Quest #39 December 1999

ME/FM CLINICAL DEFINITIONS/PROTOCOL - UPDATE - ANNOUNCEMENT

As you know, the **National ME/FM Action Network** has been working with **Dr. Anil Jain**, **Dr. Bruce Carruthers** to establish a draft standardized clinical definition for ME/FM. **Ms Marj van de Sande**, our Director of Education, has coordinated all their efforts into the draft which has taken over a year to accomplish.

This draft clinical definition was presented to the **Minister of Health** through the **Laboratory Center for Disease Control** in July 1999. Since then we have been in even closer contact with the LCDC and Health Canada in an effort to get the definitions peer-reviewed by experienced ME/FM doctors.

We are pleased to advise that there will be a **First National Conference for ME/FM and Environmental Illness (Multiple Chemical Sensitivities)** from **November 17 - 19, 2000.** This Conference will be sponsored by Health Canada/LCDC, the National ME/FM Action Network and the Environmental Illness Society of Canada.

A professional Convention Management company has been hired by Health Canada to coordinate this Convention while the planning of the conference will be performed by the Planning Committee which will be formalized at our next meeting with the LCDC/Health Canada on February 18th, 2000.

Please check our website and our newsletters for developments as they occur.

INDEPENDENT REVIEW OF COMPLAINTS & DISCIPLINE PROCESS

COMMISSIONED BY ONTARIO MINISTRY OF HEALTH AND LONG-TERM CARE

HAVE YOU MADE A COMPLAINT TO THE COLLEGE OF PHYSICIANS AND SURGEONS OF ONTARIO? OR

ARE YOU A PHYSICIAN WHO HAS BEEN THROUGH THE COMPLAINTS PROCESS?

We want to hear from both patients and physicians who have had direct experience with the complaints and discipline process.

Your input will remain confidential. **KPMG Consulting LP** has been commissioned by the **Ontario Ministry of Health and Long-Term Care** to conduct an

independent review of the complaints and discipline process of the **College of Physicians and Surgeons of Ontario**.

For input into this review, please call toll-free long distance **1-877-525-2776** or local **416-969-6559** or write to:

KPMG

405-121 Bloor Street East

Toronto, ON M4W 3M5

Attention: CPSO Review

Because of the high volume of callers, the deadline for survey returns has been extended until the **end of February 2000.**

<u>Inaccurate Evaluations Used to Assess Individuals with ME/CFS</u> -

By: Philipa Corning, C.D., B.Sc.(Hons) Ph.D.

Introduction - ME/CFS is a disease with different subtypes, varying severity of symptoms, and fluctuation of symptoms and activity levels. Unfortunately after several years, ME/CFS still remains puzzling and poorly understood by healthcare professionals. This is due mainly to the absence of standard diagnostic criteria. Furthermore, current methods used to access the physical capabilities of persons afflicted with this illness rely primarily on functional capacity evaluations (FCEs) that measure only 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 type of approach results in an unreliable portrayal of the true complexities and the interrelations among symptoms. Therefore, by inaccurately reflecting the fluctuating nature and variability of this debilitating illness, current FCEs do not capture the true nature of this disease. In addition, sincerity of effort is often examined. If the person is reluctant to carry out any items during the testing process, they may be wrongly branded insincere and malingerers.

FCEs and Sincerity Testing - Unfortunately employers, lawyers and insurers are relying more heavily on data acquired from FCEs prior to making decisions on reimbursement in disability claims, on planning treatment for rehabilitation, and on readiness to return to work. These tools are supposed to define an individual's functional abilities or limitations in the context of safe, productive work tasks. Furthermore, some tests are used to detect the "sincerity of effort exhibited by the participant to perform optimally at the time of evaluation. An insincere effort is defined as one in which the participant deliberately gives less that a full effort during physical testing.

