Information Centre) CMHC 682 Montreal Road Ottawa K1A OP7 Canada

Tel.: (613) 748-2367 Fax: (613) 748-6192

## ABSTRACT

"Survey of the Medical Impact on Environmentally Hypersensitive People of a Change in Habitat"

for Canada Mortgage and Housing Corporation

by Stephen R. Barron M.D., C.C.F.P.

This report summarizes the medical histories of 29 people with environmental hypersensitivity disorder (multiple chemical sensitivities) who have made modifications to their homes to improve indoor air quality for health purposes. It also reviews literature on environmental illness and the medical discipline of clinical ecology.

The literature review supports the existence of environmental hypersensitivity disorder as a real and serious health problem. Ongoing professional controversy over etiology and treatment prevents many affected people from obtaining appropriate medical treatment.

29 respondents completed detailed medical questionnaires, documenting a variety of symptoms associated with this chronic disorder. All respondents report improvement in health following modifications to their homes to reduce chemical exposures.

The population surveyed is not statistically random and the results of the medical survey are not statistically useful since a bias already exists in the source of the candidates.

-i-

## FOREWORD

CMHC has a commitment to improve the availability and quality of housing for Canadians. One manifestation of this is its program to facilitate the housing of disabled people. In 1982 it made provision in its Residential Rehabilitation Assistance Program (RRAP) for those who suffer chronically from allergies, including those suffering from environmental hypersensitivity disorders. This policy has been adopted, notwithstanding that Environmental Hypersensitivity is not a conventional allergy, and indeed as this report explains, the medical profession is divided as to the very reality of the condition. RRAP provides financial assistance to low and moderate income homeowners for improving conditions in existing homes, in this instance in the form of improvements that will minimize indoor pollutants.

There is a continuing problem of definition and diagnosis and it appears as though this may persist for some time. In the mean time CMHC continues to provide assistance on the basis of a doctor's certification that the patient's housing condition contributes to his or her illness and the reduction of indoor air pollution would significantly improve the patient's health.

There has been scant documentation that modifications to a house and removal of household chemicals improve indoor air quality and therefore improve the health of the occupants. This study fills a gap, providing evidence that clean houses work and are a vital component in the treatment of people with environmental hypersensitivity disorders.

P. Russell Research Division CMHC

•

-ii-

# DISCLAIMER

This report was written by Stephen R. Barron M.D., C.C.F.P. for Canada Mortgage and Housing Corporation. The opinions and conclusions expressed are those of the author and do not necessarily reflect the views of Canada Mortgage and Housing Corporation or those divisions of the Corporation that assisted in the report and its publication. The material contained in this report <u>does not</u> constitute medical advice and the opinions expressed do not necessarily reflect the views of the medical profession. The results of the medical survey are not statistically useful and are for discussion purposes only.

## ABOUT THE AUTHOR

• Stephen R. Barron M.D., C.C.F.P., is a family physician in full-time family practice in Port Coquitlam, British Columbia. He received his medical degree from Memorial University of Newfoundland in 1978 and completed his internship training at the Royal Columbian Hospital in New Westminster, British Columbia, in 1979. He is on the Active Medical Staff of the Royal Columbian Hospital, New Westminster, B.C. and Eagle Ridge Hospital, Port Moody, B.C. He is a member of the Courtesy Medical Staff of St. Mary's Hospital, New Westminster, B.C.

• He is a Certificant of the College of Family Physicians of Canada (CFPC) and is on the Board of Directors of the B.C. Chapter CFPC. He is on the Medical Education Committee and is Chairman of the AIDS Education Committee, B.C. Chapter CFPC.

In recent years he has become interested in the role of environmental factors in disease and has reviewed the literature on environmental hypersensitivity disorder. He has attended medical conferences on environmental illness and non-medical conferences on indoor air quality. In 1985 he completed the Canadian Home Builders' Association R-2000 Workshop. In 1986 he viewed Dr. William Rea's environmental isolation unit in Dallas, Texas. In 1987, he took a course in Occupational Medicine through the Department of Health Care and Epidemiology at the University of British Columbia. In 1989, he lectured at the 15th Annual Conference of the Solar Energy Society of Canada on clean environments for chemically sensitive people. He was a medical advisor for the CMHC report, <u>Clean Air Housing in Canada</u> (Drerup <u>et al.</u>, 1990).

• His practice is a traditional general / family practice in a group clinic. He is not an allergist or clinical ecologist. He estimates that patients with environmental hypersensitivity comprise less than 1% of his practice at this time.

#### ACKNOWLEDGEMENTS

• The author wishes to express his thanks to the 29 respondents who participated in this survey. For purposes of confidentiality, they will remain anonymous.

 To David Rousseau and Virginia Salares for providing the list of potential respondents.

 To my wife, Glenna Barron, journalist and scientist, who helped edit and reference this document.

• To the following organizations and individuals who provided information or access to literature: the Allergy and Environmental Health Association, Cambridge, Ontario; The American Environmental Health Foundation, Dallas, Texas; The American Academy of Environmental Medicine, Denver, Colorado; the office of Dr. Theron Randolph, Illinois; the office of Dr. William J. Rea, Environmental Health Center, Dallas, Texas; Dr. John W. Davies, Health and Welfare Canada; Mary Lamielle, president, National Center for Environmental Health Strategies, New Jersey; Earon S. Davis, environmental health consultant and editor of Ecological Illness Law Report, Illinois; Dr. Gerry Ross, Environmental Health Center, Dallas, Texas; Dr. Anna Rose Spina, Research Advisory Committee on Environmental Hypersensitivity, Ontario; Mrs. Barbara Mowat, Board of Directors, Allergy and Environmental Health Association of Ontario; and Ms. Carol MacAskill, Halifax, Nova Scotia.

 To Canada Mortgage and Housing Corporation Project Manager: Mr. Peter Russell

# TABLE OF CONTENTS

Abstracti
Forewordii
Disclaimeriii
About the authoriv
Acknowledgementsv
Table of contentsvi
*
INTRODUCTION1

# SUMMARY

SUMMARY	OF	ENVIRONMENTAL HYPERSENSITIVITY3
SUMMARY	OF	THE MEDICAL SURVEY4

# CONCLUSIONS

OVERALL CONCL	USIONS7	ţ
DISCUSSION OF	CONCLUSIONS7	

# REVIEW OF ENVIRONMENTAL HYPERSENSITIVITY DISORDER

DEFINITION9
REVIEW OF LITERATURE11
HISTORY & PROFESSIONAL CONTROVERSY14
PATIENT PROFILE & COURSE OF THE ILLNESS21
ETIOLOGY24
PREVENTION & TREATMENT27
RECENT CANADIAN DEVELOPMENTS30

# THE MEDICAL SURVEY

OBJECTI	VES		32	
METHODS			32	
SUMMARY	OF	HABITAT	MODIFICATIONS33	

PROFILE OF RESPONDENTS:

Current age34
Age at onset of illness34
Length of illness34
Province of residence34
Discussion of profile35

## OCCUPATION:

At onset of	illness3	6
Current occu	pation3	6
Discussion of	of occupation3	6

.../continued

# Table of Contents, continued...

SUMMARY OF QUESTIONNAIRE RESPONSES:

÷

	Chief complaints	-37
	Review of systems	-38
	Relative frequency of systems affected	
	Discussion - review of systems	
	Inhalant and chemical sensitivities	-41
	Past medical historyFamily history	-42
	Family history	-44
	All special investigations	-45
	Allergy and sensitivity testing	-45
	Number of medical doctors seen	-46
	Factors contributing to illness	-48
	Other diagnoses suggested	-51
	Food allergies and sensitivities	-53
	Habits & problems concerning food intake	
	Other lifestyle changes	
	All treatments received	-56
	All past medications	-57
	All current medications	-57
	Most beneficial treatments	-58
	Discussion of treatments	-58
	Estimate significance of habitat change	
	Discussion of effect of habitat change	-59
	Comparison of illness before and after	
	habitat change	-61
	Additional comments	-62
		•-
REFERENCI	ES	-63
APPENDIX	A	-66
APPENDIX	B	-68
ADDENDTY	C	- 71
AFFENDIX		-/1

APPENDIX D-----73

# INTRODUCTION

In the winter of 1989-1990, CMHC completed a Canada-wide survey to identify those people with environmental health problems who have made modifications to their homes - <u>Housing for the Environmentally Hypersensitive</u> (Survey and Examples of Clean Air Houses in Canada). (Drerup <u>et al.</u>, 1990). 92 respondents were surveyed. The survey focused on building and renovation techniques used to reduce exposure to indoor inhalants and chemicals. It documented a variety of different approaches representing a partial picture of the nature and extent of "clean air" housing in Canada. It will serve as a resource for those who are planning, building, renovating or moving due to special environmental health concerns.

The original report focusses on construction techniques and specifications. Only a small portion of the report addresses health conditions of the respondents. CMHC felt that more detailed medical information would be valuable. This report summarizes medical histories of a select sub-group of respondents to the original survey.

To put things in perspective for the reader, a review of Environmental Hypersensitivity Disorder is also presented.

SUMMARY

### SUMMARY - REVIEW OF ENVIRONMENTAL HYPERSENSITIVITY DISORDER

The studies reviewed in this report each had their own definition of environmental hypersensitivity disorder. There is no universally accepted definition. However, features common to most of the definitions include: chronic, multisystem and polysymptomatic; reactions to chemicals, foods and other environmental agents at low levels; improvement with avoidance; normal physical examination and investigations.

Several detailed studies express concern about increasing reports of individuals with this disorder. The volume and consistency of these reports suggest that the problem may be larger than realized.

There is ongoing professional controversy about environmental hypersensitivity disorder. This prevents information from reaching the primary health care professionals as well as the lay public. As a result, many affected individuals do not have access to reliable information or proper treatment. Traditional allergists do not recognize the work of clinical ecologists despite a large amount of clinical and research evidence.

The disorder can lead to serious disability. Many of those affected have to quit work. It is often necessary to make major changes in lifestyle to accommodate restrictions imposed by the illness. Family and friends are often reluctant to recognize the problem.

Cause of the illness is not known. Genetic and environmental factors are probably involved. Increasing chemical pollution of the environment may well be the most significant factor.

While a variety of treatments are used, the most important thing in managing the illness is avoidance of incitants. Avoidance of chemicals in the home and workplace, as well as eating clean food and drinking clean water, is very important. Breathing unpolluted air is also important.

Despite the chronicity of this illness, and the degree of disability it causes, there are many case histories of recovery. If the medical community was more aware of the disorder and could intervene at an early stage, much illness and disability would be avoided.

In recent years there is better awareness in some Canadian provinces. Access to treatment and information is improving slowly. As awareness of environmental pollution in general increases, there will be more interest in the environmental causes of disease.

Environmental hypersensitivity disorder is a real and serious health problem and genuine interest is long overdue.

#### SUMMARY - THE MEDICAL SURVEY

29 respondents each completed a questionnaire designed to document the types of medical problems associated with environmental hypersensitivity disorder. They were chosen from a larger group of 92 respondents to a previous CMHC survey entitled <u>Clean Air Housing in Canada</u> (Drerup <u>et al.</u>, 1990).

The respondents were all identified as people with environmental hypersensitivities who had made modifications to their homes in order to improve indoor air quality for health reasons.

Several observations about the respondents are summarized:

- 83% are female
- 93% are over the age of thirty years
- 76% became ill in adult life
- 93% have been sick for more than six years
- 27% are currently totally disabled

Most respondents reported a variety of chief complaints. The most common was <u>extreme fatigue</u> and <u>weakness</u> (72%). Symptoms of confusion and difficulty concentrating were present in 41%, and gastrointestinal symptoms were also 41%. Depression and anxiety (37%), joint and muscle pain (34%), asthma and bronchitis (31%), and headaches (27%) were next in line.

Review of systems also revealed a wide variety of symptoms. Musculoskeletal symptoms were reported by 74% of respondents. However, musculoskeletal symptoms did not rank highly in the section on chief complaints. This suggests that, while common, musculoskeletal symptoms are not the most severe symptoms.

All respondents reported sensitivities to many chemicals found in common daily activities. Most reported some past overexposure (acute and/or chronic) to chemicals as a factor triggering illness.

Past medical histories were equally heterogeneous and the only observation of note was the high rate (93%) of past hospitalization.

Family history did not appear to be different from the general population.

Respondents reported numerous medical investigations over the course of illness. They also reported seeing many physicians as well as alternative practitioners. They had many different "diagnoses" suggested.

Respondents also reported a variety of sensitivities and allergies to foods. Most eat a restricted diet and drink purified water.

Other reported lifestyle changes include discarding of synthetic fabric clothing in favor of natural fibres such as cotton, giving up hobbies and recreational activities in order to avoid chemical exposures, and quitting or changing occupation.

Respondents have tried many different medical treatments and alternative therapies. When asked which treatments were most beneficial, however, they consistently replied that clean air, clean water, clean food, and avoidance of chemical exposures were very important aspects of "treatment."

Regarding modifications to habitat to reduce chemical load, 86% said the changes were "very important." <u>All</u> reported improvement in health following habitat modifications. 23 respondents (79%) reported daily symptoms prior to habitat changes and only three (10%) continued to have daily symptoms afterwards.

The sample population surveyed had a strong preexisting bias and the results are not "statistically" useful. Nevertheless, the results do mirror the information reviewed in the literature about the clinical characteristics of the illness. CONCLUSIONS

# <u>CONCLUSIONS - SURVEY OF THE MEDICAL IMPACT ON ENVIRONMENTALLY</u> <u>HYPERSENSITIVE PEOPLE OF A CHANGE IN HABITAT</u>

As noted above, the results of this survey are not statistically useful. However, several observations are offered:

 Environmental hypersensitivity disorder is a real and serious health problem.

 Increasing environmental chemical pollution is a significant factor in triggering this disease.

 Ongoing professional debate is not helping those affected get reliable information and proper treatment.

 Avoidance of chemical exposures in the home and the workplace; getting clean food and water; and breathing clean air are the fundamentals of "treatment."

With respect to the original objectives of this survey, it is reasonable to conclude that:

 Habitat modifications to reduce chemical exposure in the home seems to improve the health of people with environmental hypersensitivities.

## DISCUSSION OF CONCLUSIONS

This survey was very small and the conclusions must be kept in perspective. The sample population was not random. The questionnaire was deliberately open-ended and therefore subject to interpretation by respondents. The questions were open to subjective response. Individual ability to recall detailed medical history information would influence results and selective recall was also a probable factor.

Nevertheless, the results provide some insight into the medical histories of individuals with environmental hypersensitivities. Future surveys could use this information to design more statistically useful questionnaires.

Finally, no control group was used. It is possible that other individuals with severe environmental hypersensitivities are able to recover without such rigorous habitat modifications.

The conclusions and discussions in this report do not constitute medical advice.

