

## **REVIEW of the NOVA SCOTIA ENVIRONMENTAL HEALTH CENTRE**

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## **I. BACKGROUND**

**An Environmental Hypersensitivity Advisory Committee was created by the Nova Scotia Minister of Health in 1986. The Committee recognized that people were complaining of environmental sensitivity but were unable to substantiate diagnostic criteria that would identify the condition. It recommended setting up a multidisciplinary group to investigate and manage sufferers from this condition. The Government of Nova Scotia underwrote the training in environmental medicine of a local physician Dr. G.H. Ross at the Environmental Health Centre in Dallas Texas. In September 1990, the Nova Scotia Environmental Medicine Clinic was developed as a pilot project by the Nova Scotia Department of Health, in cooperation with Dr. Ross and the Environmental Health Centre in Dallas. The Clinic was located in the Bethune Building at the Victoria Hospital in Halifax and was to provide investigation and treatment for people considered to have environmental sensitivity. The demand exceeded the capacity of the Clinic, and by April 1994 there were 286 patients in active treatment, with 650 on the waiting list.**

**In December 1993, the Nova Scotia Minister of Health supported the formation of the Nova Scotia Centre for Environmental Health which had been formally proposed by Dr. John Ruedy, Dean, Faculty of Medicine, Dalhousie University. The three main functions were to be clinical diagnosis and management of patients suffering from environmental health problems; research into clarifying the diagnosis of environmental sensitivity and into evaluating the effectiveness of the available treatments; and education about environmental illness for physicians, sufferers and the general public. In March 1994 Dr. Roy Fox was appointed Interim Clinical Director of the Nova Scotia Environmental Medicine Centre. In November 1996 a contract was signed between the Nova Scotia Department of Health and Dalhousie University in which the Department agreed to fund the Centre and the University to operate the Centre, to undertake research on the problem, to govern the Centre and to be responsible for all staff and operating expenses. No mention was made of treatment, rehabilitation, or issues of governance or liability associated with the operation of an active treatment centre. The Centre moved to a dedicated building in May 1997, located in Fall River.**

**An internal review of the Centre was conducted in November 1997 after the initial 6 months of operation. In January 1998, the Environmental Hypersensitivity Advisory Committee completed a report based on a thorough review of the medical literature and interview of experts in which they indicated a need for targeted research into the causes and treatment and offered guidelines for management. Two critiques of this report appeared later.**

**The provincial government elected in July 1999, made a commitment to an external review of the Centre as part of its platform.**

Parallel to the foregoing, public awareness of environmental sensitivity was heightened by the appearance in 1989 of environmentally attributed complaints among close to half of the 1100 staff workers of the 2 year old Veterans' Memorial Building at Camp Hill Medical Centre. Specific air quality problems were identified and corrected over several years and a coordinated return to work programme was initiated in June 1993. The costs to the Province of dealing with this problem have been estimated to be 20 million dollars, including consultations to identify the causes, remedial actions, and compensation of workers. These costs continue to grow due to about 90 workers not yet having been rehabilitated. WCB has provided compensation only for workers with job-related asthma or dermatitis, and denied full disability benefits for illness in which no objective causal linkage could be established with workplace.

## **II. TERMS of REFERENCE for REVIEW OF ENVIRONMENTAL HEALTH CENTRE**

### **1. PURPOSE**

to assist Dalhousie University in determining if the Centre's current practices are congruent with scientifically-recognized, national and international guidelines and accepted practices for research into the diagnosis and treatment of "environmental intolerance of uncertain etiology".

### **2. AUTHORITY**

Nova Scotia Department of Health

### **3. SPECIFIC OBJECTIVES**

The consultants should also specifically address and comment on the following issues and policy considerations:

- ? whether the EHC is properly constituted, and institutionally-related, to carry out its mandate safely and effectively;
- ? whether there is sufficient scientific research evidence to expand the EHC's mandate to offer treatment;
- ? the clinical criteria for access to the services, or treatments, offered through EHC and the conditions under which they may be provided.

### **4. STEERING/ADVISORY COMMITTEE**

A Steering/Advisory Committee, within the N.S. Department of Health, will assist the consultants with the review. Membership of the Steering Committee will include:

- ? Provincial Medical Officer of Health or Associate Provincial Medical Officer of Health;
- ? Director, Acute Care Programs, DOH.

