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Medical Milestone: First Clinical Definition of Fibromyalgia Syndrome

Marjorie van de Sande, Director of Education

May 12, National ME and FM Awareness Day, brings new help for Fibromyalgia Syndrome patients. Haworth Press will have completed the printing of **Fibromyalgia Syndrome: Canadian Working Case Clinical Definition, Diagnostic and Treatment Protocols. A Consensus Document.** *Journal of Musculoskeletal Pain 11(4), 2004.*

This Consensus Document offers physicians a "comprehensive manual" for the diagnosis and treatment of fibromyalgia syndrome. In addition, there is an extensive discussion of research, and numerous helpful, practical appendices.

Haworth Press is also publishing the Consensus Document as a soft cover book later this year. The title of the book will be **"The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners"**.

The National ME/FM Action Network spearheaded the drive for a clinical definition and guidelines for FMS. Health Canada selected the Expert Consensus Panel. The FMS Consensus Document is the first concerted effort to provide the practitioner with a clinical definition and guidelines for FMS patients. It will allow family physicians and other clinicians to confidently diagnose FMS and provide appropriate treatment. **To order** the *Journal*, please see page 8 under **RESOURCE BOOKS**.

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

Dr. Sherkey was one of the members of the Expert Consensus Panel for the ME/CFS Clinical Working Case Definition, Diagnostic and Treatment Protocols – Consensus Document, which was published in February 2003 by Haworth Press.

Dr. Sherkey has been ill for a long time with ME/CFS and has retired from his practice. Sadly, Dr. Sherkey has developed cancer of the brain and has been undergoing surgery and radiation. In 2004, Dr. Sherkey needed more surgery.

Dr. Sherkey is a very kind and compassionate physician, who faithfully made house calls to his housebound ME/CFS patients.

If you were a patient of Dr. Sherkey and even if you were not, please send Dr. Sherkey a card or note. Let's give back to Dr. Sherkey some encouragement and support which he so generously gave to us. Please mail the card or note to his office and they will forward it to his home.

His address is: **Dr. Jeff Sherkey**,**169 Annette Street**, **Toronto, ON M6P 1P4**

Excerpt from: In the Spotlight: The Tymes Trust View on the ME/CFS Clinical Working Case Definition, Diagnostic and Treatment Protocols.

Jane Colby, Executive Director, Tymes Trust,
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Tymes Trust has issued a Statement on the Canadian Definition of ME/CFS (2003). "In our opinion it is the best contemporary definition. It was developed for clinical practice and was compiled by physicians who have seen over 20,000 patients.

It addresses many misunderstandings caused by 'catch-all' definitions, which have so disastrously affected research into treatments and clinical practice.

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

Al Neilson Honoured

Marjorie van de Sande, Director of Education

The National ME/FM Action Network is most pleased to honour **Al Neilson** with a plaque for the wonderful work he did in creating our website. A number of years ago Al Neilson, Lydia's husband, worked diligently to make a website for the National ME/FM Action Network. Our website has served us well throughout the years as over 115,000 have visited it. We are greatly appreciative and exceedingly grateful for all the time Al spent and the work he did to get us into the world of the internet. On behalf of the Board of Directors and all the members of the National ME/FM Action Network, I would like to extend our sincere thanks and gratitude.

New Website Being Developed

We are pleased to announce that **Bob van de Sande**, Marjorie's son, has kindly offered to make the **National ME/FM Action Network** a new website using the latest technology. Bob, an electrical and computer engineer, developed one of NASA's security programs, has developed programs for a number of the Fortune 500 companies, colleges, school boards, numerous professional organizations, real estate companies, etc. He is presently Programs' Development Manager and Lead Systems Architect for a consulting firm in North Carolina. We wish to thank Bob for the generous donation of his time and expertise.

The focus of our new website is to simplify it and make it as user-friendly as possible. Please visit our new website at http://www.mefmaction.net

We will now have a **secure** "Members Only" section. Members with computers will be able to choose to download our newsletter, "Quest", online. This means that you will be able to receive your copy of Quest as soon as it is finished rather than waiting for it to be printed and sent to you by snail-mail. Members who choose this online service will also have the benefit of accessing hundreds of selected research abstracts on ME/CFS, FMS, and whiplash, and accessing past issues of QUEST. Other features will be added to the "Members Only" section in the future. If you wish to take advantage of being an "on-line" member, a form will be enclosed in our next newsletter.