REVIEW OF ENVIRONMENTAL HYPERSENSITIVITY DISORDER

#### DEFINITION OF ENVIRONMENTAL HYPERSENSITIVITY DISORDER

Depending on the source, other common terms for environmental hypersensitivity disorder include multiple chemical sensitivity, environmental illness, chemical hypersusceptibility, ecologic illness, environmental allergy, total allergy syndrome, and 20th century disease. Currently there is no universally accepted definition of the disorder. However, several working definitions exist.

The document, <u>Report of the Ad Hoc Committee on Environmental</u> <u>Hypersensitivity Disorders</u> (Thomson, 1985), published by the Ontario Ministry of Health, uses this definition:

> Environmental hypersensitivity is a chronic (i.e., continuing for more than three months) multisystem disorder, usually involving symptoms of the central nervous system, and at least one other system. Affected persons are frequently intolerant to some foods and they react adversely to some chemicals and to environmental agents, singly or in combination, at levels generally tolerated by the majority. Affected persons have varying degrees of morbidity, from mild discomfort to total disability. Upon physical examination, the patient is normally free from abnormal objective findings. Although abnormalities of complement and lymphocytes have been recorded, no single laboratory test, including serum IgE, is consistently altered. Improvement is associated with avoidance of suspected agents and symptoms recur with re-exposure.

The document, <u>Chemical Sensitivity - A Report to the New Jersey</u> <u>State Department of Health</u> (Ashford and Miller, 1989) proposes the following operational definition:

> The patient with multiple chemical sensitivities can be discovered by removal from the suspected offending agents and by re-challenge, after an appropriate interval, under strictly controlled environmental conditions. Causality is inferred by the clearing of symptoms with removal from the offending environment and recurrence of symptoms with specific challenge.

The journal <u>Clinical Ecology</u> (Stigler <u>et al</u>., 1989) uses this definition:

Ecologic illness is a chronic multisystem disorder, usually polysymptomatic, caused by adverse reactions to environmental incitants, modified by individual susceptibility and specific adaptation. The incitants are present in air, water, food, drugs and our habitat.

# Cullen (1987a) offers a case definition:

Multiple chemical sensitivities (MCS) is an acquired disorder characterized by recurrent symptoms, referable to multiple organ systems, occurring in response to demonstrable exposure to many chemically unrelated compounds at doses far below those established in the general population to cause harmful effects. No single widely acceptable test of physiological function can be shown to correlate with symptoms.

## REVIEW OF LITERATURE

Extensive literature on environmental hypersensitivities exists, spanning many decades. This report will not review the literature directly, but will report on those publications that have. Several are current and three have already been referenced in the section on definition.

The most significant report published in Canada is the <u>Report of</u> <u>the Ad Hoc Committee on Environmental Hypersensitivity Disorders</u> (Thomson, 1985). The report was prepared for the Ministry of Health of Ontario. The committee was chaired by Provincial Court Judge George M. Thomson and had members from four Canadian universities, including faculty from three medical schools.

From November 1984 to August 1985, the committee members performed an extensive literature review and interviewed a variety of physicians, patients, and interested third parties. They visited offices of clinical ecologists and also visited environmental isolation units in the United States. They spoke to experts in Canada, the United States, and Great Britain. On page 238 of the report, they state: "Consideration of all these factors tempered but did not alter the Committee's opinion that the diagnosis of environmental hypersensitivity has validity." Further salient conclusions are:

> We wish to begin by stating that our study...raised our collective concern about the role of environmental factors as a cause of human illness...It seems clear that we are inexorably increasing the toxicity of our environment.

> In our opinion, there is good reason to believe that environmental hypersensitivity goes beyond what has already been verified, and to suggest that there are a number of persons who are being adversely affected in various ways by exposure to one or more agents in our environment.

In December 1989 <u>Chemical Sensitivity - A Report to the New</u> Jersey State Department of Health (Ashford and Miller, 1989) was published. The report was commissioned by the New Jersey Department of Health to clarify the nature of chemical sensitivity and to identify ways the state could assist chemically sensitive people. The scientific and medical literature was reviewed and key individuals in the various medical disciplines were interviewed. Their conclusions include:

> While a definitive and accurate picture is yet to come, at this time the pieces--viewed collectively--provide sufficient evidence to conclude that chemical sensitivity does exist as a serious health and environmental problem and that public and private sector action is warranted at both the state and federal

## Ashford and Miller (1989) continued...

levels. Just how large a problem exists is not known at this time...Our review of the existing evidence suggests that chemical sensitivity <u>is</u> increasing and could become a large problem with significant economic consequences related to the disablement of productive members of society.

Some of the evidence for chemical sensitivity is anecdotal (and for the most part not double-blind) and much of this anecdotal evidence has been reported by clinical ecologists - physician practitioners whose clinical practices have come under intense criticism. The authors, too, recognize the need for control populations, as well as double-blind challenges in the study of chemical sensitivity. We, however, are persuaded that the collective evidence, in part anecdotal and in part based on good scientific studies, does present a sufficiently compelling case to warrant future study.

Acceptance of chemical sensitivity as <u>bona fide</u> physical disease may also be facilitated by the recognition that it is widespread in nature and is not limited to what some observers would describe as malingering workers, hysterical housewives, and workers experiencing mass psychogenic illness. We are struck by the fact that individuals in such demographically divergent groups as industrial workers, office workers, housewives, and children, report similar polysymptomatic complaints triggered by chemical exposures.

OCCUPATIONAL MEDICINE: State of the Art Reviews - Workers With Multiple Chemical Sensitivities was published in 1987. Cullen (1987a), was concerned about increasing numbers of workers with multiple chemical sensitivities (MCS) who were visiting occupational medical clinics - "...we became aware of how widespread the problem is and how incredibly expensive the costs are for medical care and disability in each case..." and "...we felt that there might be some purpose at this time in summarizing the current state of knowledge and opinion about these unfortunate and challenging patients." He also states, "...we became aware of the considerable theoretical work in this area that had been generated by...clinical ecology."

No concrete conclusions were drawn. Nevertheless, Cullen (1987b) made two pertinent statements:

MCS patients suffer from a real and serious chronic disorder that cannot be dismissed trivially as a 'normal' variation or the 'low end' of a continuous distribution of host responses to irritant, odoriferous or intoxicating chemicals. Cullen (1987b) continued...

The health problems of workers who react to low levels of environmental pollutants and chemicals, increasingly reported and recognized in recent years, has posed a serious dilemma for health providers from a wide area of disciplines, including generalists, internists, family practitioners, allergists, psychiatrists, social workers, and frequently occupational physicians and nurses.

Mooser (1987) reviews epidemiology:

Despite the virtual absence of epidemiological data, it has become increasingly evident to many occupational medicine clinicians around the country that there exists a not insignificant minority of patients with MCS.

The sheer volume and consistency of reports of individuals with chemical sensitivities is impressive and should be viewed as initial data in formulating research initiatives.

#### HISTORY AND PROFESSIONAL CONTROVERSY

Currently, there is much controversy in the medical and scientific community concerning the existence of environmental hypersensitivity disorder. There is also debate about its treatment.

As a result of the controversy, very little information is available in standard medical texts and major medical journals. Most medical schools do not address the issue in their curricula. Traditional allergists, who hold most teaching positions in allergy departments of medical schools, are generally skeptical about the existence of environmental hypersensitivity disorder. Major journals avoid the topic. Consequently, few practicing physicians are aware of the controversy and most are unfamiliar with the disorder.

the first physicians to address the existence of One of environmental sensitivities was Theron Randolph. He received his M.D. from the University of Michigan in 1933 and completed a residency in internal medicine in 1936. He completed a fellowship in Allergy and Immunology at Massachusetts General Hospital and the Harvard Medical School from 1937-1939. During 1939-1942, he founded the Allergy Clinic at the Milwaukee Children's Hospital was on the staff of Marquette University Medical School and and Columbia Hospital. In 1942, he became Chief of the Allergy Clinic at the University of Michigan Medical School. In 1944, he moved to Chicago and began private practice. He continues to practice to this day and is considered to be one of the fathers of Clinical Ecology and Environmental Medicine.

When Randolph began documenting and writing about chemical sensitivities in the 1950's, his views were contrary to other allergists. Some other allergists followed Randolph's lead but ultimately their views became more and more removed from those of traditional allergists. In the late 1950's, Randolph chose the term "Clinical Ecology" to distinguish his approach from that of traditional allergists.

In 1965, the Society for Clinical Ecology was founded. Physicians from specialties other than allergy and immunology have since joined the society and are practicing clinical ecology in North America and Great Britain. In 1984 the Society changed its name to the American Academy of Environmental Medicine.

Randolph (1987) published <u>Environmental Medicine - Beginnings and</u> <u>Bibliographies of Clinical Ecology</u>. It is an extensive review of the history of clinical ecology as a medical discipline. Randolph has also published approximately 400 scientific articles.

Traditional allergists primarily limit their work to immune dysfunction, involving hypersensitivity mediated by antigen/antibody interactions and sensitized lymphocytes. Since the discovery of IgE in 1967, which helped explain these reactions, traditional allergists have not generally explored other possible mechanisms of hypersensitivity reactions. As a result, IgE-mediated immune dysfunction is now synonymous with "allergy," to the exclusion of other types of hypersensitivity. Since theories of clinical ecology encompass more than IgEmediated immunity, clinical ecologists continue to be alienated from traditional allergists. They continue to grow apart despite common roots and a common interest in environmental causes of disease.

Thomson (1985) makes several comments on the controversy:

As a committee, we have become increasingly dismayed at the polarized and adversarial positions being taken in the United States on the issue of environmental hypersensitivity.

We believe that confidence in the health care system is eroded when productive dialogue between different medical specialists disappears or is replaced by acrimonious debate before a confused public.

This committee feels strongly that taking an absolute stance in this field is not only risky scientifically, given that there is a great deal we do not know about the environment and its effects on us, but it is also unproductive and divisive, antithetical to the task of promoting collaborative efforts that will help in understanding and treating the problems of a growing number of patients.

Committee members believe...that ongoing debate about the etiology of the disorder has obscured the fact that there are a number of persons who are ill, whose condition has not been recognized and who are being poorly served...because of the existing controversy about the validity of environmental hypersensitivity as a diagnosis. Some patients seem to serve as classic examples of how people can 'fall between two stools' when professionals disagree about the nature of their problem.

...we are concerned that individual applicants...are being denied medical benefits because there is failure to see beyond the controversy...there seems to be a preference for the 'objective' opinion of a physician practicing conventional medicine that the patient is mentally disabled rather than for the 'objective' opinion of a clinical ecologist that the cause is environmental.

... people who are sick -- especially those who are severely ill -- need help, compassion and support as they struggle with their disabling conditions.

## Ashford and Miller (1989) also address the controversy:

We cannot overemphasize the important distinction between recognizing the existence of a disease and knowing its <u>cause</u>. Clinical ecologists are criticized for attributing their patients' illnesses to environmental factors when these patients clearly have other well-defined clinical diseases, such as depression. In some cases, these criticisms are justified. However, while ecologists are accused of over-zealously diagnosing environmental illness and overlooking other important medical conditions, some allergists have assumed that applying an accepted medical label to a patient's condition somehow rules out an environmental etiology. This is simply not the case. Indeed, both approaches are in error.

Some psychiatrists are of the opinion that individuals with multiple chemical sensitivities suffer from atypical depression, hypochondriasis, post-traumatic stress disorder, hysteria, panic disorder, conversion disorder, or combinations of these. The symptoms of low-level chemical exposure may include depression, difficulty concentrating, anxiety, peculiar bodily sensations, headaches, and other subjective symptoms. However, psychiatric disorders may be the <u>result</u> of the patient's illness, not the cause of it.

At present, the allergists do not identify with the clinical ecologists, even though the ecologists are concerned with 'altered reactivity.' The toxicologists and epidemiologists do not seek to establish communication with the ecologists, even though the ecologists share their concern about exposure to toxic substances. If the model employed by clinical ecologists offers any insight into a cause-and-effect relationship between environmental incitants and illness, its application will be seriously hampered given the present state of affairs.

Two distinct areas of controversy exist. There is debate about the existence of environmental hypersensitivity disorder and debate about the validity of therapies used by clinical ecologists. People with chemical sensitivities become enmeshed in these debates and have difficulty locating useful information and good treatment. It is imperative that these questions be addressed in an objective and cooperative manner. Initially, the existence of environmental hypersensitivity disorder must be accepted. The above-noted review studies present very convincing evidence to support the existence of environmental hypersensitivity disorder.

The efficacy of treatments used by clinical ecologists must be accepted. Extensive and conclusive research has been done by clinical ecologists, but is currently undervalued by the medical community. Detailed review of this primary research will help guide future efforts. Thomson (1985) and Ashford & Miller (1989) agree that establishing an environmental health unit for treatment and research purposes is important. Several prominent clinical ecologists, including Theron Randolph and William Rea, have already done extensive research and treatment in such units and can be valuable resources.

Meanwhile, patients need to be recognized and cared for. As stated by Ashford and Miller (1989), "Avenues for chemically sensitive patients must be established for obtaining information; appropriate medical referrals and ... access to an environmental unit; and medical insurance and disability compensation." Thomson (1985) states: "...there is a definite need for patient support services for people diagnosed as environmentally hypersensitive..." As other members of the medical profession become aware of this problem, clinical ecologists still have the most experience treating these patients. Access to clinical ecologists should not be denied.

Critics argue that theories and treatments associated with clinical ecology have not been adequately studied in controlled double-blind settings. Thomson (1985) comments:

... in many cases in the past, the decision to support a medical procedure was made in the absence of demonstrated effectiveness. Moreover, we are certain that similar decisions will be made in the future.

...there are often difficulties in designing, funding and completing good research and...certain theories may not apparently lend themselves to accurate evaluation. In addition, there is the inconsistency of adhering staunchly to strict criteria when considering new tests or treatments when, in the past, these have not been applied to treatments that have long obtained financial support. The problem is even further compounded by the fact that the Committee is dealing with investigations and therapies used by qualified doctors; the medical profession has for a long time, strongly -- and properly -- defended its right to seek and apply new clinical approaches.

We recognize that...research will take some time to complete and that there are many people who argue that support should be given to these procedures until the results of that research are known. The most persuasive reason in favor of that argument is the plight of those seriously ill patients who find these tests, and the treatment that flows from them, helpful. In addition to the primary research already done, the <u>clinical</u> experience of clinical ecologists is extensive. Randolph (1987) summarizes:

... the original observations... which lead to the present concepts and techniques of clinical ecology were all made inductively, ... based on thousands of detailed clinical observations of chronically ill patients in the course of their responses to given environmental exposures. This...led to hypotheses which were then confirmed and extended as they were applied more widely in the practice of medicine. Workable concepts and techniques from this accumulated evidence of causal interrelationships led to the development of the diagnostico-therapeutic technique of comprehensive environmental control in a hospital unit. Many of the major clinical interpretations in this book are based on the application of this methodology in thousands of cases. This technique of isolating a patient from inadvertent exogenous exposures as a baseline for observing the clinical effects associated with single re-exposures to previously avoided materials turned out to be the ultimate diagnostico-therapeutic technique in this new approach to this old field. In my clinical experience, this regimen has served as the standard of reference with which the results of less rigidly controlled diagnostic and therapeutic techniques must be compared.

