NATIONAL ME / FM ACTION NETWORK

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The Guidelines Advisory Committee of the Advisory Committee of the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care Reviews the ME/CFS Consensus Document

Alison Bested, MD, FRCP(C), who was a member of the Expert Consensus Panel for the ME/CFS Consensus Document; and a representative of The Myalgic Encephalomyelitis Association of Ontario, met with Dr. David McCutcheon, Assistant Deputy Minister, Health Services Division, Ministry of Health and Long-Term Care for Ontario to discuss whether the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care would review the ME/CFS Consensus Document. Dr. McCutcheon agreed to have the Guidelines Advisory Committee of the Ontario Medical Association and Ontario Ministry of Health and Long Term Care evaluate the ME/CFS Consensus Document.

We are pleased to report that the **Guidelines Advisory Committee of the Ontario Medical Association** and the **Ontario Ministry of Health and Long Term Care** gave "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols", *Journal of Chronic Fatigue Syndrome* 11(1):7-116, 2003 a three out of four-apple rating. In a letter from the Guidelines Advisory Committee, the chairman reported, "Three apples denote a very good guideline". Dr. Davis continued, **"three-apple guidelines are well produced and useful for practicing clinicians"**. The chairman added, "We hope that this information proves useful as you deliberate on how to ensure the early diagnosis and medical care of patients with chronic fatigue syndrome."

The **Myalgic Encephalomyelitis Association of Ontario** sent their congratulations to the **National ME/FM Action Network**, in particular, to **Lydia Neilson** for initiating this project, and to **Marjorie van de Sande** for her hard work coordinating the project and compiling the document. Both Myalgic Encephalomyelitis Association of Ontario and the **National ME/FM Action Network** would like to extend a special thank you to **Dr. Bruce Carruthers and Dr. Anil Jain**, who wrote the original draft document, and to all the physicians and researchers who were members of the Expert Consensus Panel for the ME/CFS Consensus Document, for generously donating their time and expertise to establishing the first clinical definition and guidelines for ME/CFS.

Please note that when you are discussing the ME/CFS Consensus Document with your physician, it is important to tell your physician that the Guidelines Advisory Committee of the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care favourably reviewed the consensus document, "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols". *Journal of Chronic Fatigue Syndrome*, 11(1):7-116, 2003.

The **National ME/FM Action Network** would like to give four well polished apples to Dr. Allison Bested and the Myalgic Encephalomyelitis Association of Ontario for their initiative and the work they did in getting the ME/CFS Consensus Document evaluated by the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. *Journal of Chronic Fatigue Syndrome*, Volume 11(1):7-116, 2003 is available, at a cost of US$14.95 plus a US$5.00 shipping and handling charge, from The Haworth Press Delivery Service: 1-800-429-6784, fax (607) 771-0012, e-mail: order@haworthpressinc.com. Web: http://www.haworthpressinc.com/store/product.asp:sku=4958
[Note: The Myalgic Encephalomyelitis Association of Ontario can be reached at P.O. Box 84522, 2336 Bloor St. West, Toronto, ON M8S 4A7. Phone (416) 222-8820 or 1-877-632-6682. Web: www.meao-cfs.on.ca]

United Kingdom is Grateful for Canadian ME/CFS Consensus Document

"…The ME/CFS community in Britain found the Clinical Working Case Definition, Diagnostic and Treatment Protocols developed by your team in March 2003 to be a huge step towards excellence in care of ME/CFS sufferers, and have been endeavouring to promote these protocols in the U.K., wherever possible. So, firstly I would like to thank you and your team for this outstanding work…" From Angela Kennedy, who is a caregiver for a teenager with ME/CFS and also a lecturer and researcher in the social sciences in the U.K.

Gender Differences Make Females More Prone to Fibromyalgia Syndrome (FMS) and Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Than Males

Marjorie van de Sande, B Ed, Grad Dip Ed,
Director of Education

All too often it is snidely implied that the higher prevalence of FMS and ME/CFS in females is somehow due to women being "the weaker sex", unable to cope with the stress of their daily lives, so they make up physical symptoms to explain this. While the understanding of all the mechanisms is incomplete, a few fundamental physiological, gender differences can help explain why females are more prone to FMS and ME/CFS. Some of these gender differences may apply more to the development of symptoms of FMS while others apply more to the symptoms of ME/CFS.

