



NATIONAL ME/FM ACTION NETWORK

JOURNAL OF ACHIEVEMENTS

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...the Goose Story next

2010-1993

Our Logo:

Canadian geese flying in formation portray working cooperatively and supporting each other. It is based on "The Goose Story".

The Goose Story

*Next Fall, when you see Geese heading South
for the Winter . . . flying along in a 'V' formation
you might consider what Science has discovered.*

*As each bird flaps its Wings, it creates
an Uplift for the bird immediately Following.
By flying in 'V' formation the whole flock adds
at least 71% greater flying range,
than if each bird flew on its own.*

**PEOPLE WHO SHARE A COMMON DIRECTION
AND SENSE OF COMMUNITY
CAN GET WHERE THEY ARE GOING MORE QUICKLY AND EASILY
BECAUSE THEY ARE TRAVELING ON THE THRUST OF ONE ANOTHER.**



*When a goose falls out of Formation
It suddenly feels the Drag and Resistance
of having to go it alone . . and quickly
gets back into Formation to take Advantage
of the lifting power of the bird in front.*

**IF WE HAVE AS MUCH SENSE AS A GOOSE
WE WILL STAY IN FORMATION WITH THOSE
WHO ARE HEADED THE SAME WAY WE ARE.**

***When the Head Goose gets tired it rotates back
in the Wing . . and another goose flies Point.***

**IT IS SENSIBLE TO TAKE TURNS DOING
DEMANDING JOBS
WITH PEOPLE OR WITH GEESE FLYING SOUTH.**

***Geese honk from behind to Encourage those up
Front
to keep up their Speed.***

**WHAT DO WE SAY WHEN WE HONK FROM
BEHIND?**

***Finally . . . and this is important, when a goose gets
sick,
or is wounded by Gunshots, and falls out of
Formation,
two other Geese fall out with that goose and
follow it down to lend Help and Protection.***

***They stay with the Fallen Goose until it is able to fly
or until it Dies; and only then do they launch out on
their own
or with another Formation
to catch up with their Group.***

**IF WE HAVE THE SENSE OF A GOOSE
WE WILL STAND BY EACH OTHER LIKE THAT.**

Source Unknown



Who We Are

NATIONAL ME/FM ACTION NETWORK

COMMITTEE MANAGEMENT

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Lydia E. Neilson, M.S.M. - Founder, Chief Executive Officer
Margaret Parlor - President and Treasurer
Odile Gerin - Advisor to CEO

BOARD OF DIRECTORS

Philipa Corning, Ph.D., B.Sc.

Lynda Cregan

Judith Day

Joyce George

Sherri Todd

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Dr. Alison Bested

Dr. Richard Bruno

Dr. Bruce Carruthers

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Honorary International Adviser For ME/CFS

Dr. Elizabeth Dowsett

Essex, United Kingdom

Special Advisor on Parallels between ME/CFS,
FMS & Post Polio

Dr. Richard Bruno

Englewood, New Jersey, USA

LEGAL COUNSEL

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Scher Law Group

We would like to acknowledge Lynda Cregan, Director of Special Projects, in the preparation of this document.

Our Mission

The National ME/FM Action Network is a Canadian, registered, non-profit organization dedicated to advancing the recognition and understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS) through education, advocacy, support, and research.

The Network seeks to effect positive change in the attitudes, policies, and practices of government, medical governing bodies, business, the media, and the general public.

The National ME/FM Action Network works cooperatively with all support groups across Canada and the U.S. as well as internationally, not only for ME/CFS and FM communities but also for related illnesses.

As our name implies, we are an ACTION organization. We do not react to unfairness, we act for change. We are actively involved in issues that affect individuals who have myalgic encephalomyelitis / chronic fatigue syndrome and fibromyalgia syndrome. We assist our membership through education, advocacy, support, and research.

Our Motto

"People helping people help themselves."

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Our Plans

The National ME/FM Action Network has been chosen to host *the first International IACFS/ME Research and Clinical Conference in Ottawa on September 22-25, 2011*. The Network undertakes to raise \$200,000 required to host this event. The conference will bring together over 300 medical physicians, Researchers and professionals to meet for 3 days. It is an opportunity to have the best researchers in the world here in Ottawa, Canada to meet with our Government officials, Public Health Agency of Canada, Canadian Institutes of Health Research to advocate for more research and service funding for ME/CFS and FMS. The Conference themes focus on fatigue, pain, sleep, pediatrics, cognition and brain function in Chronic Fatigue Syndrome, Fibromyalgia, and Related Illnesses (e.g., cancer fatigue). These themes will be addressed in scientific sessions on (a) assessment and treatment (from biological to behavioral), and (b) original research in the fields of immunology, virology, and neuroendocrinology.

There will also be a series of lectures and professional workshops for clinicians and researchers. It is anticipated that this event will be accredited for continuing medical education.

The Network continues to follow research on XMRV closely and we have renewed our efforts once again to lobby the government health agencies to support additional research in Canada towards this breakthrough.

All research coming to the forefront is reviewed by the Network and examined by our administration and our medical advisors continuously. Our goal is to share this information with our members and the medical community by means of our Newsletter and our website.

The Network is currently revising our Canada Pension Plan Disability Guide. This guide helps people with ME/CFS and FMS and other illnesses through the process of applying for benefits. We are also revising our Legal Disability Manual which provides advice on legal matters.

We aim to have the consolidated data user-friendly website for current and historical information retrieval in Canada on the subject of ME/CFS and FMS with regards to research, legal, and medical data. Many of our members are housebound and therefore the information and help we provide is an important and sometimes essential support system. Development is currently underway to enhance our current website and provide a more user-friendly interface for our members. The changes to the programming will attract more to visitors to our site and thus reach more people. The current system will remain online and will be continually updated until such time as the new system is ready to go live.

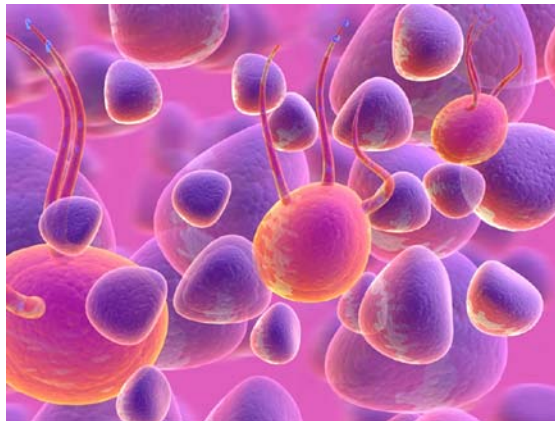
We provide assistance by phone, email, fax, website and our quarterly Newsletter.



Our History

2009

- Reported in our Newsletter and website regarding the **Significant Link Discovered between Retrovirus and ME/CF**: In October 2009 **Whittemore Peterson Institute (WPI)** located at the University of Nevada, Reno, together with their collaborators, discovered a retroviral link to ME/CFS. Their findings were recently published in the journal, *Science* under the title “Detection of Infectious Retrovirus, XMRV, in the Blood Cells of CFS Patients”. It was found that 95% of ME/CFS samples tested positive for XMRV antibodies in the plasma and points to the retrovirus as “a significant contributing factor in the illness” said Judy Mikovits, Ph.D., director of research for WPI and leader of the team who discovered the association. A retrovirus inserts a DNA copy of their genome into the host cell in order to replicate. With anticipated funding, WPI will begin the work of determining if any currently approved drugs can suppress XMRV which will follow closely by human clinical trials to advance the most effective patient treatments. Ms Annette Whittemore, founder and president of WPI says that “Patients and their doctors will soon have a blood test to verify their diagnosis and provide the answers that they’ve been seeking”.





Lobbying Government

- Wrote to the Public Health Agency of Canada regarding XMRV and CFS as they were having a meeting with CIHR. We requested that 3 very significant issues be addressed at the meeting:
 - 1) The announcement showed that a high percentage of people with ME/CFS had evidence of the XMRV retrovirus. This raises the distinct possibility that XMRV is a cause of the illness, and this could lead to new diagnostic and treatment possibilities. The retrovirus concept is resonating within the ME/CFS community because it seems to reconcile with what is already known about the illness. There is a great need for follow-up research. In addition, the announcement had the effect of seriously undermining the credibility of the CDC with regards to ME/CFS. The CDC is known to have quashed retrovirus research in 1991, used research funding in unproductive ways, developed definitions that hamper rather than help our understanding of the illness, and generally given the illness little respect.
 - 2) The announcement suggested that 4% of the general population carries this retrovirus. This raises the possibility that other chronic illnesses may be related to XMRV. Very preliminary testing found XMRV in people with FMS. The announcement also raises the possibility that people with XMRV who are currently healthy may develop chronic illnesses just as people with the retrovirus HIV may develop AIDS. There is a great need for follow-up research.
 - 3) The announcement suggests that the retrovirus is transmissible through the blood donation system and perhaps through other channels. There is a great need for follow-up research.

To get some perspective on this announcement, look at some statistics. Up to the end of 2005, approximately 20,000 Canadians had been diagnosed with AIDS (<http://www.avert.org/canada-aids.htm>). The Canadian Community Health Survey for 2005 showed 334,000 Canadians diagnosed with CFS, which is FIFTEEN TIMES as many. While CFS is not normally fatal, CFS patients are said to be at least as debilitated as AIDS patients.

- Prepared 5 factsheets based on the data captured by the Canadian Community Health Survey of 2005 for 23 Chronic Health Condition Cohorts. The factsheets conveyed important information about all 23 chronic conditions, but highlighted the numbers for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities. According to CCHS, more than a million Canadians, predominately female and middle aged, had a diagnosis of one or more of these illnesses. All three conditions reported high levels of impairment, socio-economic disadvantage, and unmet health delivery needs.



This information package was sent out in our Newsletter # 80 and was presented to health officials in Ottawa by our President Margaret Parlor who requested the data from CCHS and analyzed and presented it in graphical format.

Mr. Rob Oliphant, Member of Parliament for Don Valley West placed a question on the House of Common's Order Paper concerning many of the issues these statistics generated. His inquiries and the response from the Minister of Health are posted on our Website.

- Announced a 3 million plus award for Fibromyalgia case: Degennaro v Oakville Trafalgar Memorial Hospital.
- Reported on new research indicating Immune and Hemorheological Changes in Chronic Fatigue Syndrome on our Website in our Research Library (Full Article)

- Reported on our website on research indicating that Coenzyme Q10 Deficiency is related to fatigue autonomic and neurocognitive symptoms and is another risk factor explaining the early mortality due to cardiac failure.
- Reported on our website research indicating that XMRV was susceptible to AZT.
- Reported on our website research indicating cardiovascular dysfunction with low cardiac input due to a small heart in patients with chronic fatigue syndrome.
- Reported on our website and in our newsletter an alliance regarding the MECFSKnowledgeCenter and their international website, the All Canadian member's site and some encouragement for utilizing that resource.
- Published in print form all newsletters in one book form for 2004-2008 entitled Quest III.



2008

Keays v. Honda—Supreme Court upholds wrongful dismissal but overturns awards of Wallace and punitive damages

By Hugh Scher

Note on Author: Hugh Scher is a partner in the law firm of Scher & De Angelis where he practices civil litigation with a focus on employment, insurance and human rights law especially in the area of disability rights. He serves as counsel to the National ME/FM Action Network, ME Ontario and Fibromyalgia Society of Ontario and has represented dozens of individuals from across the country with Fibromyalgia and Chronic Fatigue Syndrome in disputes with long-term disability insurers, the Canada Pension Plan, employers and Revenue Canada. Mr. Scher served as our counsel in the Lowe v. Guarantee Insurance (2005), O.J. (O.C.A.) and was counsel to Kevin Keays in Keays v. Honda.

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Partial excerpt from Newsletter No. 68, Summer 2008:

The Supreme Court of Canada unanimously upheld the trial decision awarding Kevin Keays 15 months' notice for the wrongful termination of his employment by Honda Canada. However, in a surprising 7-2 decision, the court overturned the awards of *Wallace* and punitive damages previously awarded to Keays and reduced his reimbursement for legal costs.

At trial, the trial judge had awarded 15 months' notice, together with an additional 9 months' notice for Honda's bad faith in the manner of termination of Keays. The trial judge further awarded \$500,000. in punitive damages and \$610,000. in legal costs on a substantial indemnity basis, together with a bonus premium. The awards of bad faith and punitive

damages were based on Honda's unreasonable conduct in the manner of termination and its discrimination and harassment of Keays in his employment.

In particular, the trial judge found that Honda had engaged in a litany of acts of discrimination and harassment against Keays, had retaliated against him for retaining a lawyer to advocate on his behalf with respect to the protection of his human rights, and for unilaterally terminating his accommodation for his CFS disability. The award of punitive damages was based upon Honda's discrimination and harassment in employment contrary to human rights law, in the intimidation and ultimate termination of Keays in order to evade Honda's duty to accommodate under human rights law.

The trial judge found that Honda's conduct justified punishment to the tune of \$500,000.00. Justice Goudge of the Ontario Court of Appeal would have upheld this award, while Justices Rosenberg and Feldman ordered that the \$500,000.00 punitive damage award be reduced to \$100,000.00. All judges at the Court of Appeal were unanimous in the application of the law relative to punitive damages, including the ability to grant an award of punitive damages based upon a breach of human rights law.

- **Calgary Conference on disabling fatigue:** Nov 2008. Many thanks go to Dr. Stein for spearheading this series of meetings. Judi and Margaret attended, along with reps from the Multiple Encephalomyelitis Access Ontario (MEAO), MEAO, AQEM and ME/FM Alberta.

There were four parts to the conference: 1) a continuing education module, 2) a research symposium, 3) an opportunity for patient advocates to meet, and 4) a public lecture.



- **Statistics:** Huge thanks to an ally who had questions on CFS, FM and MCS included on the Canadian Community Health Survey for 2001, 2003 and 2005. A report was prepared by the President, Margaret Parlor using 2005 data:



Among other things the data show that, for Canadians with ME and FM:

- medical needs are not being met
- home care needs are not being met
- food security needs are not being met
- social needs are not being met (low sense of belonging to community)

Addressing these four issues would go a very long way toward improving the quality of life for Canadians with ME and FM. Making these statistics more widely known and discussed is a key priority for next year.

- Education: Margaret Parlor, President attended a national conference on Educational Rights for Students with disabilities in Toronto in September 2008. This conference was organized by CASHRA, the Canadian Association of Statutory Human Rights Agencies. There were several hundred attendees including human rights commissions, educators, students and advocates. The major benefit of attending was getting ME and FM noticed. The major accomplishment of the meeting overall was bringing out the tremendous obstacles that disabled students and their advocates face in accessing education.



Margaret has worked very hard on behalf of MEAO trying to interest the Ontario Ministry of Education in ME and FMS with remarkably little tangible to show for the efforts. However, Maureen MacQuarrie, an advocate in Toronto, picked up the cause and approached the Minister. It appears that this issue may go to the Minister's Advisory Committee on Special Education next month. The new executive director of MEAO, Theresa Dobko, is actively involved.

- Federal Government Relations: Lydia Neilsen and Margaret Parlor have had contact with a number of federal government officials. The Network has been asking for specific actions like:
 - posting of consensus documents on government web sites,
 - more support for research, and
 - permanent reinstatement of questions on the Canadian Community Health Survey.More broadly, we need government to address the issues raised by the statistics.
-

- Extensive article written in Newsletter to members on how to improve your CPP Application by John Wodak, Canada Pension Plan Advisor, to the Network.
- An article is written and reported in our Newsletter by George Cameron Caluori entitled `Revisiting the T2201 Form, The Disability Tax Credit Certificate`.
- The National ME/FM Action Network continued to work with the Canadian Lyme Disease Foundation for better recognition of Lyme disease in Canada. The term Lyme disease is used in two ways - as an umbrella term for a set of infections transmitted by ticks and to refer specifically to *Borellia burgdorferi*, the primary infection.
- Reported on a study indicating severe, persisting fatigue is a prominent symptom of Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS), but individuals with this illness frequently report the occurrence of unique fatigue states that might be different from conventional symptoms of fatigue by Leonard A. Jason PhD.
- Reported on new research by **Professor Alan Light**, a research professor in the anesthesiology department at the **University Of Utah School Of Medicine**, discovering a gene responsible for ME/CFS.
- Reported on the news that ten leading scientists in Europe have formed a Think Tank for ME and held their first meeting on the 13th of June. They want to initiate an effective research effort to find the secret behind the mystery disease that cripples an increasing number of lives.
- Reported in our Newsletter regarded Unprecedented Research Program to help identify biomarkers for the illness and improve diagnosis and treatment of CFS. The announcement was made by the CFIDS Association of America, which is funding the program, called the Accelerate CFS Research Initiative.
As part of this initiative, the CFIDS Association also announced today research grants totaling \$647,940 to six research teams in the U.S. and Canada.
- Received an article from Dr. Jacob Teitelbaum, MD regarding Vision Problems in CFS and Fibromyalgia to publish in our Newsletter #79.
- Reported on Soy Kefir – A Novel Food Product With Implications for CFS and Fibromyalgia Part II, Effects on Pain by Stan Kubow, Ph.D. and Dominique Garrel, M.D.

Journal of Achievements

- Requested an expert opinion for our members from Dr. Alison Basted regarding the flu vaccine and whether people with ME/CFS should have it. This article was printed in our Newsletter in the Fall of 2009.
- Reported on FDA approving a new Fibromyalgia drug Savella.



2007

Website: In 2007 our Website www.mefmaction.net received the **Hope Award** in recognition of the positive support and encouragement it gives to people suffering from chronic illness.



Our website was created by the late Al Neilson. It is now managed by Bob van de Sande, B. Sc. EE and the content of the website are developed and edited by Marj van de Sande, B. Ed., Grad. Dip. Ed. Congratulations and thanks to all of you.

- Reported on Chronic Pain and Disability Claims being denied by Alf Kwinter, Senior Partner, Singer & Kwinter. Advice from the perspective of a personal injury lawyer who only represents plaintiffs, there is probably no greater challenge than the disability claim of a person suffering from chronic, disabling pain where there is no “objective” evidence to support the condition. The complete article can be found in newsletter No. 74.
- Reporting continuously on the Keays v Honda case – Supreme Court Agrees to hear Appeal
- Reported on the news received for Allergic Living magazine that Health Minister Tony Clement announced legislation would be moving forward requiring the food industry to label, clearly and plainly, any priority allergens among the ingredients on food packages. The Announcement was made following a campaign in which almost 4,000 individual Canadians e-mailed a form letter to Prime Minister Stephen Harper requesting that these important regulations, long delayed, be passed into law.



- Received an article from our medical advisor Dr. Bruce Carruthers on the Definition and Aetiology of Myalgic Encephalomyelitis (ME): How the Canadian Clinical Definition of ME works and reported this in our Newsletter

- Announced in our Newsletter regarding the FDA approval of Lyrica (pregabalin) to treat fibromyalgia in June 2007.
- The Network presented an Award of Distinguished Merit and presented it to Bruce M. Carruthers, M.D.,C.M.,F.R.C.P.(C) in recognition and appreciation of his distinguished excellence in medical practice, courtesy and compassion demonstrated in patient care; and exemplary commitment to furthering the understanding and acceptance of ME/CFS and FM.



Dr. Bruce Carruthers M.D., C.M., F.R.C.P. (C)

Dr. Carruthers was retiring after many years of practicing medicine and provided much of the tremendous original research, investigation and the publication of what is now known as the ME and FM Consensus Documents, the TEACH-ME sourcebook for Teachers and Parents, and his never ending interest, care and compassion towards his patients, have truly made him an outstanding health professional.

- Announcement was made in our Newsletter regarding the FDA approval of Lyrica (pregabalin) to treat fibromyalgia in June 2007.
- Participated with the Center for Community Research at DePaul University who were studying fatigue in children and adolescents. An announcement was made in our Newsletter requesting any voluntary assistance for this study.
- Margaret Parlor (Director) provided an updated article on Lyme disease in spring 2008.
- A review of "Cellular Hypoxia and Neuro-immune Fatigue" by Dr. David S. Bell, M.D. F.A.A.P., published June 2007, was completed by Dr. Philipa D. Corning, PhD. BSc,CD, and Linda MacDonald BA, BSc (Physical Therapy). A report of this review was included in our Newsletter #76, Winter 2007-08.
- Received and printed a column for our Newsletter entitled "Coping with CFS" By Janette M. Collier, Ph.D. Dr. Collier's parents were both stricken with CFS over 15 years ago. In her report she describes the significant impact that CFS had on all of their lives.

- Received and printed a column for our Newsletter entitled “Piecing Pain Together – Understanding Pain in Fibromyalgia” by Dave J. Hayes (at the time a PhD Candidate in Neuroscience at the University of Alberta, Centre for Neuroscience & Dept of Psychiatry and a science writer for our Newsletter. Currently Dave is a Postdoctoral Fellow, Institute of Mental Health Research at the Royal Ottawa Hospital. In his column he explains the idea that FM-associated pain may be due to the abnormal processing of these nociceptive signals with the central nervous system (i.e. the brain and spinal cord). The nervous system learns to anticipate these nociceptive signals over time and begins to respond in full force and the slightest hint of them.
- Received and printed an article entitled “Fibromyalgia – How I See It and Treat It” by R. Paul St. Amand, M.D.
- A summary was prepared by our Vice-President and Director of Science Dr. Philipa Corning, PhD, BSc, CD regarding Chronic Fatigue Syndrome-Associated with Chronic Enterovirus Infection.
- Reported on a Calgary Research Study being planned by Dr. Brian MacIntosh, Department of Kinesiology at University of Calgary and Dr. Ellie Stein who were planning a study in collaboration with a fatigue research group at the University of the Pacific in Northern California.
- Report published entitled “Symptom or Cause? Trying to Correlate Immune and Sleep Deregulations in Chronic Fatigue Syndrome” *Based on research reported in:* Van Hoof E, De Becker P, Lapp C, Cluydts R, De Meirleir K. Defining the occurrence and influence of alpha-delta sleep in chronic fatigue syndrome. *Am J Med Sci* 333(2): 78-84. 2007.



2006

- Reported that in November 2006, the Centers for Disease Control & Prevention in the US formally announced recognition of ME/CFS as a biomedical condition and have started a multi-million dollar national education program for health care professionals and the public to increase awareness and improve access to the appropriate treatment.
- Margaret Parlor, Director for the Network reported that in January 2007 Statistics Canada published statistics on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Corp.(2006) 39 C.C.L.T. (3d) 201 (OCA)
- An extensive article was written by Philipa Corning, Ph.D., B.Sc.; Odell Pui, B.Sc., Medical Laboratory Science; and Linda MacDonald, B.A., B.Sc. (Physical Therapy) and reviewed by Dr. Bruce M. Carruthers, M.D., C.M., FRCP(C), entitled "Post-Exertional Fatigue and Malaise – There is Hope". Fibromyalgia, as well as Multiple Chemical Sensitivities. The information was obtained through interviews with a large number of individual Canadians in 2002 and 2003. We contacted the Minister of Health and the health critics for the three opposition parties and asked for a response to the Statistics Canada report. We got no replies. Obviously, a lot more work is required to convince decision makers that these issues are real and deserve more attention than they are currently receiving. In the meantime, we should be thankful to Statistics Canada for drawing attention to the data.
- A new case definition for ME/CFS, with accompanying questionnaires and scoring guide, has just been published by Haworth Press and posted on our website.
- An article originally appeared in the *CFIDS Chronicle*, a quarterly publication of the CFIDS Association of America, entitled "When Working Out Doesn't Work Out" was reported in our newsletter. A foreword to this article was prepared by Dr. Philipa Corning, Ph.D.B.Sc., Vice President.
- An article is written for our Newsletter by Hugh Sher entitled "Insurance Companies can be biased; insurance companies may be unfair – and it is not defamation to say it! – *AssessMed Inc. v. Canadian Broadcasting*
- An Article was written by J. Roy Nickerson B.A LL. B on Mediating Disability Claims for our members which was published in Newsletter No. 72.
- An article is written for our Newsletter by Norm Cuddy, Barrister & Solicitor, entitled "Winning a Fibromyalgia/Chronic Fatigue Case: 10 Rules
- Reported on the case of Insurance Bad Faith: The case of *Fidler v SunLife*.
- Intervenor Status //by National ME/FM Action Network in *Lowe v. Guarantee Insurance Update*.