### **III. ON SITE BRIEFINGS and INTERVIEWS**

- 1. May 24 2000, 8:00-8:45 am meeting at Department of Health boardroom in Halifax, with Deputy Minister Dr. Tom Ward.**
- 2. May 24 2000, 9:30 am-3:15 pm, meetings at Environmental Health Centre, Fall River. A tour of the Centre was provided and briefings and interviews were held with the following:**
  - I. Dr. Roy Fox, EHC Clinic Director;**
  - ii. Dr. Michel Joffres, EHC Director of Research;**
  - iii. Dr. Jonathan Fox, EHC Clinic Physician;**
  - iv. Anne Murphy, EHC Administrator;**
  - v. Susan Coldwell, EHC Rehabilitation Co-ordinator;**
  - vi. Lauren Marsh-Knickle, EHC Psychologist;**
  - vii. Elizabeth Berlasso, Director of EHC Body/Mind Awareness Program;**
  - viii. Audrey Barrett, Karen Archibald and Debbie Lawrence, EHC nurses;**
  - ix. Bridgette Houwelling, Theresa Thomas and Patricia Tingley, EHC Community Advisory Resource for the Environmentally Sensitive Committee**
  - x. Rona Cathcart**
- 3. May 24 2000, 4:15-5:30 pm, meetings at Department of Health boardroom in Halifax. Briefings and interviews were held with the following:**
  - I. Karen Robinson and Eric Slone, Nova Scotia Allergy & Environmental Health Association;**
  - ii. Dr. Patricia Beresford and Dr. Elizabeth Gold.**
- 4. May 25 2000, 7:45 am-3:45 pm, meetings at Department of Health boardroom in Halifax. Briefings and interviews were held with the following:**
  - I. Dr. John Ruedy, VP Research, QEII Health Sciences Centre (former Dean of Medicine, Dalhousie University) by teleconference;**
  - ii. Dr. Noni Macdonald, Dean of Medicine, Dalhousie University;**
  - iii. Dr. Robert Strang, Medical Officer of Health, Central Region Nova Scotia;**
  - iv. David Wimberly, Shirley Arsenault, Maureen Reynolds and Crystal Williams, Citizens' Task Force on Environmental Sensitivities & Health of Nova Scotia;**
  - v. Brian MacDougall, Finance Department, IWK-Grace Health Centre**
  - vi. Dr. David MacLean, Chair, Community Health & Epidemiology, Dalhousie University;**

- vii. **Alison Edwards, Director of Finance and Carl Stevens, Assistant Director of Finance, Dean of Medicine's Office, Dalhousie University;**
- viii. **Deputy Minister Dr. Tom Ward.**

#### **IV. DOCUMENTS REVIEWED**

**A number of documents were provided to the reviewers preceding, during and following the on site visit. These have been grouped in the following categories, by date of origin.**

##### **1. BACKGROUND and STAKEHOLDER DOCUMENTS**

- i. **18-12-86 Report of the Environmental Hypersensitivity Advisory Committee to the Minister of Health Province of Nova Scotia (Dr. G.R. Langley chair).**
- ii. **18-12-86 Response to Recommendations of Advisory Committee on Environmental Hypersensitivity (Dr. J. Patricia Beresford).**
- iii. **23-02-87 letter to Dr. Ronald S. Russell Minister of Health, from Dr. J.P. Beresford, re Report, Advisory Committee on Environmental Hypersensitivity.**
- iv. **05-93 Report of the Evaluation of Camp Hill Hospital Staff Affected by the "Veteran's Memorial Building Syndrome". Final Report. Prepared by The Nova Scotia Environmental Medicine Clinic and The Environmental Health Centre - Dallas.**
- v. **03-96 Draft Report in the Matter of the Complaint of the Camp Hill Environmental Victims Society (CHEVS) Against the Workers' Compensation Board of Nova Scotia. Office of the Ombudsman.**
- vi. **24-06-97 Report of the Advisory Committee on Environmental Sensitivity to the Deputy Minister of Health Province of Nova Scotia.**
- vii. **05-01-98 Report on Environmental Hypersensitivity in response to Report of the Advisory Committee to the Minister of Health, Province of Nova Scotia, January 5, 1998. Submitted by Dr. Patricia Beresford BA MD.**
- viii. **02-03-98 Response to the "Langley Report" entitled "Report of the Advisory Committee on Environmental Hypersensitivity." From The Nova Scotia Environmental Health Centre, Faculty of Medicine, Dalhousie University, by Roy A. Fox B.Sc., MD, FRCPC, FRCP, FACP., Michel Joffres MD, PhD, and John Ruedy MD, FRCPC.**
- ix. **26-05-98 ASSEMBLY DEBATES, RESOLUTION No. 115.**