Differences in Structure: An obvious gender difference is males have a denser bony structure. Females have a more delicate bony structure, longer necks, and a smaller head circumference making them more prone to whiplash injury, as greater head acceleration occurs.(1) The pelvis of a male is a denser structure, while the female pelvis is more delicate and has a different shape to reflect the female role in childbirth. The female pubic and sacroiliac joints and their ligaments are stretched during pregnancy and childbirth.(2) This stretching can cause these joints to become less stable and more prone to lower back injuries. Failure of the joints and other supportive structures can inhibit the time a person can stand and cause pain and the structural fatigue experienced by FMS patients.(3)

Differences in Muscles and Ligaments: For those who are involved in a motor vehicle accident, particularly a whiplash injury, gender differences make females more prone to developing FMS. In addition to the denser male skeleton, their larger and stronger neck muscles help protect males from whiplash injuries. Females, who have thinner, less massive and more delicate neck muscles, longer necks, and tend to be more flexible, are more prone to whiplash injuries as they are likely to experience a greater degree of extension and flexion of the neck. Ligaments are easily injured when they are over-stretched. Over-stretched and/or injured ligaments can remain over-stretched and not heal completely as they have a poor supply of blood, particularly where they attach to the bone.(3) Lax ligaments do not hold vertebrae and joints in place properly, which result in abnormal movement of vertebrae or joints. When the ligaments are not able to do their job of protecting and breaking joint movement, muscles around the vertebrae or joints tend to react by contracting in order to help stabilize the vertebrae or joints and protect them from further injury. Lax ligaments can result in joints being hypermobile (they move beyond the normal range), or restricted (due to contracted muscles). Subluxation (partial dislocation) of the vertebra or other joints may occur and irritate or compress nerves causing pain. The hypertonic (tight) muscles squeeze their small blood vessels and increase pain and fatigue.(2) The constant pull of contracted muscles and their hypersensitivity to pain can lead to the development of FMS.(3)

Differences in the Spinal Canal: Females generally have a narrower spinal canal than males.(4) The study by Pettersson et al,(4) showed that patients who had persistent whiplash injury symptoms had a significantly narrower cervical (neck) spinal canal, particularly females. A subluxation of a vertebra is more likely to compress the spinal cord in the narrower spinal canal of females.

Differences in Pain Threshold: Females have a lower pain threshold (the point when a stimulus is perceived as painful) than males.(5) A study of the processing of thermal pain in healthy females and males indicated that females had a lower pain threshold and tolerance, and increased pain over time.(6) Pain-related muscle reflexes, pupil dilation, and brain responses to painful stimuli are more intense in females.

Neuroradiologists did a positron emission tomography (PET) scan study(7) of the brain to determine the gender difference in the synthesis and metabolism of serotonin, which is produced from tryptophan, by the central nervous system of healthy adults. They found that the conversion rate of tryptophan to methyl-5-hydroxyindole acetic acid was approximately seven times lower in females than males. This provides a logical explanation of why females have less anti-pain capacity and are more sensitive to painful stimuli than males since there is an inverse relationship between the concentrations of serotonin and substance P (which increases pain sensations) in the spinal cord.(3) Another dramatic finding was that when endogenous (inside the central nervous system) tryptophan was depleted, there was a 7-fold drop in serotonin synthesis in men but a remarkable 42-fold drop in serotonin synthesis in women.(7)

Zubieta et al(8) evaluated brain PET scans and μ-opiod receptor-selective radio tracers to determine if there was a difference in opioid response to a standardized painful stimulus in healthy males and females at the same part of their hormonal menstrual cycle. Males showed a greater activation of the μ-opioid system in a number of regions of the brain associated with this pain and stress suppressing system (anterior thalamus, ventral collidum/substrantia, Innominata, nucleus accumbens, and amygdala). On the other hand, females exposed to the same painful stimulus only showed activation of the ventral pallidum/substantia. Unlike the males, two-thirds of the females showed an actual decrease in the activation of the nucleus accumbens, thus, suggesting a decreased ability of this pain inhibiting system to block pain and resulting in females having a higher sensitivity to pain. Both the direction and magnitude of the brain’s response to pain differs in males and females with the females being more sensitive to pain.(8)