- Reported that the Court of Appeal unanimously upholds Trial Judgement but majority reduces record quantum of Punitive Damages - Keays v. Honda Canada Inc., 2006 CanLII 33191 (O.C.A.).
- Article written by Hugh Sher on ``Conduct of Medical Assessors May Now Be Subject to Court Scrutiny`` Worthman v. AssessMed, [2006] O.J. No. 925 (Ont. Div. Ct.).
- An article is written for our Newsletter entitled ``Litigating Your Long Term Disability Action in Ontario`` by Sandra Drozd, LLP & Peter Downs, LLP.
- The Network reported that the Overviews of the Consensus Documents for ME/CFS and FMS were well received by both physicians and patients and that they would be posted on our website.



- An article was written by Dr. Alison C. Bested for our Newsletter entitled "Fibromyalgia, Chronic Fatigue Syndrome and Multiple Chemical Sensitivities. What do they have in common?"



Dr. Alison C. Bested

- The Network was asked to assist the Women Affiliate of the Canadian Health Network (CHN). In a letter to our organization from CHN, they stated: "As a network contributor to the CHN and an expert in the area of fibromyalgia, we would like to ask for your assistance

in reviewing the revisions and updates that we made to the following FAQs: ***What is fibromyalgia? How can I cope with fibromyalgia?***

- The Network provided financial assistance in support of an important research study conducted by Jon Russell, MD, Ph D, of San Antonio, Texas and Stuart Donaldson, Ph D, of Calgary to examine numerous aspects of fibromyalgia including blood markers, spinal fluid, brain wave patterns and muscle activity.
- Reported on the Canadian Conference on Lyme Disease, March 2006. In this conference it was noted that when a person meets the criteria for ME/CFS or FMS, the health professional is supposed to consider the possibility that the symptoms are caused by Lyme disease, a group of infections primarily transmitted to humans through tick bites.
- Announced a study on Symptoms of Fatigue in Children and Adolescents by the Center for Community Research at DePaul University, in Illinois, USA. A request for voluntary assistance from children and adolescents ages 5-17 and their parents/guardians to complete the DePaul Pediatric Health Questionnaire (DPHQ).
- Announced that MESH Awareness Day would be taking place on May 21, 2006, and location. MESH Ottawa held their annual awareness day campaign by inviting Dr. Paul Newton who did a workshop on "How to be Self-full". Louise Richard RN, Gulf War Veteran, was in attendance and told her story. Dr. I Jon Russell Lectured on the developments in research, treatment and diagnosis.
- Reported on Dr. De Meirleir's first Conference in Canada being a great success in Calgary, Alberta on April 1-2, 2006. Sixty-five medical practitioners attended his full day workshop and 300 people attended his lectures for patients.
- An article was prepared for our newsletter entitled "Advances in ME/CFS – Highlights from Dr. Kenny De Meirleir's Lecture – Calgary, Alberta, April 2, 2006, By Marjorie van de Sande, B Ed, Grad Dip Ed.

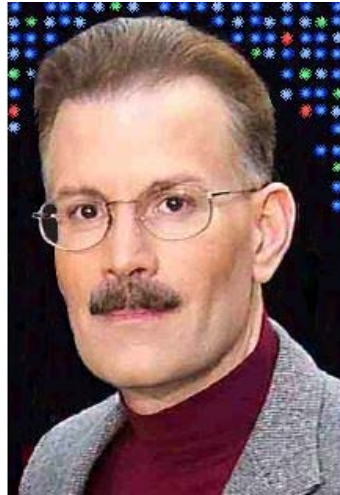


Marjorie van de Sande

- A paper was written by Dr. G. Dowsett, MB CHB. Dip. Bact. Entitled "Redefinitions of ME/CFS – A 20th Century Phenomenon and published in our newsletter.

- Announcement was made to our members that the new K037 OHIP billing Code – For Fibromyalgia/Chronic Fatigue Syndrome Care in Ontario. Many helped this come about: Dr. Alison Bested for her excellent presentation to the Ontario Medical Association; the National ME/FM Action Network for initiating the Canadian ME/CFS and Fibromyalgia Definitions, Diagnostic and Treatment Protocols; the Board of Directors of The Myalgic Encephalomyelitis Association of Ontario for their meetings and advocacy with the Ontario Ministry of Health and our Members who have written, called their MPPs and written to the Ministry of Health; the Ontario Support Group Leaders and their Members and individuals throughout the province who have advocated on behalf of CFS.
- An article on the Importance of Mobilizing the Lymphatic System was written for our newsletter by Philipa Corning, Ph.D., B. Sc. with David Gerald Scrivens, C.L. (Lymphologist)
- Margaret Parlor prepared an article on Diagnosing Lyme Disease in People with ME/CFS and/or FMS Symptoms.
- Reported on preliminary research being done by two UK researchers at the genetic and molecular level that, in the near future, could lead to a diagnostic test and groundbreaking genetic research studies.
- Summarized a report by the Ontario Human Rights Commission on education rights for students with disabilities that should be very helpful to students with ME/CFS in Ontario.
- Announced the Second Edition of TEACH-ME: A Sourcebook for Teachers of Young People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).
- An article was prepared by Marjorie van de Sande, B. Ed., Grad. Dip. Ed on Prolotherapy for Fibromyalgia Syndrome.
- An article was received by Dr. David S. Bell, MD, FAAP entitled “The Symptom of Orthostatic Intolerance in Chronic Fatigue Syndrome” and published in our newsletter.
- Dr. Bruce Carruthers, MD, CM, FRCP (C) prepared an article entitled “The Importance of Clinical Definitions for Defining and Studying Syndromes” and was published in our newsletter.
- Article written and published in our newsletter by Marjorie van de Sande, B. Ed., Grad. Dip. Ed. Entitled “Physiological Mechanisms Discriminated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) from Depression and Healthy Controls.
- Article written and published in our newsletter by Dr. Alison Bested regarding Flu Vaccination and Chronic Fatigue Syndrome. Dr. Bested gives her recommendations.
- An article was published on The Student with ME/CFS in the Ontario Public School by Margaret Parlor, Advisor Youth Issues (*This article is based on work of The Myalgic Encephalomyelitis Association of Ontario.*
- An article was published entitled “Brain Problems in ME/CFS – Is There a Simple Explanation? - “The Too Many Symptoms Syndrome” by E.G. Dowsett, MB ChB, Dip. Bact.

- An article regarding disturbing side-effects of “Provigil” by Dr. Bruno was published in our Newsletter.



Medical Advisor on Parallels between ME/CFS, FMS & Post Polio

- An excerpt from In the Spotlight: The Tymes Trust View on the ME/CFS Clinical Working Case Definition, Diagnostic and Treatment Protocols by Jane Colby Executive Director, Tymes Trust, United Kingdom's National Voluntary Charity for Children and Young People with ME and their Families

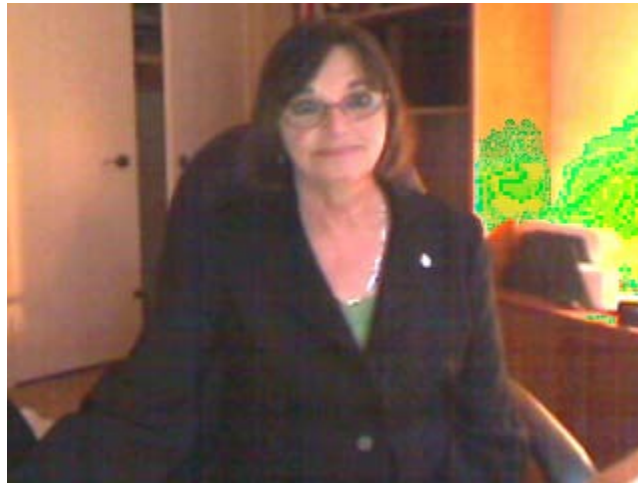
Also published with this article was a letter from Dr. Byron Hyde.



2005

- Lydia E. Neilson, President and CEO of the National ME/FM Action Network was awarded and presented with the Meritorious Service Medal by Her Excellency the Right Honourable Adrienne Clarkson, the former Governor General of Canada, in recognition of her work for the ME/CFS and FMS communities and for her spearheading the Consensus Document, The Clinical Case Definitions, Diagnostic & Treatment Protocols for both ME/CFS and FMS. This award was presented to Lydia Neilson at a ceremony at Rideau Hall in Ottawa on May 30, 2005.

The Meritorious Service Medal, civil division, was created by Her Majesty the Queen to recognize a deed or service performed in a highly professional manner or according to a very high standard that brings benefit or honour to Canada. The initials M.S.M. have now been added to Lydia Neilson's name.



- Published a Summary of a Research Study on the Clinical and Biochemical Characteristics Relating to Dysfunction of RNase L Pathway Differentiate ME/CFS from Major Depression and Healthy Controls by Marjorie van de Sande, B. Ed, Grad. Dip. Ed.
- Published an article by Dr. Leonard Jason entitled "Comparing the Canadian Clinical Definition and the Fukuda Criteria for Chronic Fatigue Syndrome.
- An article was written for our Newsletter by Marjorie Van de Sande, B.Ed., Grad. Dip. Ed., on the Physiological Mechanisms Discriminated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) from Depression and Healthy Controls.
- Dr. Bruce Carruthers published an article in our Newsletter entitled "The Importance of Clinical Definitions for Defining and Studying Syndromes.
- An article was written by Dr. David S. Bell on the Symptom of Orthostatic Intolerance in

Chronic Fatigue Syndrome.

- Marjorie van de Sande wrote an article for our Newsletter on Prolotherapy for Fibromyalgia Syndrome.
- An announcement was made the Second Edition of "Teach-Me: A Sourcebook for Teachers of Young People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome with Dr. David S. Bell, Dr. Bruce M. Carruthers, and the TEACH-ME Task Force.
- Philipa Corning, Ph.D., B.Sc., Vice-President wrote an article for our Newsletter entitled "Near Future, this could lead to a diagnostic test and Groundbreaking Genetic Research Studies on ME/CFS".
- An article was submitted by Margaret Parlor, Advisor – Youth Issues & Director, entitled "Diagnosing Lyme Disease in People with ME/CFS and/or FMS Symptoms.





2004

Medical Milestone:

First Clinical Definition of Fibromyalgia Syndrome

- May 12, National ME and FM Awareness Day, brings new help for Fibromyalgia Syndrome patients. Haworth Press will have completed the printing of Fibromyalgia Syndrome: Canadian Working Case Clinical Definition, Diagnostic and Treatment Protocols, A Consensus Document. Journal of Musculoskeletal Pain 11(4), 2004. This Consensus Document offers physicians a “comprehensive manual” for the diagnosis and treatment of fibromyalgia syndrome. In addition, there is an extensive discussion of research, and numerous helpful, practical appendices. Haworth Press is also publishing the Consensus Document as a soft cover book later this year. The title of the book will be “The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners”.

Authors include: Anil Kumar Jain, B Sc, MD, and Bruce M. Carruthers, MD, CM, FRCPI, Co-editors.

Jon Russell, MD, Ph D, FACP; Thomas J. Romano, MD, Ph D, FACP, FRCPI; Dan S. Heffez, MD, FRCS; Daniel G. Malone, MD; Donald G. Seibel, B Sc (Med), MD, CAFCI; Stephen R. Barron, MD, CCFP, FCFP; C. C. Stuart Donaldson, Ph D; James V. Dunne, MB, FRCPI; Emerson Gingrich, MD, CCFPI; Frances Y-K Leung, B Sc, MD, FRCPI; David Saul, MD, CCFPI; Marjorie I. van de Sande, B Ed, Grad Dip Ed.

- **Tymes Trust** has issued a Statement on the Canadian Definition of ME/CFS (2003). “In our opinion it is the best contemporary definition. It was developed for clinical practice and was compiled by physicians who have seen over 20,000 patients. It addresses many misunderstandings caused by 'catch-all' definitions, which have so disastrously affected research into treatments and clinical practice.

We believe that under the Canadian Definition it is harder for people with 'chronic fatigue' to be misdiagnosed with ME/CFS. We also endorse the use of the name Myalgic Encephalomyelitis as used by the World Health Organization along with Chronic Fatigue Syndrome, listed as a neurological disease under ICD10 G93.3. To use another name means there is no official categorization. There are arguments both for and against the 'itis' ending, meaning 'inflammation' but in our opinion the WHO name and categorization should be respected.

- The National ME/FM Action Network applied for and was granted Intervener Status in *Lowe v. The Guarantee Company of North America*. The outcome of this case will affect our members' rights to sue a DAC (Designated Assessment Centers) doctor. We hope that the results will also impact on future cases where a client may wish to sue a negligent I.M.E. (Independent Medical Examination) doctor
- An article is written for our Newsletter on Personal Information Protection and Electronic Documents Act (PIPEDA) by Odile Gérin, Director of Public Relations.



2003

- Published article on Health Lawsuit Tossed Out by Steve Buist of The Hamilton Spectator where AssessMed Inc. sued CBC, city doctor after auto injury broadcast. According to three respected neurological and psychological experts, Janet Hough of Caledonia was badly injured in a car accident in June 1993 and she was profiled on the November 1998 CBC broadcast. Four years after the accident, Hough was ordered by the insurance company to attend a one-day assessment at AssessMed's Mississauga office where she was examined by a psychologist named Dr. Hemendra Shah who concluded that Hough had not suffered any significant psychological impairment and that she could return to her pre-accident occupation and that she was consciously or unconsciously exaggerating the extent of her symptoms. Armed with Shah's assessment, the insurance company discontinued Hough's benefits.



Fifth Estate host Linden MacIntyre opened the episode by stating that some insurers treat accident victims, "no matter how badly damaged, as a faker". They won't take your word for it or the word of his/her doctor either. The broadcast described Dr. Jack Richman, AssessMed's chief medical officer and a director of the company, as one of the "doctors who play hardball for insurance companies." Richman and Shah objected to a number of statements made during the 20-minute episode but Superior Court Justice Paul Rivard rejected every one of the plaintiffs' claims that they had been defamed by the broadcast but the Superior Court Justice Paul Rivard essentially rejected every one of the plaintiffs' claims that they had been defamed by the broadcast. "The comments based on facts referred to in the broadcast were themselves true," Judge Rivard wrote in his 66-page decision and further stated that he could not conclude there was spite, ill will, any indirect motive or ulterior purpose on the part of the CBC. The trial was heard on 76 days over a period of eight months in 2003.

- Published letter from Byron Hyde MD on ME/CFS going into much detail as, like Dr. David Bell and a few other physicians, he has been studying the disease processes leading to this group of illnesses since 1984. That was a year in which so many patients fell ill that it shook the curiosity of a number of physicians but there are few physicians who have investigated this illness as long and at the same time have limited their patients exclusively to this group of disabled individuals.
- In the spotlight excerpt from The Tymes Trust view on the ME/CFS: Clinical Working Case Definition, Diagnostic and Treatment Protocols, a Consensus Document, Jane Colby, Executive Director of Tymes Trust in the United Kingdom's National Voluntary Charity for Children and Young People with ME have issued a Statement on the ME/CFS definition

which states in part: "In our opinion it is the best contemporary definition. It was developed for clinical practice and was compiled by physicians who have seen over 20,000 patients. It addresses many misunderstandings caused by 'catch-all' definitions, which have so disastrously affected research into treatments and clinical practice." The Tymes Trust further states that ..."We believe that under the Canadian Definition it is harder for people with 'chronic fatigue' to be misdiagnosed with ME/CFS." Tymes Trust Further endorsed the use of the name Myalgic Encephalomyelitis as used by the World Health Organization along with Chronic Fatigue Syndrome, listed as a neurological disease under ICD10 G93.3 to use another name means there is no official categorization.

- Medical Milestone: First Clinical Definition of Fibromyalgia, a Consensus Document, published in the Musculoskeletal Pain Journal 11(4), 2004 (Approximately 180 pages) in May 2004 and published by Haworth Press which will also be published in a book entitled "The Fibromyalgia Syndrome: A Clinical Definition for Practitioners. This comprehensive document provides the family physician a practical tool for diagnosing and treating patients with FMS. There are also a number of helpful suggestions for patients.

This Consensus Document when published in a book which will be in about five weeks' time, is being given to us with a 40% discount on the book at a cost of \$14.97 U.S. Code FMS40 needs to be quoted for this discount when ordering.

The National ME/FM Action Network spearheaded the drive for a clinical definitions and guidelines for FMS. Health Canada selected the Expert Consensus Panel. This FMS Consensus Document is the first concerted effort to provide the practitioner with a clinical definition and guidelines for FMS and will allow family physicians and other clinicians to confidently diagnose FMS and provide appropriate treatment.

- Sent letter to Editor Edmonton Journal, November 1, 2003 wherein it was stated that the industry act in good faith and requested information as to what the government was going to do to protect us from companies who do not act in good faith.
- National ME/FM Action Network published and responded to Alberta's new legislation and sent letter to Hon. Greg Melchin on December 12, 2003 advising of our serious concerns regarding the new regulations being established in Alberta for motor vehicle accident claims, including the \$4,000.00 limit for pain and suffering for "minor" injury, the criteria for establishing what will be included in "minor injuries, appropriate protocols, and the use of independent medical examinations.

The Alberta Government's website states that the definition of minor injury will be developed in consultation with organizations representing injured people, insurers, lawyers and health care providers.

- Published on troublesome new legislation for victims of car accidents = Alberta. In an attempt to provide drivers with fair and reasonable rates, the Government of Alberta has introduced legislation designed to lower the rates for the majority of Alberta motorists. As such, the Government has brought forth Bill 53, The Insurance Amendment Act, 2003 (No.2). This Act is designed to address a number of issues but the most contentious amendment is to limit the pain and suffering awards for "minor injuries". This would set a limit for injuries that fall within the "minor" category. It is known that the limit will be

\$4,000.00, unfortunately, but we do not know the definition of a minor injury because the actual legislation does not provide that information.

- Published article on making “Independent Medical Exams” Independent. Many insurance claimants complain that the “Independent Medical Examination” (IME’s) upon which their insurers rely to determine benefits is unfair. Insurance company adjusters typically send claimants to medical examiners who can be counted on to issue reports favorable to the insurer’s position. Doctors who routinely side with the company can expect to have an unlimited supply of referrals and can expect an appreciable income flow from their efforts, thereby making the “Independent Medical Examination” not as independent as they are being paid by the insurance companies.
- Published article on Gender Differences Make Females more prone to Fibromyalgia Syndrome and Myalgic Encephalomyelitis / Chronic Fatigue Syndrome than males. An obvious difference is structure, differences in muscles and ligament, differences in the Spinal Canal, differences in Pain Threshold and differences in blood volume. These biological differences can make women more prone to ME/CFS and FMS.



- United Kingdom’s ME/CFS community found the Clinical Working Case Definition, Diagnostic and Treatment Protocols to be a huge step towards excellence in care of ME/CFS sufferers, and have been endeavoring to promote these protocols in the U.K., wherever possible.
- Reported that the Advisory Committee of the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care reviewed the ME/CFS Consensus Document gave “Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols”, Journal of Chronic Fatigue Syndrome 11(1):7-116, 2003 a three out of four apple rating. In a letter from the Guidelines Advisory Committee, the chairman reported, “Three apples denoted a very good guideline”. Dr. Davis further stated that “three-apple guidelines are well produced and useful for practicing clinicians and added that he hoped this information proves useful as they deliberated on how to ensure the early diagnosis and medical care of patients with chronic fatigue syndrome”.

- Published Supreme Court Rules on Chronic Pain Syndrome in a Nova Scotia (Workers' Compensation Board) v. Martin. It dealt, for the first time, with the fate of persons suffering from chronic pain at the administrative and governmental level as well as in Society. The Court rules that the contested regulation provided a different treatment for persons with work-related injuries who suffer from chronic pain, compared to all other employees suffering from a work related injury and that it constituted a distinction based on the handicap.



The Court also determined that this distinction was discriminatory because it eliminated all possibility that persons suffering from chronic pain could undergo a personal assessment of their condition and of their residual capabilities. The Court judged that, by its special treatment of persons suffering from chronic pain, the Nova Scotia agency was perpetuating stereotypes about the legitimacy of their suffering.

- Published information on 2003 BCCA 306 Balzer v. Sun Life Assurance Company of Canada where the BC Court of Appeal confirmed the right of a disabled Abbotsford Woman to continue her law suit against Sun Life, her disability insurance company. Sun Life refused to pay after October 1994 and wrote her a number of letters offering to reconsider her case if she had more medical information. Ms Balzar hired a lawyer and a law suit was started. Sun Life claimed she had waited too long to sue, even though in all the letters sent to her, Sun Life never said the clock was running or that she had to do anything other than provide the medical information Sun Life wanted.

Ms Balzer's lawyer argued that up to then the rule had always been that there was a one year limitation on these kinds of suits but Mrs. Balzer's case changes all that. This is therefore a very important decision for possibly hundreds of people in BC who have not been paid by their disability insurance company due to one-year limitation.

Ms Balzer's law suit will be set for trial in the Vancouver Supreme Court in 2004, and she will ask the court to order punitive damages against Sun Life for bad faith. Sun Life has denied that Ms Balzer is disabled.

- Published article by Dr. Richard N. Podell, MD, M.P.H. on improving sleep quality despite Fibromyalgia and/or Chronic fatigue syndrome. This article goes through great lengths to outline what can be done to improve sleep and what drugs have been of help based on Dr. Podell's experiences.
- Published and alerted the medical, legal and patient communities the kind of stress test ME/CFS and FM patients need to take in special circumstances such as following a heart attack. This stress test alternative is safer for ME/CFS patients.
- Published and alerted the medical, legal and patient communities article on ME/CFS Post-Exertional Malaise / Fatigue and Exercise (better known as a stress test), alerting the medical, legal and patient communities about the post-exertional malaise and/or fatigue of

inappropriate severity which can temporarily immobilize the patient and worsen his/her symptoms following normal physical or mental activity. It takes the patient an inordinate amount of time to recover – 24 hours or more.



Even though post-exertional malaise is a hallmark feature of ME/CFS, exercise programs are often prescribed with little thought to the effect they may have on patients. In the July / August 2003 issue of the newsletter 'QUEST', it was outlined in detail what responses health people have to mental or physical exercise and how ME/CFS and FM patients respond.

- Published an essay written by Dr. Abhijit Chaudhuri for the newsletter of the National ME/FM Action Network on Chronic fatigue: looking beyond functional somatic syndrome. Dr. Chaudhuri is a Senior Lecturer in Clinical Neurosciences, University of Glasgow, and Consultant Neurologist of the Institute of Neurological Sciences, Southern General Hospital in Scotland.

Dr. Chaudhuri advised that fatigue is a symptom, not a disease and went on to discuss the many complex disorders like ME/CFS and Fibromyalgia. Recent data suggests that widespread and unpleasant skin sensitivity experienced by many fibromyalgic patients (similar to many CFS patients) may be due to central nervous system amplification of the nociception in general, not to a specific muscle disorder. There is evidence at present that the central fatigue in CFS is influenced by neurochemical changes and result from altered cortical excitability due to a lack of limbic-motor integration of volitional activities.



Recent research has also uncovered that genetic or acquired deficits in norepinephrine inactivation may underlie hypoadrenergic states leading to orthostatic intolerance and fatigue. This syndrome was first described by Da Costa more than 100 years ago.

- In our efforts to disseminate the ME/CFS Working Case Clinical Definition, Diagnostic & Treatment protocol document which was published in the Journal of Chronic Fatigue Syndrome on February 1, 2003 we continue to ask everyone to forward us names and addresses of doctors and lawyers everywhere that they know of so that we can contact them and make them aware of this most-important document. The definition is of no use unless it is in the hands of the right people.

- Announced and reported that the **National ME/FM Action Network** celebrated its **10th Anniversary** on June 16, 2003 and reported that our success was largely due to the support and assistance with our many projects by volunteers, our members and the support group networks across Canada. It was also mentioned that many doctor and lawyers, both inside and outside Canada, have lent us a helping hand with many of our projects and continue to do so. We owe them our gratitude.
- Published on Doctors in "Good Standing" and what does it really mean. Thanks to copies of letters of complaint to regulatory bodies, and copies of decisions about disciplinary actions taken against these doctors, the National ME/FM Action Network is aware that many patients are still being sent for IMEs to doctors who have received disciplinary action by their regulatory bodies. The same Colleges that disciplined these doctors are telling patients that These doctors are in good standing.