Despite the extensive literature published and the clinical experience of physicians who practice clinical ecology, the medical community continues its criticism. Several "Position Papers" have been published in recent years. Three are commonly quoted:

The California Medical Association Scientific Board Task Force on Clinical Ecology (1986) published a medical practice opinion (which has since been withdrawn [Appendix A]). They state:

> No convincing evidence was found that patients treated by clinical ecologists have unique, recognizable syndromes, that the diagnostic tests employed are efficacious and reliable or that the treatments used are effective.

The American College of Physicians also published a position paper (Terr, 1989) and state:

Review of the clinical ecology literature provides inadequate support for the beliefs and practices of clinical ecology. The existence of an environmental illness as presented in clinical ecology theory must be questioned because of the lack of a clinical definition. Diagnoses and treatments involve procedures of no proven efficacy. One of the most critical groups is the American Academy of Allergy and Immunology. In their position statement (1986), they summarize:

1

An objective evaluation of the diagnostic and therapeutic principles used to support the concept of clinical ecology indicates that it is unproven and experimental methodology. It is time-consuming and places severe restrictions on the individual's lifestyle. Individuals who are being treated in this manner should be fully informed of its experimental nature.

Advocates of this dogma should provide adequate clinical and immunologic studies supporting their concepts, which meet the usually accepted standards for scientific investigation.

Doris Rapp, a board-certified allergist who practiced traditional allergy for 18 years before switching to clinical ecology in 1975, is a strong advocate for the practice of clinical ecology. Rapp (1985) comments on the position statement by the American Academy of Allergy and Immunology:

> The comments in your paper, however, fall far short of what I would have expected from the aspect of clarity, fairness and fact. The newer applications and variations of the basic tenets of allergy require more time to confirm, but much evidence of efficacy is already in print.

> The published positive data of the ecologists is strongly suggestive that these newer approaches are most helpful. The published negative review articles about our studies, unfortunately, consistently fail to review most of the positive articles which were in print at the time of the review publications. When one looks critically at the so-called negative articles which disprove ecologic methods, any academic scientist would have to admit the latter articles leave a lot to be desired, from many aspects, research methodology not withstanding.

> At this point in time, based on the existent research, it is ludicrous that you state that what ecologists do is not allergy. I am doing the same things, for example, that I did for the first 18 years, but much better. I use the same extracts to test and treat. What I do, however, requires much more time, and the overhead is discouragingly increased. But, the rewards are that patients, not helped by others, or previously not helped by myself, often get well quickly.

> At this point it is almost ridiculous that traditional allergists continue to say that our work is unproven.

Of all the review studies quoted here, Ashford and Miller (1989) is the most current. They examine <u>all</u> the studies and position papers noted above, as well as much other material. In this thorough review they conclude: "chemical sensitivity does exist as a serious health threat and environmental problem." They also say:

We are at a critical crossroads. There is at this time a small window of opportunity which may be closed if we do not take action to address the problems of the chemically sensitive individual in a caring and sensitive way.

## PATIENT PROFILE & COURSE OF THE ILLNESS

Several definitions have been quoted , but they do not fully describe environmental hypersensitivity disorder. The Human Ecology Foundation of Canada (1988) describes the disorder:

> The symptoms of environmental hypersensitivity vary considerably from one person to another, but may include malfunctioning of the immune system, allergy (IgE mediated), food sensitivity, celiac disease, colitis, tension-fatigue syndrome, disorders of the nervous system, depression, hyperactivity and nervousness. Symptoms may be acute or chronic, and vary in severity from a minor inconvenience to chronic disability.

> An environmentally hypersensitive person's body reacts intensely to infinitesimal exposure to pollutants, toxic chemicals and seemingly harmless substances.

> Individuals are all sensitive to their surroundings. An environmentally sensitive person is excessively reactive to external and internal factors, and reacts much more intensely than others to the substances that s/he is sensitive to, and often other factors such as chilling, fatigue and infections.

> A person may develop a sensitivity at any time in his or her life. Sometimes the illness develops following a viral infection. There appears to be a genetic factor connected with environmental hypersensitivity. However, repeated and prolonged exposure to almost any toxic substance will result in hypersensitivity to that substance regardless of genetic inheritance.

> Environmental overload can occur anywhere in the body. A reaction may involve any organ or tissue, from the head to the soles of our feet, inside the body or on its surface. Everyone is familiar with these manifestations: hives, hay fever, asthma, eczema, and stopped-up noses. Headaches, Dizziness, ringing of the ears, irritated eyes, diarrhea, or vomiting may also be due to environmental overload.

Sensitivity to the same food may produce an intestinal upset in one individual, hives in another, and asthma in a third. Particles breathed in may cause hay fever in one and skin sensitivity in another. Why this should vary from one person to another has not yet been determined, but heredity seems to play a role. Different people have different 'target organs,' as they have been termed. Bascom (1989), in a report to the State of Maryland Department of the Environment, describes chemical hypersensitivity syndrome:

It is an acquired disorder, whereby individuals develop a strong aversion to a wide variety of chemicals, many of which are mixtures of volatile organic compounds (VOC's). Examples of exposures which trigger symptoms include gasoline fumes, cigarette smoke, perfumes, household cleaners and paints...The symptoms which patients report as being triggered by the exposures can involve many organ systems, and include fatigue, headache, mucous membrane irritation, rhinitis, wheezing, intestinal disturbances, muscle and joint pains, feelings of irritability or depression, and difficulty with concentration.

William J. Rea is a leading figure in clinical ecology and environmental medicine. He is the Medical Director of the Environmental Health Center in Dallas, Texas and has recently been appointed First World Professional Chair in Environmental Medicine, Robens Institute, University of Surrey, England. Rea has researched, published and lectured internationally on topics related to environmental illness. Rea (1988) describes chemical sensitivity:

> One prominent aspect of environmentally triggered disease is chemical sensitivity. This is defined as an adverse reaction to low levels of toxic chemicals which are generally believed to be subtoxic (i.e., not harmful) in air, food, and water. How these adverse reactions are manifested will depend on: (1) which tissues or organs of the body are involved, (2) the toxicity and pharmacological nature of the substance(s) involved, (3) the exposed individual's susceptibility...and (4) the length of time, and amount and variety of other body stresses (total body pollutant burden). There can also be complications from reactions to combinations of exposures (synergism).

Rea (1988) describes three ways in which chemical sersitivity can be triggered. Massive, acute exposure can occur as in cases of serious industrial accidents. Low-level exposure in workplace or home over a long period of time can result in accumulation of toxins. Infection (viral or bacterial) or massive injury may also be a trigger.

Rea (1988) explains that symptoms usually manifest in major organ systems, especially those with smooth muscle (respiratory, gastrointestinal, neuro-cardiovascular, genito-urinary) and the skin. There are usually a variety of symptoms in each individual. Early symptoms and signs may include unexplained weakness, cold intolerance, swelling of eyes, hands, feet, easy bruising, clumsiness, memory loss, irritability, extreme fatigue, and intolerance to medication and alcohol. Joint aches and muscle pains, irregular heart beat, bloating and gas, recurrent infections, and food intolerances are other possible symptoms.

This condition may progress to serious illness and disability. Many have to quit work, school and hobbies. Activities of daily living are difficult. Marriages, family relationships and friendships are often stressed. Financial difficulties occur due to lost income and medical expenses. Most see many doctors. If they do find a doctor who recognizes the illness, it still may take years to recover. Many treatments offered are not covered by medical insurance plans. Many changes in home environment, work environment, diet and other activities are also necessary.

Rea (1988) describes four working principles necessary to understand the process behind the illness.

• TOTAL BODY LOAD is the total number of incitants (i.e., environmental factors which contribute to disease) that are present at any one time. Total load can include physical, chemical, and biological contaminants in air, food, and water and can be influenced by emotional, psychological, and spiritual wellbeing. Since this total load can fluctuate daily, symptoms can fluctuate.

• MASKING or ADAPTATION is the phenomenon whereby a person develops tolerance to the <u>acute</u> effects of an incitant and fails to recognize that it causes illness. Only on re-exposure after some time (3-5 days) away from the incitant does it become obvious. Persons often suffer <u>withdrawal</u> symptoms initially when away from an incitant. It can be difficult to distinguish between withdrawal symptoms and acute exposure, especially since most individuals have multiple sensitivities with exposures at different times and at different concentrations.

BIPOLARITY relates to two phases of the body's immune and detoxifying systems. The first phase is <u>stimulatory</u> and body defenses respond to combat incitants. This phase may last for minutes, hours, days, or even years, depending on the toxicity, length and volume of exposure. Once these response systems become depleted, a <u>depressed</u> phase follows with the development of early symptoms, and later, identifiable diseases. This phase may progress to organ dysfunction and failure.

BIOCHEMICAL INDIVIDUALITY refers to individual uniqueness which accounts for individual susceptibility. Some of us easily clear noxious substances while others do not. This depends on genetic makeup (quantities of specific detoxifying enzymes, etc.), nutritional state, and individual differences in total body load. Rea (1988) says "...there are over 2,000 genetic metabolic defects already described in the research literature that appear to be 'time bombs,' awaiting environmental triggers to elicit their expression. The odds are high that any given individual may have one or more of these genetic defects."

# ETIOLOGY

Environmental hypersensitivity is a disorder in which individuals become symptomatic when exposed to environmental incitants. While chemical exposures "cause" symptoms, this does not necessarily explain "cause" of the illness. We know the symptoms and clinical presentation, but we really do not know the underlying cause(s).

However, recognizing the existence of an illness (and treating it) without knowing underlying cause(s), or without having a universally accepted definition, is often necessary in medical practice. It is a frequent occurrence.

For example, in the early days of the AIDS epidemic we knew the clinical presentation but we did not know the "cause." A clear definition was elusive. Persons with AIDS were ill and dying from rare infections and cancers. They were particularly susceptible to certain fungal, bacterial and parasite infections. These organisms were known to be widespread in nature - but generally did not "cause" serious illness in humans. AIDS - Acquired Immunodeficiency Syndrome - was a <u>clinical</u> diagnosis and the underlying etiology was not known. Treatment was based on a <u>clinical</u> understanding of the illness. Eventually, scientists discovered a <u>single</u> "cause" for AIDS - the Human Immunodeficiency Virus - which damages a part of the immune system that defends against viruses, fungi, parasites, and certain bacteria.

Individuals with environmental hypersensitivity are sensitive to incitants that are widespread in the environment which do not appear to precipitate illness in the majority. While we do not know the precise cause(s) of environmental hypersensitivity, we do have consistent and reliable case reports in large numbers which confirm its existence.

Unlike AIDS, however, environmental hypersensitivity disorder does not have epidemiology consistent with an infectious agent. Also, since traditional medical investigations are generally negative, formal recognition of its existence is slow to develop. The cause(s) will likely be found in genetic and/or environmental factors. More research is necessary and we should give the same consideration to environmental hypersensitivity research as we do to other diseases.

Nevertheless, we do have a <u>clinical</u> understanding of the illness and we do have <u>clinical</u> approaches to treatment. Chemical exposures "cause" symptoms in affected individuals. Avoidance of chemicals leads to improvement. There are medical doctors experienced in its treatment. Access to treatment should not be denied because we do not know the "cause(s)." Medical insurance plans should pay for treatment despite the lack of a universally accepted "definition." Those affected already cost the system much money by seeing many doctors and having many expensive investigations over many years. It would cost much less to diagnose and treat this illness properly from the beginning. However, chemical pollution of the environment may well be a significant causative factor. Today, a wide variety of chemicals are found in our environment. Most of our food is contaminated with food additives, chemical fertilizers, pesticides, and other chemicals used to process foods and to maintain freshness.

Drinking water contains most of the pollutants found in the air and soil. Rain water and bottled water may also be contaminated. Outdoor air pollution is a well recognized problem, especially in urban areas.

Indoor air pollution is getting more attention in recent years and may be a major factor in the total load of chemicals encountered in daily life.

The World Health Organization (1986) states:

The study of the non-occupational indoor environment has attracted increased interest in the last dozen years. This interest was in part stimulated by an increased awareness of specific sources of indoor air pollutants.

Small (1983) states:

....

This author's experience with individuals sensitized to indoor chemical exposures indicates that there is an identifiable Canadian population of chemically susceptible persons, numbering in the thousands and growing quickly as awareness of the problem has increased.

Seba <u>et al</u>. (1987) discuss the problem of chemicals in our daily lives:

On a daily basis the human population comes into contact with thousands of chemicals that are the products of human endeavour. This influx of xenobiotic ('foreign to life') chemicals and their biological and abiological breakdown products into modern society has long concerned both health professionals and citizens. In most instances there is a lack of scientific information which might allow the effect of acute exposures on health to be accurately assessed. The effects of chronic exposures are even less well understood. Almost no information exists on the consequences of exposure to mixtures of environmental toxins.

The connection between the availability of low-dose chemical contaminants in our society, body load of chemical and health effects should not be ignored. The peoples of the modern world can be regarded as being engaged in a mass epidemiological experiment, which would never be approved by any governmental agency or human subjects committee. It may be many years before

## Seba et al. (1987), continued...

the implications of the combined and sustained intake of low-level toxic chemicals are known. Certainly, vast numbers of these chemicals are available and too little is understood about the interactions involved.

Ziem (1988) discusses the role of petroleum-based chemicals in the development of multiple chemical sensitivity (MCS):

In my own clinical experience with patients having multiple chemical sensitivity, most of the original chemical overexposures were to petroleum-based chemicals. Some of these were pesticides, some were not. A number were to chlorinated petroleum-based compounds, including chlordane, heptaclor, and chlorinated solvents. I do not believe that all chemicals can cause multiple chemical sensitivity, but we do not yet know enough to be able to identify which can and which cannot. My discussions with other physicians seeing MCS, as well as my reading of case reports in which the specific chemical exposures preceded the development of MCS, confirms my impression that petroleum-based chemicals are a major and probably the major class, of culprit chemicals in inducing MCS.

Regarding triggering episodes once multiple chemical sensitivity has developed, many (but probably not all) of the triggering agents are also petroleum derivatives: filling station vapors, traffic exhaust, petroleum-based pesticides, various petroleum-based solvents in paints, various household and personal products containing petroleum derivatives, and other substances. Some patients have problems with foods (and water) which contain petroleum-based pesticide residues: these patients find that the foods the rest of us eat trigger illness but that non-pesticide ('organic') food and distilled water do not trigger illness. Our ground and drinking water is known to be substantially (and increasingly so with time) contaminated with petroleumbased products.