Differences in the Blood Volume: Females have a smaller heart and lower blood volume than males. Men have approximately 79 milliliters of blood volume per kilogram of body weight compared to 65 millilitres per kilogram for women.(9) Eg. A 150 pound woman would have approximately 4875 millilitres of blood volume compared to 5925 milliliters for a man of the same weight – a difference of 18%. In addition women lose approximately 50 to 150 millilitres of blood during each menstrual cycle.(10) The capacity to produce red blood cells is also approximately 20% less in females than males.(9)

These biological differences can make women more prone to ME/CFS and FMS for a number of reasons:
One of the roles of red blood cells is to carry oxygen from the lungs to the tissues. The oxygen is bound to iron-containing hemoglobin in the red blood cells. As females have less blood and less ability to produce red blood cells, they have a lower capacity to deliver the oxygen and nutrients necessary for the production of energy in the cells. This is further exacerbated by the loss of blood and iron during menstrual cycles. Inability to deliver an adequate supply of oxygen to the tissues results in oxygenation fatigue, and may play an important role in the development of ME/CFS and FMS.

If females are exposed to virus, other pathogens, or toxins, these will reach the critical level more quickly than in males, as the same number of pathogens or quantity of toxins are more concentrated in the lesser blood volume of females. Many pathogens cannot live in an oxygen-rich environment; thus the oxygen-reduced blood may encourage growth and replication of pathogens. Post-exertional malaise and fatigue may also be a sign of immune system activation.(11)
As the blood delivers oxygen to the tissues, it picks up carbon dioxide, other metabolic waste, and toxins to eliminate on its return to the heart. Thus, females have less blood volume to cope with pathogens and toxins. Streeten et al(12) found that 93.8% of female ME/CFS patients had significantly reduced red blood cell mass, 52.6% of patients had subnormal plasma volume, and 63% had subnormal total blood volume. Beyond these gender differences, another study(13) suggested that ME/CFS patients only had an average of 70% (and as low as 50%) of their red mass actually circulating.

SPECT scan(14,15) and PET scan(16) analysis indicated that there is a significantly reduced regional blood flow in ME/CFS and FMS patients. The reduced regional blood flow to the brain was found to correlate with pain perception.(15) As females have less blood volume, any reduction in blood flow may result in more pronounced effects.

A John Hopkins University study(17) suggested that approximately 95% of ME/CFS patients experience neurally mediated hypotension, which is also common in FMS patients.(18) There is a drop in blood pressure when the patient stands up or stands motionless causing symptoms of dizziness, weakness, and an urgency to lie down. It is thought that the low resting blood volume and pooling of blood in the extremities play a role in the neurally mediated hypotension, fatigue and post exertional malaise experienced by ME/CFS and FMS patients.(13) The reduced regional blood flow in the brain may also be a contributing factor to orthostatic intolerance. Again, these effects may be more detrimental in a female who has a lesser blood supply.

Differences in Hormones: Although little study has been done in this area, it has been speculated that gender differences in hormones also play in the development of FMS as the painful symptoms worsen during the last few days of the female's menstrual cycle.(19) During this time progesterone and other hormone levels are high. There is also a significant drop in the level of the opioid peptide nociceptin, which helps control pain, at this stage of the menstrual cycle.(20) The rate of serotonin synthesis in the brain, and estrogen are related to gender differences.(3)

Given these physiological differences between females and males, is it any wonder that females are at greater risk of developing FMS and ME/CFS?

[Bruce M. Carruthers, MD, CM, FRCP(C), *kindly reviewed this article for medical accuracy.]*

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The following article appeared in Communications #32, month of October/November 1998 issue of Quest. We reprint it now because the National ME/FM Action Network is working hard to convince governments to implement this method of conducting fair I.M.E.s. Please help us put pressure on the appropriate government body in your province by writing personal letters. Please consider also sending a copy of the article on next page. Always place c.c. National ME/FM Action Network at the bottom of your letter and mail us a copy. It is important for the government bodies to know that we are tracking their responses to your letters.