Armed with this information, on May 20, 2003, the National ME/FM Action Network sent a letter to one of the provincial colleges of Physicians and Surgeons and asked "Doctors listed on the Financial Services Designated Assessment Centres' Roster are purported to be 'members in good standing' with the College of Physicians and Surgeons of Ontario. So too are doctors listed on the Workers Safety and Insurance Board's Roster. On precise what criteris is the 'good' in good standing bestowed and on what grounds would the 'good' in good standing be revoked? We are still awaiting a reply to this question and we will keep pursuing this issue.

- Published article by our Advisor on Youth Issues on ME/CFS and FM in young people and school issues. A leading study on the prevalence of ME/CFS was done by Dr. Dowsett and Jane Colby in the United Kingdom wherein they asked schools about student absences of two months or more during the previous two years and ME/CFS was the reason given in 51% of the cases, well ahead of cancer, depression, school phobia, injury, or any other reason for absence that might have been expected. The study found a rate of ME/CFS of 70 per 100k students, there is reason to suspect the study understates the real rate.
- Published article by Lawrence E. Pierce of Pierce Law Group how an insurance company's stalling backfires re: Valzer v. Sun Life.
- Published article by David Lackman, Esq. of Firestone Law Offices in Toronto on investigations & surveillance in Long-Term Disability Claims. Mr. Lackman reported on the video surveillance, privacy concerns; perception is reality, avoiding the pitfalls etc.

- Reported and published on the new testing now available in Canada to assess cognitive problems in ME/CFS, Fibromyalgia, Multiple Chemical Sensitivity, and Toxic Chemical and Mold Exposure. The E-Team is a joint venture of independent professionals united in the quest to bring Validation, Hope and Healing to individuals who suffer from these illnesses. The E-Team consists of: Gerard Alberts, M.Ed C.Psych; Diana Monea Optometrist; Eleanor Stein MD,FRCP(C); Matthew van Olm MD FRCP(C); and Anne Woolliams Aud (C) - all located in Calgary, Alberta.

The test protocol was designed drawing heavily on the research of Dr. Kaye Kilburn, a professor at the University of Southern California and the clinical work as psychologist Dr. Nancy Didriksen who runs a busy private practice in Dallas, Texas.

The testing cost of the E-team is not only to ascertain whether areas of functioning are below the normative range but to compare areas of functioning e.g. memory which is usually affected in ME/CFS and related disorders with areas of functioning that are rarely affected e.g. abstraction, vocabulary. The cognitive profiles in ME/CFS, FM, MCS and certain toxic exposures are similar and therefore the E-Team decided to combine many of the tests reported in the literature as being sensitive for each of the disorders into one large protocol and use the same protocol for every client.

For more information on the cognitive testing, contact Mr. Gerard Alberts at Alberts & Associates at **(403) 254-8400** or albertsg@shaw.ca.

- The Expert Consensus Panel for the **'Fibromyalgia Syndrome: Clinical Case Definition, Diagnostic and Treatment Protocols: A Consensus Document'** consists of: Dr. Anil Jain and Dr. Bruce Carruthers: co-editors, Dr. John Russell (U.S.A.), Dr. Thomas Ramano (U.S.A.), Dr. Dan Heffex (U.S.A.), Dr. Daniel Malone (U.S.A.), Dr. Donald Seibel, Dr. Stephen Barron, Dr. Stuard Donaldson, Dr. James Dunne, Dr. Emerson Gingrich, Dr. Frances Leung, and Dr. David Saul.

The National ME/FM Action Network thanks the Expert Consensus Panel who had full autonomy over the document for donating their time and expertise to the development of this document.

- Published an article in our Newsletter entitled **"How to Hire a Lawyer"** by Norm Cuddy.
- Announced that all members of the expert consensus panel have approved the final revisions for the FMS consensus document and that the document has now been submitted to a medical journal. The diagnostic protocol includes a clinical definition for FMS, a discussion of the major features, and the clinical evaluation of the FMS patient. The treatment protocol section includes goals and principles/guidelines, life world adjustments, guidelines for self-powered FMS exercise programs, pharmacological treatments, and alternative/complementary approaches. There is a comprehensive discussion of the research on FMS. In addition, there are a number of appendices including worksheets, scales, questionnaires, appropriate stretches and exercises for FMS patients, how to assess occupation disability, etc.
- Reported on the inherent bias against insurance claimants and the Independent Medical Examination. A doctor requested that the Health Professions Appeal and Review Board of Ontario (HPARB) review a decision of the Complaints Committee of the College of

Physicians and Surgeons of Ontario concerning a complaint made by a patient about an Independent Medical Examination. HPARB ruled that the matter should be returned to the College of Physicians and Surgeons "an inherent bias against insurance claimants in general" is to be decided upon.

- Published article by Paralegal, Mr. George Cameron-Caluori, with more details on the disability tax credit amends that were withdrawn due to opposition by the disability community.
- Published Information for ME/CFS Physicians - Cognitive Function in ME/CFS by Dr. Ellie Stein. Dr. Stein had prepared this article from the medical literature (July 2001). She states that subjective cognitive dysfunction is a complaint of over 80% of patients with ME/CFS and is a diagnostic criteria in all of the 4 of the extant working definitions.

Dr. Stein goes on to explain the different findings and also advises of tests which most commonly discriminate ME/CFS from controls.

- Published article by Mr. Hugh Scher, Barrister & Solicitor and the impact on assessing occupation disability with the new ME/CFS definition. Mr. Scher stated the definition and diagnostic and treatment protocols will have significant implications for the manner of assessment and adjudication of disability benefits' claims. The definition sets out specific criteria for the diagnosis and assessment of ME/CFS and it makes it clear that there is no known cure or magic bullet for the treatment of ME/CFS.
- Received positive feedback from the medical and legal communities on the new ME/CFS definition.
- Requested help from the Medical and Legal Professionals, Support Group Leaders and all patients to spread the word that the Canadian ME/CFS Clinical Working Case Definition, Diagnostic and Treatment Protocols was published and how this definition can be purchased from The Haworth Press, Inc. We asked that everyone help us to alert doctors and lawyers; that support groups may wish to fundraise in order to purchase copies for the doctors of their members in their community; and contact their local media and advise them the ME/CFS definition has a copy of the definition on its website at <http://www.mefmaction.net>
- Reported that in August 2002 the Federal Department of Finance announced that it was considering amendments to the Income Tax Act which would further limit who would qualify for the Disability Tax Credit. Due to the outpouring of the disability community, the controversial proposal was withdrawn and new consultations have taken place for a revised proposal. Deadline for submissions was January 17, 2003. We wait to see whether the new proposals will help or hinder applying for this Tax Credit.
- Published article by Dr. Eleanor Stein from Calgary who announced that there is a new service designed specifically for people with cognitive difficulties secondary to ME/CFS, FM, Multiple Chemical Intolerance and Chemical and Mold Exposure or any combination thereof. She advised that this testing protocol has been several years in the making and is the result of a multidisciplinary effort between Dr. Stein, Psychiatrist, Dr. Gerard Alberts, Chartered

Psychologist; Diana Monea, Optometrist; Anne Wolliams, Audiologist and Dr. Matt van Olm, Pulmonary Physician.

The objective of the testing protocol is to objectively measure the cognitive and sensory dysfunction experienced by people with the above disorders and the protocols are based on those used now in the United States by Kaye Kilburn MD and Nancy Didriksen, Ph.D.

- Reported on the College of Physicians & Surgeons of Ontario passing policy position on Third Party Reports in November 2002 which is the good news. The bad news is that these new CPSO guidelines are much weaker than Alberta's as they failed to address the fundamental issues i.e. 1) The physician should be wholly objective and impartial; 2) The physician should clearly declare qualifications; 3) The physician can perform assessments only within one's area of expertise; 4) The physician must avoid demeaning or judgmental comments in reports; 5) The physician should not disparage other professionals (physicians or non-physicians; and 6) The physician must base opinions on the best scientific evidence available and not on a personal belief system.
- Published article by Richard R. Evenson, of Evenson Bundgard Flynn, Lawyers "ME/CFS & FM and the problem with "Multi-Disciplinary Health Services Clinics". In recent years, disability insurers have increasingly adopted a new approach in respect of disability income claims based on conditions such as ME/CFS and FM. This approach involves the use of "Health Services Clinics" (HSC). Mr. Evenson reports that it is arguable that the HSC, in carrying out both the assessment *and* the treatment program, it has a serious conflict of interest.
- Published article by Dr. Antonio Taverniti on What Makes for a Good Assessment Clinic. Dr. Taverniti reports that many of the Functional Capacity Evaluations (FCE) and Functional Abilities Evaluations (FAE) that are performed are done incorrectly.
- Our Vice-President, Dr. Philipa Corning reported on Cognitive Behaviour Therapy (C.B.T.) and how insurance companies are aggressively promoting C.B.T. for ME/CFS. C.B.T. is one of the dominant approaches used in psychotherapy today, and was pioneered in the early 1960's by psychiatrist Dr. Arron Beck. Dr. Corning reported on why C.B.T. should NOT be used by insurance companies as a remedy for ME/CFS.



2002

- Reported on and sent letter to the Registrar of the College of Psychologists of Ontario on October 28, 2002 advising her of the number of complaints we have received from our members who have been subjected to unfair Independent Medical Examinations (I.M.E.s) generally and insurer-sponsored psychological assessments in particular. Our growing alarm prompted us to establish a method of tracking these complaints and have encouraged people who have raised concerns with us in terms of unfair IMEs to bring their concerns to the appropriate College in a formal complaint. This is an on-going matter on which we will keep reporting.
- Reminder that the website of the National ME/FM Action Network has a section 'My Story' where people can write their story anonymously in the hope that their experiences will help others.
- Reported on Dr. Richard L. Bruno's television broadcast on 'Health on the Line', a nationally broadcast, hour-long medical discussion program which aired on the Discovery Health Channel and discussed similarities between the post-polio syndrome, ME/CFS and FM. Dr. Bruno is Chairperson of the International Centre for Post-Polio Education and Research and the Fatigue Management Programs at New Jersey's Englewood Hospital and Medical Center and was a speaker at the National ME/FM Action Network's Symposium in June 2002.
- Reported on the B.C. Liberals plan for major cuts to disability benefits and our Director for BC and Youth Ambassador's letter to the Liberals objecting to the cuts.
- Published report on Assessing Functional Capacity of Persons with ME/CFS by Dr. Antonio Taverniti, B.Sc., D.C., C.C.R.D., including ME/CFS profile.

Announced the up-coming publication date for the ME/CFS Clinical Working Case Definition, Diagnostic and Treatment Protocols, with details below. This definition has been long awaited and now is slated for publication in February 2003. A copy of the National ME/FM Action Network's announcement is printed below and that of The Haworth Press, Inc. printers of the Journal of Chronic Fatigue Syndrome 11(1), 2003. ©2003 by The Haworth Press, Inc. All rights reserved. Reprinted with permission from The Haworth Press, Inc. Available new or used on Amazon.com under Haworth Press Medical Inc. or on Chapters.ca used only.



NEWS RELEASE

CANADA LEADS THE WORLD WITH A CLINICAL DEFINITION FOR MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME (ME/CFS)

A Clinical Definition (clinical diagnostic criteria) for ME/CFS has been developed by an Expert Consensus Panel. Although created to standardize research, the American Centers of Disease Control (CDC) Definition is being used in Canada and most other countries to diagnose ME/CFS. There has been a growing demand for diagnostic criteria designed for a clinical setting. In response to a survey by the **National ME/FM Action Network**, doctors across Canada overwhelmingly concurred that a clinical definition, along with diagnostic and treatment guidelines, would be the most helpful items in diagnosing and treating ME/CFS patients. In addition to the clinical definition, the consensus document includes a discussion of the prominent symptoms, clinical practice diagnostic and treatment guidelines based on the best available research evidence, and an overview of research on ME/CFS. Dr. Bruce M. Carruthers of B.C., lead author, stated that "The Clinical Definition will enable clinicians to make an early diagnosis which may assist in lessening the impact of ME/CFS in some patients. It will reduce the expensive problem of patients being sent to many specialists before being diagnosed, and will allow patients to receive appropriate treatments in a timely fashion."

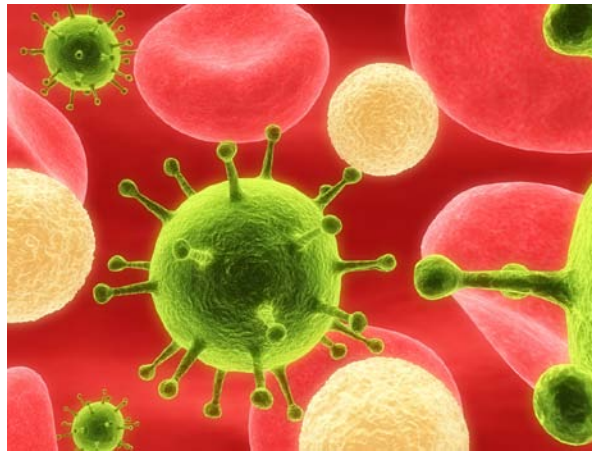
A definition was developed and published in 1988 and later revised in 1994 under the aegis of the CDC. These definitions along with the Australian and Oxford, U.K definitions were developed to standardize research and not designed to be used for clinical settings.

The CDC definition requires that the patient must have persistent or relapsing fatigue that lasts more than six months and four of eight other criteria. One problem with this definition is that fatigue is a symptom of many diseases. By making other cardinal symptoms optional, it increases the diagnostic difficulty of distinguishing the pathological fatigue of ME/CFS from other fatiguing illnesses with overlapping symptoms.

The Expert Consensus Panel developed a clinical case definition that provides a flexible, comprehensive framework. More of the prominent symptoms are compulsory and symptoms that share a common region of pathogenesis are grouped together to give clarity and completeness. In addition to severe prolonged fatigue, the definition includes the hallmark symptoms of post-exertional malaise and/or fatigue, sleep dysfunction, pain, two or more of the given neurological/cognitive manifestations, and at least one of the given symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations. The illness must persist for at least six months. Diagnostic exclusions and common co-morbid entities are also mentioned.

The Expert Consensus Panel felt that the Clinical Case Definition more adequately expresses the complexity of symptoms in a given patient's pathogenesis. It should reflect ME/CFS as a distinct medical entity and help distinguish it from other overlapping medical conditions in the absence of a definitive laboratory test. The eleven physicians, who made up

the Expert Consensus Panel, have between them diagnosed and/or treated more than 20,000 ME/CFS patients. All authors approved the Consensus Document.



According to a large American study by Dr. Leonard Jason, approximately 422 per 100,000 people (approximately 150,000 Canadians) suffer from ME/CFS compared to 26 per 100,000 women who have breast cancer. ME/CFS is a severe illness that can be debilitating. There is no known cure. It often begins with a viral type infection such as an acute respiratory or flu-like illness. But instead of recovering, the person's health deteriorates and many other symptoms appear. A number of viruses have been studied but so far there is no conclusive support for any one pathogen causing the illness. Numerous studies have confirmed that there is a biochemical breakdown of one of the body's defense pathways used to fight viruses, which supports the theory that ME/CFS is triggered by an infection. Other triggers and mechanisms are also being investigated.

The development of a clinical definition and clinical diagnostic and treatment guidelines is a milestone in the fight against this complex and often debilitating illness!

Many credits must be given

- The **National ME/FM Action Network**: for spearheading the drive for the development of a clinical definition, and diagnostic and treatment protocols. **Lydia Neilson**, President, has lobbied Health Canada for years to make this a reality.
- **Dr. Bruce Carruthers** and **Dr. Anil Jain**: who kindly donated their time and expertise to write the draft document. Dr. Carruthers also spent countless hours on the revisions and editing.
- The **Expert Consensus Panel** (**Dr. Carruthers, Dr. Jain, Dr. Kenny De Meirleir [Belgium], Dr. Daniel Peterson [USA], Dr. Nancy Klimas [USA], Dr. Martin Lerner [USA], Dr. Alison Bested, Dr. Pierre Flor-Henry, Dr. Pradip Joshi, Dr. Peter Powles, and Dr. Jeffrey Sherkey**): for their genuine concern for the ME/CFS patient, for donating their time and expertise to the development of the Clinical Definition and Clinical Protocols, and their determination to make the Consensus Document a reality.

- **Marjorie van de Sande**, Consensus Coordinator, (and Director of Education for the **National ME/FM Action Network**): for the countless hours she spent working with Dr. Carruthers and the other members of the Expert Consensus Panel, for compiling the consensus document, and getting information back and forth between the panel members.
- **Health Canada**: for the selection of the Expert Consensus Panel, and establishing the Terms of Reference for the panel.
- **Crystaal**: for sponsoring the Expert Consensus Panel Workshop.
- **James McSherry**: MB, ChB, CCFP, FCFP, FABMP, FAAFP, who was a member of the Expert Consensus Panel and participated in the review process, but was unable to attend the consensus meeting. We regret that Dr. McSherry has since passed away.
- **Kim Jones**: RNC, PhD, FNP, exercise physiologist, for her input in the exercise/treatment section.
- **Kerry Ellison**: OT (non-practicing), for her input in the patient management/treatment and assessing disability sections.
- **Hugh Scher**: LLP, for his input in the assessing disability section.
- **All the members of the National ME/FM Action Network**: for their continuing encouragement and support.

Kenny L De Meirleir, MD, Ph D

Daniel L Peterson, MD

Nancy G Klimas, MD

**Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:
Clinical Working Case Definition,
Diagnostic and Treatment Protocols**

Bruce M Carruthers, MD, CM, FRCP(C)

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A Martin Lerner, MD, PC, MACP

Alison C Bested, MD, FRCP(C)

Pierre Flor-Henry, MB, Ch B, MD, Acad DPM, FRC, CSPQ

Pradip Joshi, BM, MD, FRCP(C)

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Jeffrey A Sherkey, MD, CCFP(C)

Marjorie I van de Sande, B Ed, Grad Dip Ed

ABSTRACT. Recent years have brought growing recognition of the need for clinical criteria for myalgic encephalomyelitis (ME), which is also called chronic fatigue syndrome (CFS). An Expert Subcommittee of Health Canada established the Terms of Reference, and selected an Expert Medical Consensus Panel representing treating physicians, teaching faculty and researchers. A Consensus Workshop was held on March 30 to April 1, 2001 to culminate the review process and establish consensus for a clinical working case definition, diagnostic protocols and treatment protocols. We present a systematic clinical working case definition that encourages a diagnosis based on characteristic patterns of symptom clusters, which reflect specific areas of pathogenesis. Diagnostic and treatment protocols and a short overview of research are given to facilitate a comprehensive and integrated approach to this illness. Throughout this paper, "myalgic encephalomyelitis" and "chronic fatigue syndrome" are used interchangeably and this illness is referred to as "ME/CFS". *Journal of Chronic Fatigue Syndrome 11(1), 2003.*

- **FOR IMMEDIATE RELEASE**

Announced the forthcoming publication of a special issue of the *Journal of Chronic Fatigue Syndrome* devoted to an expert consensus document, which includes a clinical definition (clinical diagnostic criteria) for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). The clinical case definition was developed by an expert medical consensus panel of treating physicians, teaching faculty and world leaders in the research of ME/CFS. An expert subcommittee of Health Canada established the Terms of Reference for the consensus panel. The definition more adequately reflects the complexity of symptoms of a given patient's pathogenesis and should establish ME/CFS as a distinct medical entity and help distinguish it from overlapping medical conditions in the absence of a definitive laboratory test.

"The clinical definition will enable clinicians to make an early diagnosis which may assist in lessening the impact of ME/CFS in some patients," said Dr. Bruce M. Carruthers, lead author of the definition. "It will reduce the expensive problem of patients being sent to many specialists before being diagnosed and will allow patients to receive appropriate treatments in a timely fashion."

The panel's clinical case definition determines that more of the prominent symptoms are compulsory and symptoms that share a common region of pathogenesis are grouped together for clarity. In addition to severe prolonged fatigue, the definition includes the hallmark symptoms of post-exertional malaise and/or fatigue, sleep dysfunction, pain, two or more of the given neurological/cognitive manifestations, and at least one of the given symptoms from two of the categories of autonomic, neuroendocrine, and immune manifestations. Diagnostic exclusions and common co-morbid entities are also given.

The special issue of the *Journal of Chronic Fatigue Syndrome* also includes a discussion of prominent symptoms, clinical practice diagnostic and treatment guidelines based on the best available research evidence, and an overview of available research on ME/CFS.

The expert panel of 11 physicians—who have diagnosed and/or treated more than 20,000 ME/CFS patients between them—has developed a clinical case definition that provides a flexible conceptual framework based on the characteristic patterns of symptom clusters, which reflect specific areas of pathogenesis. The expert subcommittee of Health Canada selected the expert consensus panel. Authors include:

- * Dr. Bruce M. Carruthers, lead author of the consensus document; co-author of the draft of the original version of the ME/CFS clinical definition, diagnostic and treatment protocols document; internal medicine.
- * Dr. Anil Kumar Jain co-author of the draft the original version of the ME/CFS consensus document, affiliate of Ottawa Hospital, Ontario.
- * Dr. Kenny L. De Meirleir, Professor Physiology and Medicine, Vrije Universiteit Brussel, Brussels, Belgium; ME/CFS researcher and clinician; organizer of the World Congress on Chronic Fatigue Syndrome and Related Disorders; a board member of the American Association for Chronic Fatigue Syndrome; and co-editor of *Chronic Fatigue Syndrome: Critical Reviews and Clinical Advances* (Haworth)
- * Dr. Daniel L. Peterson, affiliate of the Sierra Internal Medicine Associates in Incline Village, Nevada; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the International Chronic Fatigue Syndrome Study Group
- * Dr. Nancy G. Klimas, Clinical Professor of Medicine in Microbiology/Immunology/Allergy and Psychology, University of Miami School of Medicine; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the federal CFS Coordinating Committee
- * Dr. A. Martin Lerner, staff physician at William Beaumont Hospital in Royal Oak, Michigan; Clinical professor and former chief of the Division of Infectious Diseases at Wayne State University's School of Medicine; and ME/CFS researcher and clinician

* Dr. Alison C. Bested, hematological pathologist; former head of the Division of Hematology and Immunology at the Toronto East General and Orthopedic Hospital; affiliate of the Environmental Health Clinic and Sunnybrook & Women's College Health Sciences Centre, Toronto, Ontario; ME/CFS researcher and clinician

* Dr. Pierre Flor-Henry, Clinical Professor of Psychiatry, University of Alberta; Clinical Director of General Psychiatry and Director of the Clinical Diagnostic and Research Centre, both based at Alberta Hospital in Edmonton, Alberta, Canada; ME/CFS brain researcher

* Dr. Pradip Joshi, internal medicine, Clinical Associate Professor of Medicine at Memorial University of Newfoundland in St. John's, Canada

* Dr. A. C. Peter Powles, Professor Emeritus, Faculty of Health Science, McMaster University, Hamilton; Professor, Faculty of Medicine, University of Toronto; Chief of Medicine and Sleep Disorders Consultant, St. Joseph's Health Centre, Toronto; Sleep Disorder Consultant at the Sleep Disorder Clinic at St. Joseph's Healthcare, Hamilton, and Central West Sleep Affiliation, Paris, Ontario

* Dr. Jeffrey A. Sherkey, family medicine, affiliate of the University Health Network, Toronto, Ontario; and diagnosed with chronic fatigue syndrome nearly 10 years ago

* Marjorie I. van de Sande, Consensus Coordinator; and Director of Education for the National ME/FM Action Network, Canada.

About the *Journal of Chronic Fatigue Syndrome*

The *Journal of Chronic Fatigue Syndrome* presents original research, practical clinical management, case reports, and literature reviews that provide a comprehensive understanding of CFS. The journal is edited by Dr. Kenny DeMeirleir, organizer of the World Congress on Chronic Fatigue Syndrome and Related Disorders, co-editor of *Chronic Fatigue Syndrome: Critical Reviews and Clinical Advances* (Haworth), and a board member of the American Association for Chronic Fatigue Syndrome; and Dr. Neil Roland McGregor, author of a large number of published papers, conference presentations and conference abstracts on chronic pain, chronic fatigue and chronic neurological diseases.