# PREVENTION AND TREATMENT

Rea (1988) outlines the basic treatment - avoidance of as many pollutants as possible and strict control of the indoor environment to reduce chemical exposures. Food must be as little chemically contaminated as possible, with as large a variety as possible (depending on food sensitivities). Drinking, cooking and bathing water should be as pure as possible. Supplemental vitamin and minerals can be helpful, if tolerated.

In essence, clean air (indoor and outdoor), clean water, and clean food are the fundamentals of management. Next, avoidance of other chemical exposures is important. Finally, a variety of other treatment modalities can be employed.

The American Academy of Environmental Medicine (A.A.E.M.) outlines treatment modalities in their position statement (1988):

The American Academy of Environmental Medicine is principally concerned with adverse reactions experienced during the dynamic interrelationship between the individual and the environment. The resulting disorder, as determined by the individual's susceptibility is termed Environmentally Induced Illness.

The comprehensive ecologically oriented medical history and objective physical examination form the basis for a provisional diagnosis. This approach is both cognitive and procedural. Sensitivity to excitants incriminated by the history of exposure and resultant symptoms is tested for by several methods.

A.A.E.M. ENDORSED DIAGNOSTIC TECHNIQUES INCLUDE:

Serial dilution endpoint titration for defining sensitivity to inhalants as dust, mites, molds, spores, pollens and danders;

Clinical titration with antigenic extracts administered intradermally, subcutaneously or sublingually used for defining the role of inhalants, foods and chemicals;

Individual deliberate feeding tests, elimination diets, and rotary diversified diets to determine food intolerance, sensitivity or allergy;

Comprehensive environmental manipulation by avoidance and challenge performed in the home, work place, physicians office, modified hospital room or environmental care unit;

Quantitative laboratory measurements such as specific and total IgE and other immunoglobulins;

Body measurements of specific chemicals and toxins.

A.A.E.M. - position statement, continued (1988)...

A.A.E.M. ENDORSED THERAPEUTIC TECHNIQUES INCLUDE:

Avoidance of substances determined to cause adverse reactions;

Immunotherapy based on serial dilution endpoint titration, In-Vitro tests or clinical titration administered by injection or orally;

Dietary manipulation including rotary diversified diet for therapy and prevention;

Reduction of environmental exposures by proper selection of building materials, furnishings and cleaning substances;

A specific goal is less contaminated air, food and water;

Assurance of optimal nutrition.

THE FINAL GOAL of these therapeutic techniques is the cost-effective return of optimal health and psychological well-being to vigorous activities of daily living, with improved tolerance to incitants previously causing adverse reactions.

A pamphlet prepared by A.A.E.M. explains some of these diagnostic and therapeutic techniques that are used along with the avoidance strategies. "Intracutaneous serial end point titration" in conjunction with "optimal dose therapy" is used to evaluate and treat the organic particulate inhalant allergies associated with IgE mediated allergy.

"Provocation neutralization" is used to determine other (non-IgE mediated) environmental excitants - usually common foods and environmental chemicals. Sublingual, subcutaneous, intracutaneous, and nasal inhalation techniques are used to provoke symptoms. Weaker dilutions of the same extract are then used to find a dose that will neutralize the symptoms. This "neutralizing dose" is then used therapeutically.

The "individual deliberate feeding test" is used to confirm suspected reactions to common foods. The "rotary diversified diet" - eating the same food no more than one day out of every four - is both a diagnostic and therapeutic tool. It is a series of individual deliberate feeding tests that allows the patient to determine which foods must be totally avoided and which foods can be tolerated on a rotational schedule.

While A.A.E.M. sanctions the diagnostic and therapeutic modalities discussed above - and while ample research exists supporting their efficacy - many patients do not have access because of the ongoing controversy and political debates. As a result, individuals often seek help outside the medical community and are subjected to a wide variety of "alternative" therapies which have not been carefully evaluated. This medical survey will document the wide variety of "alternative" practitioners seen by these patients.

Despite the chronicity of this illness, many patients do recover and resume a productive life once they understand their illness and follow the necessary advice concerning avoidance, diet, and so on. However, it often takes time and money. If the medical community was more aware of this problem and was able to intervene in the early stages, much illness and disability would be avoided.

Ziem (1988) observes:

I find that all of my patients have improved with a program of chemical avoidance...

Reduction of the use of household chemicals, pesticide exposure reduction, and workplace exposure reductions are often very helpful when geared to the specific triggering agents. Gradually, the severity, frequency, and duration of the triggered episodes typically decreases, as though the immune and neuroendocrine/neurohormonal systems had time to 'quiet down' from a more toxic state.

# RECENT CANADIAN DEVELOPMENTS

Following the <u>Report of the Ad Hoc Committee on Environmental</u> <u>Hypersensitivity Disorders</u>, Zimmerman (1986) chaired an advisory panel which recommended funding for research. Since then, the Ontario Ministry of Health has encouraged research (Appendix B) and has created an advisory committee of physicians and scientists to review research proposals. At present, the University of Toronto is doing a study on food sensitivity. Other proposals are under review by the committee.

Despite poor response to the problem in the past, there is increasing awareness and concern in recent years. In 1986 the Nova Scotia Health Department prepared a report on the topic (Langley <u>et al</u>, 1986). In 1988 the Department of National Health and Welfare released a working paper entitled Healthy Environments for Canadians. Health and Welfare Canada is also sponsoring a workshop on the environment and health on May 24, 1990, in Ottawa.

While most medical insurance plans in Canada are still reluctant to recognize the problem, the provinces of Ontario, Alberta, Nova Scotia and Saskatchewan <u>have</u> funded patient evaluations at the Environmental Health Center in Dallas, Texas (Appendix C). The Worker's Compensation Board of Prince Edward Island has also funded at least one patient assessment in Dallas.

Dr. Gerald Ross, a Nova Scotia family physician, completed a two year fellowship at the Environmental Health Center in Dallas, Texas and at the Breakspear Hospital for Allergy and Environmental Medicine in England. His training program was financially supported by the Nova Scotia Department of Health and Fitness.

Since December 1988, certain items required by environmentally hypersensitive individuals are eligible for tax assistance in Canada - in particular, water filtration devices and noncarbonated bottled water, certain air purification systems, and certain electric furnaces. Claims must be accompanied by a letter from a licensed physician, certifying that the individual has environmental hypersensitivity disorder.

Some individuals with environmental hypersensitivities may also be eligible for financial assistance in order to make home modifications. Canada Mortgage and Housing Corporation has the Residential Rehabilitation Assistance Program and the Ontario Ministry of Housing has a program called the Ontario Home Renewal Program, Disabled Components. Details of these programs can be obtained from the respective organizations.

Despite this increased awareness, there are still large parts of the medical community, the scientific community, and the lay public who are completely unaware of this topic. Much more effort is needed to recognize and assist those individuals who have environmental hypersensitivity disorder. THE MEDICAL SURVEY

•

#### OBJECTIVES OF THIS MEDICAL SURVEY

• To document medical histories of not less than 25 people selected from the CMHC survey entitled <u>Clean Air Housing in</u> <u>Canada</u> (Drerup <u>et al.</u>, 1990).

 To document the medical impact on those surveyed of a change in habitat.

 To provide analysis of the findings and draw tentative conclusions.

To review and summarize the current medical literature on environmental hypersensitivity.

#### METHODS

Summaries of 92 respondents to the first survey were reviewed and candidates for the medical survey were selected. Selection was limited to those people who had completed modifications and had lived in the modified habitat for a period of time. Some of the respondents were in the process of modifying their homes and were not selected. Some were not willing to be surveyed.

A total of 34 medical questionnaires (Appendix D) were mailed out in March 1990. 29 were returned before the project deadline of April 30, 1990. The last two questionnaires to be included in the survey were received on April 27, 1990. Most of the respondents were telephoned in advance to secure their consent. 19 were contacted for telephone interview after the questionnaires were returned. The remaining ten were not able to be reached by phone before April 30, 1990. Nevertheless, there was ample information in the questionnaires for the purposes of this survey. Follow up telephone interviews were to clarify a few specific points and to gather additional anecdotal information. They were not a crucial feature.

Questionnaires were designed to document common characteristics of environmental hypersensitivity disorders and also to determine the "therapeutic effect" of a change in habitat. Design of the questionnaires was based on a number of medical history forms used by clinical ecologists, including one used by the Environmental Health Center in Dallas, Texas.

Clearly, there is strong bias in this sample population and it is <u>not</u> a statistically useful survey. Nevertheless, some observations will be made and tentative conclusions formed.

## SUMMARY OF HABITAT MODIFICATIONS

The original survey (Drerup <u>et al.</u>, 1990) documented the most common features associated with building and/or renovating for reduction of chemical exposures in the home. They include:

Low temperature electric heating system preferred.

 Ceramic tiles set in additive-free concrete or hardwood flooring. Adhesive agents avoided.

 Plaster walls and ceilings with no additives. If painted, non-toxic paints are used.

 Good outdoor ambient air quality away from heavy traffic and industry.

 Air filtration and purification systems: built-in or portable.

 Ventilation systems to bring in fresh air and exhaust stale air.

 Air-vapour barrier to prevent infiltration of outdoor pollutants and chemicals from materials in the building envelope.

Central vacuum system with exhaust to outside.

Furniture and household products that are low in chemical contaminants.

The specific measures undertaken by each individual are dependent on severity of illness, financial resources, availability of information, access to experienced contractors, degree of family support, and so on.

Of the 29 respondents to this survey, seven moved and built new homes that were chemical-free. Ten moved to different homes and renovated. 12 stayed in their existing homes and renovated. One renovated a rented house, one renovated a rented apartment. One respondent renovated her condominium. The remainder owned houses.

There was a lot of variability and respondents used different combinations of the features noted above.

# PROFILE OF RESPONDENTS

# CURRENT AGE

#### AGE NUMBER

1-10	years2	(1	female,	1	male)
11-20	years0	*			
21-30	years0				
31-40	years8	(5	female,	3	male)
41-50	years7	(6	female,	1	male)
51-60	years9	(9	female)		
61-70	years3	(3	female)		
		8			

TOTAL FEMALE: 24 TOTAL MALE: 5

# AGE AT ONSET OF ILLNESS

# AGE NUMBER

1-10	years4	(3	female,	1	male)
11-20	years3	(3	female)		
21-30	years7	(5	female,	2	male)
31-40	years10	(8)	female,	2	male)
41-50	years2	(2	female)		
51-60	years3	(3	female)		

# LENGTH OF ILLNESS

# YEARS ILL NUMBER

1-05	years2
6-10	years10
11-15	years5
16-20	years4
21-25	years5
26-30	years1
>30	years2

# PROVINCE OF RESIDENCE

British Columbia3
Alberta3
Saskatchewan1
Manitoba3
Ontario17
Quebec0
New Brunswick2
Nova Scotia0
Prince Edward Island0
Newfoundland0
N.W.T0
Yukon0

# DISCUSSION OF PROFILE

 83% (24/29) of respondents are female and this is consistent with observations in the literature that women seem to be in the majority.

93% (27/29) are over the age of thirty years. The two under 30 years of age in this survey are actually children. Again, this is consistent with the literature in that most people diagnosed with this illness are in their late 20's or older.

• 59% (17/29) report the onset of illness between age 21 years and age 40 years. 24% (7/29) report onset of illness before age 20 years and 17% (5/29) after age 40 years. A total of 76% (22/29) report onset of illness after age 20 years. This is consistent with the literature reviewed in that most report onset of illness in adult life.

• Chronicity of the illness is supported. 93% (27/29) report illness lasting six years or more. 58% (17/29) report illness lasting 11 years or more. However, chronicity may be due to the time interval between onset of illness and diagnosis. Early diagnosis and treatment (as in other illnesses) may prevent chronicity. Many illnesses, if undetected and untreated, become chronic.

These trends have to be taken in context. Awareness of this disorder in the medical community and in the lay community is low. Regional differences in recognition are high. Most (59%) of the respondents to this survey are from the province of Ontario. This probably reflects a greater degree of awareness in Ontario, rather than any epidemiologic trend. The Allergy and Environmental Health Association is much more active in Ontario than anywhere else in Canada.

#### OCCUPATION AT ONSET OF ILLNESS

Homemakers6
Childhood (2 still children)4
High school/college student4
Librarian2
Secretary2
Teacher2
Registered nurse1
Book store owner1
Anglican priest1
Loan officer in bank1
Professional vocalist1
Social worker1
Staff relations officer1
Farmer1
Public health nurse1

#### CURRENT OCCUPATION

Homemaker7
Disabled/unable to work8
Student (children)2
Graduate student1
Self-employed (sales)1
Draftsman1
Translator1
Teacher1
Retired1
Health counsellor/music teacher/journalist1
Quilt designer/work in health food store1
Writer1
Book keeper1
Counsellor1
Public health nurse1

## DISCUSSION OF OCCUPATION

Of the 29 respondents, eight (28%) currently report being totally disabled as a result of their illness. Only three of the eight report any disability pension or long term disability income.

The others changed jobs to gain more control and flexibility, and reduce chemical exposures. The number and types of jobs available for those with environmental hypersensitivities is limited. The loss of actual (and potential) earnings and employment benefits is probably high. This may be common in persons with environmental hypersensitivity disorder. Estimating the extent of financial loss due to change in employment status is not possible with the information in this survey - but one might infer that it is substantial in some cases.

#### SUMMARY OF QUESTIONNAIRE RESPONSES

Several questions are open-ended and subject to interpretation by the respondent, and other questions permit highly subjective responses. It is not possible to provide an accurate summary of responses for each question. Therefore, in these cases, responses are summarized under general headings and/or the respondents answers are quoted verbatim. While this approach does not provide statistically useful data, it is useful for discussion purposes.

# CHIEF COMPLAINTS

The questionnaire asked for the "single worst" complaint and four other complaints in order of severity. On review of the answers it became clear that this format, which tends to serve well for other illnesses, is <u>not</u> suitable for this multi-symptom disorder. Individuals with multiple complaints were not able to provide a "single worst" complaint. Chief complaint(s) as reported by respondents:

## COMPLAINT

## FREQUENCY

Extreme fatigue/weakness21/29	(72%)
Confusion/difficulty concentrating12/29	(41%)
Abdominal discomfort/G.I.upset12/29	(41%)
Depression/anxiety/mood swings11/29	(37%)
Joint and muscle pain10/29	(34%)
Asthma/bronchitis9/29	(31%)
Headaches8/29	(27%)
Blackouts/seizure-like attacks6/29	(20%)
Sinusitis5/29	(17%)
Loss of muscle control/coordination4/29	(13%)
Heart palpitations4/29	(13%)
Dizziness4/29	(13%)
Skin rash/itchiness4/29	(13%)
Swelling/edema3/29	(10%)
Urinary tract infections3/29	(10%)
Chest pains2/29	(6%)
Visual problems2/29	(6%)
Frequent infections1/29	(3%)
Infertility1/29	(3%)
Parasites1/29	(3%)
Hepatitis1/29	(3%)
Low blood pressure1/29	(3%)
Candidiasis1/29	(3%)

Despite a wide variety of presenting complaints, extreme fatigue was reported as a significant problem for 21 of the respondents (72%). Extreme fatigue/weakness may be a common feature of this illness.