- x. 12-99 HTB Health technology brief, Multiple Chemical Sensitivity: etiology, epidemiology, diagnosis and treatment. Paula Corabian, Christa Harstall, Alberta Heritage Foundation for Medical Research.
- xi. 24-12-99 Affidavit of Dr. Abba Terr, PhD
- xii. 29-12-99 Affidavit of Dr. Ronald Gots, M.D., PhD
- xiii. 29-12-99 Affidavit of Dr. Ronald Gots, PhD
- xiv. 30-12-99 Affidavit of Herman Staudenmayer.
  
- xv. 22-02-00 Appeal Decision, NOVA SCOTIA WORKERS' COMPENSATION APPEALS TRIBUNAL 98-146-AD.
- xvi. 07-03-00 NOVA SCOTIA Department of Health Backgrounder Nova Scotia Environmental Health Centre.
- xvii. 20-03-00 A History of Three Facilities Established by the Department of Health, Province of Nova Scotia, for Residents with Complaints of Environmental Illness/Hypersensitivity. David T. Janigan M.D., with revisions of 15-05-00.
- xviii. 10-04-00 letter to The Honourable Jamie Muir, Minister of Health, from the Nova Scotia Allergy and Environmental Health Association, President Frank Metzger.
- xix. 25-04-00 letter to The Honourable Jamie Muir, Minister of Health, from the Nova Scotia Allergy and Environmental Health Association, President Frank Metzger.
- xx. 26-04-00 press release from the Nova Scotia Allergy and Environmental Health Association, President Frank Metzger.
- xxi. 06-05-00 letter to Nova Scotia MLA's, from the Nova Scotia Allergy and Environmental Health Association, President Frank Metzger.
- xxii. 09-05-00 letter to The Honourable Jamie Muir, Minister of Health, from Earle L. Reid, M.D., F.R.C.P.(C)., F.A.C.C., F.A.C.P.
- xxiii. 10-05-00 letter to the Nova Scotia Allergy and Environmental Health Association, President Frank Metzger from The Honourable Jamie Muir, Minister of Health.
- xxiv. 12-05-00 letter to The Honourable Jamie Muir, Minister of Health, from David Morse MLA Kings South.
- xxv. 24-05-00 Presentation from the Community Advisory Resource for the Environmentally Sensitive, including a series of recommendations.
- xxvi. 24-05-00 Presentation from the Nova Scotia Allergy and Environmental Health Association, Volume 1 (containing 13 sections, each consisting of 1-3 documents); Volume 2 (containing two administrative letters from the EHC and a series of letters from concerned patients).
- xxvii. 24-05-00 PRESENTATION to the REVIEW COMMITTEE by Dr. Patricia

- Beresford and Dr. Elizabeth Gold, including extensive background materials.
- xxviii 25-05-00 The Nova Scotia Environmental Health Centre: notes prepared by John Ruedy for interview with Review Committee
  - xxix. 25-05-00 Letter from Dr. Noni Macdonald, Dean, Faculty of Medicine, Dalhousie University: Re Review of the Nova Scotia Environmental Health Centre
  - xxx. 25-05-00 Presentation to the Review of the Environmental Health Centre by the Regional Medical Officers of Health.
  - xxxi. 25-05-00 Submission from Citizen's Task Force on Environmental Sensitivities and Health of Nova Scotia, including material provided by the Invisible Disabilities Association of Canada
  - xxxii. 05-00 A series of patient letters supportive of the EHC.
  - xxxiii. 05-00 Newspaper clippings regarding the coming EHC review.
  - xxxiv 07-06-00 Submission from Camp Hill Environmental Victims Society (CHEVS)
  - xxxv. 4 videotapes dealing with indoor air quality, environmental sensitivity and the Environmental Health Centre