Letter From Byron Hyde, MD on ME/CFS

I am perhaps in an unusual position among physicians who investigate ME/CFS disabled individuals. I am probably the only physician in North America who has such a complex of curious qualifications.

Like Dr. David Bell and a few other physicians, I have been studying the disease processes leading to this group of illnesses since 1984. That was a year in which so many patients fell ill that it shook the curiosity of a number of physicians. But there are few physicians who have investigated this illness as long and at the same time have limited their patients exclusively to this group of disabled individuals. Of the many curious health systems in the world, only physicians in Canada can access any medical test available in Canada without cost to the patient. This gives Canadian patients an unparalleled investigational advantage. We can examine all patients irrespective of their financial means, since all Canadian patients are covered by a universal health plan. Thus, highly technological investigations can be accessed at the discretion of their physician without having to go through an antagonistic consultant or health or insurance board.

There are a few examination exceptions that have to be paid for. These are not necessary unless the patient is involved in a legal or disability action. These tests are used to better define or help confirm pathologies, and they include:

(a) Neuropsychological testing that must be performed by a qualified neuropsychologist who has experience with this group of patients, and who does not work for the insurance industry,
(b) QEEG (computer-driven Electron Encephalograms),
(c) PET brain scans.

Each of the above costs circa $1,500 - $2,500. Yet even these may be covered, if the patient is referred by a union, or if they are a Canadian native person, such as the Cree or Iroquois. In the case of a successful legal action against a recalcitrant insurer, these costs may sometimes be charged against the insurer. In other words, patients involved in court cases can often get their costs back if they win. I usually win settlements in court if I find sufficient grounds to declare the patient disabled and agree to take on the case. Patients without evidence of disability, I do not support.

Other Canadian physicians can do the same type of investigation as I do, but few have the time to do this since they simply cannot earn a living in investigational health work. Investigation is extremely time costly and the physician is not paid for taking time. This is a universal problem in every country. Other Canadian physicians must be excused if they have not done what I have done since they would not make a living. My medical earnings after expenses are in a negative level. Any clerk or school teacher would be paid more than I am and have a pension as well at the end. However, the work is fascinating and I wouldn't leave it for any money.

There are many great American and United Kingdom physicians. But both American and British physicians are blind-sided to some degree since they cannot write the tests on every patient that I do. Their private and government insurances simply do not allow this. In addition, in the USA, it is my belief that most clinical ME/CFS research is performed with patients who are on welfare, or those who have no or limited insurance, and who claim they have ME/CFS simply to obtain free medical care. It is my belief that many of these people are depressed or mentally aberrant, and so this mix highly squewers the US figures of what ME/CFS is. I worked for one day in a very prominent US clinic that produces an enormous amount of CFS paper, and literally none of the patients had been physically assessed to any degree, and most were depressed or suffering from obvious problems that it serves no purpose in getting into here.

In my investigations of ME/CFS patients I do find psychiatric disease, but only in 3% to 4% of patients investigated, and this is clearly less than the amount of psychiatric disease found in the general public. Why should this be? Clearly my population of ME/CFS patients has achieved considerable academic or financial advancement in relation to the general public prior to their falling ill. To achieve these goals, one has to be not only bright but also must have less depression or other limiting psychiatric diseases. Over 15 years we reviewed some 2000 of our patients. What we found was that the biggest incidence of illness by profession per 10,000 population was among lung assessment technicians. The respiratory technicians as a group are in constant contact with patients with chronic or acute infectious diseases.

The largest group of patients by number was that in the health and teaching professions. Again, these are front-line workers in infectious disease. Among these two groups, the individuals who had the highest levels of illness were health care workers and teachers involved in residential schools and hospitals for the mentally ill or chronically disabled children. In both environments, these are areas of rapidly spreading infectious disease and those with decreased cleanliness caused by their disability and proximity. The association again is one of infectious disease.

Then again there are the multiple epidemics, several of which I have studied personally. One has to come to the conclusion that in ME/CFS illness and disability, we are dealing with the consequence of infectious disease.