Making "Independent Medical Exams" Independent

George V. Rossie, Ph.D., Clinical & Consulting Psychologist
R. Daun Gretzinger - IME Administrators, LLC, Denver, Colorado, U.S.A.

Many insurance claimants complain, perhaps with good reason, that the "Independent Medical Examination" (IMEs) upon which their insurers rely to determine benefits are unfair. Insurance company adjusters typically send claimants to medical examiners who can be counted on to issue reports favorable to the insurer's position. Doctors who routinely side with the company can expect to have an unlimited supply of referrals and can expect an appreciable income flow from their efforts.

In Colorado, the practice of certain insurance companies using just a handful of notoriously biased doctors to perform IMEs in auto accident cases became so predictable that those doctors became known by the not-so-affectionate name, "the 'A' Team." Generally, an "A Team" report did not have to be read for one to know its contents and conclusions precisely. For example, one of the members of the "team", a psychiatrist who also sat on the board of directors of a major insurance company, performed over 200 consecutive auto IMEs in a several-year period, without ever finding a single case of emotional or intellectual problem that he could attribute to the motor vehicle accident. The vast majority of patients were labeled "malingerers", and the rest had "pre-existing psychiatric disorders." In at least one case, this included a young man who had crashed his motorcycle into the side of a truck and lay in a coma for two weeks.

Fed up with such abuse, a grass-roots effort to change the way IMEs in Colorado were conducted for auto accidents sprang to life in 1996. The initial driving force behind the effort was a legislative aide to a state senator who had been in an auto accident, and then "re-victimized" when her insurer sent her for IMEs that determined that she was no longer in need of treatment, despite being unable to resume her legislative duties. With the help of several of her therapists, and with the support of the senator, legislation was drafted and introduced into the state legislature which essentially would have prohibited insurance companies from using IMEs at all to determine benefits in auto cases. Prior to the bill's introduction, the therapists had contacted every other treating provider they knew, encouraging them to write or call their own representatives in support of the measure, and also asking them to alert other professionals and victims of IMEs of the effort and the process. The insurance industry's initial attempts to kill the bill were blocked because by that time legislators from all over the state had been barraged by doctors and patients who wrote or called expressing their support for the need of reform, and the bill was allowed to proceed to the committee stage, where public hearings were scheduled. Now, the organizing therapists began enlisting auto accident patients to show up for the hearings to tell their stories of how they had been treated by their insurers. The response was overwhelming, to the point that one critical hearing had to be moved out of the normally used hearing room into an assembly hall to accommodate the huge crowd. Faced with this massive show of opposition, the insurance industry dropped its outright resistance and agreed to work on compromise legislation which they agreed would "dispel the misperception that the IME process was biased."

The resulting legislation, Senate Bill 96-78, made several important changes to Colorado's No-Fault law. First, a new program was created under the direction of the state insurance commissioner which provides the exclusive mechanism in this state for resolving disputes over the reasonableness, necessity, and relatedness of treatment following motor vehicle accidents. The program (the Personal Injury Protection or 'PIP' Examination Program) makes available a group of licensed health care providers, experienced in the treatment of MVA issues and actively engaged in clinical practice, who have not earned more than half their income or spent more than half their professional time performing IMEs, to examine patients when a dispute with the insurance company arises. A list of five qualified practitioners in the same specialty as the treating doctor whose opinion or bills are disputed is the same specialty as the treating doctor whose opinion or bills are disputed is prepared and within five days of the request, sent to the party disputing the claim (usually the insurance company, but maybe the patient in the case that there was a dispute over an earlier IME). If neither side can agree on one person from the list to conduct the exam, the insurer and the patient each strike two names, and the remaining practitioner performs the exam. The examiner is required to address in a written report the issues in dispute, and the insurer is required to pay the benefits if the examiner agrees with the previous treatment rendered or medical conclusions of the treating doctor. If either party is dissatisfied with the findings, that party may request and pay for a second IME under the same procedures of selection. In this case, the conclusion of two out of the three practitioners (the two examiners and the treating provider) is binding. The examiner must physically examine the patient and review the records, which must be supplied by the insurance company. The patient may augment the records as necessary. The requesting party is obligated to pay the examiner's fees. The whole process is designed to be completed within 45 days of when the insurer initially disputes the claim.