## **2. DOCUMENTS PROVIDED by REPRESENTATIVES of the ENVIRONMENTAL HEALTH CENTRE**

- i. 20-11-96 THE NOVA SCOTIA ENVIRONMENTAL HEALTH CENTRE, Faculty of Medicine, Dalhousie University.
- ii. 16-12-96 Agreement between the Province of Nova Scotia represented by the Minister of Health and Faculty of Medicine, Dalhousie University (to operate the Nova Scotia Environmental Health Centre).
- iii. 14-11-97 Report of the Operational Review Committee.
- iv. 06-12-99 Proposed Annual Funding Report 2000/2001.
- v. 17-12-99 EHC Activity Report to Nova Scotia Minister of Health, with 12 Appendices.
- vi 17-01-00 letter from Dr. G.R. Langley to Dr. D.S. Reid Department of Health re EHC Activity Report.
- vii. EHC Clinical Program.
- viii. EHC Prioritization for Admission.
- ix. EHC Symptoms Questionnaire.
- x. Curriculum Vitae Dr. Roy A. Fox  
Dr. Michel R. Joffres  
Dr. Jonathan R. Fox
- xi. 24-05-00 Anne Murphy: Unique attributes and challenges of EHC for

- research.
- xii. 24-05-00 Susan Coldwell: The Nova Scotia Environmental Health Centre Rehabilitation Program.
  - xiii. 24-05-00 Elizabeth A. Berlasso: The Body/MInd Awareness Program (BMAP) at the Nova Scotia Environmental Health Centre.
  - xiv. 26-05-00 Reports of Patient Resource Usages at the Environmental Health Clinic 01-04-99 to 31-03-00.
  - xv. 29-05-00 EHC cost recovery information.
  - xvi. 30-05-00 letter from Dr. Robert G. Peterson to Elizabeth Barker requesting additional information regarding EHC research programme.
  - xvii. 12-06-00 reply from Elizabeth Barker to Dr. Robert G. Peterson with responses from EHC members Anne Murphy and Dr. Michel R. Joffres.

## V. REVIEWERS' COMMENTS and RECOMMENDATIONS

### 1. GENERAL

The EHC is dedicated to trying to find the best way of helping a large number of Nova Scotians who are variably handicapped, some totally, by an illness for which no decisive case definition exists. We agree with others, that a logical descriptive name for this condition at the present time is idiopathic environmental intolerance (IEI).

We have been introduced to a large cross-section of stakeholders in the EHC via our on site briefings and interviews, as well as through the documents and newspaper articles provided to us. These can be grouped into five constituencies: a) Nova Scotia Department of Health representatives and Members of the Legislative Assembly; b) Dalhousie University Faculty of Medicine representatives; c) medical doctors in community practice, in government service and in teaching hospitals; d) IEI advocacy groups; and e) individuals who have IEI. Generally speaking, within and between these constituencies there is a wide range of views about the EHC. Despite this diversity, there seems to be an overall consensus that the EHC serves an important community need. The staff are committed to and doing important work for a patient population in need. If the EHC did not exist or was to be abandoned, the plight of those with IEI would be worsened. At the same time the EHC manifests certain weaknesses and problems.

Our mandate as reviewers is to identify those weaknesses and problems in the EHC that are the most important, and that would result in the EHC becoming more effective if practical remedies can be formulated.



## **2. GOVERNANCE AND ACCOUNTABILITY**

**It is important that the following issues regarding accountability be seen in perspective. The EHC has achieved a number of successes. They include: constructing an excellent physical facility; demonstrating a belief in their patients' problems and providing compassionate care; developing the trust of a segment of the patient community; and beginning to initiate a culture among both patients and caregivers, showing some receptiveness towards research and evidence-based practice.**

**There are however substantial remaining challenges. Foremost among these are issues surrounding mechanisms of accountability. These issues can be effectively addressed and ameliorated if there is a clearer understanding of the EHC mandate by both the Centre and its stakeholders. The latter group, at minimum, should include the Faculty of Medicine of Dalhousie University, the Nova Scotia Department of Health, patients, advocacy groups, and the organized health care delivery system.**