Who among these groups actually fall ill, since not all of them do fall ill?
That too has become increasingly clear. They are:

(1) Individuals with previously significant head trauma so that the blood-brain barrier is probably injured and allows infectious disease more readily access to the brain,

(2) Individuals who have prior immune dysfunction illnesses or conditions and who are more likely to become involved in autoimmune diseases,

(3) Patients who have an employment where work and home conditions allow them to become chronically over-exhausted, such that these individuals cannot react to routine infections with a normal immune response,

(4) Patients who fall ill during the first few days or weeks after receiving Recombinant Hepatitis B immunization. Why? Some are immune depressed at the time of immunization, and some may encounter a neurotropic infection immediately after immunization. Recombinant Hepatitis B immunization is manufactured to form a sequence of the surface antigen of Hepatitis B. Although this sequence is not infectious, nor can it apparently be reproduced in the body, the surface antigen of Hepatitis B is known to paralyze the immune system temporarily. This allows minor neurotropic or banal infections to become chronic and recognized as self during this period of immune paralysis.

How do those who believe that ME/CFS is primarily a psychiatric disease arrive at this conclusion? First, I don't believe that those pushing for a psychiatric identity for ME patients have ever done any in-depth investigation of their patients. Psychiatric definitions tend to be made on a shoot-from-the-hip basis, in which the physicians act on total faith in their own mythology and simply have turned their backs to the wealth of investigational tools that we have today. As you also know, many physicians and psychologists who state that ME/CFS patients are primarily or in a large part psychiatric are supported by the pharmaceutical industry or insurance companies in various manners. A psychiatric diagnosis disenfranchises many insured disabled patients. This increases the profits of the insurer immeasurably if they do not have to continue paying a disabled ME/CFS patient. This connection also gives these insurance supported physicians and psychologists vast abilities to access the medical media of publication of "scientific literature".

There is a weak link in the logic of psychiatry and psychology. Individuals who are told they have a brain tumor can by scientific investigation be shown that they do or do not have a brain tumor. Yet for individuals who are told they suffer from a primary diagnosis of depression or conversion hysteria, there is no way to either prove or disprove this diagnosis. The diagnosis of depression or conversion hysteria is not subject to scientific analysis. They are diagnoses of blind faith. Well, there is one way to subject this reputed psychiatric group of ME/CFS patients to scientific analysis. All that the psychiatric physicians need to do is to perform a reasonable but in-depth scientific investigation of the ME/CFS patient. Of course they don't. It might ruin their wonderful and imaginative theories and expose them for what they are: so much hot air.

Please note, these opinions are not a criticism of psychiatrists or psychologists to whom I refer for their knowledge and assistance. It is a criticism of physicians who label patients with imaginary psychiatric diagnosis without taking the trouble to thoroughly investigate the patient they are doing injury to by the insupportable diagnoses. You might wish to refer to my chapter on "The Complexities of Diagnosis," chapter 3 in The Handbook of Chronic Fatigue Syndrome. This book was published in 2003, edited by Jason, Fennell & Taylor, and published by John Wiley & Sons. The ISBN is 0-471-41512-X. My chapter also discusses the differences between ME and CFS, as well as some diagnostic investigations that should be considered.
[**Byron Hyde, MD, The Nightingale Research Foundation**, 121 Iona Street, Ottawa, Ontario, Canada, K1Y 3M1 Tel: (613) 722-5555 (answered Monday through Wednesday, 9 AM - 5 PM local time) Fax: (613) 729-0148 www.nightingale.ca]

Arbitrator at Financial Services Commission of Ontario Socks it to Accident Injury Management Clinic (AIM)

Mary Ellen, Manager of Special Projects

Many of our Ontario members, injured in a car accident, are required by legislation to attend medical examinations at Ontario's Designated Assessment Centres (DACs), facilities approved and overseen by the Financial Services Commission of Ontario (FSCO). The DAC Guidelines state that the purpose of a disability DAC is to offer an independent opinion that will assist the insured and insurer to resolve an existing dispute.

Also under the umbrella of the FSCO is the Arbitration Unit, a neutral evaluation system designed to mediate and arbitrate disputes over claims for the statutory accident benefits of many of our members. The Decisions of the FSCO Arbitration and Appeal Unit can be found at **www.fsco.gov.on.ca/** under Insurance - Dispute Resolution, passwords 'decisions' and 'subscription'.