- Published more details on AssessMed and its medical assessment woes.
- Published Dr. E.G. Dowset (MBChB, Dip Bact.) report originally presented to the British All Party Group of MPs Re: The Late Effects of ME - Can they be distinguished from the Post-Polio Syndrome?).

Few people would dispute that ME (Myalgic Encephalomyelitis), an illness which blights the hopes and aspirations of all sufferers, especially the young, is denied equal treatment in respect of diagnostic familiarities, medical coverage and welfare provision. Comparable chronic and unpredictably disabling neurological conditions, for example Multiple Sclerosis, which was formerly ascribed to 'hysteria' and similarly neglected, now receive government recognition, facilities within the NHS, and more generous research funding - though the potential cost of effective treatment can still arouse bitter debate.

Dr. Dowsett explains what ME is (a group of linked symptoms) initiated by one or more of a related group of enteroviruses which circulate annually in the community in summer and autumn in temperate climates, but all the year round in tropical areas. She also reports on:

What are the late effects of ME;

Which group of ME sufferers are chiefly at risk of the late effects;

What is the post-polio syndrome?

Is it possible that many patients diagnosed as having ME are sufferers from an illness clinically identical to "non-paralytic" polio;

Is it necessary to differentiate between the late effects of ME and the post-polio syndrome?

What is the evidence that the late effects of ME and the post-polio syndrome can be caused by enteroviruses other than polio viruses;

How many symptoms of the late effects of ME and polio be explained;

Muscle weakness and wasting;

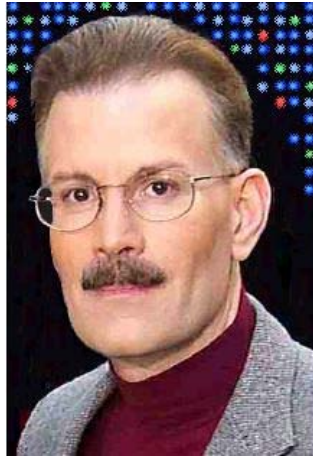
Management and comments.

- Published article by W.J. Reynolds, MD, FRCPC, Rheumatologist – Associate Professor on Fibromyalgia – A Syndrome of Disturbed Physiology. Dr. Reynolds reported that recent research has demonstrated significant physiological disturbances that may explain many of the clinical features of fibromyalgia.
It has been considered that the pain and particularly the sensitivity that patients experience relate to physiological changes in the central nervous system and Dr. Reynolds explains same in the article.
- Published article by lawyer, Hugh R. Scher – Accessing Justice – Pension Appeals Board Denies Minister's Request for Independent Psychiatric Examination for CPP claimant with

Fibromyalgia. He goes on to report on a claimant with CPP who had had her CPP disability approved, only to have the Minister' Request an Independent Psychiatric Examination.

- Reported on results of the June 15, 2002 Symposium and that it was a huge success. Over 400 people attended which was the maximum the room would hold. This Symposium had been videotaped and copies were made of it for people to purchase.

Dr. Bruno, one of our speakers, had been interviewed by David Onley of "CityPulse" Science and Technology Specialist and a CablePulse24 Anchor who also attended the Symposium. We further reported a summary of that event.



Dr, Richard L. Bruno

We are working closely with Dr. Richard L. Bruno and Dr. Elizabeth Dowsett and will keep reporting on developments. Dr. Bruno is now our Special Advisor on parallels between ME/CFS, FM and PPS and Dr. Dowsett is our Honorary International Advisor on ME/CFS.

- Letter by the National ME/FM Action Network to MacLeans' regarding the article of April 15, 2002 called Sick and So Very Tired – By: Danylo Hawaleshka. The Network, on behalf of the ME/CFS and FM community, advising them we were pleased that Maclean's highlighted the stories of patients who are severely disabled by ME/CFS and encouraged Maclean's to continue to write about this debilitating illness.

Alison C. Bested, MD, F.R.C.P.C. suggested that Manon Houle had not read the literature review on CFS when she stated that 'rest is useless'. Dr. Bested further stated she has found that Psychiatrist Fred Friedberg and psychologist Leonard Jason's suggestion that patients must "schedule rest and relaxation intervals, even when less symptomatic in her 10 years' experience with CFS, that this advice, when combined with activity pacing, leads to gradual improvement in functioning.



Dr. Fred Friedberg

- Reported that our Network's TEACH-ME: A Sourcebook for Teachers of Children with ME/CFS and/or FMS was now available in hard copy at \$22.00. This Sourcebook offers information and educational principles to teachers who may have students with ME/CFS and/or FMS.
- Reported on the Council of Canadians with Disabilities who, after many complaints from consumers regarding the Disability Tax Credit and "urged the House of Commons Sub-Committee on the Status of Persons with Disabilities to investigate the Canada Customs and Revenue Agency's administration of the Disability Tax Credit. CCD asked for an apology by Canada Customs and Revenue Agency to the 106,000 Canadians who received a poorly explained letter from the Agency indicating that they were no longer eligible for the DTC despite the fact that these individuals have been receiving this credit for anywhere between six and seventeen years; compensation for the expenses of those who successfully re-certify; and that no new reassessment of claimants will be done until the certification is revised and new procedures and forms put in place; consultations with the disability community and medical professionals to draft amendments to the Income Tax Act that spell out exactly the eligibility credit for the credit and that it reflect the reality of living with a disability; redesigning the Form T2201 that establishes eligibility for the tax credit and streamlining the approval process; an education campaign for the public, medical practitioners and tax preparers; an evaluation of the Disability Tax Credit and a re-examination of all tax measures affecting persons with disabilities.

The National ME/FM Action Network applauds the CCD for its advocacy.

- Article by lawyer, David Lackman on “Whiten v. Pilot Insurance Company: How an Insurer Got Burned in a Home Fire.



He advised in the Introduction that in almost every insurance contract there exists an implied covenant of good faith and fair dealing between insurer and insured, regardless of whether the contract exists to provide long-term disability, life, home, automobile or other types of insurance coverage. An insurer's flagrant breach of that covenant by, for example, refusing to pay a claim despite convincing evidence supporting the claim, or by engaging in a course of oppressive conduct calculated to pressure a vulnerable insured into submission. He then explains the court decision in the Whiten case.

- Announced details for registration for the June 15, 2002 1st Annual Symposium on the Parallels between PPS, ME/CFS and FM. We outlined what would be presented: the New Research on Parallels Between PPS and ME/FM; implications for Assessment of Disability and for Treatment; important treatment information.
- Report by Ms Kate Andersen, M.Ed on the National ME/FM Action Network's contribution to the Polio and ME/CFS and FM Connection and Ms Andersen's interview with Dr. Richard L. Bruno, one of the speakers to be presented at the Symposium.
- Published article by Robert H. Littlejohn, Barrister (Ontario) on The Right To Obtain Defence – Psychiatric Medicals – Is it Absolute?

The National ME/FM Action Network, in its editor's note, advised that people who find themselves in the position of being asked to attend a psychiatric independent medical examination by their insurance company or Canada Pension Plan, where there has been no medical evidence to suggest that such an examination is appropriate, consider bringing Mr. Littlejohn's article to the attention of their lawyer.

The question arises what should be done if Defence counsel asks your client to attend a Defence Psychiatric medical when this medical is patently unreasonable and unnecessary.

- Article by Dr. Jeff Ennis, Community Editorial Board of The Hamilton Spectator of Friday, January 18, 2002 on How Insurance Firms try to scare claimants.
- Dr. Ennis reported that insurance investigators who perform videotape surveillance on insurance claimants following an accident have never outgrown the game of “Peek-a-Boo”. The general public believes the insurance industry uses videotape surveillance to help catch people committing insurance fraud. This is not the case. In fact, surveillance is now used routinely on anyone who makes an insurance claim that involves personal injury and is no longer a tool to investigate insurance fraud but rather as a tool for intimidation.

- Published Fibromyalgia: Integrative Care with BOTOX for Headache/Muscle pain relief by Gordon Ko MD CCFP(EM) FRCPC FAAPM&R.



Dr. Ko reported that muscle pain can range from simple conditions like localized myofascial trigger points to complex chronic pain syndromes like Fibromyalgia (FM). Dr. Ko advised that FM is a difficult-to-treat, potentially disabling problem and it is estimated that the total cost of musculo-skeletal pain is about \$80 billion dollars. He reviewed the published randomized controlled treatment trials to date on Medications; physical therapies and complementary / Alternative Medicine Treatments.

- Reported that British Government Takes Stand on ME/CFS, written by Liana Brittain, Research Consultant & Reporter. In January 2002 the British Department of Health gave the government response to the ME/CFS Independent Working Group's Report. This report had been nearly four years in the making and the Department of health endorsed the view of the ME/CFS Independent Working Group Report that "this is a chronic illness and the Health and social care professionals should recognize it as such". Under the new guidelines, any doctor who ignores or refuses to following the guidelines, could be liable for disciplinary action, according to Chris Clark, chief executive of Action for ME. The Department of Health has tasked both the Medical Research Council and the national Institute of Clinical Excellence to address a variety of related issues and that a timetable and appropriate terms of reference will be agreed upon by the end of February 2002.
- Announced that the National ME/FM Action Network would be hosting the First International Symposium on the Parallels between Post-Polio Sequelae (PPS), Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS) On June 15th, 2002 from 1:00 – 4:00 P.M. at the holiday Inn Hotel & Suites in Toronto-Markham, Ontario. The featured speakers are two internationally-renowned researchers, Dr. Elizabeth Dowsett, leading Briths ME researcher and Dr. Richard L. Bruno, the world's leading expert on Post-Polio Sequelae.

- Published results of the CFIDS Association of America Survey, Charlotte, NC dated November 15, 2001 wherein CFIDS reported that three-quarters of medical professionals responding to the survey believe that CFS is as or more disabling than other chronic diseases such as lupus, multiple sclerosis or rheumatoid arthritis. 35% of the surveyed medical professionals feel lack of a known cause of the illness to be a barrier to diagnosis and 31% felt there is not enough basic knowledge about ME/CFS among the medical community.



According to the survey, 72 of the medical professionals surveyed rely on exclusion of other common laboratory tests and on document the presence of symptoms, other than fatigue. When respondents were asked what one symptom, other than fatigue, made them more likely to suspect CFS, or without which they would not make a diagnosis, the most common answer was post-exertional malaise (incapacitating fatigue lasting more than 24 hours after physical or mental exertion).

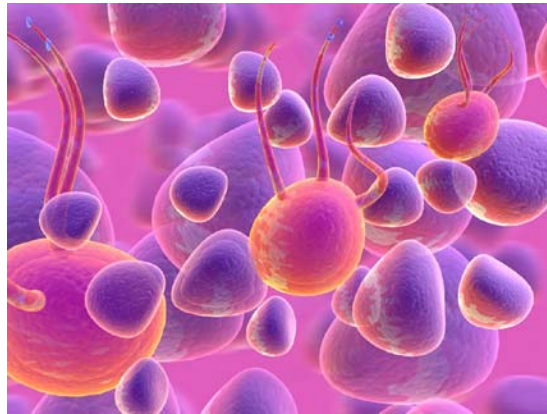
- Instituted mass mailings and a writing campaign with the ME/CFS and FM community to send a letter to the College of Physicians & Surgeons of Ontario outlining the problems with the Third Party medical reports. The National ME/FM Action Network had been hearing from an alarming number of disabled patients all over Ontario who have had their long-term disability benefits denied or terminated based on a report written by an independent medical examiner, in spite of the fact that these patients' own treating physicians and specialists insist that the patient is severely disabled and unable to work in any capacity. As the College planned to do a policy review on these Third Party medical reports, it was essential they were provided with information as to the difficulties with these reports.



The National ME/FM Action Network received a reply from the College dated November 23, 2001 in which they thanked us for the information we had provided and acknowledged that our Network is aware of our interest in this subject. We encouraged the people to keep writing.

In this article Ms Romanick highlights the benefits of exercise and that a broad treatment plan can make symptoms more manageable; and activity and exercise are important components of that plan. She states that Fibromyalgia pain may worsen with inactivity and exercise helps break the cycle of pain and decreased fitness level.

- Published a report by Allison Maree Schmidt, President, Disability Claims Advocacy Clinic Inc. on how Federal Court defines disability in Canada Pension Plan Legislation. Ms Schmidt reported on the most frequent complaints she hears from the disabled community and the apparent inconsistent manner in which Human Resources Development Canada applies the definition of disability defined in Section 42(2) of the Canada Pension Plan Act to individual claimants.
- Published article by Alan C. Logan ND's discussion based on the research of Alison C. Bested MD FRCP©, Paul R. Saunders PhD ND, and Alan C. Logan. Dr. Logan stated that recently scientists have found that the protective role of the barrier extends beyond excluding toxins – they have discovered the existence of tiny pumps in the barrier which can actively remove toxins that have either gained access to or have built up in the nervous system.
- Research has shown that the direct action of certain viruses and/or the immune response (particularly the cytokines) which the body launches in response to chronic infection can damage and inappropriately alter the normal function of the blood-brain barrier. In addition to this, elevations of serotonin and certain deficiencies such as essential fatty acids and glutathione can also cause malfunction of the barrier.



- Published article by David Lackman, Esq., of Lackman, Firestone Law Offices on the growing judicial acceptance of Fibromyalgia and similar debilitating syndromes.



2001

**CANADA MAKES HISTORY IN ME/CFS AND FMS
CONSENSUS MEETING: A RESOUNDING SUCCESS**

**By: Marjorie van de Sande, B.Ed., Grad. Dip. Ed,
Consensus Coordinator & Director of Education**

In response to the many requests for the history of the **National ME/FM Action Network**, how our organization became involved with the Clinical Definitions and more information about the Consensus Document/Meeting, this is a brief synopsis of our organization and what we are about and then information about the consensus document/process.

National ME/FM Action Network: Background

Lydia Neilson, who had been helping at a national research organization for ME/CFS, realized there was a real need for support of the patients. She therefore left the research organization to start a national organization that would support myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and fibromyalgia (FM) patients.

On **June 18, 1993 Lydia Neilson** founded the **National ME/FM Action Network** which was granted charitable status. We are an independent organization but are in contact with all support groups across Canada and the U.S.A. as well as Internationally and work cooperatively with them.



Lydia Neilson

Our mission statement is that: The **National ME/FM Action Network** advances the recognition and understanding of Myalgic Encephalomyelitis and Fibromyalgia through education, advocacy, support and research. The Network seeks to effect positive change in the attitudes, policies and practices of government, business and the general public."

Our motto is "**People Helping People Helping Themselves**".

Our logo is the maple leaf with **geese flying in "V" formation** which portrays working together cooperatively and supporting each other. It is based on the "The Goose Story"

As our name implies, we are an ACTION organization and get actively involved in issues that are of great concern to all of us. To this end, we have a second motto, "**Don't React to unfairness but Act for change.**"

Our newsletter "**Quest**" keeps members informed of recent developments in research and legal areas, etc. and keeps them abreast of the progress of our many projects. They are too numerous to mention here but range from being instrumental in having the wording changed in the Disability Tax Credit form, to developing a national registry of doctors and lawyers knowledgeable about these illnesses, to developing a research/legal package. A couple of our current projects are an educational resource book full of information and teaching strategies for teachers and parents of children and youth who have ME/CFS, and we will be making a legal challenge to the Canada Pension Plan on the eligibility criteria for a disability pension and to Revenue Canada on the eligibility criteria of the Disability Tax Credit. You can also visit our website '**ARCHIVES**' to read past newsletters.

The following points will give you some background as to what led up to the development of clinical definition/protocols documents. The **National ME/FM Action Network** successfully lobbied the federal government to proclaim May 12th as National ME/FM Syndromes Awareness Day. In honour of that day in **May 1995**, the **Honourable Beryl Gaffney MP** and other MPs representing the various provinces presented our petitions with over **15,000** signatures in the **House of Commons**, requesting recognition of ME/CFS and FM and funding for research of these illnesses. A few years ago we sent a questionnaire to 200 doctors who were knowledgeable about these illnesses, asking what was the most important thing that needed to be done towards recognition of these illnesses and assisting the medical community. Approximately **150 doctors** replied and all voiced the opinion that clinical definitions and treatment protocols for these illnesses are of prime importance. The stage was set.

We recruited **Dr. Anil Jain** of Ontario and **Dr. Bruce Carruthers** of British Columbia, two of Canada's top experts in these illnesses, who kindly and generously donated their time and expertise to co-author the draft clinical definitions, diagnostic and treatment protocols documents. As consensus coordinator, I have had the privilege of working with these doctors for the past two and a half years.

Lydia presented the draft documents to **Health Canada** in **July 1999**. The **Honourable Alan Rock**, Minister of Health, responded, "The development of draft clinical definitions for ME/FM is a milestone in the fight against this complex and tragic condition". The **National ME/FM Action Network** worked in partnership with **Health Canada** on the review process for a year and a half.

The **Expert Medical Subcommittee** established by **Health Canada** selected two **Expert Medical Consensus Panels**, one for ME/CFS and one for FMS. This subcommittee of **Health Canada** also established the "**Terms of Reference**" for the panels. One of the stipulations was that at least one member of each panel must be nominated by each of the five stakeholder groups of government, universities, clinicians, advocacy and industry. The twenty-five doctors who were selected received over 80 nominations representing numerous nominations from each of the stakeholder groups. Four doctors from outside Canada were allowed to sit on each panel. A wide range of expertise was represented on the panels including rheumatologists, specialists in internal medicine and infectious disease, a neurosurgeon/ neuroresearcher, a haematologist, etc. There were treating clinicians, teaching university professors and researchers including world-renowned researcher, **Dr. Kenny De Meirleir** of Belgium who has approximately 300 scientific publications. His research on the dysfunction of the RNase L antiviral defense pathway may lead to a clinical marker for ME/CFS.

The panels have been reviewing the documents since December 2000. The consensus meetings were held in Toronto on **March 30 to April 1, 2001**.

Canada makes history in ME/CFS and FM as both expert panels came to consensus on their clinical definition /protocols document.

It will take several months before these documents will be published. The documents have to be finalized and sent back to the panels and then published in a reputable medical journal. Once they are published, we will be able to release the definitions and diagnostic and treatment protocols to the public.

The existing **U.S. Center for Disease Control (CDC)** definition for CFS and the **American College of Rheumatology (ACR)** definition for FM were established for **research** purposes. While these definitions serve a purpose for research, they are too restrictive in the clinical setting. The focus of the clinical definitions is to have the physician look at the whole spectrum of pathologies of these illnesses. The definitions are backed up in the documents by research findings. There are sections on diagnostic protocols and treatment protocols. This means that the family physician will have a "manual" that explains how to diagnose and treat these patients. Having the documents reviewed and endorsed by panels of experts gives them credibility and will empower the doctors treating these illnesses. For the patient, it means earlier diagnosis and appropriate treatment which is essential in order to lessen the impact of these illnesses.

The **Honourable Allan Rock**, who was unable to attend the consensus meeting, sent a written congratulatory message that was read at the meeting. The atmosphere of the welcome reception had an aura of excitement and the positive energy was absolutely electrical. **Crystaal Corporation**, which sponsored the consensus meeting, was awed at the enthusiasm of the doctors. They said that in all their years of working with the medical community they had never experienced such positive, productive and professional panels!

Dr. Jon Russell and **Dr. Thomas Romano**, who were both members of the panel that developed the existing ACR research definition for FM, add to the credibility of the clinical definition document. **Dr. Nancy Klimas** was excited about the unanimous agreement on the ME/CFS clinical definition and told me she previously had been on two panels in the United States to develop a clinical definition but they could not come to an agreement. When Dr. Dan Peterson, a recognized world expert in ME/CFS and was a treating physician for the Lake

Tahoe epidemic, was asked what he thought of the clinical definition document for ME/CFS, his response was, "I love it, I love it, I love it!"

I would like to thank **Lydia Neilson** for her vision of clinical definitions, her commitment and her ongoing lobbying of **Health Canada**. I would also like to thank her for giving me the honour of introducing **Dr. Jain** and **Dr. Carruthers** at the Consensus Meeting. The **National ME/FM Action Network** would like to thank **Health Canada** for selecting excellent consensus panels. A very special thank you to all the members of the **Expert Medical Consensus Panels** for their enthusiasm and productive work, with a huge special thanks to **Dr. Carruthers** and **Dr. Jain**. Their dedication is overwhelming and they have been truly wonderful to work with.

Most sincere thanks to **Crystaal** for sponsoring the Expert Consensus Meeting – they made the weekend truly memorable. A very special thanks to **Ann Hartshorn**, director of New Products, and **Frank Sze**, manager of New Products. It was a pleasure to work with **Crystaal** and **Science and Medicine Canada Inc.**, which is the company **Crystaal** contracted as organizers. We would like to thank **Science and Medicine Canada Inc.** for the excellent job they did, with special thanks to **Gary Browne**, vice-president of client services, and **Dr. Brian Morris**, medical director, who facilitated the consensus meetings. Thanks to **Corrine Daymon**, **Janice Bortoluss** and **Pat Hislop** who worked behind the scene. Also thanks to **Dr. Philipa Corning**, our vice president, who acted as secretary for the FMS panel at the meeting. Last but not least we thank all our members for your prayers and good wishes for a successful meeting!

FIBROMYALGIA EXPERT CONSENSUS PANEL: Dr. Steven Barron; Dr. Bruce Carruthers; Dr. Stu Donaldson; Dr. James Dunne; Dr. Emerson Gingrich; Dr. Dan Heffez, USA; Dr. Anil Jain; Dr. Frances Leung; Dr. Daniel Malone, USA; Dr. Thomas Romano, USA; Dr. Jon Russell, USA; Dr. David Saul; Dr. Donald Seibel.

MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME EXPERT CONSENSUS PANEL: Dr. Allison Bested; Dr. Bruce Carruthers; Dr. Kenny De Meirleir, Belgium; Dr. Pierre Flor-Henry; Dr. Anil Jain; Dr. Pradip Joshi; Dr. Nancy Klimas, USA; Dr. Martin Lerner, USA; Dr. James Mc Sherry; Dr. Dan Peterson, USA; Dr. Peter

- Reported on the Melatonin Treatment of Sleep-Wake Cycle disorders in children and adolescents at the British Columbia's Children's Hospital where a randomized double-blind, cross-over design study of effective doses of melatonin was published in the Journal of Pineal Research (2000,29,34-39). The children chosen were considered potential candidates for melatonin therapy because their disabilities involve a disruption of sleep-wake cycles and/or prevent them from fully utilizing environmental cues to set and reset their cycle.
- Published a report by Rowland Warwick, New S.E.A. Technology & Links to ME/CFS and FM on the Synaptic Technology Study on Pain Control & Associated conditions & ME/CFS and FM Study. This new therapy has a hand-held remote control which is operated by the patient, who is in total control of his/her own treatment. There are no contraindications other than Cardiac Pacemaker and Pregnancy. The device has been approved by the F.D.A. and Health Canada and its notification is under the Health Act as the ability to control acute and chronic pain and speed up the healing process.
- Published article by CPP Benefits Consultant, Kurt Arndt, as to accurately completing Questionnaire included with disability application is important for favorable decision. Mr.

Arndt went into detail as to what kind of pitfalls to avoid as well as pointing out that each medical condition affects individuals differently and it is therefore important to demonstrate how the condition specifically affects your ability to work at any job.