**The reviewers are impressed that while these mechanisms are lacking, addressing them effectively offers the opportunity to achieve the full potential of the EHC. To succeed, mechanisms of accountability must be in place for the following four domains of activity:**

- i) fiscal**
- ii) academic**
- iii) patient care**
- iv) research.**

**i) FISCAL PRACTICES. An over-riding concern is the precise positioning and consequent reporting relationship of the EHC in the Faculty of Medicine. The EHC began as a free-standing unit "within" the Dean's Office, as opposed to being a division or unit within a department. In April of 1999, (then) Dean Ruedy placed the EHC within the Department of Community Health and Epidemiology. While this is a more appropriate strategy fiscally, both the Chair and the Dean's Office acknowledged that the principle focus was simply to ensure that there be a balanced budget. The pattern and priorities of expenditures were not addressed. While it is acknowledged that a budget statement for the past two years (1998-99 and 1999-2000) was provided within 24 hours of the review, the sense is that there is more of a disconnection between the EHC and the University than there should be. The current practice is in the interest of neither. The will to improve the status is quite evident (Dean Noni Macdonald) and certainly achievable.**

It should be noted that the issue of user fees was raised. The reviewers were assured that this occurred only on a cost-recovery basis, for educational materials (tapes, booklets, etc) and resulted in a small net loss. Subsequent to the review, comprehensive financial statements were received. While reassuring, it is essential that annual reviews (at minimum) are conducted and made available for review or audit by third parties.

ii) **ACADEMIC PRACTICES.** At present there are two staff members with academic appointments in the Faculty of Medicine, Dr. Roy Fox and Dr. Michel Joffres. Dr. Fox's appointment is with the Department Medicine and Dr. Joffres' is with the Department of Community Health and Epidemiology. A cross appointment for Dr. Roy Fox is intended but not yet accomplished.

Given the importance of the academic mission of research and education, the status quo requires change. There were several questions that were raised by the review:

- a) Is the Department of Community Health and Epidemiology the best choice as a home for the EHC? Would the Department of Medicine or Family Medicine be more appropriate?
- b) Is there a regular rigorous annual review and planning meeting between EHC faculty and their Department chairs?
- c) Should other professional staff of the EHC have academic appointments? Could Dr. Jonathan Fox be appointed to the Faculty of Medicine? Should Susan Caldwell, Lauren Marsh-Knickle and Elizabeth Berlasso be considered for academic appointments to the Faculty of Health Professions?

It is the reviewers' perception that research, education and patient care would all benefit if all the foregoing were considered and acted upon. At present, the health professionals (medical, nursing and others) of the EHC are isolated, focussed on patient care and represent an under-utilized academic resource. On the part of EHC staff, there would be benefit from more regular interaction with colleagues and students. With the foregoing strategies, EHC would begin to be "main streamed" and academic accountability achieved.

iii) **PATIENT CARE PRACTICES.** The EHC is an ambulatory care setting. The Centre is seen as a crucial resource for a large population of ill people identified as having idiopathic environmental intolerance, with about 500 physicians having referred patients and 1300 referrals having been seen here or at earlier locations since 1992. There are nearly 600 active patients; 233 new patients were seen during a recent 8 month period which ended with 558 still in waiting. Clearly the EHC has been successful in

many respects as outlined earlier.

Absent, however, are normal mechanisms of patient care accountability, that is, the standards that would be required by the Canadian Council for Health Services Accreditation. It is not possible to have a clear picture of inputs, outputs or outcomes. It is essential to trace how many patients are: on the waiting list ranked according to health status and priority; duration of delay before being first seen; receiving which modalities of treatment including frequency and duration; discharged monthly and annually; withdrawing from care or while waiting; improved, unchanged or worse; satisfied or otherwise; etc.