#### REVIEW OF SYSTEMS

1

The following is a list of all the positive responses in the review of systems, maximum 29 per symptom:

SKIN: 9 eczema, 5 acne, 9 hives, 5 herpes, 16 fungal infection, 18 itches, 16 dry, 3 oily, <u>5</u> lumps, <u>5</u> bruising, <u>10</u> swelling, <u>1</u> peeling, 2 boils.

IS YOUR SKIN SENSITIVE TO 12 sun, 26 fabrics, 26 detergents.

- HEADACHE: 12 constant, 13 episodic, 10 steady, 12 throbbing, 12 sharp, 13 dull, 12 slow onset, 12 sudden, 22 forehead, 16 back of head, 12 right side, 11 left side, 13 face, 7 lasts minutes, 4 lasts seconds, 19 lasts hours, 4 lasts days, 10 clears without treatment, 14 clears with treatment, <u>18</u> visual symptoms, <u>16</u> nausea, <u>11</u> vomiting, 19 neck pain, 17 runny nose, 15 tearing of eye.
- EYES: 20 itchy, 9 dry, 23 dark circles, 11 blood-shot, 20 burning, 16 watery, 14 pain, 6 swelling, 23\_light sensitive, 22\_blurred vision, \_9\_mucous in eyes.
- EARS: 11 hearing loss, 16 itchy inside, 14 pressure, <u>9</u> drainage, <u>16</u> pain, <u>20</u> ringing, 20 sense of imbalance, 19 dizziness, 9 infections.
- NOSE: 15 itches, 20 sneezes, 11 loss of smell, 11 burns, 23 post nasal drip, 19 blocks, 11 bleeds, 3 blisters, 10 crusts, 19 sinus infections, 18 yellow mucous.

ARE NOSE SYMPTOMS PRESENT ALL YEAR ROUND? 15 YES, 7 NO WORST SEASON: <u>9</u> spring, <u>3</u> summer, <u>6</u> fall, <u>3</u> winter.

- MOUTH & THROAT: 17 cracked lips, 16 sore tongue, 19 swollen glands, <u>16 hoarseness</u>, <u>11 cold-sores</u>, <u>21 teeth</u> pain, 23 bad taste, 17 bad breath, 20 sore throats, 19 difficulty swallowing.
- HEART: 19 rapid heart, 13 skipped beats, 6 murmurs, 15 chest pains, 15 shortness of breath.
- LUNGS: 15 wheezing, 20 cough, 16 bronchitis, 13 pneumonia, 5 pleurisy, 18 shortness of breath.

STOMACH/BOWEL: <u>16</u> heartburn, <u>26</u> bloating, <u>5</u> poor appetite, <u>16</u> cramping, <u>18</u> constipation, <u>5</u> ulcer, <u>19</u> nausea, <u>23</u> indigestion, <u>15</u> vomiting, <u>17</u> diarrhea, <u>5</u> hemorrhoids, <u>11</u> gallbladder trouble, <u>10</u> parasites, <u>21</u> gas, <u>8</u> blood in stools, <u>18</u> mucous in stools, <u>15</u> anal pain, <u>20</u> stomach aches.

KIDNEY/BLADDER: <u>7</u> difficult urination, <u>5</u> burning urination, <u>1</u> genital herpes, <u>2</u> kidney disease, <u>0</u> kidney stones, <u>7</u> incontinence, <u>1</u> pass blood, <u>1</u> impotence (men only), <u>2</u> prostate trouble (men only).

MUSCULOSKELETAL: <u>27</u> muscle pain,<u>26</u> joint pain,<u>12</u> joint swelling, <u>21</u> morning stiffness, <u>22</u> back pain, <u>21</u> neck pain.

ENDOCRINE: <u>4</u> enlarged thyroid, <u>3</u> overactive thyroid, <u>9</u> underactive thyroid, <u>1</u> diabetes, <u>12</u> excessive weight gain, <u>15</u> excessive weight loss, <u>8</u> abnormal thirst, <u>16</u> increased appetite.

NEUROLOGICAL: <u>19</u> limb weakness, <u>18</u> numbness, <u>12</u> tremor, <u>20</u> blurred vision, <u>10</u> double vision, <u>5</u> convulsions, <u>17</u> lack of coordination, <u>22</u> dizziness, <u>13</u> vertigo, <u>9</u> blackouts, <u>10</u> fainting spells.

PSYCHOLOGICAL: <u>5</u> amnesia, <u>21</u> forgetful, <u>23</u> anxious, <u>18</u> tense, <u>21</u> depression, <u>18</u> hyper, <u>20</u> shaky, <u>23</u> unable to concentrate, <u>14</u> short attention span, <u>16</u> unable to reason, <u>21</u> nervous, <u>13</u> withdrawn feeling, <u>4</u> nervous breakdown, <u>11</u> cry often, <u>8</u> aggressive, <u>19</u> irritable, <u>18</u> easily angered, <u>17</u> restless, <u>13</u> difficulty falling asleep, <u>15</u> difficulty staying asleep, <u>10</u> nightmares, <u>15</u> difficulty staying awake, <u>11</u> considered suicide, <u>14</u> often unhappy, <u>5</u> have had visions, <u>5</u> heard voices.

SUBSTANCE USE: <u>5</u> have overused drugs, <u>3</u> been addicted to drug, <u>1</u> overused alcohol, <u>0</u> been addicted to alcohol, <u>11</u> smoked cigarettes, <u>1</u> still smoking.

WOMEN ONLY: <u>16</u> breast soreness, <u>12</u> breast lumps or cysts, <u>3</u> irregular periods, <u>13</u> heavy flow, <u>18</u> premenstrual symptoms, <u>11</u> painful periods, <u>5</u> menopause.

## RELATIVE FREQUENCY OF SYSTEMS AFFECTED

Based on the review of systems, and the maximum potential positive(+) responses per system, the following rank order was determined:

SYSTEM	MAX	IMU	M	(+)	ACTUAL (+)	PERCENTAGE
Musculoskeletal(	6 >	c 29	=	174	)129	74%
Mouth and Throat(1	10 >	29	=	290	)179	62%
Eyes(1	11 >	c 29	=	319	)173	54%
Ears(	9 2	( 29	=	216	) 134	51%
Stomach/bowel(1	18 >	29	=	522	)268	51%
Nose(1	11 >	( 29	=	319	)160	50%
Psychological(2	26 >	( 29	=	754	)378	50%
Lungs(	6 3	29	=	174	)87	50%
Neurological(1	11 >	c 29	=	319	)155	49%
Heart(	5 3	c 29	=	145	)68	47%
Headache(2	25 >	c 29	=	725	) 324	45%
Endocrine(	8 3	× 29	=	232	)68	29%
Skin(1						
Substance use(					•	
Kidney/bladder(	9 3	29	=	261	)25	10%
Women only(	73	<b>k</b> 24	=	168	)78	46%

#### DISCUSSION - REVIEW OF SYSTEMS

Symptoms occur in all major systems. While the musculoskeletal system had the highest response rate in this survey (74%), most of other major systems had response rates of about 50%. Kidney/bladder was quite low at 10%, but two out of the four adult males reported prostate symptoms (40%), and one reported impotence (20%). Endocrine system was only 29% and skin was low at 28%. Substance abuse did not have a very high response rate (12%).

Even though the musculoskeletal system was frequently positive in the <u>systems review</u>, joint and muscle pain was reported by only 34% of respondents as being one of their <u>chief complaints</u> (above). Therefore, while very common, musculoskeletal symptoms are <u>not</u> the most severe or bothersome complaints. The most frequent "chief complaint" was, in fact, severe fatigue and weakness (72%).

Such a mixture of symptoms can be quite intimidating to a physician and quite disabling to a patient. The answer lies in identifying the incitants that trigger the symptoms. Inhalant and chemical sensitivities can be quite numerous in these patients. However, recognizing that an individual's symptoms are triggered by incitant exposures can be the first step in successful management.

# INHALANT AND CHEMICAL SENSITIVITIES

The following is a list of the positive responses with respect to a variety of common incitants (maximum 29 per incitant):

29 perfume 28 mothballs 28 chemicals 28 cosmetics 28 dry cleaning 28 diesel fumes <u>28 exhaust fumes</u> <u>28</u> newspapers 28\_varnish <u>28 natural gas</u> <u>28 gasoline fumes</u> 28 room deodorizers 28 tobacco smoke <u>28</u>felt-tip pens 28 carpeting 27 paints 27 turpentine 27 tar 27 molds 27 floor wax 27 furniture polish 27 chlorinated tap water 27 solvents <u>27</u> synthetic fabrics 27 pesticides 26 herbicides 26\_photocopy paper

26 disinfectants 26 dust <u>26</u> nail polish <u>25</u> air pollution <u>25</u> foam rubber <u>25</u> ammonia <u>25</u> wood smoke <u>25</u> wubber 25 rubber 25 alcohol 24\_mildew 24 aerosols 24 vinyl 24 dyes 24 plastics <u>24</u> ink 23 overstuffed furniture 23 curtains 22\_toothpaste 22 pollen 19 cooking odors 19 grass 18 potted plants <u>17 grain dust</u> <u>16</u>cats 13 dogs 10 birds 8 other indoor pets

Response rates to most common chemicals and inhalants was high. This is consistent with the literature review in Part I of this report.

# PAST MEDICAL HISTORY

 93% (27/29) of the respondents report admission to hospital at some time in the past.

 76% (22/29) report having had some type of surgery in the past.

 7% (2/29 - one child, one adult) report <u>never</u> having been hospitalized for any reason.

Past surgical procedures as reported by respondents:

Tonsillectomy	
D & C	
Appendectomy	
Hysterectomy	
Breast biopsy	4/2914%
Cholecystectomy	
Bladder repair	
Ovarian cyst removal	
Exploratory laparotomy	
Hemmoroidectomy	2/297%
Thyroidectomy	
C-section	
Tubal ligation	
Foot operation	
Elbow operation	
Hernia repair	1/293%

Other, non-surgical reasons for admission to hospital as reported by respondents:

Benchlass and souther serve	
Routine maternity care	
No diagnosis determined	6/2921%
Mononucleosis	218
Pneumonia	178
Scarlet fever	
Asthmatic attack	/%
Flu	
Sinusitis	
Hepatitis	
Psychiatric admission	
"Probable" M.S	
Parasites	
Chickenpox	
Colitis	
Petit mal seizures	
Chronic EBV	
Tachycardia	
Pancreatitis	
Polio	1/293%
Acute chlorine poisoning	
Broken bones	
Burns	1/2938

One of the respondents spent some time in an environmental control unit in Dallas, Texas for assessment and treatment of environmental hypersensitivities.

Questions pertaining to past medical history were open-ended. There probably is under-reporting due to lack of recall; especially in individuals with longstanding chronic illness who have undergone extensive investigation and treatment over many years.

Past medical histories have no obvious consistent features except for the high (93%) rate of past hospitalization. An obvious compounding factor is the 15 respondents who had been hospitalized for maternity care. However, each case was carefully reviewed and each had history of admission to hospital on other occasions for reasons unrelated to maternity.

Therefore, it is reasonable to say that 93% of respondents have been in hospital at some time in the past for a variety of problems, some related to their environmental illness and others not. The "normal" rate of past hospitalization for a similar group (same age and sex distribution) in the general population is unknown. It is not possible to interpret this finding in any depth. It is consistent with an illness that is prolonged and chronic.

# FAMILY HISTORY

# DISEASE

# NUMBER

# PERCENTAGE

Heart disease		76%
Arthritic disorders		
Cancer	17	59%
Hayfever	14	48%
High blood pressure	13	45%
Asthma	12	41%
Depression	12	41%
Migraine headaches	12	41%
Alcoholism	11	38%
Stroke	10	35%
Hives	10	35%
Eczema	9	31%
Diabetes	9	31%
Thyroid disease	8	28%
Ulcer disease	7	24%
Tuberculosis	4	14%
Anemia	3	10%
Kidney disease	2	78
Emphysema	2	78
Leukemia	2	78
Multiple sclerosis	2	78
Schizophrenia	2	78
Epilepsy	1	3%

No obvious trend was identified in the family history and the results are probably consistent with the general population.

## ALL SPECIAL INVESTIGATIONS

Again, this open-ended question yielded a variety of responses. All respondents reported multiple blood & urine tests and plain film x-rays; the most common x-ray being chest x-ray.

Nine respondents reported barium studies of gastrointestinal tract. Six reported CT scans without referring to region scanned. Four reported abdominal ultrasound. Three reported having had an intravenous pyelogram. Three reported electroencephalograms. Three reported electrocardiograms. Two reported lumbar puncture. Two reported mammography.

There was <u>one</u> report of each of the following: anoscopy, gastroscopy, bone scan, liver ultrasound, myelogram, sigmoidoscopy, cystoscopy, bone marrow aspirate, gallbladder scan, heart scan, HIV testing, stool samples, holter monitor, hair analysis, heart catheterization, discogram, tomography foot, electromyography, exercise tolerance test.

Two respondents chose to answer with comments: "every blood test and x-ray imaginable," "everything."

#### ALLERGY AND SENSITIVITY TESTING

Fraditional skin scratch and/or intradermal20/	29
Sublingual10/	29
Vega testing7/	29
Provocation/neutralization5/	29
Kinesiology4/	29
Elimination diet3/	29
"Clinical ecologist testing"3/	29
Intero-computer testing2/	29
Fast followed by reintroduction of foods2/	29
Rast1/ Patch1/	29
Cytotoxic testing1/	29
Sniff test1/	
Challenge testing1/	29
Ear acupuncture1/	
Pulse testing1/	
None1/	29

These patients undergo many tests trying to uncover the "things" they are sensitive to. The variety and number of tests tried suggests there is no single testing technique that is accurate reliable, and simple. Some of the tests noted above are clearly unproven. Tests for specific sensitivities are, at best, a rough guide to treatment. Such test results must be taken in context with history and other physical findings.

# NUMBER OF MEDICAL DOCTORS SEEN

#### DOCTORS SEEN

#### RESPONDENTS

[ 1-5 ]2
[ 6-10]10
[11-15]5
[16-20]3
[21-25]2
[ >25]1

Clearly, these patients seek advice from many medical doctors. Some of the respondents chose to answer this question using descriptive terms rather than number estimates: "too many," "many," "dozens," "lots," "innumerable," and "15?,20?, more?"

Beyond general practitioners, many specialists were seen by respondents. Following is a list of the each type of specialist seen with the number of respondents seen by each type:

Traditional allergist16
Ear Nose Throat12
Psychiatrist12
Internist11
Neurologist11
Gynecologist10
Gastroenterologist8
Endocrinologist7
Cardiologist5
Ophthalmologist5
Urologist3
Respirologist2
Rheumatology2
Dermatologist2
General Surgeon2
Neurosurgeon1
Orthopedic Surgeon1
Infectious Diseases1
Pediatrician1
Tropical Diseases1
Occupational Medicine1

18 respondents reported seeing a Clinical Ecologist.