- Article by David Lackman of Lackman, Firestone Law Offices in Toronto, Ontario outlining decision in *McCormick* who was successful in appealing a decision of the Minister of Human Resources Development, Canada, which had denied her claim for CPP disability benefits. The tribunal concluded that the appellant met the requirements of the CPP disability test on the balance of probabilities. It would appear that the *combination* of the two conditions (Chronic Fatigue Syndrome and Neurogenic Orthostatic Hypotension) was found to have rendered the appellant's disabilities both "severe and prolonged" as required under the CPP legislation in order to qualify for the benefits.
- Article by Steve Buist, Science Reporter, of The Hamilton Spectator entitled "Ensuring Insurers Play Fair" dated February 8, 2001. The case before the Supreme Court of Canada is known simply as *Whiten v. Pilot Insurance Co.* The law compels insurance companies to be fair with all claims for losses but that legal obligation must be backed up with potentially large penalties to deter insurers from unfairly denying claims, a Hamilton lawyer argued at the Supreme Court. It is a case that affects every person with insurance. We are presently awaiting the decision.
- Reported on the Ontario Government's launching of a 24-hour hotline for healthcare in Toronto area. 144 Registered Nurses with at least five years experience will determine if the individual, who telephoned needs immediate help, requires a visit to the doctor or can take care of the ailment at home. The nurses will be able to link calls to 911 for emergency and can fax information to hospital emergency rooms.
- Instituted letter campaign and requested all support groups etc. to write letters to the Colleges of Physicians & Surgeons across Canada urging them to adopt the Alberta guidelines or establish similar guidelines for medical doctors who perform Independent Medical Examinations (IMEs) on behalf of third parties, such as private insurance companies. Addresses of all Colleges were included with all the Network's mailings to support groups as well as included with our QUEST newsletter.



- Published article on Chronic Fatigue Syndrome Versus Depression - By Drs. P.I. Flor-Henry, J. Lindle, J. Morrison, H. Pazderka-Robsion and Z. Kolas from the Clinical Diagnostics and Research Centre of the Alberta Hospital Edmonton in Edmonton, Alberta and from the Department of Biomedical Engineering, University of Alberta, Edmonton, Alberta.
- Article by Kate Anderson, M.Ed. on the Alberta Hospital in Edmonton research regarding groundbreaking Canadian research by Dr. Flor-Henry and his team who examined the brain waves and conducted other measurements of central nervous system function in 46 right-handed women with chronic fatigue syndrome who were not taking any medication. When the brain waves of women with CFS were compared with those of healthy women, there were some findings that were statistically significant – that is, there is an extremely low

probability that they were due to chance. The CFS group had a different pattern of brain wave activity compared with health women. As well, special electrical skin-conductance (electrodermal psychophysiology) tests were also carried out on 43 women with CFS and compared with those of 42 health women. There again were statistically significant differences between the women with CFS and the healthy women.

- Reported on Stu Donaldson, Ph.D.'s announcement on new concepts in muscle activity as a source of pain in Fibromyalgia. Dr. Donaldson reported that research suggests that muscles associated with the tender points are activated inappropriately with movement of the head. The articles apparently show that rotation of the head causes muscles (i.e. in the knee, in the lower back, in the arms) to fire when they should be quiet. This activity was approximately twice as prevalent in fibromyalgia sufferers as compared to controls. Further analysis of the data indicates a central neurological basis for this rather than a metabolic component. A future article will appear in our newsletter regarding more research results.



- Published article by David Lackman at Lackman, Firestone Law Offices on "Doctoring with a difference". This article is directed primarily to medical professionals and the opinions expressed by Mr. Lackman are those of a lawyer practicing almost exclusively in the area of injury and disability law, representing claimants.
- Reported that the peer-review of the draft of the Canadian ME/CFS and FM clinical definitions, diagnostic and treatment protocols was scheduled for March 30th to April 1st, 2001 in Toronto and was on schedule. We were able to get a sponsor, Crystal Corporation of Mississauga, who also hired Science & Medicine Canada Inc. and ETC Communications to help the National ME/FM Action Network run this important event. Below is a summary of how the clinical definitions came to be.
- The TEACH-ME Sourcebook for teachers was put on our youth website which offered information and coping strategies for teachers who may have students suffering from ME/CFS and FM. The Sourcebook will help teachers to develop practical approaches to developing modifications to educational plans and the curriculum. A hardcopy of the

Sourcebook is now available through the National ME/FM Action Network and a copy of an order form is displayed on the website.

The authors of this Sourcebook are Canadian teachers, disabled with ME/CFS and/or FM. In addition, we were very privileged to have the consultation of Dr. David S. Bell, a renowned paediatrician and the leading international researcher on ME/CFS and/or FM in children and Mary Z. Robinson, a U.S. educator, research assistant to Dr. Bell and co-author of "A Parent's Guide to CFS. Dr. Bell's and Ms Robinson's knowledge of ME/CFS and FM is unique in that it has been acquired from following real families and children coping with this illness over many years. Our former Youth Consultant, Ms Kate Andersen, a university educator who has ME/CFS herself coordinated this most-important Sourcebook and we are deeply indebted to her.

- Published Dr. Jacob E. Teitelbaum's article on "Effective Treatment for Chronic Fatigue Syndrome, Myalgic Encephalomyelitis and Fibromyalgia" developed by him. He put the problems for ME/CFS into four categories: 1) Disordered Sleep; 2) Hormonal Deficiencies; 3) Unusual Infections; and 4) Nutritional Supplementation and explains in detail his method of treating these illnesses.
- Published "Effective Treatment for ME/CFS and FM developed by Jacob E. Teitelbaum MD. The lead article in the edition of the Journal of CFS published the results of a randomized, double-blind, Placebo-controlled study, after decades of hard work by hundreds of researchers in the field. Dr. Teitelbaum reported that they had progressed to the point where effective treatment is now available for ME/CFS and FM and that over 90 percent of patients improved with treatment.

Dr. Teitelbaum reported that in the average patient, after two years of treatment, the average improvement in quality of life was 90 percent; pain decreased by over 50 percent and many patients no longer even qualified for the diagnosis of ME/CFS or FM after treatment.

Dr. Teitelbaum is a board certified internist and director of the Annapolis Research Center for Effective ME/CFS and FM Therapies. – See _Hyperlink: <http://www.endfatigue.com>

- Reported that new Canadian research was published in Medical Journal in July 2001 under Chronic Fatigue Syndrome: neurological findings may be related to blood-brain barrier permeability. See Med Hypotheses 2001 Jul;57(2):231-7 Bested AC, Saunders PR, Logan AC. Environmental Health Clinic, Sunnybrook and Women's College, Health Sciences Centre, Toronto, Canada PMID:11461179.
- Published article by David Lackman of Lackman, Firestone Law Offices on Doctoring with a Difference. This article is primarily for medical professionals and focuses on the role of physicians in the injury and disability claims process and how physicians might best view and carry out certain administrative and professional responsibilities toward their patients in a medical-legal or benefits-based setting.

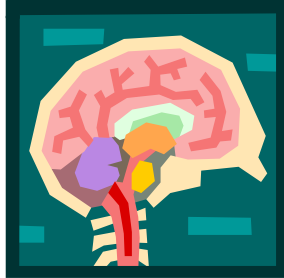
Mr. Lackman stated that while other types of evidence may also be necessary to support a claim, the central issue usually seems to involve the proof of disability. He outlined the different categories the medical professional's help is needed: Understanding and Supporting Patients' Claims; Assisting Patients by Challenging Insurer Medicals; and Cooperation with Counsel.

- Reported on the potential new treatment for the severe pain associated with FM and/or ME/CFS. The former Federal Health Minister, Allan Rock, announced new regulations governing possession and production of marijuana for medical purposes and these regulations were published in Canada Gazette PART II, July 4, 2001, and are available at the Health Canada website at 222.hc-sc.gc.ca and came into force on July 30, 2001.
- Reported that new Canadian research was published on Chronic Fatigue Syndrome: neurological findings may be related to blood-brain barrier permeability.
- Our Director of Education, Marjorie van de Sande, was honoured by the “Fibromyalgia Resource Group of Southern Alberta” with an honorary life membership to that organization. This was in recognition of Marjorie’s dedication and work she has done on behalf of fibromyalgia and myalgic encephalomyelitis patients. Her work as consensus coordinator for the definition/protocols documents is greatly appreciated by the National ME/FM Action Network.
- Published Evaluating Disability – A Medical Legal Dilemma by Russell J. Howe, B.A., LL.B., of Bolland Howe. Mr. Howe stated in his report that the essence of the problem is that all the parties involved with the claimant, medical practitioners, insurers, lawyers and the government are all speaking different languages. In each case, the word “disability” has a specific meaning to each individual and to be effective as a medical practitioner writing a report to a disability evaluator, you must learn to speak their language and goes on to explain What is Disability; Types of disability policies; own occupation policies; any occupation policies; does part-time work qualify; objective versus subjective symptoms; the good faith environment and conclusion.
- Published article by Alan C. Logan ND on the Harvard Chronic Fatigue Syndrome / Chronic Pain Program held in the summer of 2001 under the Mind/Body Medicine Program run under the direction of Herbert Benson MD, who has devoted much of his career to researching the beneficial physiological consequences of eliciting relaxation.



The Harvard CFS program is an education and behavioural therapy group involving 11 weekly sessions for the purpose to provide the skills necessary in dealing with a chronic illness, symptom reduction and to identify factors or situations that may be contributing to setbacks or lack of progress.

- Published article by Alan C. Logan ND's discussion based on the research of Alison C. Basted MD FRCP©, Paul R. Saunders PhD ND, and Alan C. Logan. Dr. Logan stated that recently scientists have found that the protective role of the barrier extends beyond excluding toxins – they have discovered the existence of tiny pumps in the barrier which can actively remove toxins that have either gained access to or have built up in the nervous system.



Research has shown that the direct action of certain viruses and/or the immune response (particularly the cytokines) which the body launches in response to chronic infection can damage and inappropriately alter the normal function of the blood-brain barrier. In addition to this, elevations of serotonin and certain deficiencies such as essential fatty acids and glutathione can also cause malfunction of the barrier.

- Published Hamilton Spectator's November 14, 2001 article, written by Linda Haist, on the Low Blood Volume in ME, according to Dr. David Bell. According to Dr. Bell, there is nothing psychosomatic about ME/CFS and states that studies he conducted with American endocrinologist Dr. David Streeten yielded the startling discovery that patients with the illness have an extraordinarily low circulating blood volume, and that the decreased volume is present in up to 80 per cent of patients.
- Announced new medical direction at Environmental Health Clinic of the Sunnybrook and Women's College Health Sciences Centre in Toronto. Dr. Lynn Marshall became the Medical Director on January 1, 2001 replacing Dr. Frank Foley.
- Announced new 24-hour health guide nurse line in British Columbia which puts you in touch with a Registered Nurse any time day or night.
- Published Summary of a decision of the CPP review Tribunal dated May 1, 2001 in Peterborough, Ontario. This decision is about a 53 year-old woman diagnosed with Fibromyalgia and the reasons for the decision under Section 42 of the Canada Pension Plan. The issues of the Tribunal were to determine whether or not the Appellant's medical conditions were severe and prolonged and whether or not the onset of a severe disabling condition occurred prior to the end of 1999 and have continued to the date thereof. The Tribunal found that she was disabled effective January 1998, which was the month following the month she left the workforce.
- Published article by Richard R. Evenson and Roderick C. Flynn, Lawyers on Supporting Players: The role of professional associations and unions in assisting disabled members. They report that it is not uncommon in their practice to encounter people at or near their lowest ebb- physically or psychologically, drained and disabled, financially imperiled, embattled by a lack of cooperation from insurers and employers alike (and sometimes even

their own doctors), and are despondent at the prospect of an uncertain financial and medical future.

- Published Accessing Justice – Reassessments of Disability Tax Credit Application by Hugh R. Scher of Scher & De Angelis LLP, Barristers & Solicitors. Mr. Scher goes on to explain how people with disabilities, including ME/CFS and FM, are being subjected to reassessment of their application for the Disability Tax Credit, even though they may have been receiving this tax credit for more than 10 years.
- Mr. Scher goes into detail explaining what needs to be done by the claimants and by the medical professionals involved with these claims.
- Published Fibromyalgia and Active Living by Susan Romanick, BSc.P.T., Coordinator Fibromyalgia Program at the Halton Health Care Services Corporation, Oakville Site.



2000

- **Lydia E. Neilson, Founder**, President & CEO was honored on February 21, 2000 on Parliament Hill in the office the Hon. Andy Scott MP, Fredericton, NB. Mr. Scott presented her with a National Award from the New Brunswick ME/CFS Association for her outstanding commitment to those with ME/CFS and Fibromyalgia. The award was signed by the NB President who stated "In your lifetime you may be lucky enough to meet the one person who inspires you. For me, it is Lydia. She has integrity, knowledge of people and a steadfast determination to help sufferers and their families gain awareness, respect and understanding from governments, the medical community and the general public. In spite of her own ill health, she is a model of dedication."



- Published Ms Faith E. Hayman's report on MMPI: Its validity in assessing people with CFS and she outlines what the test is designed to do i.e. assess the psychiatric state of the person by eliciting information relevant to the categories which she then outlined.
- Published Dr. David S. Bell's article out of the Lyndonville Journal, Volume 1, Issue 6 wherein he related symptom variation: illness or host?
- Published Suggested Tests for assessing cognitive functioning, personality, and neuropsychological factors of CFS patients - By Dr. Larry W. Waterman, Registered Psychologist. These tests, originally mentioned in a chapter by Dimitrov and Grafman (1997) summarized their suggestions for tests to which Dr. Waterman included more up to date versions of some of the tests which he believes show promise in assessing CFS.



With those changes and additions, he believes that the list provides the basis for a good targeted neuropsychological assessment based on the research to date.

- Published article by Nancy Bradshaw, Education Coordinator, at the Environmental Health Clinic. The EHC is located in Toronto, Ontario and is the clinical part of the joint clinical and research program of the Sunnybrook and Women's College Health Sciences Centre and the University of Toronto. In this article it was pointed out that not only does EHC diagnose for Environmental Illness but also for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia.
- Review of Dr. Paul Cheney's treatments with Whey Protein by Dr. Philipa D. Corning. Dr. Cheney found that this treatment worked to some degree for all his very ill participants deficient in glutathione, whose abundance in the body is indicative of good health. By treating this deficiency with an undenatured whey protein, the participants in this study all felt better to varying degrees.
- Report by Dr. Mark Baily on Pain Management and Treatment. He reports that chronic pain often leads patients into a downward spiral of physical debilitation, increasing analgesic use and depression.
- Published article by lawyer, Richard M. Bogoroch, Lawyer, on winning the fibromyalgia case.
- Published the Quest collection which consists of important medical and legal etc. information published over 5 years in the bi-monthly newsletter 'QUEST' and put into an easy to read book. Many people have wanted easy access to certain medical or legal articles and we therefore, by popular request, agreed to publish such a book.
- In partnership with Health Canada / Laboratory Center for Disease Control, the National ME/FM Action Network and The Environmental Illness Society of Canada will host the First national Symposium on Chronic Fatigue Syndrome, Multiple Chemical Sensitivities, Fibromyalgia: environmentally triggered and emerging illnesses from November 17-19, 2000. On November 19, 2000 a panel consisting of ME/FM experienced doctors will peer-review the draft clinical definitions and a panel of MCS experienced doctors will peer review the Multiple Chemical Sensitivities clinical definition.
- Published article written for our Ask a Lawyer section of the newsletter regarding members' concerns on the new Release of Information Forms that they must sign for the private insurance company. These new forms entitle the insurance company to receive information about the claimant from a broad range of sources, sometimes including information from "financial institutions" or "any other person holding personal information" or 'any investigation agency' etc. Mr. Richard M. Bogoroch of Bogoroch & Associates in Toronto stated that the Release Form is much too broad and goes beyond the requirements of the long-term disability carrier. He stated that all the disability carrier should be entitled to receive is employment information and medical and other hospital reports and records. Records from any investigation agency and "any other personal information" are intrusive and represent an unjustified invasion of privacy.
- Published article on How To Save Thousands of Dollars on Your Income Tax in regards to Canada Pension Plan Lump Sum Payments. It was pointed out to telephone Human

Resources Development Canada and request written confirmation of the year-to-year calculations of your lump sum CPP disability payment. In the article, it explains step by step what needs to be done.

- Published article by Frank Albrecht, Ph.D., Licensed Clinical Counsellor at the Regional Clinic at Talbot, Maryland entitled “Are psychological factors important in ME/CFS? Dr. Albrecht states that because he is a psychotherapist trained in psychology people often assume that he believes that psychological factors are important in predisposing people to ME/CFS or in impeding recovery from it. He answers “My experience in diagnosing and treating emotional disorders makes me sure that these factors are NOT important”. In summary he states that “...my experience is that psychological factors have little or nothing to do with acquiring ME/CFS, or in preventing recovery from it, but they can be important in keeping people from managing their illness in an optimal way.”
- Dr. Albrecht’s view on Children & Youth Section can be seen on our website/Youth Section.
- Published article by Julia Driver, Plaintiff vs. Sun Life Assurance Company of Canada on the Judgment handed down which stated that three hours before the Pretrial Conference, her lawyers received a fax from the insurer reinstating her long-term benefits. Despite this, they proceeded to court as even the insurers’ independent medical examiners hired by the insurance company had acknowledged her severe limitations. The judge awarded her the total disability benefits payable to the Plaintiff pursuant to the Policy from July 27, 1996 to June 14, 2000 in addition to reinstating her benefits.
- ASK a lawyer Questions and Answers from Mr. Douglas Faulkner, Barrister & Solicitor who replies to the question whether or not people are required to go through an Independent Medical Examination or Functional Ability Examination.
- Reported on the Independent Review of Complaints & Discipline Process commissioned by Ontario Ministry of Health and Long-term care and alerted doctors and patients in our newsletter as well as on our website of same.
- Published article by Dr. Philipa Corning on Inaccurate Evaluations Used to Assess Individuals with ME/CFS. Dr. Corning states that current methods used to assess patients physical capabilities of persons afflicted with ME/CFS really only measures the occurrence of symptoms and nothing more. Such methods do not provide information on the severity of symptoms, the fatigue, the fluctuations of symptoms and activity level and severity of symptoms that occur over time. This approach results in an unreliable portrayal of the true complexities and the interrelations among symptoms. She then outlines the different types of testing done and its results.
- Article by Heidi Mayer, B.Sc. (Hons) Nutrition on CFS and FM. She related the ability of the intestine to digest and absorb all nutrients necessary for the health of the body and also houses a major portion of the immune system.
- Weekly meetings with Health Canada and LCDC re: November symposium on CFS, MCS and FM.

- Announcement to public of the First National Symposium on Multiple Chemical Sensitivity, Chronic Fatigue Syndrome and Fibromyalgia to be held at the Château Cartier Resort in Aylmer, Quebec from November 17-19, 2000. This Symposium is designed to raise awareness of MCS, ME and FM, share information on the state of the science and to begin a preliminary review by medical experts of the draft clinical case definitions.
- Announcement to the ME/FM community requesting help with locating doctors who are ME/FM experienced in diagnosing/treating patients or in related research and should be open-minded and have an attitude that will encourage consensus. These doctors would be considered for the peer-review panel of the ME/FM clinical definitions at the Symposium.
- Drafting sourcebook for teachers by our Youth Consultant, Ms Kate Andersen, M. Ed., who also runs our Youth Section on our website. The sourcebook entitled "Teach Me" is for Canadian teachers and for submission to the Government. Renowned doctors who are experienced with ME/FM children and youth are involved in the writing of this most important sourcebook.
- Published article in two parts by Dr. Larry W. Waterman, Registered Psychologist, "The role of psychological testing in diagnosing ME/CFS-FM". In his report Dr. Waterman outlines the kinds of psychological tests that have been found to yield some information about CFS. He also outlines tests which appear to provide the best information at this time and some possible implications arising from this set of suggested tests. Fibromyalgia is mildly touched on as Fibromyalgia is diagnosed primarily by Rheumatologists and not by psychological testing. In Part II of Dr. Waterman's report he suggests tests for assessing cognitive functioning, personality, and neuropsychological factors of CFS Clients.
- Dr. Waterman proposed to our Network that if we would like, he would be willing to look into the possibility of developing a small team of clinical psychologists and neuropsychologists who, on a once a year or once every two year basis, would review the literature and make suggestions as to how the list of tests could be revised to reflect the most recent research and other findings. Dr. Waterman believes that only in this way can we ensure that the recommended lists of testing material serves its stated purpose to help identify and diagnose CFS. The National ME/FM Action Network has gratefully accepted Dr. Waterman's offer.
- Reported on the National Democratic Party's (NDP) Mr. Dave Christopherson who is the party's finance critic who stated that a complete overhaul is required of the current medical system designed to resolve disputes between complainants and insurance companies. He reported that 83 per cent and 87 per cent of people who claim they've been injured in auto accidents fail an independent exam taken at the province's (Ontario) Designated Assessment Centres. They fail, Mr. Christopherson says, even though their own doctors have found their injuries to be legitimate. He further added that the relationship between the Centres and the insurance companies are "too close for comfort".
- Published report by Martin L. Pall, Ph.D. (Professor of Biochemistry and Basic Medical Science at Washington State University) on Elevated, sustained peroxynitrite - a new theory on the cause of chronic fatigue syndrome. This article was published in the Medical Hypotheses 2000; 54:115-125. This theory is based on known biochemistry and is centered on the potent oxidant, peroxynitrite. This theory proposes that infections, which trigger

about 70% of CFS cases, and also certain other stresses, act by inducing an enzyme known as the inducible nitric oxide synthase which produces high levels of the compound nitric oxide and reacts rapidly with another compound, superoxide to form the potent oxidant peroxynitrite. Peroxynitrite is known to produce a number of types of tissue damage, including damage to the mitochondria and to cell membranes through oxidative chain reactions.

- Published results of lawsuit by Ferry Boat Worker in the amount of \$2,372 Million Dollars against the State of Washington. The ferry boat worker became disabled with Fibromyalgia after being hurt while working on a ferry boat 4 years ago. It is believe to be the largest jury verdict ever on behalf of a victim inflicted with post-traumatic Fibromyalgia, a debilitating pain syndrome that emerges from trauma or injury.
- Requested that mass mailer be sent by the ME/FM community to the Minister of Health to stress their support for the important work that our Network is doing in establishing standardized clinical definitions, diagnostic and treatment protocols for ME/CFS and FM.
- Published article by Dr. David S. Bell, MD, FAAP on Orthostatic Intolerance. O.I. is a term used for illnesses which are characterized by inability to maintain the upright posture. It is a group of illnesses that overlaps with CFS just as fibromyalgia does, and it may give us leads as to the underlying pathology of the illness.



- ASK A LAWYER question and answer published on whether there is a legal time limit from the point when a person's disability benefits have been terminated d by the insurance company and the claimant is able to file a statement of claim in order to initiate a court proceeding. Apparently special circumstances might forgive a claimant's late filing for bringing an action against an insurer. The terms in the policy in question will undoubtedly be analyzed by a court. Different terms such as "forthwith", "promptly" and "within a reasonable time" will affect the court's opinion.
- The "First National Symposium on Multiple Chemical Sensitivities (MCS), Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM)" was originally scheduled for November 17-19, 2000. There are seven partners on the Planning Committee which include: Health Canada, Environmental Illness Society of Canada (EISC), National ME/FM Action Network, Canadian Public Health Association, College of Family Physicians of Canada, Canadian Society of Environmental Medicine, and the University of Calgary. The partners have been actively seeking resources to fund the event.



- On June 27, 2000, in a special meeting of the Planning Committee, it was decided that the Symposium was unable to secure sufficient resources in time for the November date and that the Symposium has been delayed until the spring of 2001 - **March 30 to April 1, 2000.**
- Reported on a drug from Rives Pharma Inc. who was interested in sending information on its drug Imunovir™ those physicians who are treating patients with ME/CFS. This drug had been approved in Canada since 1982 for the treatment of sub acute sclerosing panencephalitis but has now been found useful in treating people who suffer from ME/CFS. In addition of announcing it in our newsletter, we also sent letters with the information to doctors were aware of who are seeing ME/CFS patients. The letters were sent by our Network to protect the confidentiality of the doctors on our listings.
- Announced that the College of Physicians and Surgeons of Alberta had published new Guidelines in June 2000 for doctors performing Independent Medical Examinations on behalf of third parties, such as insurance companies or CPP. Clear patterns are emerging which suggests that strong guidelines are needed so that patients will be evaluated fairly and treated with the respect they deserve when they must undergo such evaluations. A key point raised in the Alberta guidelines is that “A medical examination by a non-treating physicians means that the physician has not been involved in the patient’s care previously and will not be involved actively in the care afterward...” It is clear that in Alberta a doctor who performs an assessment for an insurance company cannot treat the patient later at its rehabilitation centre. The guidelines in Alberta clearly state that the claimant does have the right to have a physician of his/her choice in attendance at the IME. Many doctors won’t allow a friend or spouse into the examination, let alone the claimant’s own attending doctor. A link on our website to the College & Physicians of Alberta is on our website. Our Net work will apply pressure to other colleges in other provinces by sending copies of the Alberta Guidelines to all other Colleges and urging them to change their guidelines.
- Published report by Bruce Flig, D.C. and Dwight R. Chapin, B.Sc., D.C. of High Point Chiropractic Clinic in Mississauga who reported that more and more research is implicating the spinal column and nervous system in fibromyalgia and published protocols that can be helpful for some patients. Drs. Flig and Chapin stated that based on over 20 years of private practice it has been their experience that a multidisciplinary team approach to the management of fibromyalgia has proven to be the most effective. They went on to outline their approach with pain management, spinal manipulation and acupuncture, exercise, nutritional counseling etc.
- Published short obituary Dr. David Streeten who had passed away in late September 2000. Dr. Streeten was a leading researcher on orthostatic hypotension and made a significant contribution to our understanding of ME/CFS.