Functional Capacity Evaluations - Current issues associated with the use of FCEs are:

qualifications of the evaluators;

reliability and validity of the tests;

length of assessment;

projection of endurance to 8-hour workdays;

standards of practice;

selection of FCE; and

safety protocols.

General - FCEs are currently used to contain healthcare costs, reduce the amount of time and money spent on rehabilitation , and determine whether a claimant has wage-earning potential in litigation based on the participant's tested physical abilities. There a great number of FCEs available and in use. They vary widely in the number measurements obtained, degree of standardization, clarity of the concepts and underlying theories, variety in choice of measuring instruments, and adequacy of measurement for certain injury groups. Thus, no one test is totally comprehensive for one or a great number of situations.

Qualification of Evaluators - Occupational and physical therapists appear to be the primarily healthcare professionals to perform FCEs. They have the background and training to evaluate function, analyze performed-tasks, and understand disease pathology and the musculoskeletal system. Currently, other healthcare professionals are involved in the administration of FCEs including chiropractors, nurses, athletic trainers, vocational evaluators, physical therapy assistants, exercise physiologists, psychologists, kinesiologists and physicians. Given the variation in skill levels among these disciplines, evaluator training should be required to for an individual to become a "certified evaluator". Certification would ensure quality and consistency in evaluation, scoring and report writing related to FCEs. All FCEs on the market provide training, but there is variance in how the training is delivered, i.e., train-the-trainer or individual certification of each administrator. Therefore, certified administrators will vary in knowledge and competence depending on their experience background and the type of training preparation undertaken.

Furthermore, beyond training on administration and evaluation, several assessors have emphasized the importance of logical and clear reporting of observations that are easy to read and free of jargon. The report should provide the reader with a clear picture of the participant's physical capabilities and limitations as they relate to the critical demands of his/her job. This would include input from both employer and employee, and compare the participant's status of functional capability with the requirements of the job vacated. This practice is not done.

Reliability and Validity of Test - The purpose of the FCEs is to provide "objective" data high in reliability and free from examiner bias. Reliability studies of FCEs are performed on subjects without disabilities. The reliability of FCEs on individuals seen in clinics is unknown. Therefore, caution should be exercised when conclusions are based on these tests results or extrapolations made from these results. Such extrapolations may be highly misleading, for example, it is determined that a person with ME/CFS who does the paperwork associated with the test procedure for 3 hours can work at a desk for 8 hours. In reality, the person may do nothing but rest for the next day after the 3 hours of testing, because the activity led to exhaustion. In many cases, the reliability and validity of FCEs have not been documented in published peer-reviewed research journals.

Validity is an essential requirement for all measurements. A score is considered valid if it measures the properties that it purports to measure and can be used to make inferences. In FCEs this means a score predicts real-world function. Establishing validity is more difficult than establishing reliability due to the prediction aspect. External factors such as the work environment, work level of performance, and work schedule may affect the participant's level of performance and ability to return to work. Once again, a lack of peer-reviewed publications on the validity of FCEs leaves their validity open to question.

Length of Assessment - The time taken to administer FCEs varies. Some take less than 2 hours whereas others take 2 days for administration. Literature indicates that 4-6 hours are required to assess general work demands, e.g., lifting, carrying, reaching, sitting, standing, walking, hand strength and coordination. Those who favour a 2-day test indicate that this duration leads to the greatest accuracy because it allows for retesting on day-2.

Projection of Endurance - Performance exhibited on a FCE conducted over a few hours does not reflect the participant's endurance for a full-day's work schedule. Specific formulas for projecting performance to an 8-hour workday are not available. Each person has a unique set of physical capabilities that cannot be generalized through generic formulas that would thus be subject to inaccuracy. Documentation of heart rate, endurance factors (e.g., oxygen consumption, blood pressure and respiratory rate), changes in body mechanics and fatigue can be helpful in such a projection. Literature suggests that participants should not be required to exceed a cardiovascular effort of 65% of their maximum heart rate. Individuals with ME/CFS are incapable of and should not do aerobic activity as it leads to damage to mitochondrial DNA. This reduces the person's ability to carry on aerobic activity even more and the individual's condition could be made worse.