Respondents also reported seeing a large number of alternate practitioners:

Chiropractor-----19 Naturopath-----14 Homeopath-----7 Osteopath-----3 Acupuncturist-----3 Herbologist-----2 Reflexologist-----1 Iridologist-----1 Rolfers-----1 Cranio-sacral therapist----1 Metabolic technician-----1 "Quacks"-----1

Other paramedical professionals seen by a few of the respondents include psychologists(5), nurses(4), physiotherapists(4), massage therapists(4), and dentists(3).

# FACTORS BELIEVED (by respondents) TO HAVE CONTRIBUTED TO ILLNESS

There are a wide variety of responses to this question. As per the respondents (quotations):

# ENVIRONMENTAL FACTORS

WORKPLACE:

- Working in poorly ventilated government building
- Move to new air-tight office tower
- Working in bank while undergoing renovations . followed by hospitalization and move into a new home
- Working in new building .
- Terrible quality and state of the school building . - stagnant water under building - creosoted cork insulation

  - poor ventilation
- Sprayed in face with perfume (at work)
- Extensive exposure to textiles
- Exposure to multiple gases and chemicals in . smelter/refinery
- Acute chlorine gas poisoning in 1966 .
- Exposed (careless handling) to farm chemicals .
- Working as printer in unventilated room
- Energy efficient building recycling fumes from . photocopy machines
- Working with paints and printing inks
- Exposure to formaldehyde in science classes

# HOUSE & HOME:

- Exposure to particle board in kitchen
- Something in old house .
- Constant exposure to cigarette smoke .
- Move to a new rectory with exposure to DDT and other . contaminants
- Use of chemicals in home .
- Move to energy efficient house
- Indoor use of fireplace
- Major renovations in home .
- Oil furnace
- Painting without respirator in closed area .
- Move from electrically heated rural house to oil . heated city house
- Exposure to strong cleaning agents
- Severe mold problem in house
- Living in home with propane stove
- Inefficient gas furnace in home .
- Renovating house and office at same time
- Pesticide spraying of apartment building

# Contributing factors, continued...

#### ENVIRONMENTAL, continued ...

## OUTDOOR AIR POLLUTANTS:

- Move to city
- Cumulative effects of indoor and outdoor pollutants
- Living near refineries
- Pollution from pulp and paper mill close to home
- Air pollution (Toronto)
- Spraying of pesticides
- Over-exposure to pesticides
- Move to southern Ontario industrial area
- Exposure to formaldehyde/chlorine/insect sprays
- Living in city
- Exposure to heavy agricultural pesticides

# **OTHER:**

Chlorinated water

# MEDICAL CONDITIONS

- Chronic candidiasis
- Mononucleosis
- Allergies from a very early age
- Bad virus at age of 17
- Septicemia after surgery
- Scarlet fever

# MEDICAL TREATMENTS

- Radiation exposure during medical treatment at birth
- 6 years of fertility drugs
- Use of beta-blocker medication
- Excessive use of antibiotics in past
- Continual use of antibiotics
- Too much medication
- Hepatitis caused by drugs for asthma
- Pharmaceuticals
- Medical intervention
- Depo-provera treatment
- Birth control pills
- Epidural anesthetic with pregnancies

# MISCELLANEOUS

- Severe reaction to something eaten while on vacation in Florida
- Genetic susceptibility
- Mercury amalgams in teeth
- Allergic family
- Heredity
- D.E.S. exposure

Respondents report a wide variety of factors believed to contribute to their illness. Many report exposures to chemicals in the home or workplace as being important contributing factors. Some report other medical problems and medical treatments as factors.

Since etiology of the illness is still not clearly understood, these reports constitute an important source of preliminary data.

Patients' observations should not be dismissed because they are "anecdotal" or "subjective." The large volume of similar "observations" by patients reported in the literature is significant.

# OTHER DIAGNOSES SUGGESTED (by physicians)

This question also yielded a variety of answers. As per the respondents (quotations):

- No one could give me a diagnosis
- First stage of lupus
- Probable multiple sclerosis
- Myositis
- Asthma
- Obstructive pulmonary disease
- Hepatitis
- Hypothyroidism
- Irritable bowel syndrome
- Autoimmune thyroiditis
- Hypochondriac
- Manic-depressive
- Nervous exhaustion
- Depression
- Multiple personality
- Heart problem
- Stress
- Emotional instability
- Sinus problem
- Digestive problem
- Anxiety
- Bad nerves
- Allergies
- Colitis
- Spastic bowel
- Chronic cystitis
- Diabetes
- Arthritis
- "Over the hill"
- Sinusitis
- Asthma
- Reynauds
- Migraines
- Lack of exercise
- All in my head
- Psychotic
- Schizophrenic
- Postpartum depression
- Some kind of immune problem
- Celiac disease
- Don't know
- Hyperthyroidism
- Flu
- Women's problems
- Hormone problem and neuroses
- Petit mal
- Anxiety disorder
- M.S.
- Emotional problem

Other diagnoses, continued...

- Meningitis
- Prostatitis
- Hypochondria
- Conversion hysteria
- Overtired
- Heart virus
- Poisoning
- Hyperactive
- "Bored, unhappy housewife"
- Hysterical
- Lymphatic disorder
- Inflammatory disease
- Renal disorder
- Psychological
- Depression
- Prolapsed mitral valve
- Porphyria
- Epilepsy
- Hypoglycemia
- Sinusitis
- Bronchitis
- Asthmatic
- Chronic anxiety
- Agitated depression
- Idiopathic edema
- Disassociation reaction
- Myalgic encephalopathy
- Chronic fatigue syndrome
- Somatization disorder

These responses reflect the difficulty these people have finding an explanation for their illness. Medical models of describing illness are geared towards finding "single" diagnoses. This approach works well for single entity diseases such as acute appendicitis, but it does not work well for chronic multi-system illness. Patients also seek a "single" diagnosis in order to gain understanding of (and credibility for) their illness.

As discussed earlier in this report, one problem with respect to validity of environmental hypersensitivity disorder is the lack of a universally accepted definition; i.e., it cannot be "diagnosed" until it has been "defined" - and if it cannot be "diagnosed," it must not exist.

Also, there are times when the line between "diagnosis" and "symptom" is cloudy. Clearly, appendicitis is a disease with the symptom of abdominal pain; but, is depression a disease or a symptom? Many "diagnoses" for which we do not know the etiology may, in fact, be "symptoms."

The discussion is academic. The point is that people with environmental hypersensitivities (? diagnosis / ? symptom) are not well-served by the current language used to describe illness. Ongoing arguments over definition do not help patients.

# FOOD ALLERGIES AND SENSITIVITIES

Many individuals with chemical and environmental hypersensitivities also report allergic, adverse, and sensitivity reactions to foods. There is extensive literature on the topic of food sensitivities. Monro (1987) notes: "Most patients who are food sensitive are unlikely to be sensitive to a single food."

Brostoff (1987) offers the following classification of food allergy and intolerance:

- Food intolerance
   Pharmacological action, e.g. caffeine, tyramine
   Foods releasing mediators
   Toxic substances
   Irritants to the mucosa
   Fat-bile salt deficiency
  - 2. Food idiosyncracy Enzyme defects e.g. lactase deficiency lipase deficiency
  - 3. Food fads 'Popular' diets Anorexia nervosa Bulimia

4. True food allergy Immunologically mediated reactions Antibody mediated Immune complex mediated Cell mediated

Brostoff (1987) also says:

The cornerstone of diagnosis of food sensitivity is the removal of that food from the patient's diet with concomitant improvement in the patient's symptoms which then reappear when the food is added back - preferably in a double-blind manner. At the clinical level, pragmatism is all important to the patient, the mechanism of the allergic reaction being less so.

# Gerrard (1980) puts food sensitivity into perspective:

The diseases under study are triggered by the three elements on which we depend for our survival-air, water, and food. Our air is most highly polluted where it should be most pure-where the population is thickest-and though our city waters are bacteriologically safe, they are far removed from their original source and certainly are no longer 'pure.' Our foods, although much safer bacteriologically than in the past, are no longer the simple products they used to be. It would seem likely that our various immune systems, which had adapted over many generations to their local environments, have been jolted and thrown off balance. The recent substitution of cow's milk for the breast certainly is the greatest single change in our dietary habits for the whole of our evolutionary history and has undoubtedly been responsible for more disease than is generally realized. The processing of foods and the rapid transport of foods and populations have also lead to tremendous changes in dietary habits, so it is not surprising that diseases related to foods and to chemicals added to them, and being added daily to our environment, should be triggering our immune systems and leading to disease.

This survey was <u>not</u> primarily interested in food sensitivities, but since most chemically sensitive individuals also have food sensitivities, a small section of the questionnaire was devoted to the problem.

Respondents were asked to list all foods which cause symptoms. This open ended question drew a wide variety of answers which included over 70 different foods. Each of the respondents reported sensitivities to several foods. There were several foods that were mentioned only once. The entire list will not be reproduced. The more common responses are summarized:

Milk & dairy products19	/2966%
Wheat18	/2962%
Beef16	5/2955%
Sugar12	/2941%
Pork12	/2941%
Yeast11	/2938%
Corn10	/2934%
Potato09	/2931%
"Food additives"07	/2924%
Tomato06	5/2921%
Eggs06	5/2921%
Onion05	5/2917%

Other information from the section on food sensitivities reveals that 83% (24/29) of respondents use purified water, 76% (22/29) have to avoid certain foods, 72% (21/29) eat a rotational diet, and 59% (17/29) can eat only organic foods.

# HABITS, PROBLEMS OR PECULIARITIES CONCERNING FOOD INTAKE

The most common response to this question was that of food craving, especially when reacting to some environmental incitant. Ten respondents specifically mentioned food cravings. Some other responses include (quotations):

Generally have a huge appetite. Organic food is sometimes hard to locate and very expensive

Organic food only, very limited

Much improved if stick to organic diet, no preservatives

Many foods can be tolerated only on a wide rotation

Cannot sleep if I eat late

Boredom

Very difficult to find food I can eat, I'm very limited, it's very boring, it's very costly, I have to cook separate meals for myself and my family

# OTHER LIFESTYLE CHANGES

DIET: Discussed above.

WORK: Discussed above.

CLOTHING: Common responses include discarding synthetic fabrics in favor of natural fibers (eg. cotton), and wearing loose fitting clothing.

HOBBIES: Giving up hobbies associated with exposure to chemicals e.g. quit painting, quit sewing, quit cooking. Some say "no hobbies". Some have taken up organic gardening.

OTHER: Respondents report having to stop many activities. Some have returned to selected previous activities after improvement in health. The list of activities stopped or reduced includes: driving car or driving in heavy traffic, going to public buildings, going to movies, using perfume, having hair perms, going to church, traveling, shopping trips, eating out, photography and darkroom work, swimming in public pools, going to theatre, visiting friends' homes, going to parties, walking on city streets, reading.

# ALL TREATMENTS RECEIVED

Respondents report many treatment modalities tried or prescribed at different times. Remember that there are only 29 respondents. The treatments are mirrored by the list of health professionals seen (above). As listed by respondents:

- Chiropractic
- Homeopathic
- Massage
- Oxygen therapy
- Vitamin injections (intramuscular and intravenous)
- Neutralization
- Phenolics
- Cranio-sacral manipulation
- Immunotherapy drops
- Sodium shots for immune system
- Counselling
- Herbs
- Nystatin
- Organic germanium
- Antibiotics
- Antifungals
- Nutrition therapy
- Allergy shots
- Candida neutralization
- Desensitization injections and sublingual drops
- Vitamin therapy
- Therapeutic touch
- Meditation
- Colonic detoxification
- Coffee enemas
- Intravenous chelation therapy
- Intravenous vitamin C
- Body balancing
- Kinesiology
- Reflexology
- Acupressure
- Bach flowers
- Sauna
- Admission to environmental control unit in United States
- Drops for formaldehyde
- Mega-dose vitamin C
- Vitamins and minerals
- Vitamin B-12
- Acupuncture
- Amino acid supplements
- Glandulars
- Digestive enzymes
- Full spectrum light
- Biofeedback

# ALL PAST MEDICATIONS

Respondents also reported a full spectrum of prescription medications used - usually at the earlier stages of illness before the diagnosis of environmental hypersensitivity. Most reported little relief and many reported that prescription medications made things worse. Depending on the system most affected and symptoms, medications tried include:

- Anti-inflammatories
- Antibiotics
- Antifungals
- Anticonvulsants
- Pain killers
- Antihistamines
- Decongestants
- Bronchodilators
- Heart medication
- Birth control pill
- Diuretics
- Thyroid supplements
- Muscle relaxants
- Antispasmodics
- Tranquilizers
- Antidepressants
- Antipsychotics
- TB drugs
- Steroids
- Diet pills

There was no identifiable trend.

#### ALL CURRENT MEDICATIONS

Most respondents report <u>not</u> taking any prescription medications at this time. Many report using vitamin and nutritional supplements. The only prescription medications reported include: ventolin and beclovent by one respondent, thyroid supplement by four respondents, nystatin by two respondents, and antihistamines by two respondents.

## MOST BENEFICIAL TREATMENTS

With such a small group of respondents and the large number of treatments tried, it is difficult to determine which treatments are most beneficial. Obviously, many of the treatments are tried out of desperation by people who are chronically ill and have not found relief through mainstream medical channels. It is understandable that people will try a wide variety of alternative treatments with a "nothing to lose" attitude.

However, it is clear from the histories reviewed that most respondents <u>did</u> consult a variety of traditional medical specialists. It was not the initial choice to seek advice and treatment from alternative disciplines.

Nevertheless, when asked what "treatments" were most beneficial, the responses were surprisingly consistent. The following responses were very frequent:

- Avoidance of chemicals
- Eating organic food and drinking clean water
- Living in an environmentally safe "clean air" home
  Rotation diet
- Lifestyle changes consistent with avoidance of chemicals
- Detoxification-homeopathy
- Desensitization
- Phenolics

Other, less frequent responses were:

- Candida treatment with nystatin
- Vitamins
- Massage
- Cranio-sacral manipulation
- Therapeutic touch
- Naturopath
- Air cleaning machine
- Digestive enzymes
- Sauna
- Acupuncture
- Herbs

# DISCUSSION OF TREATMENTS

Considering the large number of treatments tried, it is interesting that most report improvement by adopting lifestyle changes necessary to have clean air, clean water, and clean food. Many of the "treatments" tried did not get into the "most beneficial" list.

# ESTIMATE OF SIGNIFICANCE OF HABITAT MODIFICATION

The area of most interest to this survey is the "therapeutic effect" of a change in habitat. All of the respondents have made modifications to their homes in order to reduce chemical exposures.