Of interest to our members is the case of Rumak v Personal Insurance, FSCO A01-000065. The decision of November 2003 suggests that the efforts of the **National ME/FM Action Network** and its members may be having more of an effect on the system than we realized. It used to be that if an Arbitrator rejected the findings of the insurer's IMEs and/or a DAC, there were a few words of disapproval in a handful of cases with a page or two commenting on such problems with the DAC doctors as inflated credentials or offering opinions outside of a physician's specialty area. Many of our members have sent us copies of letters of complaint written to the Policy Unit of the FSCO about unfair and biased DACs and insurer- sponsored Third Party Assessments.

In Rumack v Personal Insurance, Arbitrator Joyce Miller takes a critical view of the Disability DAC assessment examination and report prepared by Accident Injury Management Clinic ("AIM") that Personal Insurance relied on as evidence. At pages 45 to 86 are Arbitrator Miller's comments about the quality of AIM's work product and she raises serious questions of credibility, competence and bias. Those concerns include failure to review a proper medical history and that the report had been modified 'substantially' by the DAC coordinator. Arbitrator Miller found that many of the reports (some unsigned by the physician) had little substance, were unreasonable or unreliable, and that the AIM DAC report was inherently flawed. Ultimately, Arbitrator Miller, after reviewing the totality of the evidence, decided that Personal Insurance had unreasonably withheld Mr. Rumack's income replacement benefits and she exercised the right of an Arbitrator's authority to raise a special monetary award on her own initiative. (In this case a special monetary award had not been sought by the plaintiff).

The FSCO's mandate is to enhance consumer confidence and public trust in the regulated sectors; and also to make recommendations to the Minister of Finance on matters affecting the regulated sectors. We urge our members who feel that they have been unfairly treated at one of Ontario's DAC centers to communicate their concerns to the Automobile Insurance Policy Unit at the Financial Services Commission or in the case of an IME to the governing college of the physician who performed the assessment. Our website contains this contact information under the heading “IME”. Please cc. National ME/FM Action Network and send us a copy of your correspondance. We must keep up the pressure to ensure that all third party medical assessments are truly "independent", objective and neutral evaluations based on sound medical science.

Please pass this information along regarding the Accident Injury Management Clinic Designated Assessment Centre (AIM), to your legal representative, union representative, etc. It could be important to someone who has attended at AIM or been evaluated by these physicians.

Health Lawsuit Tossed Out: Thursday, April 1, 2004 p. A5

Steve Buist, The Hamilton Spectator

AssessMed Inc. sued CBC, city doctor after auto injury broadcast

A Mississauga-based company that performs health assessments primarily for the insurance industry has lost a lengthy libel lawsuit it filed against the Canadian Broadcasting Corporation and a Hamilton neurologist.

AssessMed Inc., which also has a Hamilton office, sued the CBC and Dr. Michel Rathbone over a November 1998 broadcast of The Fifth Estate entitled Prove It If You Can.

The episode dealt with three auto accident victims who had suffered head injuries and then were subsequently denied benefits from their insurance companies.

Janet Hough of Caledonia, badly injured in a car accident on Highway 6 near Millgrove in June 1993, was one of the victims profiled.

According to three respected neurological and psychological experts who had been treating her, including Rathbone, Hough had suffered permanent brain damage in the accident.

Four years after the accident, Hough was ordered by the insurance company to attend a one-day assessment at AssessMed's Mississauga office, where she was examined by a psychologist named Dr. Hemendra Shah.

Shah's report concluded that Hough had not suffered any significant psychological impairment, that she could return to her pre-accident occupation and that she was consciously or unconsciously exaggerating the extent of her symptoms.

Armed with Shah's assessment, the insurance company discontinued Hough's benefits.

Fifth Estate host Linden MacIntyre opened the episode by stating that some insurers treat accident victims, "no matter how badly damaged, as a faker."

"They won't take your word for it," MacIntyre told the camera. "They won't take your doctor's word either."

"Instead, they probably send you to people whose hard-nosed attitude, right from the start is 'Prove it...if you can."