Standards of Practice - This means the development of a clear set of procedures for administering and scoring tests. Under these circumstances, administration and scoring should not change regardless of the person conducting the assessment. No such standard exists as yet.

Selection of FCE - Many tests lack comprehensiveness, therefore, there is no single most appropriate test for any one client or any one assessment situation. No one assessment can provide all the answers concerning work injury and return to work.

Safety Protocols - There is little reference in the literature to the inclusion of fitness evaluations in FCEs. These should be conducted in order to assess the physical limitations of the participant. It is left to the examiner to administer each task with no knowledge as to what harm it may cause.

Injury can occur when the participant is asked to perform at a level of maximum voluntary effort. There are two schools of thought on this issue:

Intervention by the assessor decreases the test's validity and reliability; and

No intervention by the assessor places the participant at an unacceptable risk of injury.

Sincerity of Effort - Reliability and Validity - Despite the widespread use of methods to detect the sincerity of participant's efforts during clinical assessment, little is found in the literature addressing reliability and validity of measurements using this method. Until research on these methods is reported in peer-reviewed literature, clinicians should avoid basing evaluation of sincerity of effort on such tests. For example, a person afflicted with ME/CFS may feel all right and have energy on the day of the examination. It would look as if the individual was faking. This would not give a true picture of the ill person's capabilities.

Clouded Terminology - The understanding of biobehavioral factors affecting recovery are clouded by the terms "symptom magnification" and "exaggerated pain behavior". These two terms are frequently used in evaluation reports by clinicians. Neither term can scientifically be measured and therefore should be avoided.

Self-limiting Behavior - Participants can give less than a full effort during physical evaluations for a variety of reasons:

..pain due to musculoskeletal dysfunction;

..fear of pain;

..fear of re-injury;

..anxiety;

..depression;

..lack of understanding of instructions;

..lack of understanding of the importance of the test; and

..secondary financial gains.

If self-limiting behavior predominates during an FCE, lack of sincerity of effort may be inferred and reported.

Waddell's Nonorganic Signs - These are nonorganic clinical signs, e.g., tenderness of nerve roots. They are not intended for use in detecting sincerity of effort or malingering, however, they are used frequently in clinical practice to imply sincerity of effort or an exaggeration of symptoms. For example, the tenderness test may be used and contribute to the erroneous classification of participants requiring further psychological assessment when their primary problem with pain stems from organic sources other than nerve roots. In addition, techniques of test administration, e.g., amount of pressure exerted in tenderness test, are not standardized. This can lead to variability of testing and scoring the nonorganic signs. Therefore, statements regarding sincerity of effort cannot be supported through application of the Waddell nonorganic signs.

Documentation of Pain Behavior - In reports of musculoskeletal evaluation or FCE of participants, clinicians frequently document that participants have "exaggerated" pain behavior. Pain behavior is only one aspect of the complex experience of pain. Failure to include measures that address other cognitive and psychosocial variables that affect the pain experience may result in an incomplete assessment and inappropriate treatment.

Muscle Performance Tests - There is no correlation between sincerity of effort and consistent effort during testing. Measurements not substantiated in the literature but frequently used by clinicians as an indication of lack of sincerity are:

coefficient of variability;

musculoskeletal evaluation and FCE; and

grip measures.

None of these approaches has been supported in the literature as reliable and valid measures of sincerity of effort.

Relationship of Heart Rate to Pain Intensity - The premise is that heart rate increases directly as pain increases and when participants report high pain scores without increase in heart rate, it is concluded that they are exaggerating their pain. There has been no correlation between increased pain and increased heart rate and increased rate of respiration in the literature.