- In an article written by James E. Allin, Barrister & Solicitor of Chatham, Ontario entitled "Fibromyalgia - How Much Is It Worth? - Swain v. Moore Estate Helps to Decide. Mr. Allin relates the story of an innocent car crash victim who is forced to endure a lifetime of daily pain caused by a negligent driver. Prior to Swain v. Moore Estate, the general accepted range of compensation for a fibromyalgia victim in Ontario was in the \$30,000.00 to \$60,000.00. At the same time, however, fibromyalgia victims in other provinces were recovering in the \$100,000.00 to \$150,000.00 range. Mr. Moore drove his car through a stop sign at an intersection and was struck on the driver's door by the front of the Swain motor vehicle. Mr. Moore died at the scene and Joyce Swain sustained multiple orthopedic injuries and later developed post traumatic stress disorder and fibromyalgia. The matter went to trial and the central issue in the case became; Fibromyalgia, how much is it worth? Mr. Justice Patterson of the Ontario Superior Court of Justice wrote a decision awarding Joyce Swain \$100,000.00 for her injuries. This is the highest damage award in Ontario case law for a claimant with Fibromyalgia.
- Reported that the law firm of Quadrino & Schwartz of Garden City, New York stating that they had become aware of a fraudulent nationwide scheme by an insurer, First Fortis/Fortis Benefits that may enable them to reopen thousands of denied claims and were looking for people who fell into that category.
- In our October / November 2000 issue of our newsletter 'QUEST' we announced that the Symposium for ME/CFS, FM and Environmental Illness needed to be cancelled due to lack of funds. Our Network has always preferred that we hold a Symposium after the ME/FM clinical definitions, diagnostic and treatment protocols were peer reviewed and published so that doctors would be able to gather together and share the information. However, when Health Canada invited us to participate in the planning of a Symposium, we took the opportunity to do so. However, our main goal is and always was the peer review of the ME/CFS and FM definitions. Therefore, although the Symposium was cancelled, we continued with the date of March 30th and April 1st, 2001 as the date for the peer-review of the ME/CFS and FM definitions. We asked our members to permit us to take the funds to be used for the Symposium and instead use them for the cost of the clinical definitions which was granted.



- National ME/FM Action Network urges the Canadian Colleges of Physicians and Surgeons to develop guidelines for Independent Medical Examinations or adopt the guidelines set by the College of Physicians & Surgeons of Alberta. Each College, except for Alberta, was sent a copy of the Alberta guidelines for their consideration.
- Announced that Dr. Richard Bruno and his research team have been known for over a decade for exploring the link between viral damage to the brain stem and the fatigue associated with Post-Polio Syndrome. Apparently there are abnormalities in both Post Polio Syndrome and ME/CFS that are evidence of damage to the brain stem neurons that activate

the brain - the brain activating system that keeps the brain awake and focuses attention. Dr. Bruno states that there were reports of CFS and polio occurring at the same time in the 30's and 50's. He further states that "Potentially half of those diagnosed today with CFS-- especially those with symptoms that come on slowly -- may in fact have had Summer Grippe or undiagnosed non-paralytic polio as children in the years before the polio vaccine became available. Dr. Bruno is now working on an international survey looking at a possible link between childhood diseases, with symptoms like fever and a stiff neck, even without muscle weakness, and ME/CFS and FM symptoms in later life. When the survey is ready, the National ME/FM Action Network will be distributing copies to our members as well as posting the survey on our website.

- Reported that the Credibility of IME Reports from King's Health Centre may be in question due to the public scandal of the private Toronto clinic which had been closed down following the disappearance of both millions of dollars and it found Ron Koval and his wife on October 12, 2000. The Ontario Provincial Police are investigating fraud charges and allegations of double-billing, the unlawful act of charging both a third Party, such as an insurance company, and the provincial health insurance plan for the same service. An overwhelming number of strong complaints were received of unfair treatment from the former MRS Health Services of Hamilton, Ontario, who became King's Health Services in July 1998, the insurance arm of the clinic. It seems that numerous insurance companies across the country were using the services of King's Health for independent medical evaluations and in light of the recent scandals, lawyers are suggesting that the credibility of all IME reports from King's can now be questioned in court.
- Russell J. Howe of Bolland Howe, Barristers & Solicitors of Aurora, Ontario reported on the Clarfield decision stunning the long-term disability industry. On October 30, 2000 Justice Juriansz of the Superior Court of Justice in Ontario, released the decision in *Clarfield and The Crown Life Insurance Company*. In the future long term disability insurers who treat their claimants in a shoddy or inappropriate way, bear the risk of substantial punitive damages. In the *Clarfield* case, Crown Life refused to pay benefits to a claimant based on some questionable claims practices that were systemic across their company. After a trial the court awarded \$200,000.00 in punitive damages against Crown Life, in order to deter the insurer's inappropriate conduct. However, the final chapter has not been written. The *Whitten* case is due to be argued in front of the Supreme Court of Canada on December 14th, 2000 and the Supreme Court's pronouncement will have a significant impact on the availability and size of punitive damages awards in the future in Canada.
- Russell J. Howe further reported on the insurance industry organizing an aggressive response at the November 6th and 7th, 2000 conference.



1999

- Received another grant from Health Canada in the amount of \$30,000 to help us with our operational costs and to continue our efforts to become self-sufficient through fundraising.
- We have been approved by the Court Challenges Program for case development funding for our challenge to the Canada Pension Plan Disability Pension. As with the Disability Tax Credit, a form has been designed and distributed to the ME/FM community to help find a test case to present in court for our Challenge as it appears that people with ME/FM are being discriminated against. Under the CPP rules, it must be proven that an illness is severe, prolonged and the individual cannot perform any work. However, CPP usually turns down cases of ME/FM as they do not consider them severe or prolonged.
- Responded to Chatelaine's article of July 1999 "Can a diagnosis make you sick"? In this article, it left the impression that when the individual mentioned in the article was advised by her doctor that she suffered from FM, she was ill for a long time. One day she decided to change her attitude and from that point onward she became completely cured. We sent a letter of protest to Chatelaine which was published in its September 1991 issue. This was also followed up by our Director of Education, Ms Marj van de Sande, who sent a letter detailing what FM is all about. In Chatelaine's written reply to us they stated that they knew it was controversial but found that most of their readers appreciate strong points of view. However, they did say that this article will not be their final word on the subject of Fibromyalgia.
- Published a summary of the lecture by Dr. Majid Ali held on May 30, 1999 in Toronto entitled Reversing Chronic Fatigue and Fibromyalgia. Dr. Ali permitted us to publish his protocol of diagnosis and treatment of ME/FM. The Toronto Clinic for Preventive Medicine sponsored Dr. Ali and his protocol is strictly followed at this clinic.
- Published survey from Ms Colleen Beaumier, MP of Brampton West-Mississauga, who canvassed the Peel Region General Practitioners on their knowledge of ME/FM. On the question of a standardized criteria being used to diagnose FM, 75% reported that it was very important.
- Further published a report by Ms Carmela DiMondo, Constituency Advisor for Colleen Beaumier, MP detailing what one needs to know about Canada Pension disability and Fibromyalgia.
- Reported on insurance companies who can use research on exercise and CFS for own advantage. It has been proven through research that sleep deprivation causes even healthy people to suffer fatigue, which leads to reduced productivity. In the ME/FM community, physical exertion causes individuals to relapse with ME/FM symptoms and therefore experience reduced physical performance. In fact, post-exertional malaise, fatigue and weakness, and impairment of cognitive functions last for more than 24 hours. It is often described as muscle exhaustion and weakness similar to that experience. Although there is ample scientific research evidence that supports the reduced physical capabilities of ME/FM people, some insurance companies have been using this reference as an excuse to cut off benefits to ME/FM people. The British Medical Journal No. 7095, Volume 314, Papers-

Abstracts on Saturday, June 7, 1997 by Kathy Y. Fulcher and Peter D. White indicated in the introduction that fatigue may be caused by physical de-conditioning or sleep deprivation or psychological distress, or a combination of the three. However, they also stated that they did not include those with sleep deprivation or psychological distress into this particular piece of research. Some insurance companies have used this research to its own advantage by failing to advise that these particular categories were excluded.

- Questions and answers by Professor Garth Nicolson, Institute for Molecular Medicine, CA on cardiac problems in ME/FM people. He stated that heart problems were various and found that they usually can be attributed to cardiac infections (Mycoplasma, Chlamydia, etc.) that can cause endocarditis, myocarditis, pericarditis, progressive cardiac enlargement, arrhythmias and valve problems. Prof. Nicolson further advised that patients on a protocol of Zithromax for mycoplasma were usually found to have an initial worsening of signs/symptoms but it is thought to be due to “die off” or “damage” of the microorganisms by the antibiotics and release of toxic materials that can affect cells and tissues in many adverse ways and may involve the host’s immune system as well. In general, this condition passes within days to a few weeks and patients then generally begin a slow process of recovery from the signs/symptoms but not all at the same rate and not in all patients.
- Collaborated and sponsored the ongoing research of Ms Dilnaz Panjwani, the teen who had discovered high levels of 2,3-Diphosphoglycerate in people who suffer from ME/FM. We helped to organize and assembled the ME/FM patients needed for the second research study conducted in March of this year and organized the interactive public education presentation at the Credit Valley Hospital Auditorium near Toronto on May 29th. At this time Miss. Panjwani and her father, Dr. Dilkush Panjwani, who is the qualified Scientist and Supervisor on the ongoing research and Dr. Panjwani was available to discuss individual research results. A plaque engraved with our logo and an inscription was presented to Miss Panjwani at that time. This conference was also videotaped and made available to the ME/FM community.
- Reported further on the law suit by AssessMed Ltd. who is suing the CBC and advised that on March 8, 1999 CBC filed its Statement of Defense at the Toronto, Ontario Federal Court House. In addition the “Hamilton Spectator: in a series of newspaper articles June 2 and 3 also highlighted the treatment by AssessMed of one of the disabled people in the same CBC program. Prior to its publication, they received a letter from the lawyers representing AssessMed and therefore in the last paragraph of its report related what the lawyer’s letter contained. Lawyers acting for AssessMed also sent a threatening letter to “The Spectator” prior to publication of this story informing the Editor-in-Chief that the company ‘takes these matters very seriously, and will take all actions to preserve the good name and reputation of AssessMed as an independent medical evaluator, and of all of its personnel and medical professionals”.
- Reported an article by Occupational Therapist who advised that as of February 1998, Occupational Therapists are authorized to complete the Disability Tax Credit Certificates as Occupational Therapists are trained to assess a person’s abilities and disabilities in these basic activities of daily living. O.T. is a branch of rehabilitation medicine which addresses the physical, mental, environmental, spiritual, vocational and social aspects of maintaining daily routine. Revenue Canada also recognizes Occupational Therapy services as a tax deductible medical expense when receipts are included.

- For the past year, Dr. Bruce Carruthers of British Columbia, Dr. Anil Jain of Ontario, and Marj van de Sande of Alberta who is our Director of Education, have worked diligently to draft and compile the ME/FM clinical definitions, diagnostic and treatment protocols. This document is now ready for peer-review. Therefore on July 21, 1999, Dr. Philipa Corning, our Vice-President and our President CEO, Lydia Neilson, presented this draft to the Minister of Health's representatives. At this meeting we were advised that there are presently no funds available for the peer-review as Health Canada has not allocated any funds for ME/FM. We requested therefore a meeting with the Minister of Health and the Director General of the Laboratory Center for Disease Control. In a letter received from the Minister he stated that his schedule did not allow him to meet with us but he has instructed the Director General of the LCDC to meet us on his behalf to discuss the funding issue. The Minister in his letter of May 31, 1999 stated that "The development of draft clinical definitions for ME/FM is a milestone in the fight against this complex and tragic condition". We hope to have the ME/FM definitions/treatment protocols published and distributed by Health Canada, LCDC and our network as it is essential for the recognition and acceptance by the medical community.
- Reported on a letter received by our Co-Directors of B.C., Mr. Ian Waymark, from the College of Physicians & Surgeons of British Columbia in which the Deputy Registrar of the College, Ms Patricia Rebbek, commented on doctors performing an independent medical examination upon a patient's condition at the time of the examination. She stated that an insurance company is free to choose any physician it wishes to for the I.M.E. and that the physician does not necessarily have to be an expert in the ailment from which the patient suffers. She further stated, however, that one would think that evidence from an expert would outweigh that of a non-expert in a court of law. She further stated that the College does have strict rules about physicians or surgeons who hold themselves out to be specialists. Only those who have qualifications in the "Royal College of Physicians and Surgeons of Canada (F.R.C.P.(c)) are recognized as experts. In legal terms it is used in a court of law when the court recognizes that the qualifications of a physician or surgeon entitle him/her to be an expert in the subject at hand.
- Reported the Sick-Air lawsuit by a 49 year old translator, Bernard Miller, who had been fired five years ago by the International Civil Aviation Organization after he refused to come to work, complaining the air in ICEO's headquarters was seriously damaging his health. He claimed the pumped-in air was toxic, sapped his energy and made him chronically ill. The federal government and Monit International Inc. immediately fought back claiming that the translator could not sue in Canada because he was an employee of an international organization. More than two years after he launched the suit, the Quebec Court of Appeal tossed out that argument and gave Mr. Miller the right to sue both defendants.
- In helping raise awareness of ME/FM this year for May 12th we asked the ME/FM community to contact the Minister of Health and the Director General of the Laboratory Center for Disease Control requesting their support for our Network in our efforts to establish a standardized clinical definition for ME and FM.
- A two-part Report by lawyer, Hugh Scher, on accessing justice and overcoming the barriers to obtaining benefit entitlements under long-term disability insurance policies and the Canada Pension Plan. Mr. Scher explained how people with ME/FM experience consistent challenges trying to access entitlements to long-term disability benefits and the CPP

disability pensions. The prime message he emphasized in the article is that there is no substitute for solid medical documentation and evidence and often for strong legal advocacy for individuals who enter the maze of long-term disability benefits.

- Announcement that the U.S. Centers for Disease Control has a new booklet out on Chronic Fatigue Syndrome dated October 1998 and how to obtain same.
- Reported on Physician, Arnold J. Voth MD, LMCC, FRCP(c) who addresses his peers on the ethical issues of Independent Medical Examinations and Chronic Fatigue Syndrome. He related the fact that in the past ten years there has been an abundance of excellent articles written about CFS but no one has ever addressed the more difficult ethical issues CFS presents. He further stated that in their relentless quest for any means, whether foul or fair, of denying these patients disability coverage, insurance companies have taken to hiring independent medical examiners to assess these patients but that it has becoming all too clear that they are often anything but independent.
- Presently drafting an educational book entitled "TEACH-ME" which is spearheaded by Kate Andersen, M.Ed. We hope to publish this book and distribute it to schools to help Children and Youth with ME/FM as well as bring awareness to teachers. Dr. David Bell, a well-known physician who sees children and youth in his practice, is our Honorary Senior Editor.
- The British Columbia Coalition of People with Disabilities (BCCPD) who publishes a newsletter called "Transition", in their January/February 1999 issue published an article on ME/CFS and also included our Network's Independent Medical Examination Registry form for distribution to its members. This is an on-going project as the more details we have on the Independent Examinations done by the insurance industry and the doctors who do these I.M.E., the more useful this Registry will be.
- Sponsored and organized interactive public education presentation at Credit Valley Hospital Auditorium near Toronto on Saturday, May 29, 1999 and helped organize the second research study conducted in March of 1999 with ME/FM patients and Ms Dilnaz Panjwani's results on readings of the 2,3-DPG test. Special assistance was
- At Credit Valley Hospital, Ms. Dilnaz Panjwani and her father, Dr. Dilkush Panjwani, the former Chief of Psychiatry at Queensway General Hospital, Toronto, is the qualified Scientist and Supervisor of the ongoing research, presented her research findings on 2,3-Diphosphoglycerate as being a potential marker for a diagnosis of ME/FM to a packed audience of interested people from the ME/FM community. Dr. Philipa Corning, Vice-President and Lydia Neilson, President CEO of the Network were present and Ms Neilson presented Dilnaz Panjwani with a plaque engraved with the Network's logo in recognition of her hard work and commitment to the ME/FM community.
- Reply from Deputy Registrar, Ms Patricia Rebbeek, dated April 9, 1999 of the College of Physicians & Surgeons of British Columbia in regards to our question on Independent Medical Examinations and who is considered an expert. She stated that it was "The duty of a doctor performing an independent examination is to report upon the patient's condition at the time of the examination. An insurance company is free to choose any physician it wishes. The physician does not necessarily have to be an expert in the ailment from which the patient suffers, however, one would think that evidence from an expert would outweigh

that of a non-expert in a court of law. It is the duty of a treating physician to advocate for his or her patient. As far as the insurance companies are concerned this introduces bias which is why independent examiners are used.” Ms Rebbeek further states that “The College does have strict rules about physicians or surgeons who hold themselves out to be specialists. Only those who have qualifications in the Royal College of Physicians and Surgeons of Canada (F.R.C.P.(c) are recognized. The term expert is a legal term used in the court of law when the court recognizes that the qualifications of a physician or surgeon entitle him or her to be an expert in the subject at hand”.

- Three newspapers across Canada have published articles highlighting the difficulties that disabled people face when an independent medical examination is requested by a private insurance company. Forms of our Independent Medical Examination Registry Submission have been spreading steadily across the country. The Victoria Times, The Calgary Herald and The Hamilton Spectator have spoken out about the problems of I.M.E.s and the articles led to more publicity for our I.M.E. questionnaire. Many of these forms have been copied by doctors and lawyers to pass on to their clients.



- Designed and distributed Canada Pension Plan disability questionnaire, with assistance from our Lawyer, Hugh Scher, for the purpose of finding the perfect test case to take to court.
- Video tape made of May 29, 1999 presentation at the Credit Valley Hospital in Mississauga of Ms Dilnaz Panjwani and Dr. Dilkhush Panjwani's research on 2,3-DPG and net proceeds of the tape was deposited in our new research account.
- At the July 21, 1999 meeting at the laboratory Centre for Disease Control (LCDC) in Ottawa, we presented a draft clinical definition/treatment protocols on ME/FM to the Minister of Health's representatives. At this meeting were advised that there were no funds available for the peer-review as Health Canada has not allocated any funds yet for ME/FM. On May 31, 1999 the Hon. Allan Rock stated that "The development of draft clinical definitions for ME/FM is a milestone in the fight against this complex and tragic condition." We therefore requested a meeting with the Hon. Allan Rock and the Director General of the LCDC for the purpose of requesting that Health Canada allocate funds for the peer-review and distribution of these clinical definitions.
- Network responds to Chatelaine July 1999 article on Fibromyalgia which was not accurate and gave a very bad overview about FM. Our reply was published in the September 1999 issue of Chatelaine wherein we chided them about their inaccuracies. Our Director of Education, Marj. van de Sande, also wrote a letter to Chatelaine enclosing educational material on FM.

- Published article on Dr. Majid Ali's presentation in Toronto of May 30, 1999 wherein he outlines treatment protocol and his belief that CFS/ME is a progressive immune disorder which affects all body organs and systems. It is caused, according to Dr. Ali, by accelerated oxidation to the human enzyme systems. Oxidation is the process of decay, loss of energy (electrons). . Dr. Ali is well-known in the CFS Network in the U.S. and Canada for his book, *The Canary and Chronic Fatigue*.
- .Published Consensus Definition of Multiple Chemical Sensitivities (MCS). 34 researchers and clinicians published a consensus definition of MCS in the U.S. Archives of Environmental Health. Barta et al. Multiple Chemical Sensitivity (MCS): A 1999 Consensus Archives of Environmental Health 1999; 54(3) 147-149.
- The Calgary Herald on July 25, 1999 published its third newspaper article on Independent Medical Examinations and also quoted our President CEO, Lydia E. Neilson, and mentioned our survey on I.M.Es.
- Reply from the Minister of Health advising he is making arrangements with the Director General of the Laboratory Center for Disease Control to meet with us on his behalf. Published Director General's name and address to encourage ME/FM community to support us by writing letters to him.
- Dr. Jeff Sherkey, a Toronto MD, CCFP, reported on a treatment called "Gancyclovir", a new antiviral drug which has been approved by the F.D.A. Dr. Martin Lerner in his study of a group of CFIDS patients who he proved had a viral cardiomyopathy, treated 18 of his patients with intravenous gancyclovir 5 mg/kg I.V. every 12 hours for 30 days, while monitoring blood parameters for potential problems to bone marrow, liver or kidney. The treatment was tolerated by all 18 patients without incident. He had a success rate of 72%.
- Published articles on pain and Fibromyalgia by Dr. Allan F. Chino of the Pain Institute of Nevada.
- Published Questions and Answers by Dr. David S. Bell, regarding whether or not it would be bad medical practice to use central nervous system stimulants (judiciously and under medical supervision) during periods of relapse.
- Published Fibromyalgia - The Patient's Role by David Saul wherein he outlines general strategies that can be used to decrease pain and increase energy.
- Filed Access to Information Application on July 26, 1999 under the Access to Information/Privacy Act requesting such things as the original intent of Section 118.4 of the *Income Tax Act*. We had contacted people at Revenue Canada but none of them were aware of what the original intent of this Act is. Somehow with all the changes in the past the intent has been buried.



1998

- Conducting a National Survey on Independent Medical Examinations (I.M.E.) or Functional Ability Examinations (F.A.E.) which was developed by Mary Ellen of Pickering, Ontario. This was started as a result of the many ME/FM people who had been sent for an I.M.E. or F.A.E. by their insurance company and were disqualified for disability insurance on the basis of the I.M.E. or F.A.E., in spite of their own doctors' professional opinions that they were unable to work. We are therefore developing a registry of disability applicants who have gone for these examinations, both denied and accepted, to accumulate a data-bank on the doctors involved in these examinations. Some doctors have made a living based on doing these examinations for the insurance industry and a big percentage of their income is dependent on it. We hope to accumulate data to support that view. This information will assist us to make changes to what seems to indicate an unfair practice.
- Reported on the Neurotransmitter/Receptor Dysfunctions report done by Dr. Jeff Sherkey which was primarily based on Dr. Goldstein's book "Betrayal by the Brain: The Neurological Basis of Chronic Fatigue Syndrome, Fibromyalgia Syndrome and Related Neural Network Disorders".
- Reported in detail on the ME/FM/MCS conference held on October 3, 1998 at The Environmental Clinic of Women's College Hospital entitled "Chronic Fatigue, Fibromyalgia and Environmental Hypersensitivity - Practical Pears". The list of accomplished speakers consisted of Dr. Frank Foley, Medical Director of The Environmental Health Clinic, Drs. Alison Bested, Lorenz, Lynn Marshall, Gerald Ross, Paul Sterling and Beverly Tomkins.
- Published a report by George V. Rossie, Ph.D., Clinical & Consulting Psychologist and R. Daun Gretzinger - IME Administrators on making the "Independent Medical Exams" Independent. They reported on a grass-roots effort to change the way IMEs in Colorado were conducted for auto accidents which sprang to life in 1996. The initial driving force behind the effort was a legislative aide to a state senator who had been in an auto accident and then re-victimized when her insurer sent her for IMEs that determined that she was no longer in need of treatment, despite being unable to resume her legislative duties. With the support of the senator and her therapists, legislation was drafted and introduced into the state legislature which essentially would prohibit insurance companies from using IMEs to determine benefits in auto cases.
- Reported on the research proposal to expand the original studies and to develop a new diagnostic test for ME/FM was submitted to the Environmental Health Clinic at Women's College Hospital by Miss Dilnaz Panjwani to expand the original study on 2,3-Diphosphoglycerate (2,3-DPG) to include a randomized larger sample size of new experimental subjects and healthy volunteers as controls; to explore the potential role of 2,3-DPG levels as a potential biological marker for ME/FM; and to develop a specific and sensitive diagnostic biochemical test for ME/FM.