This represents a minimum data set and is crucial to further the understanding of environmental related illnesses. It is the basis for more definitive research and better care and should also be a requirement for continuing accreditation. Finally, it is essential information for reassuring the many supporters of the EHC, and their funders as well as critics. In order to achieve this goal, a formal link would be beneficial with an existing hospital (eg Queen Elizabeth II) and/or the proposed Capital District Health Authority.

iv) **RESEARCH PRACTICES.** The EHC has not had to compete for research funds and so has not been strictly required to satisfy the usual peer review requirements. This process ordinarily would involve the preparation of detailed proposals for internal and/or external critiquing, at both the scientific and human ethics level. Such proposals would consist of a defensible hypothesis, objective, study design, data collection methodology, consideration of feasibility, sample size justification, description of results analysis, and a time line including milestone progress reports. These proposals would generally be signed off by the researcher, the department, the human ethics establishment and the administering institution such as the hospital or university, before being introduced into the external review process. This form of peer review process evolved over the past 40 years or so and ensures that all required minimum and optimum requirements are met. Funding would ordinarily be provided on a competitive and prioritized basis, and ongoing support would be contingent on adequate progress being reported at milestone intervals.

The foregoing process would conventionally become activated whenever intramural or extramural research funds are being requested. Since the research activities of the EHC have been supported through its operating budget, this process has been largely by-passed. Nevertheless, the process mechanisms exist institutionally and will appear as soon as the

fiscal and academic practices described above are introduced.

v) **ACCOUNTABILITY BENEFITS.** The following warrants emphasis. Accountability should be constructed to capture current strengths and enhance the EHC's capability through partnerships with the academic sector, the broader health care community within Halifax and Nova Scotia, as well as linkages nationally and internationally. A robust enterprise can thus be created to deal with a very perplexing health challenge by developing an appropriate balance between necessary independence and freedom of enquiry on the one hand, with strong and transparent accountability on the other.

#### **4. ENVIRONMENTAL HEALTH CENTRE LEADERSHIP**

The current leadership of the Centre consists of parallel positions of Clinic Director and Director of Research.

i) **CLINIC DIRECTOR.** The Clinic Director is to be praised for the successful development of the EHC physical plant, as well as the implementation of the Clinic that has provided evaluative and support services for a large number of environmentally troubled patients. Nevertheless, the EHC inherited a lengthy waiting list and prospective patients have historically had to expect a delay of up to several years before they could be seen, unless their need was considered to be among the more critical. This long waiting period is high among the major complaints of both the environmental advocacy groups and individual afflicted people. Equally contentious has been the widespread dissatisfaction and serious deterioration of public relations resulting from the discontinuation of certain medical services. Questioning the appropriateness of these services by the Clinic Director was and is justified, but the mode and speed of their withdrawal seems to have resulted in considerable difficulty both at the personal level for many patients, and at the public relations level for the EHC. One finds among the many patients' letters responding to these measures, a widespread expression of strongly troubled feelings, including abandonment, frustration, mistrust and animosity.

The clinical approach of the EHC is appropriately directed towards the use of a combination of conventional symptomatic measures, as well as education in lifestyle changes including environment and diet. Where allergy is important, enzyme potentiated desensitization may be used, but has not been sufficiently validated. Some patients may be entered into a

**study of the use of intravenous magnesium, which is an unvalidated approach and although highly acclaimed anecdotally, possible long term risks are a concern. Various forms of counselling and individual and group therapy are utilized depending on the patient's circumstances, including stress management conditioning, and a back-to-work rehabilitation programme. A number of empirical physical therapy procedures also may be used including yoga, meditation, exercise and sauna. There has been the intention to study the efficacy of various of these approaches. The emphasis on back-to work rehabilitation has been particularly commendable**

**ii) DIRECTOR of RESEARCH. Praise is due for one important research report which appeared in a respected peer review journal. The inception and some data collection for this study preceded the opening of the EHC. There has otherwise been an absence of significant research accomplishments since the opening of the EHC, although some descriptive observations have appeared in the published proceedings of a scientific meeting dealing with environmental themes. Significant intramural funding has been available for research, but studies formulated coincident with the opening of the Centre in 1997 are yet to be seriously launched. In fact, the flagship study of intravenous magnesium therapy is under consideration to be cancelled. Various extenuating circumstances are described in explanation of these difficulties, which one can appreciate. Nevertheless, one justifiably expects that conditions which interfere with the realization of achievable major objectives ought to be overcome.**