The legislation also allowed the Insurance Commissioner to contract with an outside source to create and run the program. Through the normal state bidding process, IME Administrators, LLC, contracted with the Division of Insurance to administer the program, create the provider registry, process the requests, establish the reporting standards, train the panelists, and prepare the lists of five examiners. To accomplish this, IME Administrators first recruited over 1400 providers in approximately twenty-five specialties, including chiropractors, psysiatrists, orthopedists, surgeons, psychologists, dentists, optometrists, and others, from throughout the state to serve on the panel. A detailed list of biographical and practice information was gathered from each provider, and this data was entered into an automated database which was developed to generate the list of five providers from the county in which the patient resides, in the same specialty as the treating doctor whose care was disputed. The database automatically produces a "dossier" on each of the five candidates, incorporating the extensive educational, business, and personal information already supplied by each recruit, and that information is sent on to the insurer and the patient, to aid them in making the appropriate selection of the best candidate to perform the exam. The automated database "revolves through" all available blocks of five members of the specialty within each county, then randomizes the names and creates new blocks of five, as the demand for exams dictate, so that the same five examiners are not always paired against each other. IME Administrators monitors the flow of the examination process and tabulates the outcome of the exams in terms of conclusions, costs, and time to completion. The proprietary automated database then produces summary reports regarding the utilization of the program.

The PIP Examination Program went into operation on January 1, 1997. By June 30, 1998, over 4600 requests for IMEs had been processed. Approximately 75% of the IMEs completed to that point indicated that the prior treatment rendered or the medical conclusions of the treating provider were reasonable, necessary, and accident related. Approximately 20% found that the care was only partly reasonable, necessary, or accident related, and generally in those cases an apportionment was made. Five percent found that the care was not reasonable, not necessary, or not related to the accident. At the present time, more detailed data analysis is not generally available.

For the most part, the response to the program from patients, attorneys, and treating doctors has been overwhelmingly positive. Insurance company response has been less enthusiastic, but still positive. Major complaints center around their opposition to the "same specialty" review requirement, especially when chiropractors are involved. Most insurers strongly favor allowing M.D.'s, especially psysiatrists and orthopedists, to review any treating doctor's work, regardless of the specialty. Obviously, the other independently licensed practitioners oppose this type of oversight. Also, there have been some complaints of overcharging for the exams, and some unsuccessful efforts to establish a uniform fee for IMEs. Finally, some conflicts have surfaced when the patient has multiple providers from various specialties, and the insurer or the patient doesn't want to pay for or undergo multiple IMEs. Despite this, there is broad consensus that the process is an inherently fair one, and the frequency of suits alleging bad faith breach of contract is reportedly down in the state. To date, there has been virtually no "second guessing" of the IME by patients or attorneys, who could demand a second exam when the results are not in accord with the treating provider's opinion, and almost no cases in which the patient has failed to cooperate with the examiner. Fears that examiners would abuse their discretion by "retaliating" against insurance companies have not been borne out. It would appear that many treating doctors have become more conscientious in their record keeping and their treatment planning, knowing that their work may be evaluated by a competent peer.

IME Administrators, LLC, believes that the process it has created could be successfully exported to many other geopolitical settings and could be applied to any situation in which an insurer requires an independent medical exam, including worker compensation injuries, general medical conditions, or disability cases. The principal rate-limiting factor in its application to other conditions is strictly political. It appears that the process, the technology, and the philosophy for providing truly "independent" IMEs now exist.

(The authors are available for training and consultation, and can be contacted at 4200 West Conejos Place, Suite 111, Denver, Colorado, 80204; tel 303-893-9300 or 303-628-9338; fax 303-893-4384; e-mail gvross19@idt.net)

Troublesome New Legislation for Victims of Car Accidents

James Ludwar, LL.B.