The broadcast described Dr. Jack Richman, AssessMed's chief medical officer and a director of the company, as one of the "doctors who play hardball for insurance companies."

On camera, Rathbone discussed the neuropsychological report that Shah prepared on Hough and said he found it to be "biased" and "clearly in error.

AssessMed, Richman and Shah objected to a number of statements made during the 20-minute episode.

But Superior Court Justice Paul Rivard essentially rejected every one of the plaintiffs' claims that they had been defamed by the broadcast.

"The comments based on facts referred to in the broadcast were themselves true," Rivard wrote in his 66-page decision.

"The comments were based on facts upon which a person could honestly hold the opinions expressed."

"On the evidence before me," Rivard wrote, "I cannot conclude there was spite, ill will, any indirect motive or ulterior purpose on the part of the CBC."

The CBC's only comment on the ruling was a one-sentence prepared statement.

"The CBC is gratified that the Superior Court of Ontario has found that the statements made in the Fifth Estate broadcast aired Nov. 10, 1998, were 'fair comment' and that the plaintiff's legal action against the CBC has been dismissed," Ruth-Ellen Soles, CBC's head of media relations, said in a statement.

The trial was heard on 76 days over a period of eight months last year.

The judge also said he was impressed with Rathbone's evidence and agreed with his statement that Shah's report was in error.

Rathbone declined to comment on the decision.

AssessMed did not respond to a request for comment. The company has not indicated if it intends to appeal Rivard's decision.

Shah also launched a libel lawsuit against The Hamilton Spectator following a June 2000 article to the Hough case.

He is seeking $2 million in damages. - sbuist@the spec.com

OOOPS – In our newsletter No. 62 we gave you the wrong email address for **Mr. John Wodak,** who is one of the advocates on **the National ME/FM Action Network's Roster and specializes in CPP and AISH**. Email address should have read **jwodak@techwcs.com** – Tel. **(780) 417-3574**

Independent Medical Examinations: Doctor Disciplined in PEI

The College of Physicians & Surgeons of Prince Edward Island has recently disciplined Dr. Rosemary Marchant of St. Catharines, Ontario, for practicing medicine without a license in PEI. Dr. Marchant's I.M.E. on Ms. Joan MacDonald was heavily relied upon by The Honourable Justice Gordon L. Campbell's Decision in favour of Sun Life.

The next hurdle is Ms MacDonald's Appeal in the Supreme Court of P.E.I., which follows from her losing her case against Sun Life. We will keep you advised.

[**Ed Note**: Joan MacDonald vs Sun life Assurance Company of Canada, in the Province of Prince Edward Island in the Supreme Court – Trial Division. Docket No. GSC-18128]

Junk Science and Unreliable Experts: "The Daubert Principle"

Norm Cuddy LL.B

Until recently, the law with respect to expert witnesses was that the evidence need only be relevant, necessary to determine the case and be given by a properly qualified expert(1). This rule has meant in effect that any person who styled themselves as an expert who had some modicum of credentials was usually allowed to testify at a trial.

This resulted in an alarming number of expert witnesses closely connected with the insurance companies giving evidence on any number of issues such as life expectancy, timing of the injury, diagnostic criteria, etc., when many of these experts were not, in fact, considered experts by their peers and their methodology was not generally accepted by the medical community.

In 1993, The Supreme Court of the United States decided ***Daubert v. Merill Dow****(2)*. Merill Dow was the manufacturer of a drug that had been prescribed for morning sickness to approximately 17.5 million pregnant women in the United States between 1957 and 1982. The Plaintiffs proposed to call experts in the field that were not recognized or proven, and were termed to be by many "junk science". The United

States Supreme Court, in a landmark ruling, determined that the Court had a gatekeeper role to reject scientific evidence that was not "reliable and fit".

This decision has found its way into Canadian law and has been accepted by The Supreme Court of Canada(3). In a Criminal case, the defence was attempting to call an expert in penile plethysmography. In this form of testing, wires were attached to the penis of a person while he was shown deviant photographs.

The Court rejected this evidence, relying on ***Daubert***. The Court commented on the risk of undue weight being given to evidence cloaked under the mystique of science.