**There remains a critical need to conduct the type of research on IEI that was visualized when the EHC was being planned. It is further important to consider the possibility of broadening the research focus in the direction of the '1999 Consensus Statement on Multiple Chemical Sensitivity' (Arch Envir Hlth 54:147-9, 1999). This statement made the plea that future research on IEI must occur jointly or collaboratively with that on chronic fatigue syndrome and fibromyalgia, since all three problems have been recognized for some time to show considerable overlap.**

**iii) QUESTIONS. In view of the foregoing problems and considerations, the reviewers question whether the original leadership model for the Centre should be reconsidered. Should there be one director overall, having skills that would facilitate the steering of the clinical, research and public relations activities of the EHC, as well as the forging of collaborative links with other clinical divisions dealing with the extended areas of fibromyalgia and chronic fatigue syndrome?**

If feasible, such a change would result in strengthening and integrating the key activities of the EHC. Equally, the promotion of collaborative research with other medical specialists could open significant opportunities for all concerned, and allow the development of proposals that would be locally and nationally competitive in a number of research granting organizations. Such an initiative would also provide a major first step in leading the EHC out of academic, clinical and research isolation. The EHC would have considerable to offer in return, and would continue to have research requirements oriented towards evaluating its empirical modes of treatment.

## **VI. SUMMARY of REVIEW and RECOMMENDATIONS**

### **1. SUMMARY**

The reviewers were presented with a diversity of views about the EHC via informative on-site briefings, interviews and documents provided by a broad cross-section of stakeholders. There was nevertheless a clear consensus that the EHC is serving a major need in striving to relieve the suffering of residents of Nova Scotia who have idiopathic environmental intolerance. The EHC further has the potential to contribute to the understanding of this serious and perplexing medical problem and to help those afflicted obtain even better treatment in the future. The EHC has made significant progress since its inception in 1997, but realizing its full potential requires the resolution certain weaknesses and problems.

### **2. RECOMMENDATIONS**

- i) The EHC should continue with current funding levels until further developments warrant change.**
- ii) Accountability must be improved and to that end fiscal, academic, patient care and research practices must be brought up to current national standards and positioned to evolve with emerging needs.**
- iii) The research mission must occupy a position of priority which is equal to that currently attached to patient care.**
- iv) The leadership of the EHC must be addressed with either professional development support for the incumbents or a change of personnel, congruent with the evolution of EHC needs as well as usual university and hospital practices.**

## **VII. REVIEWERS' SPECIFIC RESPONSE TO ITEM #3 of the TERMS OF REFERENCE**

**1. The extent to which the term “scientifically-recognized” can be applied to the practices of diagnosis or treatment of IEI is arguable, since there is very little evidence-based information on this subject. There are only consensus diagnostic guidelines, which the EHC utilizes. The approach to treatment is largely arbitrary and in some instances is based on a common sense approach. The EHC has evaluated the usefulness of one of the major foundations of diagnosis and treatment of IEI, antigen provocation-neutralization; they found this to be sufficiently unreliable that they have discontinued its use. The EHC also has commendably discontinued the routine use of intravenous treatment with a cocktail of magnesium and other substances, another arbitrary mainstay in the treatment of IEI, and have been limiting its use to a peer-reviewed research protocol for evaluation of its efficacy. Although these actions elevate the EHC to a leadership role in the IEI field, they have resulted in considerable alienation at the community level in Nova Scotia, among both individual IEI patients and the advocacy groups.**

**2. Whether the EHC is properly constituted and institutionally-related is dealt with extensively under Governance and Accountability in section V. 2.**

**3. Whether there is sufficient scientific research evidence to expand the EHC's mandate to offer treatment, requires a slightly indirect answer. The EHC is having trouble satisfying the current demands for patient evaluation and treatment. The Clinic requires a major overhaul before any increase in their clinical mandate can be considered.**

**4. The EHC should confine its clinical services to documenting and characterizing its clinical population, providing conventional symptomatic therapies and refraining from the use of arbitrary treatments unless these are adequately justified and the subject of properly documented, scientifically reviewed and approved protocols. Various services and non-invasive treatments which are in use, such as psychological therapy, return to work rehabilitation, sauna and others described above, could be considered within the scope of conventional, non-invasive, symptomatic therapies. Nevertheless, it is inappropriate for even these to be administered in the absence of either entrance criteria, or methodology to determine their usefulness and to identify those patients most likely to benefit.**