[Ed. Note: Insurance companies and governments in the rest of Canada are watching the response.]

In an attempt to provide drivers with fair and reasonable rates, the Government of Alberta has introduced legislation designed to lower the rates for the majority of Alberta motorists. As such, the Government has brought forth Bill 53, The Insurance Amendment Act, 2003 (No.2).

The Act is designed to address a number of issues but the most contentious amendment is to limit the pain and suffering awards for "minor injuries". This would set a limit for injuries that fall within the "minor" category. We know that the limit will be $4,000.00, unfortunately, we do not know the definition of a minor injury because the actual legislation does not provide that information.

The Act simply provides the framework for insurance reform however the actual details are found in the Regulations. By keeping the Act very generic and not providing details, the Government can minimize the opposition to limiting awards for pain and suffering (all proposed legislation must be reviewed and debated in the legislature). However, with regulations, all details can be passed behind closed doors by an "Order in Council". Essentially, this allows the Government to flesh out the Act with regulations it feels are appropriate without the uncomfortable glare of the opposition or the media and public.

The Klein Government has formed a committee to workout the definition of a "minor" injury. It appears "no permanent injury" and "18 months" may be in the regulations. This means that if you were to have a car accident, be bed-ridden for 17 months (or even in a coma) and then have a full recovery, your entitlement to pain and suffering compensation is capped at $4,000. But again, until we have access to the regulations, we simply do not know for sure.

What we do know is that according to polls, the vast majority of Albertans do not want caps on pain and suffering; we do know that the insurance industry is on target to reap record profits (and this is still under the present system *without* caps). We also know that Rob Renner, the MLA who is in charge of coming up with the insurance reform package, essentially guaranteed that 80% of Albertans will see reductions in auto-insurance rates and that no Albertan will pay more under the new insurance regime. However, when the Government put up a website allowing motorists to find out what they would pay under the new system, many were shocked to find that their rates were actually *increasing*. Not surprisingly, the Government quickly removed that website.

At this time, we do not have enough information to speak with complete accuracy on the details of the insurance reform legislation, but based on what we do know, the victims of car accidents will end up with less compensation. And that raises the question, who will pocket the savings?

** Please note that the above statistics were obtained from www.albertainsurancedebate.com . This website is dedicated to the issue of insurance reform and gathers information from media, government and researchers. I urge you to visit this website and become informed on what the various stakeholders and others are saying about insurance reform. Review the material and form your own opinion. **

[Ed. Note: Mr. Ludwar of Bayda Ludwar Law Firm, Calgary, AB, Tel. (403) 670-0055, is on our National Lawyers' Roster]

National ME/FM Action Network Responds to Alberta's New Legislation

Letter sent to Honourable Greg Melchin , #29, 735 Ranchlands Blvd.
N.W.,Calgary, AB T3G 3A9 - December 12, 2003

Pursuant to our telephone conversation, I am writing you on behalf of the National ME/FM Action Network, which is a Canadian, registered, non-profit organization dedicated to advancing the recognition and understanding of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS) through education, advocacy, support, and research. Our bimonthly newsletter "QUEST" goes out to individuals including doctors and lawyers experienced in ME/CFS and FMS, as well as over 450 support groups across Canada.

Our organization has serious concerns regarding the new regulations being established in Alberta for motor vehicle accident claims, including the $4,000 limit for pain and suffering for "minor" injury, the criteria for establishing what will be included in "minor injuries", appropriate protocols, and the use of independent medical examinations.

It is my understanding that the original time period recommended for the limit for pain and suffering for "minor" injuries was four months, which is reasonable. However, it has since been reported in the news that the government is considering extending this time period beyond 18 months. How can pain and suffering that last 18 months or more, be considered minor? In cases where insurance companies dispute the accident claim of up to the ceiling of $4,000.00 for "minor injuries", the accident victim will be discouraged from pursuing the matter in court because the prohibitive legal costs would never be recovered.