Clinical Implications - The concept of sincerity of effort is illusive and difficult to measure. If judgements based on currently available methods, clinicians are taking great risk of incorrectly classifying some people as malingerers and insincere. Such unwarranted conclusions violate the rights of those tested.

There is a Better Way - Current measures to assess ME/CFS such as FCEs and sincerity of effort do not consider either the severity of symptoms nor their fluctuations in symptom severity and activity level that occur over time. The test results will reduce the probability of clear understanding of the complexities of the illness.

Instead, one piece of current research suggests a better approach to provide an accurate picture of the complexities of this illness. It involves the combination of a self-reporting scale and a devise called CSA actigraph to measure the frequency and intensity of activity. This devise is capable of measuring the intensity of activity and recording values at 1-minute intervals through the day and night for 22 consecutive days. The implication of this assessment system is that it captures the symptom dynamics and variability involved in ME/CFS.

<u>A COMMON AND FRUSTRATING SYNDROME: FIBROMYALGIA:</u> By: Dr. David Saul

Introduction:

Fibromyalgia (FM) is the second most common medical condition seen by Rheumatologists, (after osteoarthritis). The incidence of FM ranges from 1 to 5% of the population, with women outnumbering men by a ratio of 8 to 1. The average age of FM patients is 45 to 55. FM is frustrating for both the patient and the physician because there is still no recognized cause and no established cure for the chronic pain and fatigue.

Symptoms include: sleep disturbance (often with alpha wave intrusion into deep sleep), migrating and episodic pain "everywhere", extreme fatigue, digestive problems (often Irritable Bowel Syndrome), cognitive changes (decrease in memory and concentration) and a high incidence of depression. Almost always, laboratory testing, X rays, EMG tests etc. are unremarkable. The presence of at least 11 out of 18 specific "tender points" on palpation are required to help establish a diagnosis of FM syndrome.

Traditional treatment options attempt to alleviate the symptoms. Low dose antidepressants (usually tricyclics) can sometimes help the sleep disturbances. Muscle relaxants and tranquilizing medications are also commonly used. Control of pain requires analgesics (often resorting to long-acting and long-term opiod medications). Patients are encouraged to remain active with regular physiotherapy and exercise routines. Learning stress management techniques and joining FM support groups are also advocated.

Frustration

Unfortunately, the symptomatic relief approach is frustrating for both the patient and the doctor. Traditional treatments provide some mild to moderate relief from the continuous pain and unrelenting fatigue. If relief is achieved it is only temporary, and calls for another pill in a few hours. Many patients resort to alternative medical systems (naturopaths, vitamins, supplements, etc.) to try and find more consistent improvement. Large sums of money later, a few are definitely better, while most patients just have lighter pockets.

After spending six years and treating thousands of patients with FM, I too am frustrated. I have witnessed a recent change in the majority of FM patients - resignation. That's because repeatedly being told, "it's all in your head", "stop complaining" or "you look too good to be in pain", have taken a heavy toll. Patients have searched in vain for the "magic bullet" trying to get some relief and have only been offered narcotic medications (often carefully rationed, as well). The whole ordeal becomes too demoralizing. Finally, there is little sympathy from insurance companies, Government Pension Plans and from those doctors who steadfastly refuse to believe in the existence of FM/CFS.

A new paradigm is required

When I present the topics of the program, which I have developed over the past five years to FM/CFS patients showing them ways to overcome chronic pain and fatigue, many patients shed tears of gratitude. A few are openly skeptical and a small minority doesn't care anymore. Everyone's antennae perk up when I say, "You will definitely find rapid and consistent improvement in your level of pain and fatigue." Patients have heard that line too many times before (but almost never from doctors). The old paradigm of symptomatic relief from pills and exercise needs to be overhauled. They all want (but don't all demand) a permanent reduction in pain and fatigue.