Respondents were asked a simple question. They were asked to estimate (on a scale of 1 - 5, with 5 being <u>very</u> important) how significant the modifications made to their homes had been in improving their health. The results are:

IMPORTANC	<u>E</u>	RESPONSES	PERCENTAGE
Very	(5)	25/29	86%
	(4)	3/29	10%
Somewhat	(3)	1/29	48
	(2)	-	-
Not	(1)	-	-

### DISCUSSION OF EFFECT OF HABITAT CHANGE

After years of chronic illness, many and varied practitioners, and multiple treatments; all the respondents to this survey report improvement in health after home modifications to reduce exposure to chemicals.

Many of the changes made to habitat are well within the bounds of modern building technology and are simple methods that avoid the use of chemicals in construction.

Nevertheless, individuals who build or renovate to improve indoor air quality will also take care to reduce chemical load from contents of the home. They are careful in the selection of furnishings. They keep most common household chemicals out of their homes (cleaning agents, solvents, detergents). Most will declare their homes as "non-smoking" and "no-perfume" zones. They are likely to eat clean (organic) food and drink clean (purified) water.

While most (86%) rated changes made to their habitat as "very important", it must be stressed that many factors are involved in the creation of a safe habitat, not just those elements dealing with building technology.

It is quite possible to build a "safe" house and then pollute it with "unsafe" furnishings, carpets, cleaning agents, pesticides, and so on. Once a house is built or renovated to be "safe," it takes ongoing diligence to keep it that way. It is also possible to locate the house in a "unsafe" environment, such as near a busy city street or next to a pulp mill.

The respondents to this survey represent a small subgroup of individuals with environmental health problems who have chosen habitat modification as one of the ways to improve their health. <u>All</u> report that it was a worthwhile effort.

The sample population is small and there are many variables. No statistically valid or general conclusions should be drawn. Although the information is anecdotal - when taken together with the literature reviewed - it strongly suggests that people are ill as a result of chemical exposures in the environment. Also, changes in the home to reduce chemical load can improve the health of those affected. Whether or not reduction of chemicals in our day to day environment can <u>prevent</u> such illness is yet to be determined.

# COMPARISON OF ILLNESS BEFORE AND AFTER MODIFICATIONS TO HOME

Respondents were asked to estimate frequency of attacks of "chief complaint" before and after habitat modifications. In retrospect, this question is poorly designed and most found it difficult to answer. As noted above, most respondents have difficulty choosing a single "chief complaint". This, along with the poor question design, prevents any meaningful summary of responses. It was not answered by everyone.

Nevertheless, 23 respondents reported daily symptoms prior to habitat modification and only three reported daily symptoms after habitat modification. Three still had symptoms weekly and eight still had symptoms monthly. Others described frequency of symptoms after habitat modification with terms such as "seldom," "never," "sometimes," "rarely," and "occasionally."

Some respondents offered additional comments:

•

• It lightened the load on my body and enabled my body to work on rebuilding itself. It has been a long and slow process. I went from being on death's door with 'no hope of recovery' to hope now of full recovery.

 Removal of natural gas caused a sudden and permanent increase in energy approximately ten days after its removal.

• I really can't relate the improvements in the house to specific attacks. It was simply a sense of well being i.e. gradual regaining of energy, gradual improvement in sensitivities.

 None (symptoms) as long as proper food and no pollution in outside air. Still sick in spring from farming and at times from burning.

 Gradual lessening in frequency, severity, and duration.

I am generally better, less foggy, more rested.

 I could not say I have attacks now - except as a shadow of the original illness.

Some things improved, others worsened.

#### ADDITIONAL COMMENTS

This part of the questionnaire was optional and not everyone responded to it. Others provided extra written information that was beyond the one page set aside in the questionnaire. Much of the information was interesting but only a few comments are applicable to the objectives of this survey (as per respondents):

 I know I owe my life to the clean environment in which I live. I had become so sensitive, I was sick everyday - I had no resistance to flus, colds etc.

After some time in a 'clean' environment I feel better. Visiting other people's homes is my best comparison. Air from hot air vents, dust and fumes affect me immediately - dizzy, spacey, light-headed. If I stay too long - stomach and liver pains. Good to get back home!

I have made my home as much as possible into a protective bubble or refuge. It is a relatively (although not completely) safe haven from which I can venture out into our chemical world. When my body needs to recuperate or work on healing and restoring, I just stay in my apartment and don't venture out.

• I am stronger and can think more clearly and see better. It seems recovery does not happen overnight, or even at a steady pace. There are ups and downs. The downs are not as debilitating. We are not quite finished renovating, but already I can see a marked improvement in my level of accomplishments...I am grateful that we were able to make changes that have helped me and my family. Otherwise, we were facing family disintegration.

 Before moving to a house that was modified for environmental health, I was paralyzed (legs), bedridden constantly and could not function at all - needed constant care. Since living in a modified home I am no longer bedridden, can walk normally and care for myself as long as I spend most of the time in the house.

 My general health and all my minor symptoms improved greatly with the house and food (diet) changes.

I do not believe that house renovations can cure sensitivities but my everyday life proves to me that it goes a long way to help a hypersensitive person function normally. Having a safe haven to come back to, where I can take care of myself, is making me see progress much faster than in the past ten years. Too bad, avoidance seems to be the operative word for us, still.

Reading and writing is now, once again, the focus of my daily activity. Exercise is now possible. Dining out and theatre and concerts are once again on the agenda.

#### REFERENCES

- American Academy of Allergy and Immunology: Position statements - clinical ecology. Journal of Allergy and Clinical Immunology (1986) 78(2): 269-271.
- Ashford, N.A. and Miller, C.S.: Chemical Sensitivity. A Report to the New Jersey State Department of Health. (1989)
- Bascom, R.: Chemical Hypersensitivity Syndrome Study: Options for Action, A Literature Review, and a Needs Assessment. Prepared for the State of Maryland Department of the Environment. (1989)
- Brostoff, J.: Mechanisms: An Introduction. In J. Brostoff and S.J. Challacombe (Eds): Food Allergy and Intolerance. (1987) 433-455 Toronto: Baillière Tindall/W.B. Saunders
- California Medical Association Scientific Board Task Force on Clinical Ecology: Clinical ecology - a critical appraisal (Information). The Western Journal of Medicine (1986) 144(2): 239-245.
- Cullen, M.R.: The Worker with Multiple Chemical Sensitivities: an Overview. In M. Cullen (Ed): Workers with Multiple Chemical Sensitivities - Occupational Medicine: State of the Art Reviews. (1987a) 2(4): 655-661 Philadelphia: Hanley & Belfus, Inc.
- Cullen, M.R.: Multiple Chemical Sensitivities: Summary and Directions for Future Investigators. In M. Cullen (Ed): Workers with Multiple Chemical Sensitivities - Occupational Medicine: State of the Art Reviews. (1987b) 2(4): 801-804 Philadelphia: Hanley & Belfus, Inc.
- Drerup, O., Mattock, C., Rousseau, D. and Salares, V.: Clean Air Housing in Canada. A report for Canada Mortgage and Housing Corporation, Research Division. (1990)
- Gerrard, J.W.: Editorial Preface. In J.W. Gerrard (Ed): Food Allergy: New Perspectives. (1980) ix-xi Springfield: Charles C. Thomas, Publisher.
- Langley, G.R. (chair): Report of the Environmental Hypersensitivity Advisory Committee to the Minister of Health, Province of Nova Scotia. Halifax. (1986)
- Monro, J.: Food Families and Rotation Diets. In J. Brostoff and S.J. Challacombe (Eds): Food Allergy and Intolerance. (1987) 303-343 Toronto: Baillière Tindall/W.B. Saunders

- Mooser, S.B.: The Epidemiology of Multiple Chemical Sensitivities (MCS). In M. Cullen (Ed): Workers with Multiple Chemical Sensitivities - Occupational Medicine: State of the Art Reviews. (1987) 2(4): 663-668 Philadelphia: Hanley & Belfus, Inc.
- Randolph, T.G.: Environmental Medicine Beginnings and Bibliographies of Clinical Ecology. (1987) Fort Collins: Clinical Ecology Publications, Inc.
- Rapp, D.J.: Comments on the Position Paper on Clinical Ecology by the American Academy of Allergy and Immunology. In T.G. Randolph: Environmental Medicine - Beginnings & Bibliographies of Clinical Ecology. (1987) 301-307 Fort Collins: Clinical Ecology Publications, Inc.
- Rea, W.J.: Environmental Illness. In D. Rousseau, W.J. Rea, and J. Enwright: Your Home, Your Health, and Well-Being. (1988) 207-216. Vancouver: Hartley & Marks Ltd.
- Seba, D.B., Milam, M.J. and Laseter, J.L.: Uptake, Measurement and Elimination of Synthetic Chemicals by Man. In J. Brostoff and S.J. Challacombe (Eds): Food Allergy and Intolerance. (1987) 401-415 Toronto: Baillière Tindall/W.B. Saunders
- Small, B.M.: Indoor Air Pollution and Housing Technology. A report for Canada Mortgage and Housing Corporation, Planning Division - Policy Development and Research Sector. (1983)
- Stigler, D. et al.(Eds): What is clinical ecology? Clinical Ecology (1989) 6(3): i
- Terr, A.I.: Position paper for the American College of Physicians - Clinical ecology. Annals of Internal Medicine (1989) 3(2): 168-178
- The American Academy of Environmental Medicine: The Discipline of Clinical Ecology (an information pamphlet and preliminary application form). Denver, Colorado
- The American Academy of Environmental Medicine: Position statement - The Discipline of Clinical Ecology (an information pamphlet). (1988)
- The Human Ecology Foundation of Canada: What is environmental hypersensitivity? Human Ecology Foundation Canada Quarterly (1988) 10(4): 3-5.
- Thomson, G.M. (chair): Report of the Ad Hoc Committee on Environmental Hypersensitivity Disorders. Ontario Ministry of Health, Toronto. (1985)
- World Health Organization: Indoor Air Quality Research Report on a WHO Meeting. Euro Reports and Studies 103, Stockholm. (1984)

- Ziem, G.: Multiple Chemical Sensitivity: My Clinical Experience and Response to the Bascom Report. In: Chemical Hypersensitivity Syndrome Study - Comments of the Review Committee. Prepared for the State of Maryland Department of the Environment. (1989)
- Zimmerman, B. (chair): Report of Advisory Panel on Environmental Hypersensitivity. Ontario Ministry of Health, Toronto. (1986)

APPENDIX A

# California Medical Association 221 Main Street, P.O. Box 7690, San Francisco, CA 94120-7690 (415) 541-0900

April 9, 1990

Earon S. Davies, JD, MPH Ecological Illness Law Report P.O. Box 6099 Wilmette, IL 60091

Re: Clinical Ecology

Dear Dr. Davies:

You have requested information concerning an informational report entitled "Clinical Ecology -- A Critical Appraisal" which appeared in the Western Journal of Medicine, February 1986 edition. I have attached a copy of this report for your review.

As you can see, this article is not a "position statement" with respect to clinical ecology. As is set forth in my letter dated March 26, 1990, <u>CMA's medical practice opinion concerning</u> <u>clinical ecology was withdrawn and is no longer in effect</u>. Rather, the article sets forth a detailed historical description of a hearing conducted by a task force in April of 1985 which reviewed the scientific evidence concerning clinical ecology. As an informational document only, the report has not been withdrawn.

Sincerely,

askep my

Astrid G. Meghrigian CMA Legal Counsel

. . .

cc: Bob Elsner Linda Ramsey

D:\LET\AGM\cd040990.ce

REPRINTED BY PERMISSION OF EARON S. DAVIES, JD, MPH.

APPENDIX B



Ministry Ministère of de la Health Santé

Contact: Phone:

86/nr-296 Rick Winston, Toronto Communications and Information Branch (416) 965-5167

MINISTRY ENCOURAGES RESEARCH STUDIES ON ENVIRONMENTAL HYPERSENSITIVITY

TORONTO, December 19 -- The Ministry of Health will encourage research proposals for studies on environmental hypersensitivity, a first step in understanding the nature of the disorder and developing effective treatment, Health Minister Murray Elston announced today.

Currently, little is known about the nature of the condition called environmental hypersensitivity, which is described as multiple sensitivities to a wide range of foods, chemicals and environmental substances.

"We are encouraging the research community to submit proposals for an epidemiological study on environmental hypersensitivity and for proposals for controlled studies to evaluate the effectiveness of current methods of treating the symptoms," Mr. Elston said. "Epidemiological studies would provide researchers with information to enable them to identify common factors and develop consistent tests or standards for diagnoses. This is the first step in finding a cause for the disorder and developing effective treatment."

An epidemiological study is one that examines the prevalence and spread of disease in a community to determine the links between causes of the illness and the resulting symptoms.

"There may be a debate as to the nature of the illness from which these people are suffering," Mr. Elston said. "But there is no doubt that they suffer disabilities. These studies may clarify the causes of their complaints and lead to more effective management."

The ministry hopes to receive the proposals in time for its annual spring research grants competition. The ministry awards approximately \$5 million annually through research grants programs. Currently, projects on subjects ranging from Acquired Immune Deficiency Syndrome (AIDS) to hypertension control at the worksite are being supported through these programs.

More research was recommended by both the Ad Hoc Committee on Environmental Hypersensitivity, chaired by George W. Thomson, and the subsequent Advisory Panel which examined the Thomson report, convened by The Hospital for Sick Children and chaired by Dr. Barry Zimmerman.

Although clinical ecology is not a recognized field of practice, there are about 15 medical practitioners in the province who specialize in treating symptoms believed to be related to environmental sensitivity.

APPENDIX C

CONTROL THE ENVIRONMENT



## **Environmental Health Center – Dallas**

8345 Walnut Hill Lane, Suite 205, Dallas, Texas 75231 • Telephone - (214) 368-4132 - FAX: (214) 691-8432

October 18, 1989

Williem J. Res, M.D. F.A.C.S., F.A.A.E.M. Abdominal and General Surgery First World Professional Char in Environmental Medicine, Robens Institute, University of Surrey, England

Alfred R. Johnson, D.O. F.A.A.E.M. Internal Medicane argy and Environmental Medicane

Alph E. Smiley, S.M., M.D. Internal Medione ergy and Environmental Medione

> Gerald H. Ross, M.D. C.C.F.P., D.I.B.E.M. Family Practice Environmental Medicine

Joel R. Butler, Ph.D. Clinical Psychology Behavioral Medicine

Ervin J. Fenyves, Ph.D. Environmental Science

Said Youdim, Ph.D. Immunology

ise A. Glimer, R.D., L.D. Nutrition

Linda Carlisle, R.D., L.D. Nutrition

Barb Maynerd, R.D., L.D. Nutrition

Irolyn Gorman, B.A., M.A. Health Education

> Sue Herbig, R.N. Physical Therapy

Dr. Steven Barron Leigh Square Medical Center 2275 Leigh Square Port Coquitlam British Columbia, Canada V3C 3B9

Dear Dr. Barron:

In response to your inquiry recently, our business office informs us that the Canadian Provinces of Ontario, Alberta, Nova Scotia and Saskatchewan have funded patient evaluations here in Dallas in the past. We have also had a patient here who was funded by the Worker's Compensation Board of the Province of Prince Edward Island.