- The Health promotion and Program Branch of Health Canada awarded us a Grant in the amount of \$20,000 to help us become independent and raise our own funds. The department stated that they recognize the value of the work we have undertaken to support patients, family members and support research. Again they expressed their appreciation to the Board, volunteers and staff of our Network for their dedication and contribution to improving the health and well-being of Canadians. This was signed by the Assistant Deputy Minister.
- Reported on the judgment by the Hon. Justice Mr. Phillip Clarke in the *Baillie v. Crown Life Insurance Company* wherein the judge found that not only was the Plaintiff totally disabled with chronic fatigue syndrome but the judge also found chronic fatigue syndrome to be an organic illness. Although an appeal was considered by Crown life on July 29, 1998 Crown Life made an official announcement that they will not appeal the ruling that chronic fatigue syndrome is an organic illness.
- Reported that on June 8th, 1998 the College of Physicians of Quebec issued Guidelines on CFS for physicians. Both the Association of Fibromyalgia of Quebec and the Quebec M.E. Association had lobbied the Minister of Health of Quebec for a recognition of FM and CFS. The Minister in turn in 1995 had requested that the College study both ME and FM and establish guidelines.
- Participated in a Rest-A-Thon which was part of an International event to raise funds for Canadian researchers. The researcher chosen to receive the benefits of the Rest-A-Thon is Dr. Pierre Flor-Henry at the University of Alberta, Edmonton.
- Reported on the July 27, 1998 "Dominion Tax Cases" wherein it was reported that a tax payer suffering from Chronic Fatigue Syndrome and Multiple Chemical Sensitivities had initially been denied a tax credit by the Tax Court of Canada as it was concluded that the taxpayer was not unable, with therapy, to perceive, think and remember all or substantially all of the time, and that she did not take an inordinate amount of time to perform these functions. On appeal to the Federal Court of Appeal for a judicial review of the Tax Court's findings it was concluded that the taxpayer's application was allowed as the Federal Court of Appeal pointed out that in *Johnston v. The Queen* (98 DTC 6169 the disability tax credit provisions of the Act are to be given a humane and compassionate construction. The matter was accordingly referred back to the Tax Court of Canada for rehearing on the basis of the principles articulated in the *Johnston* case.
- Reported on two Long-Term Disability claims in recent British Columbia Court decisions. *Mathers v. Sun Life Insurance Company of Canada* (March 11, 1998) in which case the Court dismissed the Plaintiff's claim for disability benefits while in the *Eddie v. Unum Life Insurance Company of Canada* (May 28, 1998) the Court accepted that the Plaintiff was "totally disabled" and entitled to disability benefits. These two approaches adopted by the trial judges pose problems for insurance companies, for claimants, and for their lawyers in making decisions about individual disability claims.
- Dr. Philipa Corning (Vice-President) wrote a report on the discovery of the 2,3-DPG levels in CFS and how this solves another part of the puzzle, namely that there are three significant pieces of research in different aspects of blood components and cardiac structure that have surfaced in connection with ME/CFS: misshapen red bloods as reported by New Zealand Dr.

Leslie O. Simpson; cardiac myopathy as per Dr. Martin Lerner of the United States and enzyme deficiency as per Miss Panjawani's research on 2,3-DPG.

- Reported on the Baillie v. Crown Life Limited, 1988 A.M. No. 235 wherein the Alberta Court accepts CFS as an organic illness. In this trial, the trial judge was highly critical of the evidence presented by Crown Life as they relied on the evidence of one psychiatrist who diagnosed the Plaintiff as having a conversion disorder, a type of psychoneurotic complaint. The judge further felt that his diagnosis was done on the basis of a pre-conceived notion of what the diagnosis should be.
- Reported on Cugliari v. White wherein the Ontario Court of Appeal ruled that Canada Pension Plan disability benefits payable under the Canada Pension Plan are not deductible from an award of damages for income loss arising from an automobile accident claim in Ontario.
- The Network applied for and received approval by the Court Challenges Program for case development funding for our challenge to the Disability Tax Credit (Form T2201) in regards to Section 118.4(1)(c) of the *Income Tax Act* on the basis that this section discriminates against persons suffering from ME/FM. Mr. Hugh Scher, Barrister & Solicitor of the firm Scher & De Angelis, has been retained to look for suitable plaintiffs that might be able to carry forward a court challenge of this kind and who have been denied the disability tax credit for reasons that they either do not comply with the definition contained in the Act of disability or that they have been denied the tax credit because they have ME/FM, regardless of the functional effects of these conditions on their abilities to carry out the activities of daily living. A questionnaire was distributed to the ME/FM community in order to find a possible test case. At this time, the tests cases have been reduced to 10 for consideration by our lawyer.
- Reported on Dr. A. Martin Lerner's research breakthrough. Dr. Lerner offered "hard data" that shatters the myth that ME/CFS is a psychiatric disorder, depression, hysteria or deconditioning due to a patient's refusal to exercise. Dr. Lerner who is an infectious specialist at William Beaumont Hospital and at Wayne State University, and his colleagues, have found evidence that ME/CFS may be caused by a persistent herpesvirus infection of the heart. In Dr. Lerner's study, 100% of the ME/CFS participants showed abnormal oscillating T-waves at 24 hr. holter monitoring and 24% showed weakened function on the left side of the heart. This is the side of the heart that pumps oxygenated blood to all of the body, except the lungs. Data gathered showed that patients exhibited evidence of cardiomyopathy or disease of muscle in the heart.
- Presented a brief to the Standing Committee on Health on February 17th, 1998 regarding food supplements and non-drug medication. This brief was instigated by the Fibromyalgia Society of Ontario and ourselves. We pointed out to the committee that it was essential that the following recommendations are addressed: establish methods of licensing and regulating for all complementary medical health care professionals; establish a board of professionals with extensive knowledge of herbs and other natural substances to ensure quality control of natural nutrient supplements and herbs; ensure that all products sold in health food stores or other modes of marketing as nutrient supplements and herbs should be properly tested and their packages labeled, including warnings of possible side effects; establish a body that can regulate network marketing and address any grievances from consumers against network marketers; and insist that any claims regarding cures, made by

health care professionals or companies selling herbs or nutrient supplements, are backed up with scientific fact.

- Reported on teen, Miss Dilnaz Panjwani who had won a national science award for research into CFS. Miss Panjwani may have discovered a possible physiological basis of CFS as she has identified a 'statistically highly significant' relationship between levels of a blood enzyme called 2,3, diphosphoglycerate (2,3-DPG) and patients with CFS. If further tests support this evidence, there is the possibility of having a blood test for the disease.
- Reported on a survey conducted by Ms Colleen Beaumier, MP of Brampton West-Mississauga of General Practitioners Peel region and their knowledge of ME/FM. Of the doctors surveyed who are treating ME/FM people, 73% reported treating from 1-10 patients; 6% reported from 11-20; and 13% reported more than 20 patients suffering from ME/FM.
- Published report from Ms Carmela DiMondo, Constituency Advisor for MP, Colleen Beaumier of Brampton West-Mississauga. Ms Beaumier has taken a great interest in the frame work of Canada Pension Disability and its length of time in case processing as well as qualifying for same. Ms. Beaumier therefore had discussions with the Minister of Canada Pension and his staff and provided us with information to aid those applying for disability who suffers from ME/FM. This information was then made available to the ME/FM community.
- Report on Independent Medical Examinations by U.S. Attorney, Bernard Kanskey wherein he outlined steps that can be taken by the ME/FM person in an effort to obtain a disability pension. He pointed out that the purpose of the insurance company is not to obtain an impartial review but to obtain a medical opinion which could justify the discontinuance and/or denial of benefits.
- Reported on AssessMed Ltd. suing CBC on an article aired November 10, 1998 on 'The Fifth Estate' entitled 'Prove it...If you can' wherein three disabled individuals and their experiences with insurance companies were highlighted, including the experience with the independent medical examination conducted at AssessMed Ltd., a registered facility specializing in I.M.Es and F.A.Es. The Statement of Claim of AssessMed was made available to the ME/FM community.



1997

- Reported on the Neurotransmitter/Receptor Dysfunctions report done by Dr. Jeff Sherkey which was primarily based on Dr. Goldstein's book "Betrayal by the Brain: The Neurological Basis of Chronic Fatigue Syndrome, Fibromyalgia Syndrome and Related Neural Network Disorders".
- Reported on Dr. P. Flor-Henry's Research and lecture of April 17, 1997 at the Foothills Hospital Auditorium in Calgary. Dr. Flor-Henry is the director of the Clinical Diagnostics & Research Centre, Clinical Professor, University of Alberta and Clinical Director of Acute Psychiatry Services of the Alberta Hospital in Edmonton. Dr. Flor-Henry is engaged in research on Brain Mapping of ME/FM patients in order to determine differences between the functions of their brains compared to healthy controls.
- A two-hour meeting with official of the Laboratory Center of Disease Control on July 28, 1997 wherein we presented him with evidence that we had the support of the ME/FM medical community to establish a standardized clinical definition for ME/FM.
- Reported on the September Sudbury Conference entitled "The Emerging Viruses. Where are they coming from? Can they be stopped? - Dr. Leonard Horowitz who believes that in the next 5 to 10 years a "super germ" would be designed to wipe out the human immune system - the defense system against infectious diseases, leaving us susceptible to opportunistic infections such as TB, pneumonia and cancer.
- Reported on the Hepatitis B vaccine research being conducted by Bonnie S. Dunbar, Ph.D. (Professor - Baylor College of Medicine). Dr. Dunbar has done extensive literature research on the Hepatitis B vaccine and it became apparent to her that the serious adverse side effects of this vaccine may be much more significant than generally known or admitted. Professor Dunbar obtained an FDA adverse reaction list of over 23,000 individuals who reported adverse reactions for a 4-year period from 1992 to 1996 from the vaccine.
- Reported on Dr. Garth Nicolson's September 1997 Sudbury Conference on Stealth Microorganisms in the blood of Gulf War Veterans and Chronic Fatigue Syndrome people. Dr. Nicolson is Chief Scientific Officer and Research Professor at the Institute for Molecular Medicine at Huntington Beach, California. Dr. Nicolson reported that the Gulf War veterans exhibited symptoms similar to those of chronic fatigue syndrome within a few months to several years after their return home. Dr. Nicolson further reported that some of the signs and symptoms were those of chemical exposures but the infectious nature of the illness exhibited by many of the veterans strongly suggests they were exposed to biological agents. Dr. Nicolson found that approximately 45% of Gulf War vets and approximately 60% of ME/FM patients were infected with mycoplasma fermentans (incognitus strain) which were located deep inside blood leukocytes. Dr. Nicolson has developed a treatment protocol using a series of specific antibiotics.
- Reported on our communication with Women's College Environmental Health Clinic wherein they advised us that they did assessments and consultations for persons with chronic Fatigue Syndrome and fibromyalgia but did not, however, offer specific treatments but had

applied for a grant. On following this up due to people calling us advising us that when they called the Clinic for an appointment they were advised that they only see people who suffer from multiple chemical sensitivities in addition to ME/FM.

- Reported on Revenue Canada who had started to send out a new three-page questionnaire directly to the patient's doctor as a follow-up to the doctor completing Part B of the Disability Tax Credit application. In this questionnaire the doctor had to rate the individual's disabilities in percentages, making it more difficult to qualify for the tax credit. A letter of complaint was therefore sent to the Minister of Revenue Canada.
- Reported on the Government of Ontario appointing its first insurance ombudsman and details of how to apply for her assistance. She was the first government-appointed insurance ombudsman in Canada. The ombudsman, however, will only get involved in cases after they have gone through the insurance company's own process. A senior person at each company must sign a letter stating what the company's final position is on the issue before she will initiate a review.
- Reported on Manitoba's Superintendent of Insurance who had offered her help by approaching insurance companies outlining the concerns they have become aware of. The Superintendent will mediate disputes between consumers and their insurance companies.
- We established a website which was under construction to make us even more accessible. <http://www3.sympatico.ca/me-fm.action/>, in addition to our email capabilities.
- Received another Grant from Health Canada in the amount of \$20,000 to enable us to hire an assistant to help with the ever-increasing workload.
- The Board of Directors of Drugless Therapy/Naturopathy again got in touch with us advising us that a letter had been forwarded to the naturopathic doctor who wrote misinformation about ME/CFS and that she must: 1) rewrite the Health article mentioning the exact wording in the article and the relevant corrections with an explanation e.g. mononucleosis not CFS is highly contagious; 2) include in the retraction an apology to the readers; 3) forward a copy of the retraction letter to our Board of directors for approval, followed by sending it to the newspaper and a separate apology letter addressed to our organization.
- Received another Grant from Health Canada in the amount of \$25,000 towards our many projects as well as bringing our Board of Directors from across Canada to Ottawa to attend a workshop in financial planning and organization as well as attend our Annual General Meeting. in person. This grant was accompanied with a letter from the Minister of Health congratulating our Board, staff and volunteers for their dedication and achievements over the past year.
- Reported on the International Commission of the United Nations which is meeting in Ottawa to discuss the labeling of food produce and their derivatives. Regulations were being considered that would allow genetically engineered products on the global market, without labeling. A letter-writing campaign of protest to the Head of the Canadian delegation was therefore instituted to voice our opposition to the regulations.

- Report on Dr. Les Simpson's blood sample results on the ME/FM people who had participated which indicated only one sample was within normal levels of blood cells out of 72, the remainder showed abnormalities.
- Hosted in Ottawa, Dr. Les Simpson of the New Zealand University who gave a presentation to the health care professionals on his research findings entitled 'The Role of Erythrocyte Morphology in the Pathogenesis of Degenerative Diseases'. We also sponsored the collection of blood samples from interested ME/FM people which was then sent to New Zealand for analysis. This process consisted of electron microscope examination of the blood. The participants each received an electron microscope picture of their blood, and concrete data on how the percentage of red cell shapes in their blood compares with blood from healthy males and females.
- Ontario Human Rights Commission finally takes a stand on ME/FM and its Chief Commissioner advised us that he had reviewed our concerns about ME/FM people with his senior staff at the Commission and assured us that persons with ME/FM have the same rights and protections as any other person in Ontario. If any ME/FM person approaches the Commission, then the Commission will deal with the matter as it would in any other disability complain. The Commissioner further advised that the Corporate Services Branch will be developing staff training sessions to address the needs of persons with disabilities which were planned for the next fiscal year (1998).
- Reported on the new rules at Revenue Canada regarding the Disability Tax Credit application. They reported that at the time of them processing the Income Tax Return and Tax Credit application the individual, from now on, would be advised as to whether or not the Disability Tax credit is accepted or denied at the time they process the return, not years later.
- Reported on the six-center longitudinal study by the Arthritis Research Center & University of Kansas School of Medicine whose objective it was to determine the intermediate and long-term outcomes of Fibromyalgia in patients seen in rheumatology centers in which there is special interest in Fibromyalgia. The Longitudinal study was based on an assessment questionnaire which went to 538 patients from 6 rheumatology centers whose median duration of disease at first assessment was 7.8 years and the final assessment took place after 7 years. The results indicated that although functional disability worsened slightly and health satisfaction improved slightly, measures of pain, global severity, fatigue, sleep disturbance, anxiety, depression, and health status were markedly abnormal at the beginning and end of the study period.



1996

- Published Agenda of May 10, 1996 Parliament Hill Activities which include: Press Conference, Meeting of Press and Invited Guests, House of Commons attendance for presentation of signatures and Private Members' Bill requesting the Federal Government to recognize ME/FM as official diseases to set identification guidelines and to ensure care treatment, comfort and dignity to those afflicted. This all done for May 12th National and International ME/FM Awareness Day. ME Canada, Compassion in Action, Environmental Illness Society of Canada as well as private individuals were present in the public section of the House of Commons. Our Network representatives were seated in the Senate seats of the House of Commons.
- On Friday, May 10th, 1996 Mrs. Beryl Gaffney, MP presented our Petitions for Ontario together with a speech she had prepared to the House of Commons. The Petitions for the other provinces were presented by: Mr. John Harvard (Winnipeg St.James, Lib.); Mr. Andy Scott (Fredericton-York-Sudbury, Lib.) for New Brunswick and Nova Scotia; Mr. Nick Discepola (Vaudreuil, Lib.) for Quebec; Ms. Bonnie Brown (Oakville-Milton, Lib.) for British Columbia; Mr. Wayne Easter (Malpeque, Lib.) for Prince Edward Island; Mr. John Loney (Edmonton North, Lib.) for Alberta; and Ms. Jean Augustine (Etobicoke-Lakeshore, Lib.) for Newfoundland. It was like there was a multiple echo in the House of Commons when one member after the other stood up and asked the government to ensure care, treatment, comfort and dignity and recognition for persons afflicted with ME/FM.
- Reported on The Standing Committee on Health of which Mrs. Beryl Gaffney, MP is a member. Mrs. Gaffney has been meeting with people of the Health Protection Branch etc. Dr. Joseph Lozos, Director General of the Laboratory Center for Disease Control stated at these meetings that the ball has been put directly in the court of the basic science researchers to come up with some objective measure or case definition that we in public health can then pick up to take the next steps.
- Meeting with Mrs. Beryl Gaffney on September 3, 1996 as a result of our Petition to the House of Commons on May 10, 1996.. Present at this meeting was Special Assistant to the Hon. David Dingwell, Minister of Health, Senior Consultant of the Health Care & Issues Division - Health Canada, Director of the Cardio-Respiratory Diseases and Diabetes department, who also looks after ME/FM and MCS and represented the Director General of the Laboratory Center of Disease Control. From this lengthy discussion it was felt that a ME/FM/MCS sub-committee should be set up under the Standing Committee of Health in an effort to convince the governments that it is important to admit that these illnesses must be studied so that ME/FM people will be treated with respect and compassion. A letter-writing campaign was instituted for the ME/FM community to write the Chair of the Standing Committee asking for a ME/FM/MCS sub-committee.
- In collaboration with our Network, On December 2, 1996 Mrs. Beryl Gaffney, MP again spoke in the House of Commons requesting Health Canada to formally announce the recognition of ME/FM, and again requested the setting up of the sub-committee under the Standing Committee on health.

National ME/FM Action Network

Journal of Achievements

- In a letter dated November 28, 1996 Mrs. Beryl Gaffney advised us that she had been informed by the Clerk of the Committee of the Standing Committee of Health that the subject of ME/FM was added to a list of items which may be studied, in the future, by the Standing Committee.
- Collaborated with the ME/FM support group leaders across Canada by sending them a Petition form to distribute to their ME/FM people requesting that they give a copy of this form to their physicians and asking for their participation if they approved of our plan to establish a standardized clinical definition for ME/FM. This resulted in a list of about 200 ME/FM experienced doctors signing this Petition endorsing our plan for establishing this definition. This letter was also inserted in support group newsletters.
- Sent letter of protest to the Director of the Pharmaceutical Assessment at the Health Protection Branch as well as enlisted the help of the ME/FM community to do the same advising the Director that we should have the freedom of choice as to health care and doctors, including access to natural health products.
- Sent letter of protest to the Board of Directors of Drugless Therapy/Naturopathy protesting an article that had been written by a naturopathic doctor who had written that CFS is highly contagious and can be passed by close contact, kissing, sharing food, coughing or sexual relations. A letter of reply dated November 28, 1996 advised us that the doctor who was the author of the newspaper article was under investigation by their Complaints Committee. They further stated that this was definitely not representational of the current knowledge base or expertise of the naturopathic profession. They asked us to put them on our mailing list to receive further ME/FM information from us.
- Received letter from Ms Jane Stewart, P.C., and MP of the Minister of National Revenue's office dated July 12th, 1996 requesting our input into their intensive review of the Disability Tax Credit requirements for the year 1995. She also advised that from now on new disability credit applications will be reviewed at the time of initial assessment to ensure that the eligibility requirements are met. In the past, denials were being given years later after initial approval, leaving the person with an outstanding bill with Revenue Canada.
- Apology from MAJIC 100 Radio Station due to one of their traffic reporters referring to the traffic being so slow that everyone must have had Chronic Fatigue Syndrome. This was received immediately after our contacting MAJIC by phone and followed up by a letter. The reporter stated that she regretted she had made that comment and the Program Director was impressed by our organization's passion and drive to educate people about ME/FM and motivate changes.
- Collaborated with support group leaders asking them to advise how many ME/FM people are in its group in an effort to get statistical information. This is an on-going project.
- Since 1988 the Center for Disease Control had updated their research definition of ME, which does not exclude Fibromyalgia. We had been in constant contact with our Canadian Laboratory Center for Disease Control (LCDC) to accept the new 1994 U.S. definition or in the alternative, do one of their own. A letter was received by us from the Laboratory Center For Disease Control, from D.T. Wigle, MD - A/Director General of the Health Protection Branch of Health Canada wherein he advised that "As regarding the definition of Chronic

Fatigue Syndrome, I would like to let you know that LCDC supports the use of the revised Chronic Fatigue Syndrome Case Definition (1994) proposed by the U.S. Centres for Disease Control for research purposes.”

- Reported on Women's College Hospital who advised us that they had received a three-year grant from the Ontario ministry of Health to provide consultation and assessment service for people with multiple chemical sensitivities, to collaborate with the University of Toronto's Research Unit on Environmental Hypersensitivities to improve the management of MCS and to develop a provincial network of physicians who are more knowledgeable about MCS.
- In reply to our letter to Women's College wherein we had asked how that would help ME/FM patients, the College replied that they do not offer specific treatments since they are only funded as an assessment and research clinic. They further stated that they do assessments and consultations for persons with Chronic Fatigue Syndrome and Fibromyalgia and had written the Ontario Minister of Health to review the proposal of a treatment clinic.
- Reported Supreme Court of Canada decision which stated that Battlefords and District Co-operative and its insurance firm can't cut a woman off benefits simply because her problem is mental rather than physical. Ms Betty-Lu Clara Gibbs had complained to the Saskatchewan Human Rights commission that her employer discriminated against her when it stopped her disability benefits after two years in March 1990. Ms Gibbs, a clerk, suffered from anorexia nervosa, a bowel disorder and panic attacks. Having a mental disability is not a valid reason to cut someone's work benefits.
- Reported on the Medical Profession Amendment Act, 1996 - Province of Alberta - Bill 209 - The Legislative Assembly of Alberta, in its Fourth Session, 23rd Legislature, 45 Elizabeth II gave Royal Assent on May 1st to amend Section 34 by adding the following subsection: A registered practitioner shall not be found guilty of unbecoming conduct or be found to be incapable or unfit to practice medicine or osteopathy solely on the basis that the registered practitioner employs a therapy that is non-traditional or departs from the prevailing medical practices, unless it can be demonstrated by the College that the therapy has a safety risk for that patient unreasonably greater than the prevailing treatment.
- Meeting with Mr. K.M. Burpee, Assistant Deputy Minister and Ms Edie Pastuch, Senior Programs Officer on April 16th, 1996 to discuss the unfairness of the Disability Tax Credit Form T2201 application to people who suffer from ME/FM. They pointed out that it is their job to enforce the *Income Tax Act* and that they have no authority to change it. They stated that the disability tax credit “recognizes that people with severe and prolonged disabilities have higher costs of living and working. The *Act* spells out the rules for claiming the Credit. The law is intended to define as severe any mental or physical impairment that is equivalent in its effect to being blind (or deaf) or confined to a bed or a wheelchair.” He further stated that when establishing eligibility for the credit, a physician has to consider whether the patient's ability to perform the basic activities of daily living is restricted all or substantially all the time (90%), and whether the use of aids or assistive devices reduces or alleviates the restriction. Mr. Burpee also mentioned that in the recent budget the government announced that it would look at measures for people with disabilities and advised us who to contact about changes to the *Act*. A letter-writing campaign was then started by us to the Hon. Paul Martin, Minister of Finance, outlining the difficulties ME/FM people are faced with in regards to this Credit and asking the ME/FM community to do the same.