The Daubert principle has not been restricted to simply "junk science". In England, a parallel line of cases has developed stating that not only must the evidence be reliable, but the expert who gives the evidence must be independent(4). This reasoning has been adopted in Canada(5). In ***Fellows McNeill***, a lawyer who had previously acted for one of the parties attempted to testify as an expert witness at the trial. The Court rejected his evidence, stating that the lawyer was nothing more than an advocate dressed up as a witness.

This new line of cases has great significance to disability claims. It is all too often that an expert who is to be called by the insurance company claims to be independent, but in reality, only makes a very small proportion of his income in clinical practice and earns the vast majority of his income from the very insurance company for which he proposes to testify. Likewise, insurers often call their own in-house physicians to provide an opinion as to whether a Plaintiff is totally disabled within the meaning of the policy.

Adopting what our Supreme Court of Canada has said, this is really no different than having the insurance company put an employee on the stand and propose to give "an independent expert opinion" as to the merits of the case.

Now that the law is firmly established that such evidence may be excluded because of the "gatekeeper role of the Courts", most trials in which such evidence is proposed are the subject of "Daubert voir dires", and in many instances, the evidence of proposed experts is being rejected by the Courts without it ever being heard.

(1) *Regina v. Mohan*, [1994] 89 C.C.C. (3d) 402 (S.C.C.)
(2) D*aubert v. Merill Dow* (1993), 113 S. Ct. 2786 (U.S. S.Ct.)
(3) *R. v. J.L.J.* (2000), S.C.C., File No. 26830
(4) *The Ikarian Reefer*, [1993] 2 L.L.R. 68
(5) *Fellowes McNeil v. Kansa General International Insurance Company* (1998) 40 O.R. (3d) 456

[**NORM CUDDY of TAPPER CUDDY**, Barristers & Solicitors, 1000 - 330 St. Mary Ave., Winnipeg, MB R3C 3Z5 Tel. (204) 944-3253 - Fax (204) 947-2593 – E-mail: Mac@tcwpg.com
Web: www.tcwpg.com **Ed. Note**: Mr. Cuddy Practices with Tapper Cuddy in Winnipeg, MB. and as a "Visiting Lawyer" in British Columbia and Alberta. Mr. Cuddy is on our National Lawyers' Roster]

Chronic Pain, Chronic Fatigue and Fibromyalgia: Live Broadcast

DATE: MAY 18, 2004 TIME: 9:00 a.m. to 4:00 p.m. COST: $275.00 plus taxes
Chairs: High R. Scher, Scher & De Angelis Professional Corporation
Jeffrey P. Loudon, Assistant Vice-President & Senior Counsel Sun Life Assurance Company of Canada.

The Law Society of Upper Canada's "Chronic Pain, Chronic Fatigue and Fibromyalgia" program brings together leading lawyers and medical experts to explore the unique challenges associated with litigating and defending pain-related claims. You will learn about how these conditions impact on function, employability and long-term care needs.

If you represent clients before the courts in tort actions, insurance claims for long-term disability, wrongful dismissal, or before administrative tribunals in relation to accident benefits, Canada Pension Plan disability, Worker's Compensation, the Ontario Disability Support Plan or Human Rights matters, this program is for you.

You can enjoy the program right from the comfort and convenience of your own office, via live webcast through **www.bar-ex.com** Written materials are included in electronic (PDF) format for downloading, printing and/or searching. You will also have access to the archived version for three months – so you can review the program at your own leisure. The webcast interactivity enables participants to submit questions online. Be sure to circle May 18, 2004 on your calendar.

For more information and to register, please call **1-877-462-2739**, or email **Michael.tait@bar-ex-com**

Personal Information Protection and Electronic Documents Act (PIPEDA)

Odile Gérin, Director of Public Relations

What is the "*Personal Information Protection and Electronic Documents Act"* (PIPEDA)?

On January 1, 2004, the PIPEDA, which is legislation for the protection of personal information including health information, came into effect. It sets out ten principles that organizations, individuals, associations, partnerships and trade unions must follow when collecting, using and disclosing personal information in the course of a commercial activity.

The Act does not apply to personal information in Provinces and Territories that have substantially similar privacy legislation in place covering commercial activities that are provincially/territorially regulated, except for personal information sent outside of the province and to organizations currently subject to the Act.