A major concern is how "minor" injuries will be determined. To set criteria to establish what will be considered a "minor" injury is domed to failure. Dr. Thomas Romano, Diplomate and President of the Board of Directors of the American Academy of Pain Management, cites Dr. Stephen Gould, a famed biologist and geologist, who maintains "that if one wishes to describe a complex biological system using measures of tendency such as averages or means, he or she will be wrong".(1) The human body is a complex biophysiological system, so there is no typical patient and no typical injury. It is impossible to determine how an individual will react to trauma as identical injury site loads affect individuals differently depending on their structural elements and weakest site.(2,3) An erroneous global statement sometimes presented by the insurance industry is that if a patient is not sent to hospital, s/he could not have received substantial injuries. Soft tissue injuries, neck and back pain, headaches and many other symptoms may be delayed by weeks, or many months.(3) Another erroneous global statement often promoted by the insurance industry is that whiplash and soft tissue injuries heal within a couple of weeks to six months (a "minor injury"). Nothing could be further from the truth. Ligaments that are stretched past their capacity and injured are very difficult to heal as they have limited blood supply, particularly where they attach to the bone. Lax ligaments do not hold the joints in place properly so there is abnormal joint movement. Muscles around the joint tend to react by contracting in order to help stabilize the joint and prevent further damage. Muscles that are shortened from spasm are dysfunctional and chronically fatigued.(4) Common causes of chronic pain following whiplash injury are the development of myofascial pain syndrome (MPS) and/or fibromyalgia syndrome (FMS),(4,5,6,7,8) which take several months to develop. There is no known cure for fibromyalgia syndrome. Degenerative disease of the cervical spine also often develops.

To suggest that whiplash and soft tissue injuries are "minor" injuries is not only erroneous, but it discriminates against females. Females generally have a more flexible and delicate skeleton, longer necks, and thinner, less massive muscles than males. This gender difference in physiology makes females more prone to whiplash injuries as they are likely to experience a greater degree of extension and flexion of the neck. A study of the spinal canal diameter of whiplash injury patients revealed that the cervical spinal canal was significantly smaller in patients with prolonged symptoms, and the cervical canal was smaller in females.(9) The sacroiliac and pubic joints of females have had their ligaments stretched during pregnancy and childbirth, making them less stable and more prone to low back injury. Females have less tolerance for pain than males, as females produce more of some brain chemicals that increase pain signals and less of some other brain chemicals that decrease pain signals.(4)

Thus, injuries should not be classified as "minor" by their diagnosis. If there must be a classification, it should be on the severity of the symptoms and the patient's functional abilities/limitations.

The Alberta Government website indicates that the "best practice guidelines would ensure injured victims receive the proper and prompt diagnosis and treatment for their injuries" and "pre-approved protocols would be developed to help health care practitioners provide appropriate and consistent treatment." There is a great need for better education about FMS and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) among health care practitioners. I am pleased to advise you that consensus documents, with the first clinical case definitions, diagnostic and treatment protocols for fibromyalgia syndrome(4) and myalgic encephalomyelitis/chronic fatigue syndrome(10) have been completed. The consensus documents also have research sections as well as a number of helpful appendices. Health Canada selected the expert consensus panels and established the "Terms of Reference". I am attaching a brief article entitled "Clinical Milestones for the Diagnosis and Treatment of Fibromyalgia Syndrome and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome" that explains how these consensus documents came into being. The ME/CFS consensus document was published in February, 2003. The FMS consensus document is in press and will be in the next issue of the Journal of Musculoskeletal Pain. We strongly suggest that these expert consensus documents be used as the guidelines for the diagnosis and treatment of FMS and ME/CFS patients.

Another major concern of our Network is regarding who will be responsible for deciding the eligibility for injury compensation. Our organization has been hearing from an alarming number of disabled patients all over Canada, including Alberta, who have had compensation or benefits denied based on an "independent medical examiner's" report in spite of the reports by the patients' treating physicians and specialists confirming their injuries and/or disabilities.

The so called "Independent Medical Examinations" have been a dismal failure because insurance companies choose doctors whom they can rely upon to produce reports which will benefit the insurance companies. Frequently patients, who have no psychiatric history, are sent to psychiatrists who allege that the injuries or symptoms are all in "the patient's head".