- Reported on Dr. Luc Marengere of the Ontario Cancer Institute who has identified the protein, known as SYP that flips the switch to shut down the body's T-Cells, white blood cells that kill invaders.
- Reported on Professor Garth L. Nicolson of The University of Texas M.D. Anderson Center who had found that 50% of the Gulf War Illness-CFIDS patients have an invasive mycoplasma infection that can be successfully treated with antibiotics, such as doxycycline or Cipro.



- Reported on the study done by a research team in Glasgow (U.K.) who has found evidence of enteroviruses in some CFS patients and that most of these enteroviruses do not match those that have been previously identified by scientists. This study used polymerase chain-reaction (PCR) to make a sensitive analysis of blood and throat swab samples to identify the sub-class of enterovirus, and the kinds of enteroviruses whose PCR profiles are currently known were mostly excluded by this study. Enteroviruses are a class of virus that includes the polio virus, and many British researchers and others have long believed that enteroviruses may play a role in ME in many patients.
- Reported that we received 14,487 signatures from across Canada which was presented to Mrs. Beryl Gaffney, MP which, with the Private Members' Bill, will be presented in the House of Commons. Mrs. Gaffney also requested help from The Hon. Roger Simmons, P.C., MP, Chair, Standing Committee on Health.
- Objected to Bill 26 - Ontario which if approved would give health-fraud investigators widely expanded powers to collect medical information, including patient records. We wrote to The Clerk of the Standing Committee on General Government advising them of our alarm with this particular Bill as it seems the only people who could possibly want this type of information would be the insurance industry. Right now, a signed Release must be obtained from the patient before any kind of medical information can be obtained.
- Objected to and advised all ME/FM people that Bill C-7 Threatens Freedom of Choice regarding what foods, herbs, supplements and nutrients Canadians are allowed to consume. Advised them to write to the Health Critic opposing the Bill.
- Requested and received legal opinion from Gowling, Strathy & Henderson, Barristers & Solicitors legal opinion regarding Revenue Canada's wording regarding the Disability Tax Credit and how this disability Tax Credit seems to make it very difficult, or even impossible for any ME/FM individual to qualify for this credit on his/her Income Tax Return. Part of the opinion stated that "...It is to be noted initially that in order to sustain a challenge of the application of a particular provision of the *Income Tax Act*, it is necessary to utilize Section 15 of the Charter. This provision essentially requires the government to treat all people

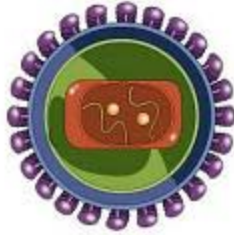
equally in the application of laws. The Supreme Court of Canada has, however, been reluctant to consider Section 15 of the Charter to be of application to income tax statutes.

- Reported on Johns Hopkins University research on Neurally Mediated Hypotension (NMH). While the results were promising, this study was performed with a small number of patients and was not randomized, blinded, or placebo-controlled. However, more studies were planned.
- Reported on The Standing Committee on Health of which Mrs. Beryl Gaffney, MP is a member. Mrs. Gaffney has been meeting with people of the Health Protection Branch etc. Dr. Joseph Lozos, Director General of the Laboratory Center for Disease Control stated at these meetings that the ball has been put directly in the court of the basic science researchers to come up with some objective measure or case definition that we in public health can then pick up to take the next steps.
- Arranged with Deputy Minister, Pierre Gravelle Q.C. that individuals who have outstanding balances due to the denial of their Disability Tax Credit application, that they contact the Assistant Director of Revenue Collections at their local tax services office in order that a review of their current financial situation may be completed and an arrangement concluded. Mr. Gravelle further stated that interest relief may also be considered in instances where an individual is experiencing financial hardship and has no ability to pay the liability in full, interest relief could be a possibility. This was followed up by us sending him information on ME/FM.
- Reported on Newcastle Research Group in the U.K. who were doing in-depth studies to endeavor to show the location of the areas of affection in the Central Nervous System of those who were diagnosed with ME. These include brain scans and spinal cord if needed, then tests for autoimmune mechanisms which may be involved and also biochemical tests to try to show the resultant cell mediated biochemical failure.
- Continuously contacted our Laboratory Centre for Disease Control (LCDC) wanting information regarding its plans for research into ME/FM. This was followed up with LCDC advising that there were no funds allocated to them to research ME/FM but were working with the Medical Research Council and the National Health Research and Development Program of Health Canada who are open to considering research submissions on this issue.
- The Panel further reported the opinions of its members: a) one doctor did not accept the diagnosis given Mrs. Doe; b) one doctor requested that the following be appended to the recommendations - the rehabilitation program is to be kept independent and observably fair to all concerned parties and that no conditions concerning acceptability, attendance and results of the rehabilitation programme are to be tied to benefit reinstatement and continuance.
- Hosted in Ottawa, Dr. Les Simpson of the New Zealand University who gave a presentation to the health care professionals on his research findings entitled 'The Role of Erythrocyte Morphology in the Pathogenesis of Degenerative Diseases'. We also sponsored the collection of blood samples from interested ME/FM people which was then sent to New Zealand for analysis. This process consisted of electron microscope examination of the

blood. The participants each received an electron microscope picture of their blood, and concrete data on how the percentage of red cell shapes in their blood compares with blood

- from healthy males and females.





1995

- In October/November 1995 Health Canada approved a Grant of \$35,000 for our National projects. The Health Minister congratulated our board and volunteers for their dedication and achievements.
- Instituted talks with Revenue Canada pointing out to them that the Disability Tax Credit - Form T2201 application was virtually impossible to obtain by ME/FM people due to its stipulated wording. Revenue Canada suggested that if you were denied this Credit 1) Appeal; 2) If Appeal denied, advise Revenue Canada that case goes through Tax Court. There is no costs involved in doing so and also will delay any payback for up to one year.
- Received reply from (former) Minister of Health, Diane Marleau to our letter of December 23, 1994 asking for research funds for ME/FM. Ms Marleau replied that ME/FM are extremely distressing disorders which, because of their many causes, are difficult to diagnose and treat. She further stated that in her correspondence to many support groups concerned with ME/FM she had repeatedly expressed awareness and concern for the distress and suffering experienced by patients diagnosed with ME/FM. She encouraged our organization to contact researchers to persuade them to submit proposals to funding agencies. She felt that if advocacy and patient-support groups were successful in directly attracting the attention of researchers and academic institutions, granting agencies could benefit from a larger pool of submissions on ME/FM and that individuals would benefit from a larger output of soundly researched data.
- Reported on the long-awaited case definition of Chronic Fatigue Syndrome which was published in the December 15, 1994's issue of the Annals of Internal Medicine; 121;953-959 and in our newsletter 'QUEST' February/March 1995 issue - Communication No. 10.\
- Arranged with Deputy Minister, Pierre Gravelle Q.C. that individuals who have outstanding balances due to the denial of their Disability Tax Credit application, that they contact the Assistant Director of Revenue Collections at their local tax services office in order that a review of their current financial situation may be completed and an arrangement concluded. Mr. Gravelle further stated that interest relief may also be considered in instances where an individual is experiencing financial hardship and has no ability to pay the liability in full, interest relief could be a possibility. This was followed up by us sending him information on ME/FM.

- Reported on insurance matters related to the British Columbia Teachers Federation (BCTF) and a specific ME/FM claimant who had been refused disability benefits. Her case was reviewed and her benefits were reinstated. The Review Panel reached some unanimous conclusions that: 1) Mrs. Jane Doe was disabled in accordance with the definitions in the Plan; 2) The Panel therefore expected reinstatement of her benefits, retroactive to date of illness; 3) The Panel recommended implementation of an impartial rehabilitation program which shall a) be mutually acceptable in all its aspects; and b) include a comprehensive psychosocial-psychiatric assessment. This, however, is not a condition or a requirement. It was a recommendation, a strong suggestion made with the hope of encouraging recovery). The Panel also stated that they considered the practice of surreptitious surveillance to be “counter-productive to a healing environment and eventual patient recovery.”
- The Panel further reported the opinions of its members: a) one doctor did not accept the diagnosis given Mrs. Doe; b) one doctor requested that the following be appended to the recommendations - the rehabilitation program is to be kept independent and observably fair to all concerned parties and that no conditions concerning acceptability, attendance and results of the rehabilitation programme are to be tied to benefit reinstatement and continuance.
- Worked very closely with Mrs. Beryl Gaffney, Federal MP, to prepare a Private Members’ Bill to be presented to the House of Commons and asked all ME/FM people to write to Mrs. Gaffney to encourage her.
- The Calgary Fibromyalgia Action Committee was formed with our Director of Education, Marj van de Sande, who was instrumental in obtaining two lawyers who were so concerned about the ramification of the Mackie ruling by Judge Rawlins that they were prepared to waive their legal fees for intervention to the Alberta Court of Appeal. Although the lawyers waived their fees, our Network was responsible for the legal disbursements and therefore made an appeal to the ME/FM community to help raise funds to cover the disbursements so that the lawyers could go to work. Our Network applied for Intervenor Status which would not address Mrs. Mackie’s concerns on appeal directly, but what it would do is intervene with Judge Rawlins decision regarding Fibromyalgia
- *Designed and distributed Petition to all ME/FM support groups and members* in order to collect signatures to be presented in the House of Commons together with the Private Members’ Bill.
- Reported the April 7th, 1995 announcement by Lloyd Axworthy that the CPP Disability Benefits would remain in place for a transitional three-month training period. In addition, the necessity to re-apply, re-accessing the plan would become easier. The onerous provisions disentitling recipients from engaging in volunteer activities will be lifted.
- Reported on U.S. Centers for Disease Control in Atlanta of Dr. William Reeves, Chief of Viral Exanthems and Herpesvirus Branch of the CDC who provided testimony at a May 12,

1995 Congressional Briefing in which he stated that ME/CFS may affect up to 50 times the number previously estimated by them. Dr. Reeves stated that 76-220 per 100,000 Americans have a CFS-like illness as opposed to earlier estimates which had pinned the numbers at 4-9 cases per 100,000.

- Filed Notice of Motion, Memorandum and Affidavit at the Court of Appeal of May 29, 1995 in Calgary Court under the organization set up specifically for that purpose, The Calgary Fibromyalgia Action Committee, set up by our Director of Education, Ms Marj van de Sande. However, we were denied Intervenor Status but the Judge did make statements which could benefit us, if he will put it in writing. We do have the audio tape which was made of the proceedings, in case the Judge's written statement does not mention anything about it.
- The response for financial help was so terrific that we had enough money to pay the legal expenses incurred by Lawyers, Maureen Morgan and Deborah Rose Harriet Straw of Calgary. The Financial Statement was published in Communication No. 12 - June/July 1995 issue and was also sent to the individuals who contributed.
- In the Court of Appeal in Alberta - Action No. 9201-12776 Mackie vs Wolfe - Application for Intervenor Status Judgment Highlights: Although the Alberta Court of Appeal dismissed our Application, we nevertheless accomplished what we set out to do. The Honourable Mr. Justice J.A. Kerans stated that we could not be adversely affected as the court "will not, in this appeal, and as a matter of law, say that there is or is not such a thing as fibromyalgia. That is not our function".
- By stating that the court of Appeal would never make a Rule of Law that spoke to the existence or non-existence of a disease entity and it is not the function of the court to rule on the existence of a disease, he implies that no Court should. Although The Judge would not classify Madame Justice Rawlins' comments as *obiter dictum* (judge's learned ramblings which do not set precedent), it did acknowledge the decision was based solely upon evidence presented in Mackie vs. Wolfe.
- In terms of public exposure of this issue, the decision certainly minimizes, if not extinguishes, the controversy over the existence of fibromyalgia. The Court did not question that the Mackie decision had adversely affected those suffering from fibromyalgia. The Court apologized at the end of the judgment by expressing regret for the effect Madame Justice Rawlins' decision had on those who suffer from the illness. Justice Kerans stated "Morgan (our Counsel) has argued most eloquently." It is rare to find a judgment where the court both apologizes for the adverse effect that the decision has had on the litigants and compliments the lawyer (our counsel) presenting the case.
- Reported that the U.S. Centers for Disease Control has reprinted 'The Facts About Chronic Fatigue Syndrome' booklet which now included the new 1994 case definition and replaced the old 1988 version. We also published the new definition on our website.
- Requested official recognition for ME/FM. Once the Petition was drafted copies were distributed across Canada to all support group leaders so that they could distribute these Reported on the long-awaited case definition of Chronic Fatigue Syndrome which was

published in the December 15, 1994's issue of the Annals of Internal Medicine; 121;953-959 and in our newsletter 'QUEST' February/March 1995 issue - Communication No. 10.

- Reported on the new Disability Tax Credit application, Form T2201.
- Collaborated with Myalgic Encephalomyelitis Association of Ontario, Fibromyalgia Society of Ontario, ME Calgary for the drafting of a Petition to be sent to the House of Commons Petitions to its ME/FM people. These people in turn would try to collect as many signatures as possible. This drive was undertaken to put pressure on the government towards recognition of ME/FM and in recognition of May 12th National ME/FM Awareness Day.





1994

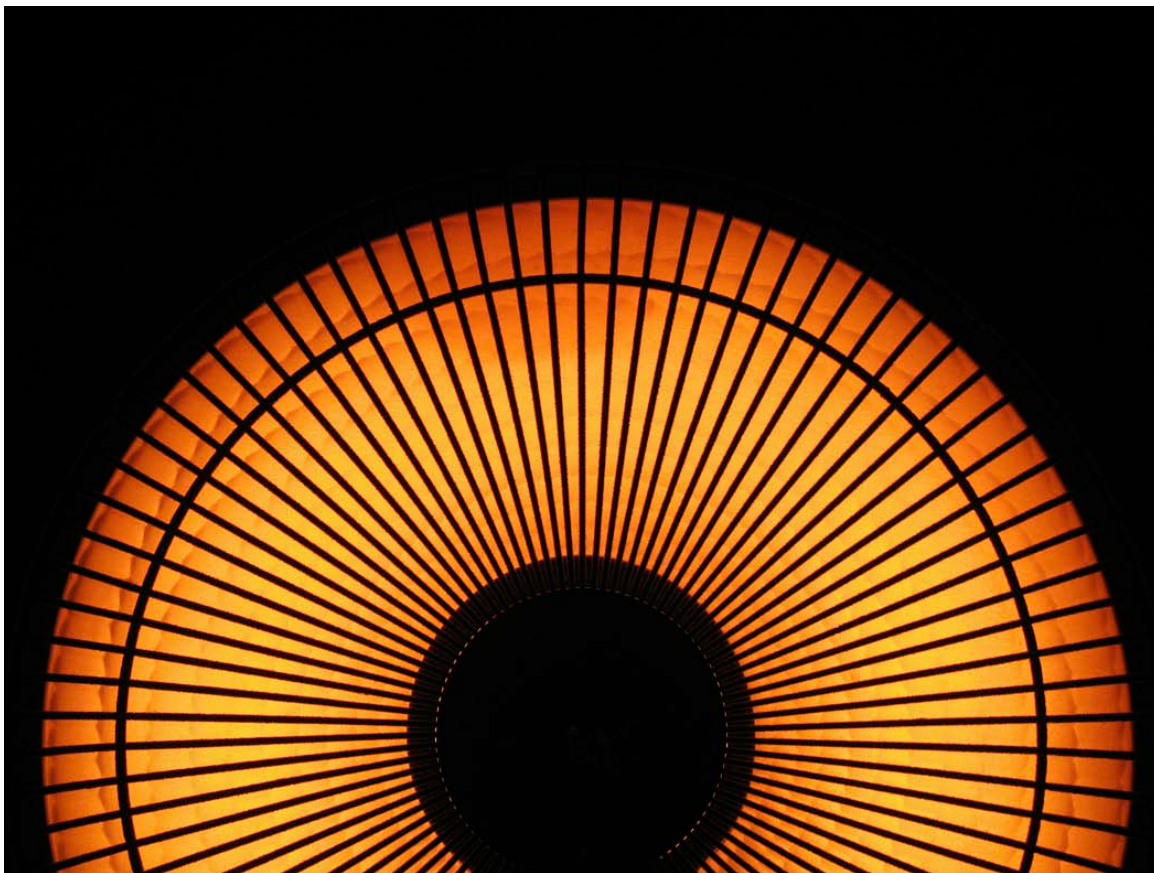
- February 1, 1994, our newsletter was named 'QUEST'. A logo was also designed based on The Goose Story. In The Goose Story it mentions that when the Canada Geese fly South for the winter, they fly in "V" formation. As each bird flaps its wings, it creates an Uplift for the bird immediately following. By flying in "V" formation, the whole flock adds at least 71% greater flying range, than if each bird flew on its own. There is more in that Story that pretty well represents what we believe support is all about. We therefore thought it fitting to adopt the Canada Geese as the Network's mascot and our logo was therefore designed to show the geese flying in "V" formation together with part of the Maple Leaf.
- Received reply from (former) Minister of Health, Diane Marleau to our letter of December 23, 1994 asking for research funds for ME/FM. Ms Marleau replied that ME/FM are extremely distressing disorders which, because of their many causes, are difficult to diagnose and treat. She further stated that in her correspondence to many support groups concerned with ME/FM she had repeatedly expressed awareness and concern for the distress and suffering experienced by patients diagnosed with ME/FM. She encouraged our organization to contact researchers to persuade them to submit proposals to funding agencies. She felt that if advocacy and patient-support groups were successful in directly attracting the attention of researchers and academic institutions, granting agencies could benefit from a larger pool of submissions on ME/FM and that individuals would benefit from a larger output of soundly researched data.
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- Filed Notice of Motion, Memorandum and Affidavit at the Court of Appeal of May 29, 1995 in Calgary Court under the organization set up specifically for that purpose, The Calgary Fibromyalgia Action Committee, set up by our Director of Education, Ms Marj van de Sande. However, we were denied Intervenor Status but the Judge did make statements which could benefit us, if he will put it in writing. We do have the audio tape which was made of the proceedings, in case the Judge's written statement does not mention anything about it.
- The response for financial help was so terrific that we had enough money to pay the legal expenses incurred by Lawyers, Maureen Morgan and Deborah Rose Harriet Straw of Calgary. The Financial Statement was published in Communication No. 12 - June/July 1995 issue and was also sent to the individuals who contributed.
- In the Court of Appeal in Alberta - Action No. 9201-12776 Mackie vs Wolfe - Application for Intervenor Status Judgment Highlights: Although the Alberta Court of Appeal dismissed our Application, we nevertheless accomplished what we set out to do. The Honourable Mr. Justice J.A. Kerans stated that we could not be adversely affected as the court "will not, in this appeal, and as a matter of law, say that there is or is not such a thing as fibromyalgia. That is not our function"
- By stating that the court of Appeal would never make a Rule of Law that spoke to the existence or non-existence of a disease entity and it is not the function of the court to rule on the existence of a disease, he implies that no Court should. Although The Judge would not classify Madame Justice Rawlins' comments as *obiter dictum* (judge's learned ramblings which do not set precedent), it did acknowledge the decision was based solely upon evidence presented in Mackie vs. Wolfe.
- Reported on Justice Bonnie Rawlins, an Alberta Judge, who ruled for the third time that "Fibromyalgia doesn't exist...." and that it "has become a court-driven ailment that has mushroomed into big business for plaintiffs." Her opinion was apparently based on the testimony of a psychiatrist and an Anesthesiologist.
- In terms of public exposure of this issue, the decision certainly minimizes, if not extinguishes, the controversy over the existence of fibromyalgia. The Court did not question that the Mackie decision had adversely affected those suffering from fibromyalgia. The Court apologized at the end of the judgment by expressing regret for the effect Madame Justice Rawlins' decision had on those who suffer from the illness. Justice Kerans stated "Morgan (our Counsel) has argued most eloquently." It is rare to find a judgment where the court both apologizes for the adverse effect that the decision has had on the litigants and compliments the lawyer (our counsel) presenting the case.
- Collaborated with U.S. support groups and the U.S. Centers for Disease Control in its planned update of the original 1988 Holmes research definition for CFS. In its draft 1994 booklet 'The Facts About Chronic Fatigue Syndrome' it stated that "Patients with CFS may

become exhausted with only light physical exertion, or stress.” We asked the CDC to amend it to read “Patients become exhausted with only light physical, mental exertion, or stress.”

- Made arrangements to unify all support groups across Canada towards fighting Justice Rawlins’ decision as it could affect research funding, disability pensions, not to mention the loss of credibility.
- April 12, 1994 Ray Worley, President of the British Columbia Teachers’ Federation (BCTF) replied to our letter requesting clarification on its insurance agreement with Great West Life Assurance Company and Insurance Disability benefits for Chronic Fatigue Syndrome. He advised that the Income Security Committee (ICS) of the BCTF was composed of five teacher members from around British Columbia and were responsible for establishing the criteria for receipt of Long Term Disability benefits for its teachers. These criteria were then applied by Great West Life. They further advised that there were 50 teachers on Long-Term Disability benefits who had ME/CFS and their benefits were not called into question. They also had an appeal process for those whose benefits were called into question consisting of a panel of three doctors. One who is directly appointed by the teacher, that doctor in turn jointly chooses the chairperson of the panel, one doctor by the Plan, and one chair. The results of this appeal process is binding on all parties.
- May 12th ***Walk on Parliament Hill*** organized by Aidan Walsh of Montreal was attended by our Network and ME/FM information bulletins were distributed to members of Parliament.
- April 1994 - Dr. Walter Potaznick, O.D., FAAO, of THE NEW ENGLAND COLLEGE OF OPTOMETRY in Boston, MA had asked for the Network’s participation to represent Canada in his research into CFIDS Ocular Symptomatology. Our organization was assigned Site #55 for identification purposes and a questionnaire was sent to all members and reported on in our newsletter. This survey was finished in 1997 and we were advised that the Network’s participation in that survey surpassed other participants.
- Commencement of collection of ME/FM legal cases for the purposes of assisting lawyers and individuals.
- The Hon. Diane Marleau, then Minister of National Health & Welfare in her letter to our Network stated “I would like to express my support for National ME/CFS Awareness Day” and commended the National ME/FM Action Network and its volunteers in self-help and mutual aid groups across the country, for the information, advice and reassurance they provided to those afflicted by ME/CFS. She ended her message by wishing us a very successful ME/CFS Awareness Day.





THE BEGINNING - 1993

The National ME/FM Action Network was ***founded by Lydia E. Neilson on June 18, 1993*** and received charitable status the following year, retroactive to June 18, 1993. As funds were being sent to Ms Neilson, the first newsletters were able to be sent free of charge so that people could decide whether or not they wanted to become members and approved of what the organization was planning to do.

The National ME/FM Action Network decided, from its onset, to include Fibromyalgia in its mandate as both ME/CFS and FM people needed support which was not being taking care of. More research is needed to determine whether ME and FM are related or are different illnesses or overlap.

- ***The newsletter was published*** on Tuesday, May 4, 1993 and continues to be published every two months. This newsletter is free with a membership of \$20.00 per year. This membership fee has not changed.

- Establishment of a ***National Lawyers' Roster*** for referral purposes of lawyers who are experienced in ME and/or FM cases.
- Establishment of a ***National Doctors' Roster*** for referral purposes of doctors who diagnosis/treat ME and/or FM.
- Establishment of ***May 12th National ME/FM Awareness Day in Canada***. May 12th is the birth date of Florence Nightingale and was chosen as awareness day by Tom Hennessey of RESCIND located in the United States. Our organization joined RESCIND as representing Canada. Each year since then we write letters for support groups for distributing to its members for their signature and individual mailings to the Ministers of Health both Provincial and Federal in an effort to get the Minister to acknowledge and support the ME/FM people. This is a yearly affair, in addition to what individual support groups do across Canada in regards to that Day.
- A letter of apology was received by us from NBC. On October 2nd, 1993 the NBS's Nightly News presented a segment on CFIDS (Chronic Fatigue Immune Dysfunction Syndrome), also known as Chronic Fatigue Syndrome. This segment showed a narrow view on ME/CFS as well as wrongfully decoding the acronym CFIDS. We therefore took the opportunity to contact NBC and sent them ME information so that they would be in a better position to report about ME in future newscasts.