Health Information Privacy

Privacy is a right underpinning health care in Canada. Such a right has been addressed in codes of ethics, legislation, practice standards, policies, and procedures. A person must understand what they are consenting to and be informed of their privacy rights including:

- What information is being gathered about them
- How that information will be used
- With whom the information will be disclosed
- The patient's right to seek access and corrections to their health record, and
- The patient's right to complain about the organization's personal information practices

What is your "personal information"?

In addition to information needed to identify you, such as your name, address, telephone number and health insurance number, your personal information also includes information about your health. Personal health information relates to health services you have received, past health conditions, current symptoms, medications prescribed, examination and test results, diagnoses, and treatment plans. This information is often referred to as your health record. Knowing what is in your health record and understanding how your personal information is used, helps you to ensure its accuracy, better understand who, what, where, why and how others may access your personal health information; and, make informed decisions regarding disclosures to others.

What you can expect from your health care provider?

- Any personal information collected will be used for your care and treatment.
- Your consent will be implied for the collection use and disclosure of your personal information for care and treatment purposes if, once you know your personal information protection rights, you continue with care and treatment.
- Your personal information will not be disclosed to anyone who is not directly involved in your care and treatment unless you give permission. Those involved in your direct care may include nurses,

other doctors, pharmacists, laboratory technicians, radiologists, dentists, psychologists, social workers, physiotherapists, nutritionists and other health care providers.

- Some of your personal information may also be disclosed without your permission to governments (Ministries of Health and others) where this is required or authorized by the law.
- A high level of confidentiality around the collection, use and disclosure of your personal information is maintained. You are assured that your personal information is handled appropriately and with care.
- Your personal information should be accurate and will be stored in a secure location.
- Any personal information that is stored electronically will be protected by appropriate security measures.
- Your health care provider will be available to respond to your questions.

What are your rights?

- Your personal information protection rights include knowing why your personal information is collected, and how it is used and to whom it is disclosed
- The right to request access to your personal information and to be provided with a copy of that information for a minimal fee.
- To ask how and to whom your personal information may have been disclosed.
- Assurances that your personal information is protected regardless of the format in which it is held (e.g. paper/electronic).
- Assurances that your personal information is safeguarded from unauthorized access, disclosure, copying, use or modification.
- The right to question the accuracy and completeness of your personal information and the right to seek amendment to that information.
- You have a right to complain. Your health care provider can advise you about complaint procedures and will refer you to the appropriate authorities.

For more details on PIPEDA, see Industry Canada's web site at: http://strategis.ic.gc.ca/private/health

Source: Health Canada Website: www.hc-sc.gc.ca; Health Canada's brochure: "*Protecting the Privacy of your Personal Health Information*".

Provigil Problems?

Dr. Bruno of The Fatigue Management Programs and Post-Polio Institute at Englewood Hospital in New Jersey has had several patients who were given Provigil by their family doctor and who have had disturbing side effects. They became excited and agitated after starting Provigil. Then they became depressed. When the local doctor stopped Provigil, they became more depressed, even suicidal.

Dr. Bruno would appreciate hearing from doctors whose patients are taking Provigil about its effects (good or bad) and side-effects. He would also like to know the dosage and what other medications are being taken along with Provigil, including antidepressants. Please contact Dr. Bruno at Toll Free: 1-877-POST-POLIO email: PPSENG@aol.com or fax: (201) 894-0324

Fibromyalgia Association Niagara Invites You to Attend Our Information Seminar
DATE: Wednesday, May 26th, 2004. TIME: 7:30 – 9:30 pm.
LOCATION: QUALITY INN PARKWAY ,327 ONTARIO STREET, ST. CATHARINES, **FREE PARKING MEMBERS: NO CHARGE – NON MEMBERS: $5.00, WHEELCHAIR ACCESSIBLE, NO RESERVATION REQUIRED**
An Evening Of Information and Question Period With:
Dr. Tim Prince M.D. (family physician),Stephen Tripodi (naturopath),Sandra Stavropoulos (registered massage therapist),Margaret Deane R.N. (chronic pain therapist),Pharmacist.For further information contact: Pat Hopkins (905) 374-1263

IME/FAE REGISTRY SUBMISSIONS

The **National ME/FM Action Network** continues to urge those who have attended an Independent Medical Examination (IME), Functional Abilities Evaluation (FAE) or any other form of assessment at the request of an insurance company, Canada Pension Plan (CPP) or Workplace Safety & Insurance Board (WSIB) to fill out our 7-question, confidential, independent medical examination Registry Submission Form so that the names of the doctors and healthcare professionals who evaluated you can be put on record. Cc. National ME/FM Action Network on any letter of complaint that you send to a regulatory body.