The Alberta Legislature now has the serious responsibility and opportunity to set up a fair and just independent medical examination process. I am enclosing the article, "Making 'Independent Medical Exams' Independent" by G.V. Rossie and R. D. Gretzinger, which was in our newsletter "Quest" #32, Oct/Nov. 1998. This article explains the most successful independent medical evaluation system that was legislated in Colorado for MVA.

We would also like to suggest: **This fair IME program should be run by an independent body outside of the insurance industry.**

I am also enclosing a copy of our position paper, "INDEPENDENT MEDICAL EXAMINATIONS IN CANADA: THE NEED FOR REFORM", which we hope the members of the group assigned to establishing guidelines, as well as the Members of the Legislature of Alberta, will read and consider while deliberating this serious issue. Although a number of examples refer to Chronic Fatigue Syndrome, they also apply to whiplash injuries, myofascial pain syndrome, fibromyalgia syndrome, and other soft tissue injuries. Ms. Noel, a member of our organization, has a Ph.D. in History, has lectured extensively and written dozens of articles on the problem of human rights. Her book on the subject won the Governor General's Award (in French) in 1989 and the updated translation in English, published in 1994 by McGill-

Queens University Press, received the American Gustavus Myers Center Award for The Study of Human Rights in North America.

Those injured in motor vehicle accidents are entitled to fair, unbiased evaluations by doctors whose expertise is in the area of the injuries. It is paramount that the human rights of injured individuals be safeguarded. Every individual deserves a fair evaluation and to be treated with respect and dignity.

The Alberta Government website states that "the definition of minor injury will be developed in consultation with organizations representing injured people, insurers, lawyers and health care providers". As Director of Education for the National ME/FM Action Network and Consensus Coordinator for both the Clinical Consensus Documents for Fibromyalgia Syndrome(4) and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome,(10) I would be pleased to participate in this group.
Would you kindly send a copy of this information to the appropriate people.

Thank you for considering our concerns and for your assistance in this matter. I look forward to a reply at your earliest convenience.

Sincerely,
Marjorie van de Sande, B. Ed., Grad. Dip. Ed,
Director of Education, National ME/FM Action Network

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Diagnostic and Treatment Protocols. *Journal of Chronic Fatigue Syndrome* 11(1):7-116, 2003.

Insurance Reform: Letter to Editor of the Edmonton Journal

November 1, 2003

"There is one issue involving insurance reform which I haven't yet seen discussed, and it concerns me. We are told (and I agree completely) that all the parties must act in good faith if an insurance scheme is going to work effectively.

We are also told by the industry (and I can neither prove nor disprove its claim) that one of its major problems is with claimants who are not acting in good faith.

One of the government's proposed solutions is to cap certain types of claim. This will protect the industry but will penalize individuals with legitimate claims.

The other side of the coin (as anyone who watched the recent W5 program on insurance will know) is that there are insurance companies which do not act in good faith. What is the government going to do to protect us from these companies?"
John Wodak., M.A., Ph.D.

[Ed. Note: John Wodak is one of the advocates on the ***National ME/FM Action Network's*** *Roster who lives in Alberta and specializes in CPP and AISH and can be reached at jwodak@teachwes.com or (780) 417-3574]*

If you live in Alberta, please write your own letter to the editor of your local newspaper, place c.c. National ME/FM Action Network at the bottom of your letter and send us a copy.

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.

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.**

National Doctors' Roster: Addition

Bruce M. Carruthers, MD, CM, FRCP(C) - Tel. (250) 652-6663
Dr. Carruthers has reopened his practice and is seeing patients on Vancouver Island and Vancouver, B.C. Dr. Carruthers was lead author of the ME/CFS Consensus Document and co-editor of the FMS Consensus document.

National Lawyers' Roster: Additions

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Our World: Muscular Pain: Feeling as though an elephant has been practicing "Flamingo Dancing' using your body as a ballroom floor. Loraine Legendre, Ottawa.

Resource Books

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: **$38.00.**

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 SHORTLY. **– Cost $50.00**

MEMBERSHIP: **$25.00 per year which includes bimonthly newsletters** – Payment can be made by **CHEQUE, VISA or MASTERCARD - 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.