In the past three years, I have lead group therapy for FM/CFS patients. For all parameters (i.e. levels of pain, fatigue, depression, sleep, memory and concentration) after completion of the program there was a significant and often dramatic improvement. Some participants achieved more improvement than others did. Limiting factors are other stresses outside of FM/CFS, missing group sessions, not doing the necessary homework and finally, reluctance to accept new lifestyle changes.

The program includes: a modified"Zone" nutritional plan, specific dosages of vitamins and supplements, stress management techniques, anger management, body language skills, meditation, creative writing, physical exercises and ends with a potpourri of additional healing arts strategies. *Only the participants who were willing to make some changes with their diets, lifestyles, stress responses, etc., found faster and more profound improvements from pain and fatigue.*

Conclusion

Don't give up! As Winston Churchill once said, "Never, never, never, never, never give up." I have seen night and day turnarounds in FM/CFS, but only for patients willing to change their paradigms. Those who expected the medical model to alleviate the FM/CFS symptoms were usually disappointed. However, those willing to:

- learn about the physiology of the mind
- accept that some changes must be made in lifestyle habits
- begin implementing those changes.

FM/CFS patients who don't improve with traditional treatments and who develop a defeatist attitude place a heavy and frustrating burden on doctors to perform some healing feats of wizardry. In those special cases, doctors must be knowledgeable, innovative and motivating. Doctors are not magicians, but when it comes to FM/CFS, the "art" of medicine is sometimes more effective than the "science".

About the author:

Dr. David Saul is a family doctor with a special interest in FM/CFS. He is the author of "Validation and hope: The Journey Towards Recovery from Fibromyalgia and Chronic Fatigue Syndrome", High Point Publications, 1999**. Dr. Saul can be reached at (416) 298-1303 or (416) 789-4343**

<u>CHRONIC FATIGUE SYNDROME</u> - By: Heidi Mayer, B.Sc. (Hons) Nutrition

Chronic Fatigue Syndrome (CFS) also known as Chronic Fatigue Immune System Dysfunction Syndrome (CFIDS), Myalgic Encephalomyelitis (ME), post-viral syndrome, yuppie flu or Chronic Epstein Barr virus is an extremely severe form of fatigue that persists indefinitely.

Variations in intensity and severity of CFS exist however, victims are known to share similar symptoms. It was first described in the early 1800's as **Muscular Rheumatism** and included symptoms such as disturbed sleeping patterns, stiffness, aches, pains and depression. The term Fibromyalgia (FM) (which describes one of the many symptoms) has also been used and literally means pain in the fibrous tissue of the muscle.

Holistic practitioners (those that treat the person as a whole and not just the symptoms of the disease), consider chronic fatigue syndrome a **multi-factorial problem** which includes poor digestive function, decreased capacity to manufacture digestive enzymes, anemia, candidiasis, poor bowel ecology, undiagnosed food allergies, weakened immune system and increased susceptibility to virus and infections. Sometimes there is a history of mononucleosis, but not always.

Untreated trauma or stress is a contributing factor and is often combined with **trigger point syndrome**. Untreated trauma can occur in one area of the body but pain be experienced in another area due to the intricate way the nerves are connected. This is known as **Internal organ referred pain.** The Injury occurred at A but is felt at B. Trigger point syndrome refers to hyper irritable nerve areas in muscles causing spasms and pain in the muscles.

Most people recognize the ability of the **intestine** to digest and absorb all nutrients necessary for the health of the body however, it also houses a major portion of the immune system. Immune defences within the gastrointestinal tract include **local** (aggregated and non-aggregated lymphoid cells known as **GALT**) and **nonimmunologic** (mechanical and chemical barriers) responsible for excluding bacteria and other substances which if released in the systemic circulation would be toxic to the body. **GALT is Gut associated Lymphoid tissue** in the intestine and contains aggregates of specialized immune system cells which possess a wide variety of specialized defense functions through intricate communication networks. The integrity of both the immunologic and nonimmunologic barriers may be affected by any number of **pathologic insults** as well as by **nutritional influences.** Extensive scientific research has established that protein/calorie malnutrition unfavorably alters immuno-competence as does deficiences in several other nutrients including Vitamin A and C, Zinc, Iron, certain lipids and nucleotides. The importance of the gastrointestinal tract as an immune system organ in the body cannot be undermined and must be considered when discussing treatment options.

