Quest #46 February 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, I will first give 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 over **450 support groups** across Canada and work cooperatively with them.

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 are 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. Highlights of some of our accomplishments can be found on our website: **http://www3.sympatico.ca/me-fm/action/** 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. And 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 Powles; Dr. Jeff Sherkey.

MESSAGE FROM THE PRESIDENT

AWARDS OF RECOGNITION GIVEN

As a small token of appreciation of their work, the **National ME/FM Action Network** presented **Dr. Anil Jain** and **Dr. Bruce Carruthers** with an award for their dedication and total commitment of the drafting of the **ME/CFS and FM clinical definitions**. These awards were presented to them at the welcoming reception, which was held the day before the consensus meeting. In addition, the **New Brunswick ME/CFS Association** honoured these doctors by its National Award echoing the praise our Network bestowed on doctors.

Marjorie van de Sande, our Director of Education, was recognized for her dedication and work as Consensus Coordinator. In this role, she has worked very closely with Dr.

Carruthers and Dr. Jain on the development and coordination of the draft consensus documents over the last three years. She also acted as coordinator of the **Expert Medical Consensus Panels** and the **Consensus Meeting**. The **National ME/FM Action Network** presented her with an award in honour of her dedication and work. Marj van de Sande is also the recipient of the "National Award for outstanding commitment to those with Myalgic Encephalomyelitis and Fibromyalgia" from the **New Brunswick ME/CFS Association**. It goes without saying that without Marj's talents and commitment, it would have been difficult, if not impossible, to have had the consensus meeting with such a positive outcome.

Last but not least, our Network presented **Crystaal Corporation** with an award for sponsoring the Expert Consensus Meeting. Their encouragement and commitment helped make this event a complete success. Our vision became their vision.

We would also like to take this opportunity to ask you to honour the **National ME/FM Awareness Day** on **May 12th** by doing what you can to help **raise funds** for the **National ME/FM Action Network** for its many projects. Our work is continuing on the clinical definitions as well as with our other projects. Thank you all for your continued support of our organization.

Lydia E. Neilson, President CEO

CHRONIC FATIGUE SYNDROME VERSUS DEPRESSION

By: Flor-Henry, P1., J. Lind1, J. Morrison,, H. Pazderka-Robinson,, and Z. Kolas

1. Clinical Diagnostics and Research Centre, Alberta Hospital Edmonton, Edmonton, Alberta.

2. Department of Biomedical Engineering, University of Alberta, Edmonton, Alberta.

Forty-Six dextral, unmedicated women with chronic fatigue syndrome diagnosed according to the Fukuda criteria (Atlanta Centre for Disease Control) were studied with quantitative EEG (48 channels) during eyes open, eyes closed, verbal and spatial cognitive activation. These were compared to 75 dextral healthy female controls. 20 1-second artifact free segments were selected. Sampling rate was 256/sec. Source localization findings will be reported here (LORETA). The CFS group had increased sources in the Eyes Closed condition in the 1-3Hz, and 21-50Hz bands in the left fronto-temporal regions. All the other significant findings, except one, showed that the controls had increased sources in the midline (fronto-occipital) and in the left temporo-parietal region. The exception is the Word Finding task where the controls had increased sources in the right temporo-parietal-occipital region (14-20Hz). The increased sources in the CFS group were maximum in the Eyes Closed condition in the slow frequency band (1-3Hz) arising from the inferior frontal gyrus and in the fast frequency band (21-50Hz) arising from the superior frontal gyrus. Another peak source was during Word Finding in the 14-20Hz band where the controls had increased sources emanating from the superior temporal gyrus. The increased sources in the peak regions are unilateral left frontal in CFS. During Word Finding the increased activity in the superior temporal gyrus seen in the controls may reflect increased transcallosal inhibition, with the result that the CFS group during verbal cognitive processing has relatively lower fast activity in the contralateral hemisphere.

Electrodermal psychophysiology was also carried out on 43 patients with CFS compared to 42 female controls. The prestimulus (tonic) electrodermal levels were lower in the CFS group ($p < 0.001$) while the prestimulus digital skin temperature was higher ($p < 0.006$). Further, habituation was significantly slower in the CFS group. Cerebral dysfunction of the fronto-temporal regions (L > R) in CFS is suggested by the EEG findings while the psychophysiological evidence indicates a down-regulation of autonomic sympathetic tone, of central origin (implicating inter-alia), mesial frontal regions and implying a state of relative right brain preponderance, presumably a consequence of the subtle left hemisphere dysfunction.

It is of interest to note that with respect to increased skin temperature unmedicated females with depression ($n = 25$) were similar to normals whereas with respect to phasic amplitude responses the depression group was lower and the CFS group similar to normals. Finally prestimulus electrodermal levels were significantly lower in the CFS group whereas here the female depressions were similar to normals. Thus we have three double dissociations indicating that psychophysiologically – in women – CFS and depression are independent categories.

In conclusion the source localization evidence and the psychophysiological findings indicate abnormal activation of the left frontal region in Chronic Fatigue Syndrome. Psychophysiological characteristics point to a down regulation of the sympathetic autonomic system and indicates that the changes seen in CFS are not those seen in women suffering from depression.

COMMENTARY - BY: **Kate Andersen**, M.Ed., Youth Consultant, National ME/FM Action Network

Dr. Pierre Flor-Henry, the principal researcher, is a neuropsychiatrist at the **Alberta Hospital in Edmonton**. This abstract of some of his groundbreaking Canadian research is quite mind-boggling. I have attempted to present the gist of it for readers like myself who get a bit overwhelmed by all the technical terms. I am not a neuropsychologist so please bear with me! Briefly, Dr. Flor-Henry and his team 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. We can see right away that this team took pains to make sure that factors such as being left- or right-handed, known to be related to differences in the brain, or the effects of medication, would not confuse the results. As well, they were also careful to state which diagnostic criteria for CFS was used. I can't go into all the ramifications of the different diagnostic criteria, but stating which ones were used permits comparisons across studies, and helps to ensure we are not mixing up apples and oranges--that is, people with different illnesses.

The brain wave test used in this study was the electroencephalogram (EEG) and, as it is known to change in healthy people during times when eyes are open or closed, or when people are doing tasks such as speaking and doing puzzles, patients were tested under all of these different conditions. Most importantly, the patients' results were compared with those of a large number of "controls" on the same tests--that is, healthy women.

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 healthy women in several ways. As well, special electrical skin-conductance

(electrodermal psychophysiology) tests were also carried out on 43 women with CFS and compared with those of 42 healthy women. Again, there were statistically significant differences between the women with CFS and the healthy women. The researchers believe that all these different findings add up to show that in CFS, in women, there are subtle but important abnormalities in the left hemisphere of the brain and that the autonomic nervous system is down-regulated. While all of these findings may prove to be useful in explaining ME/CFS symptoms in a number of ways, the researchers make particular note of the fact that in three separate ways they have shown that, in women [see note below], CFS and depression are not the same.

Footnote. Since this study involved only women, correctly speaking, the findings must be reported as "CFS in women".

I hope that we will have an opportunity to interview Dr. Flor-Henry about this study in a future issue.

NEW CONCEPTS IN MUSCLE ACTIVITY AS A SOURCE OF PAIN IN FIBROMYALGIA - By: Dr. Stu Donaldson, Ph.D.

Two new articles by Dr. **Stu Donaldson** (senior author) offer interesting new concepts in muscle activity and pain in fibromyalgia. The research suggests that muscles associated with the tender points are activated inappropriately with movement of the head. The articles 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. These results will be published later this year. For more information contact **Dr. Stu Donaldson** at **Myosymmetries**, #300, 290 Midpark Way S.E., Calgary, Alberta T2X 1P1 Tel. **(403)225-0900** - Fax: **(403) 225-2389** - Email: **myo@cadvision.com**

GROWING JUDICIAL ACCEPTANCE OF FIBROMYALGIA AND SIMILAR DEBILITATING SYNDROMES

By: David Lackman, Barrister & Solicitor, Lackman, Firestone Law Offices, 357 Bay Street, Suite 401, Toronto ON M5H 2T7 – Tel. (416) 364-0020 – Fax (416) 364-0389 – Web: www.LTDClaims.com (Initial Consultation Free)

Fibromyalgia, chronic fatigue syndrome and chronic pain claims are legend among those which have unduly challenged lawyers (and their clients) in the pursuit of fair compensation for injuries and disabilities. However, should we really be surprised at the attitude of insurers when certain physicians themselves have, for example, approached Chronic Fatigue Syndrome in a way that recently led one Alberta Judge to state:

"I was troubled by the evidence of Dr. Pearce. My first concern is that his diagnosis of the Plaintiff was done on the basis of a preconceived notion of what that diagnosis should be. It seems from his publications that Dr. Pearce is in the process of building a career based on the idea that there is no such thing as CFS and that people who claim to have that condition really have psychiatric problems…After Dr. Pearce had examined the Plaintiff and concluded that she had a psychiatric illness, the Defendant apparently decided that they would employ a private investigator to see if they could persuade the Plaintiff to engage in activities that presumably would show that she was ‘faking’ her condition".

Thankfully, that Court – in Baillie v. Crown Life Insurance Co. – had the insight and wisdom to prefer the opinion of the claimant’s expert, thus:

"The diagnostic impression is of chronic fatigue syndrome. The opinion of Dr. Pearce that such illness does not exist is bizarre since the illness has been recognized by the Atlanta Center for Disease Control, the American Medical Association…and there is enormous medical literature related to it".

The Court went on to find total disability in connection with CFS with the result that the payment provisions of the disputed benefits coverage were applicable.

The judiciary appears now to be moving in the right direction in demonstrating a greater awareness and acceptance of chronic fatigue syndrome and fibromyalgia as proper and sufficient diagnoses to support legal threshold claims of serious permanent impairment or long term disability claim criteria. In Dickson v. Canada Life Casualty Insurance Co., a 1996 decision of the Ontario Court (General Division), Elaine Dickson suffered soft tissue injuries to her neck, shoulders and low back after being thrown from a stationary motorcycle that was struck from the rear. In addition, she went on to experience difficulties with concentration and recall, and disturbed sleep, causing her to abandon her educational and recreational activities. She had abandoned attempts at physiotherapy and massage therapy as ineffectual and painful. The medical evidence put forward on behalf of Ms. Dickson presented a diagnosis of "physical changes associated with fibromyalgia".

At issue was whether Ms. Dickson’s claim could be brought within one of the exceptions to the then-existing general immunity afforded defendants in motor vehicle cases – namely, the plaintiff establishing the existence of a "permanent serious impairment of an important bodily function caused by continuing injury which is physical in nature". At that time, injuries that had at their pathologic origin a psychological or emotional bases were not viewed as compensable under the governing no-fault insurance regime. And, the onus of proof was cast upon the plaintiff to establish that her claim fell within the above-noted exception. The defendant’s insurer, of course, urged upon the Court that "fibromyalgia and related syndromes are not physical in nature but have psychological or emotional bases".

The Court’s underlying concern was that "the diagnosis of fibromyalgia, because its cause remains a matter of debate, would not be proven on a balance of probabilities to be an injury which is physical in nature". Moreover, it was not sufficient that the symptoms be physical (i.e. produce physically-disabling effects), since the physical symptoms associated with fibromyalgia and similar debilitating syndromes, according to the Court, could arise from sources other than physical injury. Nevertheless, the Court went on to find that:

Ms. Dickson had no pre-existing medical condition (other than typical life stresses associated with teen years) relevant to her current complaints;

There was no evidence of conscious or intentional exaggeration of symptoms;

Mechanical fitness (i.e. there being no observable mechanical injury) cannot be equated with the ability to perform a physical function where doing so results in intolerable pain; and

The timing and development of the chronic pain supported a finding of a causal link to the injury, it having followed upon soft-tissue injuries that did not resolve but indeed persisted and increased despite medical intervention.

The Court ultimately found that this was not a case where the impairment had as its source "cognitive, emotional or psychological genesis". Accordingly, Ms. Dickson was found to have met the onus of establishing that her claim fell within an exception to the immunity from liability otherwise afforded the defendant.

Progressive changes in the Ontario no-fault law have, since this case, sensibly removed the requirement of "physical" impairment to sustain a claim for damages. Nevertheless, this decision remains important and instructive because it is among a limited, although growing, body of jurisprudence that recognizes fibromyalgia and "similar debilitating syndromes" as legitimate medical conditions having physical and organic origins essentially on par with other health conditions which have historically attracted much less controversy and cynicism.

Swain v. Moore Estate is a very recent decision of the Superior Court of Justice of Ontario, and was the focus of a review by lawyer James Allin in the August/September 2000, Communication No.43 issue of Quest. The plaintiff, a 45-year-old highly-active mother and businesswoman, suffered extensive soft tissue injuries as a result of a serious motor vehicle accident in which the other driver was fatally injured. A combination of debilitating problems which included post-traumatic stress syndrome, fibromyalgia, chronic pain, anxiety, and depression was found by the Court to constitute the equivalent of "an extremely serious physical injury".

The Court considered Mrs. Swain's injuries to be catastrophic in nature and, in doing so, assessed her general damages at $100,000.00, apparently the highest sum awarded in Ontario for such a claim. In this writer's opinion, the Court's impression of Mrs. Swain as being a highly credible witness and an extremely industrious, hard-working and family-oriented individual prior to the accident, added importantly to the judge's acceptance of her fibromyalgia and chronic pain as genuine and on the level of "an extremely serious physical injury".

* * *

The following concluding observations are offered: Judicial attitudes appear to be changing in a positive direction. Insurers are being sent a signal that the casual dismissal by their adjusters of fibromyalgia, CFS/ME, and chronic pain claims will no longer be accepted by their claimants or the Courts. It remains particularly important, however, in pursuing these claims that the strongest supportpossible – in terms of both patient-care and medical-legal reporting – be forthcoming from health practitioners. Further, the claimant's credibility and level of motivation (as perceived by insurers and judges) can create added advantages that leverage the success of such claims.

NEW MEDICAL DIRECTION AT ENVIRONMENTAL HEALTH CLINIC

By: Nancy Bradshaw, **Education Coordinator** - **Environmental Health Clinic - 1-800-417-7092 or (416) 323-6400 Ext. 4993**

Dr. Lynn Marshall has been a Staff Physician and Physician Liaison at the **Environmental Health Clinic**, **Sunnybrook and Women's College Health Sciences Centre**, Toronto, since it opened in 1996. She became the **Medical Director** on **January 1, 2001**, replacing Dr. Frank Foley. Dr. Foley is remaining as a Staff Physician with the clinic.

Dr. Marshall has been a Research Associate in the Environmental Hypersensitivity Research Unit at the **University of Toronto** since it began in 1994. She has earned an MD from **Queen's University** and a Fellowship from the **American Academy of Environmental Medicine**. She has also been elected a Fellow of the **Royal Society of Medicine** in Great Britain.

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WANTED: REHABILITATION PROGRAM INFORMATION FOR FM/S- Carole Roy, Director of Communications

We would like to hear from anyone who has undergone a **rehabilitation** program for **Fibromyalgia** whether initiated as part of your treatment program or as a result of a disability insurance independent assessment.

We would also like to hear from those who were not able to continue their rehabilitation program. We are gathering information on exercise and rehabilitation programs and the results thereof.

We are interested in:

1. the name and address of the facility attended; and in what year;
1. who initiated the rehabilitation program;
1. a description of the program, including frequency and duration and what took place; and
1. results.

Please write **Carole Roy** c/o the **National ME/FM Action Network** or send me an e-mail at **carolroy21@home.com**

Please pass this request on to as many people as possible. As this matter is rather of an **urgent** nature, please respond immediately. This is a confidential matter and you will not be identified in any way. If you feel more comfortable sending the information without identifying yourself, please feel free to do so.

NEWS RELEASE: AUTHORS DONATE $1,000 after first book sells 1,000 copies - April 9, 2001

TORONTO - Two Ontario women have sold over 1,000 copies of their first book, ***Living with Fibromyalgia & Chronic Pain****.* Right from the start, they decided to donate $1 from each book sold to medical research.

They chose to donate **$1,000** to the **National ME/FM Action Network**,, an advocacy and information-providing organization with connections to 450 support groups across Canada for people with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and/or Fibromyalgia. The money was turned over to the Network at its **Canadian Expert Consensus Conference on ME/CFS and FM** in Toronto, Saturday, March 31, 2001.

Selected under **guidelines from Health Canada**, 23 doctors from Canada, the United States and Europe peer-reviewed drafts of clinical definitions and treatment protocols for the conditions. The drafts were prepared by **Dr. Anil Jain** of Ottawa and **Dr. Bruce**

Carruthers of Galiano, BC. Consensus arising from the conference will be published in a medical journal.

Both Stoney Creek's **Gwyneth A. Graham** and **Camilla Lawson**, a nurse from Wellington, have fibromyalgia syndrome (FMS) and live each day with chronic pain. In the book, they describe with feeling, understanding and humour their struggles and frustrations with their illness. They demonstrate how they've taken control of their lives, becoming empowered in the process.

FMS is a chronic condition of muscle pain, non-refreshing sleep and profound fatigue. It is of unknown origin and afflicts *approximately 6.5 million people* in North America, mostly women between the ages of 20 and 40.

Copies of ***Living with Fibromyalgia & Chronic Pain*** (ISBN 0-9682918-0-5), a 96 page, pocket-size, easy-to-read volume, are available by sending a cheque or money order for **$9.95** (includes postage) payable to **Gralaw Enterprises, P.O. Box 66608, Stoney Creek Postal Outlet, Stoney Creek, ON L8G 5E5.**

For more information, contact: **Norman Lawson**: phone **(613) 399-5484**; fax (613) 399-5207; e-mail **norcam@kos.net**

BOOKS/NEWSLETTERS/VIDEOS/REPORTS ETC.

Book: RECOVERING FROM CHRONIC FATIGUE SYNDROME: A GUIDE TO SELF-EMPOWERMENT - By: William Collinge, Ph.D., M.P.H. has now been posted free on line in its entirety on Dr. Collinge's website **see "The Integrative Medicine Wheel" at http://www.healthy.net/collinge.**

"HEALTH TALK, HOW TO COMMUNITY WITH YOUR DOCTOR" By: Mary Hawkins

"Health talk, How to communciate with your Doctor" is available in all large and independent book stores for $17.95. For discount bulk orders call: **Christiane**, at Tel. **1-800-963-8830 ext.489** or e-mail, **ccote@CDGBooks.com** Health Talk is a book for those wanting to get more from their doctors or allied health care providers. It has grass roots, friendly scenarios of how to get your doctor to listen. **Mary Hawkins** is a professor of communications, trainer/consultant, newspaper and magazine writer, author of three books, and a public speaker.

THE FIBROMYALGIA AND CHRONIC FATIGUE RESOURCE BOOK and LIFE PLANNER WORKBOOK - By: Dawn Hughes - Price:**$24.45 U.S. (includes S & H).** Fax **No. (954) 755-4059, or** by mail at **Universal Publishers, 7525 NW 61 Terrace, Suite 2603, Parkland, FL 33067-2421 U.S.A.** Preview on internet at: **http://www.upublish.com/books/hughes.htm -** credit cards Accepted at internet address**. $1.00 donation to the National ME/FM Action Network for each book sold. When contacting Publisher be sure to mention reference: "name/LydiaME/FM."**

<u>INFORMATION ON CANADA PENSION PLAN DISABILITY BENEFITS</u> - By: Mike Moreland, CPP Adviser

The Canada Pension Plan (CPP) Disability Benefit process is complex and requires an active role on the part of the applicant to ensure all the information concerning their medical condition is provided. The onus is on the applicant to provide evidence that clearly indicates they are suffering from a disability that is both "severe" and "prolonged" (the words used in the CPP legislation).

"Severe" means you are not physically and /or mentally capable of doing your previous job or any other type of work.

"Prolonged" means your "severe" condition is expected to be long-continued and of indefinite duration or is likely to result in death.

In addition to this, the applicant must have accumulated the correct number of years of contribution to the Plan at the time of disability and be under the age of 65 in order to qualify. Both the medical and non-medical requirements must be met in order to receive a Disability Benefit.

Therefore, the thoroughness of the initial application has a direct impact on the outcome of the case. The information provided by the applicant can affect the result in both a negative or a positive manner.

TIPS FOR A PERSON APPLYING FOR CANADA PENSION PLAN DISABILITY BENEFITS

Apply as soon as you and your doctor consider you disabled – a late application may cause a loss of entitlement.

Keep detailed records of all doctors’ appointments including dates, times, traveling time, waiting time to see doctors.

Detail how your daily living has been affected by the disability.

When completing the forms i.e. "Questionnaire for Disability Benefits" think out each reply before putting it to paper.

Keep a record of all medications and record dosage or any negative reactions.

Make sure that all medical evidence about your condition is on your CPP file.

WHAT IF YOU ARE DENIED BENEFITS?

There is a three-step appeal process that is available to anybody who has been denied a benefit. The first level is a request for a "Reconsideration". It is always wise to contact

HRDC to ask any questions that you have prior to submitting your request for a "Reconsideration".

Many disabled clients receive monthly disability benefits from Insurance Companies and do not see the purpose in pursuing CPP Disability Benefits when denied. Not pursuing and securing the CPP Disability Benefits, can result in reduced Retirement Benefits and in some cases jeopardize the surviving family's position with regards to future entitlements to benefits.

If a person is denied a CPP Disability Benefit to which he/she is entitled, the biggest mistake one can make is not to request a "Reconsideration" of the decision. Do no relinguish your rights by not meeting the imposed time deadlines, even though the qualification process is demanding for a person already suffering from a severe disability.

One should not get discouraged when an application is denied, however, one might consider the assistance of a third party that specializes in handling such cases.

Should you have questions concerning any Canada Pension Plan benefits, please feel free to contact **Mike Moreland** at:

Telephone: **(613) 841-5884** or E-mail: HYPERLINK mailto:**moreland2896@home.com moreland2896@home.com**

Mail: **Mike Moreland, Suite 359, 5929L Jeanne D'Arc Blvd., Orleans, Ontario K1C 7K2**

<u>UPDATED INDEPENDENT MEDICAL EXAMINATION (I.M.E) OR FUNCTIONAL ABILITIES EVALUATION (F.A.E.) REGISTRY SUBMISSION </u>FORM - By: Mary Ellen, Manager - Special Projects

Enclosed in this newsletter is a yellow form, a copy of our updated **Registry Submission Form** for people who have attended an independent medical examination. We felt the need to update the Form to include Canada Pension Plan because we have been receiving reports from people who have been requested to attend an independent medical examination not only on behalf of

their private disability insurance company but also on behalf of Canada Pension Plan. As well, many facilities are being used regularly by private insurance companies and Canada Pension Plan to perform multi-functional assessments and functional abilities evaluations and we want people who are filling in our Form to be able to give us the names of these places for our records. If you have already filled out a Form, please pass your copy on to someone else or show it to your doctor or lawyer so that word of our important project continues to spread. It is important that this Form is accessible to those who will be attending an IME or those who have already attended. Please read the Form carefully to decide how you can best help disseminate information to the ME/FM community. Contact Mary Ellen for more copies of the Form or feel free to make photocopies. Anyone who hopes to receive or is receiving disability payments from a private insurance company or Canada Pension Plan will probably be faced with attending at least one IME. Let's work together to ensure that the examination will be a fair one and that the patient will be treated with the respect deserved.

Please send completed form to: Mary Ellen, **P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON., L1V 6P7 -** E-mail: **marye@pathcom.com** - Phone: **(905) 831-4744** -

OUR WORLD:

SYMPTOMS: Signal to begin SEARCH for causes of distress.

SYMPTOMS: Scouts for the ‘warning zones’. Thanks to Lorraine Legendre, Ottawa.

QUEST COLLECTION BOOK - FIVE YEARS: By popular request, **the National ME/FM Action Network** has published an easy to read book consisting of a **collection** of important articles which have appeared in our **‘QUEST’** newsletters over the years. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We have kept the **cost** of the book to a minimum at **$20.00** each which includes shipping and printing. Please make **your cheque payable to the National ME/FM Action Network** and let us know how many copies you would like.

LEGAL/RESEARCH PACKAGE - **Medical** and **Legal** Information. Please make **cheque payable to Marj van de Sande** in the amount of **$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 - Tel/Fax: (403) 547-8799 - E-mail: vandesam@cadvision.com**

MEMBERSHIP: $25.00 per year includes bi-monthly newsletters - Please make cheque payable to:

NATIONAL ME/FM ACTION NETWORK, 3836 Carling Ave., Nepean, ON K2K 2Y6 CANADA -

Tel/Fax: (613) 829-6667

E-Mail:ag922@freenet.carleton.ca

WEB: http://www3.sympatico.ca/me-fm.action/

DISCLAIMER: The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for information on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia. Some of the information contained herein is intended to help patients and their physicians make informed decisions about their health. However, the NATIONAL ME/FM ACTION NETWORK does not dispense medical advice or endorse any specific medical hypothesis or product and assumes no responsibility for any treatment or action undertaken by its readers.