Patients, doctors, lawyers, advocates, support groups wishing to receive a copy or copies of the Form, or to inquire about specific IME doctors, please contact: **Mary Ellen, Manager Special Projects, Mail: P.O. Box 66172, Town Centre Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7 –** Phone or Fax: **(905) 831-4744** – Email: **marye@pathcom.com –** Or download the Form from our website at **www.mefmaction.net/medexac.html.**

OUR WORLD

HUMOUR: DESPAIR IN PERSPECTIVE

Thanks to Lorraine Legendre, Ottawa.

RESOURCE BOOKS:

Fibromyalgia Syndrome: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols. A Consensus Document*. Journal of Musculoskeletal Pain* **11(4), 2004** will also be available as a soft cover book entitled **The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners, *Haworth Press*, 2004.** The journal is only available to subscribers. The book will be available through The Haworth Press, Inc. To order, contact The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580 USA. Telephone in US/Canada: (800) 429-6784, Telephone outside US/Canada: (607) 722-5857, fax: (607) 771-0012, email: orders@haworthpressinc.com
Online: **http://www.haworthpress.com/store/product.asp**?

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols (Journal of Chronic Fatigue Syndrome, Volume 11, Number 1, 2003) is available for **U.S. $14.95** per copy plus $5.00 Shipping and Handling. To order, contact **The Haworth Press, Inc.,** 10 Alice Street, Binghamton, NY 13904-1580 USA**.** Telephone in US/Canada: **(800) 429-6784,** Telephone outside **US/Canada: (607) 722-5857, fax: (607) 771-0012,** email:**orders@haworthpressinc.com**
Online: http://www.haworthpressinc.com/store/product.asp?sku=4958

Prices below include Shipping and Handling. Cheques Payable to the National ME/FM Action Network or you may pay by VISA or MasterCard.

QUEST COLLECTION" BOOK - FIVE YEARS (1993 TO 1998) : 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 of medical, legal and advocacy. **Cost: $20.00**.

QUEST Collection II: **1999 to 2003: Will be available shortly.** Cost: **$30.00.**

TEACH-ME - Sourcebook for Teachers: An educational resource book full of information and teaching strategies for teachers and parents of children and youth who have ME/CFS and/or FMS – Cost: **$22.00** Discount on bulk orders. Please also see our youth and parents' pages on our website at: **www.mefmaction.net**

NEW: NOW AVAILABLE FOR PURCHASE: The Canada Pension Plan Disability Benefits Guidelines: New up-dated guidelines have been designed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. Understand the criteria, important items to include and how to proceed through the various steps of the process. **– Cost $7.00**

Legal Disability Manual: Extensive revisions, updating, and new articles have been added to the new Legal Disability Manual. Sections include: FMS and ME/CFS Overview; The Medical Report and Expert Witnesses; Independent Medical Examinations; CPP Disability Benefits, Disability Insurance and Other Legal Articles; Case Law; Psychological Factors, Tests, and Treatments; and Research Abstracts. Many of the articles have been written specifically for the **National ME/FM Action Network** by lawyers and doctors. Our new Canada Pension Plan Disability Benefits Guidelines are also included in the Legal Disability Manual. This manual is a must for those in litigation. AVAILABLE FOR PURCHASE SOON **– Cost $50.00**

MEMBERSHIP: **$25.00 per year which includes bimonthly newsletters**. Payment can be made by **CHEQUE, VISA or MASTERCARD to NATIONAL ME/FM ACTION NETWORK, 3836 Carling Ave., Nepean, ON K2K 2Y6 Canada**
Tel/Fax: (613) 829-6667 E-mail: ag922@ncf.ca Web: http://www.mefmaction.net

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.