Treatment options include massage therapy, nutritional supplementation, pain and sleep managements as well as psychological support (in the form of pharmaceutical intervention and counseling). Often several of these options are used together. Nutritional intervention strategies include determination of food allergies through elimination and food trials, menu planning, rebuilding of optimal bowel ecology, enzyme therapy, and multi-system buildup.

The socio-economic perspective on CFS also has a negative impact on its victims. It is known that women are affected more often than men in a ration of 4:1 and that an estimated average of 4% of the population has chronic fatigue syndrome. Many are forced to quite their jobs because they are no longer physically or emotionally capable of working. It often strikes in the prime of a person's life; leaving them with limited financial resources.

It is difficult to obtain disability income for this illness because verification of funding assistance relies on objective medical evidence such as X-rays and laboratory results when making decisions. Conventional diagnostic test results cannot confirm the diagnosis of Fibromyalgia nor can medical tests measure the amount of pain that a person is experiencing. However, in 1990 **The American College of Rheumatology** established 2 criteria (which must both be present for a positive diagnosis of Fibromyalgia). They are 1. A history of widespread pain on the left and right side of the body as well as above and below the waist. 2. Pain in 11 of 18 tender Point Sites on Digital Palpitation.

Since then however, much more headway has been made with collaborative efforts between the College of Physicians and Surgeons, The Lab Centre for Disease Control, M.D.'s and other health care professionals experienced in CFS.

The **National ME/FM Action Network located in Nepean, Ontario** serves as the headquarters for information networking, collaboration between working professionals and assistance to victims of CFS. One aspect shared by all CFS sufferers is the fact that they must learn to become acutely attuned with themselves, more specifically, their needs and expectations from themselves as well as others. Often, stronger bonds are formed between partners, families and friends.

Heidi Mayer is a Health consultant and can be reached at **(613) 475-3293**.

CFS Resources:

National ME/FM Action Network

Books: Women and Fatigue - By: Dr. Holly Atkinson

Chronic Fatigue Syndrome - By: Dr. Jesse Stoff and Dr. Charles Pellegrino

HISTORICAL ENVIRONMENTAL ILLNESS (EI) BILL

PASSES FIRST READING IN THE PARLIAMENT OF CANADA -

By: Judith Spence, RN - CEO The Environmental Illness Society of Canada

Canadians With Multiple Chemical Sensitivity (MCS), Chronic Fatigue Syndrome (CFS) And Fibromyalgia (FM) Will Be Protected And Will Have Their Needs Met When C-416 Passes Into Law

Mr. Greg Thompson, M.P. for Charlotte, New Brunswick moved for leave to introduce **Bill C-416**, an act to amend the Department of Health Act (environmental illnesses, chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivity).

M.P. Thompson introduced the first ever 'EI' Bill and in so doing, he has earned a place in history and in our hearts. This legislation is the result of collaborative efforts between the EISC and M.P. Thompson's office. The EISC had consulted with members of the Society's Emerging Illnesses Coalition regarding issues they felt needed to be addressed. The Bill was over a year in the making.

Thanks to M.P. Thompson, people with MCS-CFS-FM can venture to feel more secure because 2000 is definitely going to be THE YEAR that they will experience, first hand, the benefits that come with the recognition and acceptance of their illnesses. Only through recognition and acceptance by the public and moreover by the medical profession will people with MCS-CFS-FM have lasting peace of mind.

Bill C-416 will, in the short term, raise awareness about the illness and will draw attention to the current deficiencies in the medical and social support systems. If passed, M.P. Thompson's legislation will go a long way to correcting many of the deficiencies in the system and will set the standard for protective legislation for persons with MCS-CFS-FM all around the world.

Those wishing to support Bill C-416 can write to: **Mr. Greg Thompson, M.P. Charlotte, New Brunswick, Room 421, West Block, House of Commons, Ottawa, ON K1A 0A9 Canada (613) 995-5550, Fax: (613) 995 5226, E-Mail: thompg@parl.gc.ca**

and to:

The Honourable Allan Rock, M.P., Etobicoke Centre, Ontario, Room 441-S, Centre Block, (613) 947-5000 Fax: (613) 947-4276 E-Mail: rocka@parl.gc.ca

Please send a copy of your letters, faxes or e-mails to: **The Environmental Illness Society of Canada - La société canadienne pour les sensibilités environnementales 536 Dovercourt Avenue Ottawa ON K2A 0T9 Canada - Tel: (613) 728-9493 Fax: (613) 728-1757 http://www.eisc.ca**

ENCOURAGING NEWS!! By: Mary Ellen

While we continue to hear from people all over Canada who have had their private disability insurance benefits terminated as a result of an I.M.E. (Independent Medical Examination) or F.A.E. (Functional Abilities Evaluation), it is wonderful to hear good news as well. Since our last newsletter, we have heard from some of our members who, with the help of a lawyer who specializes in disability, have had their benefits reinstated or come to a financial settlement with their long term insurance carrier. This is encouraging news for all of us. I hope that it will give all our members the courage and confidence to fight for the benefits to which they are entitled

Please continue to pass along the word about our I.M.E. Registry Submission Form to be filled out by those who have been requested to attend an I.M.E. or F.A.E. by their insurance company. Please consider having the Forms available at your monthly support group meetings for members who may wish to fill them out. Our database is growing steadily and patterns are emerging. Many members and lawyers and doctors telephone and request whether we have any reports on doctors who the member has been requested to see for an I.M.E. While we keep everyone's personal information confidential, the details have been helpful to many so far. We need strong statistical evidence of problems with how the system is run now in order to move ahead with our advocacy work in seeking insurance reform.

To get a copy of our simple, 7 question Registry Submission Form, please contact **Mary Ellen, Manager of Special Projects - Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7 - Tel/Fax: (905) 831-4744; E-mail: marye@pathcom.com or** download the form from our website: **www3.sympatico.ca/me-fm.action/medexam.html**

TIP: Need Help with your Income Tax Return and can't afford assistance? The Canada Customs and Revenue Agency (formerly Revenue Canada) can help. For information call: 1-800-959-8281 (English) or 1-800-959-7383 (French).

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INTER-GROUP COMMUNICATIONS:

WEBSITE for those who are too ill to read a lot of material about ME and want a concise summary of the key issues: **http://members.aol.com/MEwebsite/info.html**

CHAT ROOMS: Monday Evening Peer Support Meetings at 4:30 P.M. Pacific/ 7:30 P.M. Eastern Times. at http://www.wwdp.org - Our Director, Carole Roy, in attendance for support.

QUEST COLLECTION BOOK - FIVE YEARS:

By popular request, the National ME/FM Action Network has just published an easy to read book consisting of a collection of important articles which have appeared in our 'QUEST' newsletters over the years. Many people have wanted easy access to certain medical or legal articles and we are pleased to announce that this book has now been completed. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We believe that anyone who is involved in the ME/FM community will want a copy of this book consisting of over 100 pages of information. This may also be a good book for you to purchase and give to the professionals in the medical/legal community.

We have kept the **cost** of the book to a minimum at **$20.00** each which includes the cost of 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 - 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**

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CONFUSION: Like watching 10 different TV channels at the same time.

Thanks to Lorraine Legendre, Ottawa.

MEMBERSHIP: $20.00 per year includes bi-monthly newsletters

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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