I understand that the vast bulk of those Canadian patients that we have cared for and who have received government sponsored funding have been from the province of Ontario, funded through OHIP.

I hope this information is helpful to you.

Sincerely,

Willia (free

William J. Røa, M.D., F.A.C.S. Medical Director of the Environmental Health Center Dallas First World Professorial Chair in Environmental Medicine, Robens Institute, University of Surrey, England

WJR:mis

APPENDIX D

•

THIS PAGE IS PERSONAL INFORMATION AND IS FOR DR. BARRON'S USE ONLY. INFORMATION ON THIS PAGE WILL BE KEPT COMPLETELY CONFIDEN-TIAL AND WILL NOT BE RELEASED TO CMHC OR ANY OTHER THIRD PARTY.

NAME:\_\_\_\_\_\_ADDRESS:\_\_\_\_\_

PHONE: (HOME)\_\_\_\_\_(WORK)\_\_\_\_\_ BEST TIME TO CONTACT:\_\_\_\_\_

BIRTHPLACE:\_\_\_\_\_\_\_DATE OF BIRTH:\_\_\_\_\_\_

MARITAL STATUS:\_\_\_\_\_

CURRENT OCCUPATION:\_\_\_\_\_\_ LIST WORK HISTORY WITH DATES:\_\_\_\_\_\_

LIST ALL PROVINCES/COUNTRIES LIVED IN WITH DATES:

EDUCATION:

HOBBIES:\_\_\_\_\_

#### INFORMATION

Not less than 25 persons will be surveyed using written and telephone communication. All communication will be carried out by Stephen R. Barron, M.D. of Port Coquitlam, B.C..

Stephen R. Barron, M.D. of Port Coquitlam, B.C.. Persons will be selected from those (92) who were surveyed by CMHC in the winter of 1989-90 as part of a study to identify people with environmental health problems who had undertaken modifications to their homes.

The survey will focus on details of environmental hypersensitivities and how the course of illness was affected by modifications made to the home.

#### CONSENT

I, \_\_\_\_\_\_, of the above address, agree to take part in a detailed medical history survey as part of a CMHC study of environmentally hypersensitive persons who have substantially changed their habitat to accommodate their disability.

( Signature )

.

HISTORY OF ENVIRONMENTAL SENSITIVITIES

CHIEF COMPLAINT: \_\_\_\_\_\_\_ ( single worst )

LIST FOUR OTHER COMPLAINTS IN ORDER OF SEVERITY:

AGE MAIN SYMPTOMS FIRST BEGAN:

OCCUPATION AT TIME OF ONSET:

PROVINCE/COUNTRY OF RESIDENCE AT ONSET:

IN YOUR OWN WORDS, SUMMARIZE WHAT FACTOR/FACTORS YOU BELIEVE TO HAVE CONTRIBUTED TO YOUR ENVIRONMENTAL HEALTH PROBLEMS:

.

WHAT OTHER "DIAGNOSES" HAVE BEEN USED TO EXPLAIN YOUR ILLNESS:

HOW MANY MEDICAL DOCTORS HAVE YOU SEEN?\_\_\_\_\_

LIST TYPES OF MEDICAL SPECIALISTS SEEN:

OTHER PRACTITIONERS SEEN ( chiropractors, naturopaths, etc. ):

IIII A L	100 14		IOOR DI	I DOIIDD.						
	DIET:								_	
		í.								
	WORK :									
	NOIUN_			×						
	-									S
	CLOTH:	ING:			and the second second		and the second			
	÷									
	HOBBI	ES:								
	OTHER									
LIST	י מד.ד. ידי			HAVE RECI						
DIGI	VDD 1	CLAIMLIN	15 100	IAVE ALCI	31VED.					
	t									
	8							-		_
		_								
WHICH	H TREA	TMENTS	HAVE BE	EN MOST I	BENEFICI	IAL?				
011 1	CONTE	OF 1 +		THAT I	W GTONI	ETCAN		MODI	TCAT	TONS
MADE	TO YO	UR HOME	HAVE B	TIMATE HO BEEN IN IN	PROVINC	YOUR	HEALTH			
impon	rtant,	1 is n	ot very	importan	nt ) CIP	RCLE CI	NE:			
,	5 VERY		4	3 SOMEWI	ነልጥ	2		,	1 IOT	
	PORTAN	г		IMPOR					ORTAN	ГТ <sub>.</sub>
		OTHER UR HEAL		THAT HAY	VE BEEN	MORE S	SIGNIFI	CANT	IN	IM-

APART FROM MODIFICATIONS MADE TO YOUR HOME, LIST OTHER CHANGES HAVE YOU MADE TO YOUR LIFESTYLE:

#### COMPARISON OF ILLNESS BEFORE AND AFTER MODIFICATIONS TO HOME

FREQUENCY OF ATTACKS OF "CHIEF COMPLAINT":

BEFORE:	Daily	AFTER: Daily		
	<pre> times/week times/month</pre>	times/week		
	Other	Other		

LENGTH OF ATTACKS:

BEFORE:	minutes	AFTER:	minutes
	hours		hours
	days		days
	weeks		weeks
	Other	C	ther

WHAT SYMPTOMS, IF ANY, REMAIN BETWEEN ATTACKS:



### REVIEW OF SYSTEMS

( CHECK PAST AND CURRENT SYMPTOMS)

SKIN: \_\_\_eczema, \_\_\_acne, \_\_\_hives, \_\_\_herpes, \_\_\_fungal infection, \_\_\_itches, \_\_\_dry, \_\_\_oily, \_\_\_lumps, \_\_\_bruising, \_\_\_swelling, \_\_\_peeling, \_\_\_boils.

IS YOUR SKIN SENSITIVE TO \_\_\_\_\_\_sun, \_\_\_\_fabrics, \_\_\_\_detergents, \_\_\_\_\_other.

LIST AREAS OF SKIN INVOLVED:

HEADACHE: \_\_\_\_constant, \_\_\_\_episodic, \_\_\_\_steady, \_\_\_\_throbbing, \_\_\_\_sharp, \_\_\_dull, \_\_\_slow onset, \_\_\_sudden, \_\_\_\_forehead, \_\_\_\_back of head, \_\_\_right side, \_\_\_\_left side, \_\_\_\_face, \_\_\_\_lasts minutes, \_\_\_lasts seconds, \_\_\_lasts hours, \_\_\_\_lasts days, \_\_\_clears without treatment, \_\_\_clears with treatment, \_\_\_visual symptoms, \_\_\_nausea, \_\_\_vomiting, \_\_\_\_neck pain, \_\_\_runny nose, \_\_\_tearing of eye.

- EYES: \_\_\_\_itchy, \_\_\_dry, \_\_\_dark circles, \_\_\_blood-shot, \_\_\_\_burning, \_\_\_watery, \_\_\_pain, \_\_\_swelling, \_\_\_light sensitive, \_\_\_blurred vision, \_\_\_mucous in eyes
- EARS: \_\_\_hearing loss, \_\_\_itchy inside, \_\_\_pressure, \_\_\_drainage, \_\_\_pain, \_\_\_ringing, \_\_\_\_ sense of imbalance, \_\_\_dizziness, \_\_\_infections.
- NOSE: \_\_\_\_itches, \_\_\_sneezes, \_\_\_loss of smell, \_\_\_burns, \_\_\_post nasal drip, \_\_\_blocks, \_\_\_bleeds, \_\_\_blisters, \_\_\_crusts, \_\_\_sinus infections, \_\_yellow mucous.

ARE NOSE SYMPTOMS PRESENT ALL YEAR ROUND? \_\_\_\_YES, \_\_\_\_NO WORST SEASON: \_\_\_\_spring, \_\_\_summer, \_\_\_fall, \_\_\_winter.

- MOUTH & THROAT: \_\_\_\_cracked lips, \_\_\_sore tongue, \_\_\_swollen glands, \_\_\_hoarseness, \_\_\_cold-sores, \_\_\_teeth pain, \_\_\_bad taste, \_\_\_bad breath, \_\_\_sore throats, \_\_\_difficulty swallowing.
- HEART: \_\_\_\_rapid heart, \_\_\_\_skipped beats, \_\_\_\_murmurs, \_\_\_\_chest pains, \_\_\_\_shortness of breath.
- LUNGS: \_\_\_\_wheezing, \_\_\_cough, \_\_\_bronchitis, \_\_\_pneumonia, \_\_\_pleurisy, \_\_\_shortness of breath.

STOMACH/BOWEL: \_\_\_heartburn, \_\_\_bloating, \_\_\_poor appetite, \_\_\_\_cramping, \_\_\_constipation, \_\_\_ulcer, \_\_\_nausea, \_\_\_indigestion, \_\_\_vomiting, \_\_\_diarrhea, \_\_\_hemorrhoids, \_\_\_gallbladder trouble, \_\_\_parasites, \_\_\_gas, \_\_\_blood in stools, \_\_\_mucous in stools, \_\_\_anal pain, \_\_\_stomach aches.

KIDNEY/BLADDER: \_\_\_\_difficult urination, \_\_\_\_burning urination, \_\_\_\_genital herpes, \_\_\_\_kidney disease, \_\_\_\_kidney stones, \_\_\_\_incontinence, \_\_pass blood, \_\_\_ impotence (men only), \_\_\_\_prostate trouble (men only).

MUSCULOSKELETAL: \_\_\_muscle pain, \_\_joint pain, \_\_joint swelling, \_\_\_morning stiffness, \_\_back pain, \_\_\_neck pain.

ENDOCRINE: \_\_\_\_enlarged thyroid, \_\_\_\_overactive thyroid, \_\_\_\_underactive thyroid, \_\_\_\_diabetes, \_\_\_\_excessive weight gain, \_\_\_\_excessive weight loss, \_\_\_\_abnormal thirst, \_\_\_\_increased appetite. NEUROLOGICAL: \_\_\_limb weakness, \_\_\_numbness, \_\_\_tremor, \_\_\_blurred vision, \_\_\_double vision, \_\_\_convulsions, \_\_\_lack of coordination, \_\_\_dizziness, \_\_\_vertigo, \_\_\_blackouts, \_\_\_fainting spells, \_\_\_stroke.

PSYCHOLOGICAL: \_\_\_\_amnesia, \_\_\_\_forgetful, \_\_\_anxious, \_\_\_\_tense, \_\_\_depression, \_\_\_hyper, \_\_\_shaky, \_\_\_\_unable to concentrate, \_\_\_\_short attention span, \_\_\_\_unable to reason, \_\_\_nervous, \_\_\_withdrawn feeling, \_\_\_\_nervous breakdown, \_\_\_cry often, \_\_\_\_aggressive, \_\_\_irritable, \_\_\_easily angered, \_\_\_\_restless, \_\_\_difficulty falling asleep, \_\_\_\_difficulty staying asleep, \_\_\_\_nightmares, \_\_\_\_difficulty staying awake, \_\_\_considered suicide, \_\_\_\_often unhappy, \_\_\_have had visions, \_\_\_heard voices.

SUBSTANCE USE: \_\_\_have overused drugs, \_\_\_been addicted to drug, \_\_\_overused alcohol, \_\_\_been addicted to alcohol, \_\_\_smoked cigarettes, \_\_\_still smoking.

WOMEN ONLY: \_\_\_breast soreness, \_\_\_breast lumps or cysts, \_\_\_irregular periods, \_\_\_heavy flow, \_\_\_premenstrual symptoms, \_\_\_painful periods, \_\_\_menopause.

PLEASE LIST ALL CURRENT MEDICATIONS: \_\_\_\_\_

•

PLEASE LIST ALL PAST MEDICATIONS: \_\_\_\_\_

LIST ALL MEDICATIONS WITH ADVERSE OR ALLERGIC REACTIONS:

LIST ALL HOSPITALIZATIONS, OTHER ILLNESSES AND OPERATIONS YOU HAVE HAD:

÷.

LIST ALL SPECIAL INVESTIGATIONS YOU HAVE HAD ( x-rays, scans, blood tests, etc.):

.

LIST ALL TYPES OF ALLERGY AND SENSITIVITY TESTING YOU HAVE HAD:

#### INHALANT AND CHEMICAL SENSITIVITIES

CHECK IF YOU HAVE HAD SYMPTOMS FROM:dust,cats,dogs, birds,mildew,molds,potted plants, other indoor pets,grain dust,pollen,	6
grass,tobacco smoke,wood smoke,perfume,	
alcohol,tar,gasoline fumes,diesel fumes,	
exhaust fumes,paints,dyes,plastics,	
<pre>turpentine,dry cleaning,disinfectants,</pre>	
mothballs,floor wax,furniture polish,	
solvents,varnish,photocopy paper,ink,	
newspapers,air pollution,foam rubber,	
overstuffed_furniture,carpeting,curtains,	
natural gas,room deodorizers,ammonia,	
<pre>synthetic fabrics,pesticides,herbicides,</pre>	
toothpaste,aerosols,cooking odors,	
<pre>chlorinated tap water,felt-tip pens,vinyl.</pre>	

#### FOOD ALLERGIES AND SENSITIVITIES

LIST ALL FOODS WHICH CAUSE SYMPTOMS IN ORDER OF SEVERITY:

CHECK ITEMS WHICH APPLY: \_\_\_\_overeat foods, \_\_\_\_crash diets, \_\_\_\_skip meals, \_\_\_eat daytime snacks, \_\_\_eat junk-food, \_\_\_\_crave certain foods, \_\_\_crave certain beverages, \_\_\_\_avoid certain foods, \_\_\_rotation diet, \_\_\_vegetarian, \_\_\_\_can only eat organic foods, \_\_\_purified water only, \_\_\_\_drink coffee, \_\_\_drink tea, \_\_\_drink soft drinks.

LIST PARTICULAR HABITS, PROBLEMS, OR PECULIARITIES CONCERNING YOUR FOOD INTAKE:

٩.

#### FAMILY HISTORY

CHECK ANY OF THE FOLLOWING ILLNESSES THAT HAVE OCCURRED IN YOUR FAMILY: \_\_\_\_\_\_\_aasthma, \_\_\_\_hayfever, \_\_\_\_epilepsy, \_\_\_\_eczema, \_\_\_\_\_asthma, \_\_\_emphysema, \_\_\_kidney disease, \_\_\_\_hives, \_\_\_\_\_heart disease, \_\_\_\_alcoholism, \_\_\_diabetes, \_\_\_\_\_high blood pressure, \_\_\_tuberculosis, \_\_\_\_depression, \_\_\_\_\_schizophrenia, \_\_\_arthritis, \_\_\_leukemia, \_\_\_ulcers, \_\_\_\_anemia, \_\_\_stroke, \_\_\_thyroid problems, \_\_\_\_migraines, \_\_\_\_\_multiple sclerosis, \_\_\_other.

EXPLAIN: