

## Quest #35 April 1999

### **VICTORY FOR EVERY PATIENT WHO SUFFERS FROM ME/FM**

**By: Philipa D. Corning, Ph.D., Bs.C.(Hons)**

The National ME/FM Action Network has been sponsoring the ongoing research of Ms Dilnaz Panjwani, the teen who represented Toronto in May 1999 at the 50th Intel International Science and Engineering Fair held in Philadelphia, Pennsylvania, U.S.A. Students from 43 countries around the world participated, and Ms Panjwani was one of 120 exhibitors in the category of Medicine and Health. Highly qualified professionals awarded her the Grand Award, 2nd prize in her category and she has gained international recognition for her discovery of a possible diagnostic marker for ME/FM.

The National ME/FM Action Network helped organize the ME/FM patients for the second research study conducted in March of this year and organized the interactive public education presentation at Credit Valley Hospital Auditorium near Toronto on Saturday May 29. Lydia Neilson, our President, and Dr. Philipa Corning, Vice-President, traveled from Ottawa to present Ms Panjwani with a plaque engraved with our Canada Geese logo and the following inscription: "National ME/FM Action Network - Presented to Dilnaz Panjwani - In recognition of your hard work, commitment, dedication and your outstanding achievement in your research for Myalgic Encephalomyelitis and Fibromyalgia - May 29, 1999".

At this time Ms Panjwani presented her research findings to members of the National ME/FM Action Network and a packed audience of interested people from the ME/FM community. 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. Dr. Panjwani was available to discuss individual research results.

This young researcher designed and conducted an extensive piece of research, which included a double-blind study and comprehensive statistical analysis of all results. She is about to publish a research paper on the results, thus, there is a limited amount of information that can be released at this time. During interviews with the media, she has been able to name the potential marker as 2,3-diphosphoglycerate (2,3-DPG). Her data shows significant differences in the levels of the red blood cell metabolite 2,3-DPG between healthy control subjects and those suffering from ME/FM. This makes sense as 2,3-DPG helps transport oxygen to tissues including the muscles. Any variance in the normal level of this substance would translate into a reduced rate of delivery of oxygen to body tissues and a resulting reduction in the amount of energy produced. This could explain a great deal about the many symptoms experienced by ME/FM people.

Ms Panjwani is 17 years old and a grade 13 student at Branksome Hall in Toronto. She has indicated that she wants to continue to study toward a medical degree and conduct

medical research. We commend Ms Panjwani for her commitment to our cause. Her research gives us all hope and courage to go on.

There will be more explanation and details of Ms Panjwani's research after her paper is published in a scientific journal. She is presently completing examinations at school. Once that is finished, she will devote her full attention to writing up her results for submission to a journal and preparing for the future. Larger study planned at a well-respected Toronto Hospital.

[Ed.note: **This meeting was videotaped.** To obtain a copy of this **video**, please make cheque payable to the **National ME/FM Action Network** in the amount of **\$25.00** - Please see white order form enclosed **Proceeds** of this video will be deposited in our **research account.**]

## **MOTION BY E.I.S.C. SUCCEEDS AND SENDS CFS/MCS/FM TO THE STANDING HEALTH COMMITTEE FOR AN IN-DEPT STUDY**

**By: Judy Spence, RN - President**

In 1995 the **National ME/FM Action Network** began moving CFS-MCS-FM onto the National Agenda. Since October 1998, the **Environmental Illness Society of Canada (E.I.S.C.)** has co-ordinated the effort to gain recognition of MCS, CFS and FM by asking Parliament to vote affirmatively on **Motion, M-468**, which reads: "**That, in the opinion of this House, the government should recognize: (a) multiple chemical sensitivity, chronic fatigue syndrome, and fibromyalgia as illnesses that have the capacity to cause disability; and (b) those suffering the disabling aspects of these diseases require protection and a strong moral commitment to their well-being.**" Many, many individuals and affiliate organizations took part, with cards, letters, faxes and calls making their voices heard.

On **International ME Awareness Day '99 [May 12]** the motion went before the Private Members Motions sub-committee where it was decided the motion would not be 'votable' but that it would be debated. On June 2, 1999 during the debates on the motion, **MPs Mac Harb and Marlene Catterall** and **Defence Minister, the Honourable Art Eggleton** spoke eloquently and, at great length, to the issues concerning people suffering from our illnesses. **MP Blaikie (NDP), MP Casey (PC) and MP Hardy (NDP)** spoke about the illnesses and about their own constituents who were sick with these conditions. At the end of the debates all five political parties unanimously adopted a motion referring the whole matter of CFS-MCS-FM matter to the standing Health Committee for an in-dept study.

**The Environmental Illness Society of Canada**, 536 Dovercourt Avenue, Ottawa, ON K2A 0T9. **(613) 728-9493(tel.), (613) 728-1757 (fax); 1-877-362-1103 (Toll Free); e-mail: eisc@eisc.ca** **Web: <http://www.eisc.ca>**

Plan to attend both the Joint International Environmental Medicine (JIEM) conference - Ottawa, October 4-9, 2000 and the Canadian Healthcare Advocates, Alternative Practitioners and Patients' (CHAAPP) conference - Ottawa, October 11-12, 2000.

[Ed.note: **We congratulate E.I.S.C. for a job well done.** Please see E.I.S.C.'s website for more details]

## **WARNING: INSURANCE COMPANIES CAN USE RESEARCH ON EXERCISE/CFS FOR OWN ADVANTAGE**

**By: Philipa D. Corning, Ph.D., Bs.C. (Hons)**

A research paper on exercise and ME/CFS, that appeared in the British Medical Journal (BMJ), unfortunately, can be wrongly used by insurance companies to support their position that exercise will improve the physical condition of all who suffer from this condition. The problem is that 75% of our community suffers from nervous system problems amongst which sleep disturbance is a prominent aspect. However, this BMJ cited research appears to have excluded individuals afflicted with sleep disturbances from the study. The majority of ME/FM patients do not get down into the stage of normal deep restorative sleep, because the fast alpha waves of wakefulness intrude on the slow delta waves of sleep during stage IV of non-REM (non-rapid eye movement) sleep. In addition, research has shown that dysfunction of the reticular formation (biological clock for the sleep-wake cycle) in the brainstem can cause insomnia, which prevents the replenishing of glycogen stores (form in which glucose is stored in the liver and skeletal muscle cells) used during waking hours. As a result, most patients wake up feeling unrefreshed. I believe that people experiencing sleep deprivation were left out of the BMJ cited research expressly because they are not good candidates for exercise. In the circumstances it is difficult to understand why this segment appears to be excluded from the study.

It has been proven through research that sleep deprivation causes even healthy people to suffer fatigue, which leads to reduced productivity. They experience reduced concentration, memory and problem solving capabilities, as well as reduced physical capabilities. In the ME/FM community, physical exertion causes individuals to relapse with ME/FM symptoms, and therefore they experience reduced physical performance. In fact, post-exertional malaise, fatigue and weakness, and impairment of cognitive functions last for more than 24 hours. Significant fatigue is often described as muscle exhaustion and weakness similar to that experienced with flu. But what is the cause of this unrelenting fatigue? Research points toward many different possible causes. Some research has concluded that there must be a major central nervous component explaining the reduced muscular strength. On the other hand, fatigue can be caused by a dysfunction in the thalamic area of the brain. According to Dr. Paul Cheney, "the aerobic system is injured and reactive oxygen species (free radicals) generated in the mitochondria by excessive training may not be detoxified with resulting injury which can potentially be permanent (DNA) damage. Aerobic exercise can dramatically worsen this disorder." Some researchers have found mitochondrial abnormalities in skeletal muscle

fibers of ME/CFS patients, which lead to reduced aerobic work capacity in ME/CFS individuals compared to normal subjects. Various researchers have found blood abnormalities that lowered the rate of delivery of oxygen to tissues of the body - 2,3-diphosphoglycerate in red blood cells and miss shaped red blood cells. In addition, one other researcher found gross left ventricular dysfunction with increasing workloads leading to fatigue because of the inadequate rate of oxygen delivery to body tissues resulting from the inefficient pumping action of the heart. Furthermore, other data suggests a defect of oxidative metabolism with a resultant acceleration of glycolysis (anaerobic production of energy) in the working skeletal muscles of ME/CFS patients. Although the exact etiology of the overwhelming fatigue and reduced physical capacity is yet unknown, it is logical that all or a combination of these aspects may contribute to the reduced physical endurance of these individuals.

Thus, there is ample scientific research evidence that supports the reduced physical capabilities of ME/FM people. Yet, insurance companies have been using this reference as an excuse to cut off benefits to ME/FM people. The research cited is "British Medical Journal, No. 7095, Volume 314, Papers-Abstracts on Saturday, June 7, 1997, by Kathy Y. Fulcher and Peter D. White".

The authors 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". But, they did not include those with sleep deprivation or psychological distress in this particular piece of research. At the end of this paper in their discussion of results, they said that they could "only speculate whether it was important to treat or exclude patients with psychiatric disorders or sleep disturbances". Yet, the insurance companies will likely use this paper as proof that exercise works in all cases to improve the health of individuals suffering from ME/FM. However, the subjects chosen to participate in the study were favored to succeed. Thus, the desired results were assured of being obtained. Participants were expected to start at 40% peak oxygen consumption or 50% of their maximum recorded heart rate and exercise for 5-15 minutes 5 times a week. These parameters are set at the level expected for normal healthy, not sick individuals. These types of subjects are not typical of ME /FM people. What about those who cannot exercise under any circumstances let alone under these given criteria? So, how can this research be used as a reference to apply to the majority of the ME/FM community? Theoretically, it cannot and in reality, it should not. However, insurance companies may wrongly attempt to use this limited conclusion to support their case and may lead to unhelpful or unsupported conclusions by insurance companies.

[Ed.note: References available upon request.]

### **MEDICAL QUESTIONS:**

Replies by: Prof.Garth Nicolson., Institute for Molecular Medicine, CA

*Q: I have just been diagnosed with Atrial Fibrillation but the cardiologist has no idea what has caused it. Have you heard of this in cases of ME before? Are you able to give me any information?*

A: We have been working with local cardiologists on this problem. When CFS or FMS patients have heart problems (various), we have 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. Long-term treatment with antibiotics, such as doxycycline, azithromycin, etc. can generally resolve these cardiac problems, but not always completely and not always in every patient.

Q: Would you please comment on what you have observed in CFS patients on a protocol of Zithromax for mycoplasma in terms of worsening of symptoms and time frame for same? Is it common to see CFS expressing itself more neurologically and "virally" during treatment?

A: It is common for CFS/FMS patients starting on an antibiotic protocol to have an initial worsening of signs/symptoms, often called the Herxheimer response or reaction. This is thought to be due to "die off" or "damage" of the microorganism(s) by the antibiotic(s) 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 signs/symptoms but not all at the same rate and not in all patients. Unfortunately, in most patients that do recover, their neurological signs are usually the last to correct, and some patients have neurological problems long after other signs/symptoms have reverted to normal or near normal.

### **ASSESSMED SUES CBC - UPDATE**

In an earlier edition of Quest, we reported that AssessMed Ltd., a registered facility specializing in independent medical evaluations and functional abilities evaluations, had filed a Statement of Claim on January 14, 1999 at the Toronto, Ontario Federal Court House suing CBC, the executive producer of the Fifth Estate, producer of the the program entitled "Prove It..If You Can", reporter and narrator of the Program and a doctor interviewed on the program, who disagreed with the findings of AssessMed. AssessMed Inc. believes that the words and actions of the CBC program aired on November 10, 1998 were defamatory and brought into question the impartiality, competence and credibility of their business.

Since our last report there have been two further developments:

1) On March 8, 1999, CBC filed its Statement of Defense at the Toronto, Ontario Federal Court House; and 2) The Hamilton Spectator in a series of newspaper articles June 2 and June 3 also highlighted the treatment by AssessMed of one of the disabled people in the same CBC program. Prior to publication, they received a letter from the

lawyers representing AssessMed . The newspaper included the following words in the last paragraph of their Special Report: "Lawyers acting for AssessMed also sent a threatening letter to The Spectator prior to publication of this story informing Editor-in-Chief Kirk LaPointe 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.'"

## **DISABILITY TAX CREDITS, MEDICAL EXPENSES & OCCUPATIONAL THERAPY**

**By: Kerry Ellison B.F.A. Hons., B.Sc. O.T.(c)**

Disability Tax Credits - You can apply to Revenue Canada for a Disability Tax Credit if any medical condition is causing you severe and prolonged impairment, and markedly restricting your basic daily activities. The non-refundable disability tax credit reduces the amount of federal income tax you (or your spouse) must pay. A completed Form T2201 must be submitted with your annual individual income tax return.

### Occupational Therapists Are Authorized to Complete Form T2201

As of February 1998, Occupational Therapists are authorized to complete Disability Tax Credit Certificates, or T2201 Forms. The T2201 asks questions about an applicant's abilities with regards to vision, hearing, speaking, mental functions, walking, elimination, feeding, and dressing. Apart from vision and hearing, Occupational Therapists are trained to assess a person's abilities and disabilities in these basic activities of daily living. Occupational Therapy (OT) is a branch of rehabilitation medicine which addresses the physical, mental, environmental, spiritual, vocational, emotional and social aspects of *maintaining daily routine*. *Occupational Therapists are daily routine specialists*.

Disability Tax Credit Eligibility: In order to be considered eligible to claim the disability amount on your tax return, your impairment must:

- be considered *severe* and *prolonged* (*i.e.* continuous for at least 12 months);
- *markedly restrict* the performance of *at least one of the basic activities of daily living* listed above.

**Note:** working, housekeeping, social or recreational activities are not included in Revenue Canada's *definition* of basic activities of daily living.

Part B of the T2201 Form must be completed by an Occupational Therapist or other relevant healthcare professional. *Be sure to remind the person filling out Part B of your form that if you "require **an inordinate amount of time** to perform one of these activities, **answer NO** to the application questions."* If your condition is permanent, you need not send in a T2201 each year. If your condition improves, you should advise Revenue Canada. If your federal income tax is already zero, your spouse or supporting

person may be able to claim the unused part of the disability amount. T2201 Forms and a free booklet entitled *Information Concerning people With Disabilities* are available from your local Revenue Canada office listed at the Front of your phone book. *Be sure to ask for the 1998 version.*

### Claiming Occupational Therapy Services as a Medical Expense

Revenue Canada recognizes Occupational Therapy services as a tax deductible medical expense. When filling out your individual tax return, add in any expenses which you incur obtaining OT services, and attach all receipts. This includes the fee you pay for having an OT complete Form T2201.

Occupational Therapy (as well as a number of other health professionals) are not specifically listed in the general income tax guides under "allowable medical expenses." Therefore many people do not claim these expenses for which they are eligible. A free pamphlet entitled *Medical Expense and Disability Tax Credits and Attendant Care Expense Deduction (Information Bulletin #IT-519R2)* gives a complete list of healthcare practitioners whose services are tax deductible. Contact your local Revenue Canada office for a copy.

If you have further questions, contact your Revenue Canada office, your tax advisor, or Kerry Ellison, Occupational Therapist at (403) 240-1148 or the Canadian Association of Occupational Therapists in Ottawa at 1-800-434-2268 or (613) 523-2268.

### BC COLLEGE OF PHYSICIANS & SURGEONS REPLIES ON I.M.E.s

**By: Ian Waymark, Co-Director for B.C.**

**Ms Patricia Rebbeek**, Deputy Registrar, of the **College of Physicians & Surgeons of British Columbia** in her letter of April 9, 1999 stated that "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 to. 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 goes further on and 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."

### I.M.E. SURVEY UPDATE:

Since our last newsletter, three newspapers across the country have published articles highlighting the difficulties that disabled people face when an independent medical examination is requested by a private insurance company. Word has been spreading steadily about our Independent Medical Examination Registry Submission Form and some journalists have courageously spoken out about the problem. The Victoria Times, The Calgary Herald and The Hamilton Spectator are among those newspapers who have decided that it is time this important issue is brought to the attention of the public. Each of us can feel encouraged that the climate is changing and that ME/FM people are being heard and believed.

Please help us continue to work on your behalf by passing on the Registry Submission Forms to any appropriate people. The Form contains seven simple questions about your independent medical examination experience. It will take very little of your precious energy to complete. The Forms are being handed out at support groups across the country, by doctors, lawyers, physiotherapists, massage therapists, chiropractors etc. Let us know how many forms you need and we will be happy to mail you copies.

**Contact: Mary Ellen Tel. (905) 831-4744** (If you are calling long distance and leaving a message, your call will be returned 'collect'.) Mail: **P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7** - E-mail: **marye@pathcom.com** or feel free to download the form from our website at: **<http://www3.sympatico.ca/me-fm.action/medexam.html>**

When we all do the little that we can to help spread the word, the results are remarkable. Remember that your name will be kept confidential but the details of your experience will be added to our databank.

### **ACCESSING JUSTICE---SELECTING AND INSTRUCTING A LEGAL ADVISOR - Part I of II**

**By: HUGH R. SCHER, Scher & De Angelis, Barristers & Solicitors, 69 Bloor St. E., Suite 210, Toronto, ON M4W 1A9 Canada - Tel.(416) 515-9686 - Fax: (416) 961-2534 - Email: [hscher@interlog.com](mailto:hscher@interlog.com)**

There are several factors that must be considered when selecting and instructing legal counsel to advise you with respect to the denial of a claim for benefits, either by a long-term disability insurance carrier, the Canada Pension Plan, the Workplace Safety and Insurance Board, or some other source. For people with Chronic Fatigue Syndrome and Fibromyalgia, these factors take on an even greater significance in view of the effects of the disability on the individual, the complex nature of the disability, the serious need of the individual for funds from the source and the fact that this is often an individual's first contact with the legal community at a time when they are quite vulnerable and desperate.

In selecting a legal advisor, one should identify the qualifications and experience one is looking for. For people with Chronic Fatigue Syndrome, they will often be looking for



someone with experience in insurance law, pension and benefits, personal injury, employment and general civil litigation. Few lawyers have experience dealing with cases specifically involving Chronic Fatigue Syndrome and Fibromyalgia. The national ME/FM Action Network has a directory of lawyers who do have experience with its members. It is obviously advantageous to have a lawyer who is knowledgeable about the medical research as well as the legal precedents relating to Chronic Fatigue Syndrome and Fibromyalgia and entitlements to benefits. Selecting a lawyer with this detailed knowledge and experience will cut down the time required by you as clients to explain the nature of your condition as well as the time required by the lawyer to review the medical documentation you will provide to them, and the relevant legislation and case law precedents applicable in your situation.

Another significant issue is the timing of the selection of a lawyer and their first involvement in your fight to obtain benefits to which you are by law entitled. There are a variety of situations which are common to many people with Chronic Fatigue Syndrome and Fibromyalgia. Often, people will be denied their entitlement to benefits from the start upon application for the benefit. Alternatively, people may receive a response that additional information is required and requesting that the individual submit to an Independent Medical Evaluation ("IME"), or a Functional Capacities Assessment. These assessments are with physicians or other health care providers selected by and paid for by the insurance company. In the vast majority of cases, the independent medical examination involves painfully grueling assessments that will leave you sore for days and weeks to come. In the vast majority of cases, they will result in assessment reports from a physician or health care expert indicating that you are not totally disabled and are able to engage in some kind of work. Rarely will they identify what that kind of work is, how it could be obtained or whether or not it even exists.

It is my belief that early intervention from a legal advocate is usually in the best interests of the individual battling an insurance company or Canada Pension Plan for benefits. The reason for this is two-fold. First, it puts the insurance company or Canada Pension Plan on notice that you have a legal advocate to represent your interest in any process relating to your benefit entitlement. Second, it relieves for you the stress of dealing personally with the insurance carrier or other party on a matter which is emotionally and physically draining on you at a time when you are medically least able to afford this.

It is not uncommon that a letter or telephone call from a lawyer may assist to resolve an insurance claim immediately and after a denial letter has been received. Alternatively, it enables you to learn and understand the reasons behind the decision to deny your benefits and to pin the insurance carrier or Canada Pension Plan down on their reasons for rejection of your claim and their position with respect to medical and other supporting evidence which you have provided to date.

With respect to situations where benefits are not refused, but rather an insurance carrier has taken a delay tactic and required additional medical evidence from you, or your physicians, a legal advisor can assist in ensuring that necessary and appropriate medical evidence is obtained from your physician, or another appropriate specialist. In

situations where the carrier demands an independent medical assessment by a physician selected by them, having a legal representative will enable you to ensure that the process of the assessment is as fair and unbiased as it can be. It may enable you to object to an assessor whom you know has a history of working with a particular insurance company and of denying claims to benefits in their assessment reports. Having a role to play in the assessment process can ensure a fairer and less biased assessment process which may assist an insurance company to make the determination that your claim is valid. Alternatively, a legal advisor can advise you of the wisdom of submitting yourself for an IME and provides a buffer between you and the insurer with respect to this and other decisions.

Most insurance policies entitle the carrier to require you to participate in an IME as part of the contract. However, where the carrier is already in breach of the contract by refusing to pay benefits despite medical evidence of disability, or where it is not in your medical best interest to submit to an IME, it may be appropriate to refuse an IME. Such a decision has obvious legal implications and should be discussed with a lawyer.

Very commonly, lawyers are consulted once an individual is denied their claim for benefits or when they are cut off benefits after a period of time, usually after the definition change date where the definition of disability changes from disability from performing the duties of one's own occupation to disability from performing the duties of any occupation for which one is qualified by reason of education and training. One of the advantages of having a solicitor involved early in your case is that they can assist your physician in providing the kind of relevant medical information that the insurance carrier and Canada Pension Plan will require in order to substantiate your claim for disability benefits.

Clients should be aware of the time limitation which affect a legal claim. The most common is the requirement that legal actions be brought within one year of an insurer's decision to deny a claim. This is another important reason for early legal intervention.

Your first appointment with your lawyer will be one of the most significant dates in the battle to overcome the barriers to obtain benefit entitlements. It is essential to be prepared, to be alert and to understand what it is a lawyer is going to require of you in order to best advocate on your behalf. My practice is to require clients to prepare a chronological summary of their communications with the insurance carrier, the onset of their disability, their employment history, communications with physicians and other relevant information to their claim. The reason I have the client prepare this information themselves is so that they can familiarize themselves with the timeline, the events that led up to their appointment with me and to ensure that they are in the best position to provide me with the information I will require during that first appointment. Moreover, a written chronological summary provided to me by the client can then be used by me in preparing correspondence with the insurance carrier, medical practitioners and the client with respect to their case. Along with the written chronological history, I also ask my clients to provide me with copies of all insurance documentation and communications as well as all medical reports, letters, clinical notes and other

information relevant to their claim. It is my practice to ensure that clients always retain copies of their documentation. I also ask that they provide me with a list of contact people, including physicians, employer contacts and insurance company contacts, with addresses, telephone numbers and fax numbers. This assists me in knowing who the client has been communicating with previously and advising me as to who I will need to be communicating with to process the case.

Given the difficulties with memory and concentration frequently associated with CFS and Fibromyalgia, it is not uncommon for my clients to bring with them a spouse, relative or a friend to be with them during the appointment so that this person can assist them to fill in gaps in information provided, or to assist them to remember what information they received from me in my office. It is also my practice to confirm in writing information received from the client and instructions and advice provided. This includes preparation of a written "To Do" list for the client before they leave the office.

**CORRECTION: Quest #34, Feb/Mar '99 - Page 4 "**

READS "...The most common evidence of Fibromyalgia and Chronic Fatigue Syndrome is obtained by way of examination of trigger-point sensitivity...."

**Should read: "...The most common evidence of Fibromyalgia is obtained by way of examination of trigger-point sensitivity..."**

**CANADA PENSION PLAN - COURT CHALLENGE - UPDATE**

In order to proceed with our Court Challenge, we need to find a perfect test case. Therefore, with this newsletter you will find an orange form. If you have been refused CPP disability benefits, please complete this form and return it to our office.

**DISABILITY TAX CREDIT - COURT CHALLENGE -UPDATE**

We do not need any more completed questionnaires at this time. Our lawyer, Mr. Hugh Scher, will be contacting those who are being considered as a possible test case. Thank you for your participation.

**INTER-GROUP/CONTACT COMMUNICATIONS:**

**L'ASSOCIATION QUÉBÉCOISE E.M. - GOLD TOURNAMENT SUCCESS**

**By: Odile Gérin, President**

Our gold tournament, being a first one, has been a success. We had a net profit of \$6,300.00. We also received 100 free gifts from companies, members, etc.

What was the most impressive was how everybody seemed happy with the day and the best of all, very moved by our illness. Doctor Phaneuf and the comedian Françoise

Graton did not talk long but said just the right things that moved people and made many of the business people come to us afterwards and telling us that next year they will get more involved, encourage their clients to participate and will bring more people. We came away from the tournament feeling that we have taken a big step forward and we are no longer alone.

For May 12th [National ME Awareness Day], we sent petitions to the provincial and federal ministers of health requesting them to provide funds for research and more adequate social and medical services for those afflicted with ME. In our accompanying letter to the Hon. Mr.Allan Rock, Minister of Health, we asked him to consider the ME/FM clinical definitions presently being drafted through the National ME/FM Action Network and to support the distribution of the document to the medical doctors across the country.

### **NEW BRUNSWICK ME/CFS ASSOCIATION - ELEPHANT WALK:**

**By: Brenda Duffy, President**

The **New Brunswick Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Association** hosted the Fourth Annual "Believe in M.E." Elephant Walk on May 30, 1999 in Oromocto, NB. "Working Together" we raised \$3,000. A percentage will be donated to the National ME/FM Action Network's Research Fund.

To host an "Elephant Walk" in your area call Brenda at (506) 452-9739 or write 15 Rosewood Dr., Lincoln, NB E3B 7G8

Together we can raise ME/FM awareness and research funds.

### **GLAD YOU LIKE OUR NEWSLETTER - BUT PLEASE BECOME A MEMBER**

First of all, we want to thank you for liking our newsletter so much that photocopies are being made for many people. However, we RELY on your memberships and your donations to keep active. The small government grants we are getting only helps with SOME of our expenses.

### **NATIONAL DOCTORS' ROSTER - ADDITION:**

**DR. ERIK T. PATERSON M.B., D.Obst.R.C.O.G.,F.B.I.S.**

12 - 1000 Northwest Blvd. **Diagnosis/Treatment ME/FM**

Creston, BC V0B 1G0 **Physician referral only**

**Tel. (250) 428-7887 - Fax (250) 428-7171 -**

### **NATIONAL LAWYERS' ROSTER - ADDITIONS:**

**TIM LOUIS - ME/FM**

TIM LOUIS & COMPANY

Barristers & Solicitors

108 - 2182 West 12th Avenue

Vancouver, BC V6K 2N4

Tel.(604) 732-7678 - Fax (604) 732-7579

Email: timlouis@helinet.com

Web: <http://www.helinet.com/timlouis&Co>.

**Initial Consultation: FREE**

**PETER KENEDY - ME/FM**

VINER, KENNEDY, FREDERICK, ALLAN & TOBIAS

Barristers & Solicitors

27 Place D'Armes, Box 116

Kingston, ON K7L 4V6

Tel.(613) 542-7867 - Fax: (613) 542-1279

E-mail: pkennedy@vkfat.on.ca

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**BETWEEN GARDENS - Observations on Friendship, Gardening and Disability -  
Authors: Carol Graham Chudley and Dorothy Field**

**By: Lynn Henry, Managing Editor**

Two good friends and avid gardeners find inspiration in their belief that, against all odds, "Gardeners find a way" **Polestar Book Publishers** is proud to announce the publication of an insightful, moving and beautiful new book that deals with the subjects of gardening, friendship and Chronic Fatigue Syndrome. *Between Gardens* began with a simple proposal between friends and fellow artists Dorothy Field and Carol Graham Chudley: they agreed to correspond with each other for one year about the cycles of their beloved gardens. At the end of a year, the friends found that they'd created much more than a series of letters.

Instead, they'd written a book. It was a book about the value of life itself - about tossing seeds, working the soil and reaping what the land loves to grow; and about enduring friendship and living with integrity.

One of the poignant themes that threads through the book is Carol's struggle with Chronic Fatigue Syndrome. Despite pain and sleep deprivation, Carol joined Dorothy in recording the cycles of her garden. She also kept a private journal of her struggle with illness. Eventually, excerpts from this journal were added to the letters, providing a darker counterpoint to the vibrant correspondence. Before *Between Gardens* could be published, Carol died from complications related to her illness. About this loss, Dorothy writes, "By the time we started writing, Carol had had Chronic Fatigue Syndrome for ten years. Slowly and steadily, her disability increased....Gardening and writing the letters became her outlet. Watching Carol in her last years I learned a lot about what it is to be alive..... [I] turned my mind to questions about life and death - and how to live. This is reflected in the letters. They remain something rare and precious in our sped-up world."

**Carol Graham Chudley** was a gifted potter, teacher and writer. She lived on Vancouver Island and her workshop, studio and gardens were frequented by friends and visitors. Despite becoming disabled from the effects of childhood polio and Chronic Fatigue Syndrome, she continued to express herself through her art and tend her land until she passed away in the spring of 1998.

**Dorothy Field** is a writer and papermaker who has lectured and taught courses about handmade paper throughout North America. She lives and gardens on a farm on Vancouver Island. *Between Gardens* is available at your favourite bookstore.

For further information, contact Polestar Book Publishers at: PO Box 5238, Stn B, Victoria, British Columbia, Canada V8R 6N4 - Web: <http://mypage.director.ca/p/polestar/> - Price: \$24.95 CAN/\$19.95 U.S. - Tel. (250) 361-9718 - Fax: (250) 361-9738

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A special thank you also to **Dr. Dilkush Panjwani and family** for their partnership in this endeavour.

**OUR WORLD:**

LIGHTHEADEDNESS: Excile to Mars.

MUSCULAR PAIN: Muscles gone AWOL.

Thanks to Lorraine Legendre, Ottawa.

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**Tel/Fax: (613) 829-6667**

**E-Mail: ag922@freenet.carleton.ca**

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

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