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Haworth Press Announces Publication of a Medical Milestone: A Clinical Definition of ME/CFS

Binghamton, N.Y., Winter 2002 — The Haworth Press, Inc. announces the forthcoming publication of a special issue of the *Journal of Chronic Fatigue Syndrome* devoted to an expert consensus document, which includes a clinical definition (clinical diagnostic criteria) for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). The clinical case definition was developed by an expert medical consensus panel of treating physicians, teaching faculty and world leaders in the research of ME/CFS. An expert subcommittee of Health Canada established the Terms of Reference for the consensus panel. The definition more adequately reflects the complexity of symptoms of a given patient's pathogenesis and should establish ME/CFS as a distinct medical entity and help distinguish it from overlapping medical conditions in the absence of a definitive laboratory test.

"The clinical definition will enable clinicians to make an early diagnosis which may assist in lessening the impact of ME/CFS in some patients," said Dr. Bruce M. Carruthers, lead author of the definition. "It will reduce the expensive problem of patients being sent to many specialists before being diagnosed and will allow patients to receive appropriate treatments in a timely fashion."

The panel's clinical case definition determines that more of the prominent symptoms are compulsory and symptoms that share a common region of pathogenesis are grouped together for clarity. In addition to severe prolonged fatigue, the definition includes the hallmark symptoms of post-exertional malaise and/or fatigue, sleep dysfunction, pain, two or more of the given neurological/cognitive manifestations, and at least one of the given symptoms from two of the categories of autonomic, neuroendocrine, and immune manifestations. Diagnostic exclusions and common co-morbid entities are also given.

The special issue of the *Journal of Chronic Fatigue Syndrome* also includes a discussion of prominent symptoms, clinical practice diagnostic and treatment guidelines based on the best available research evidence, and an overview of available research on ME/CFS.
The expert panel of 11 physicians—who have diagnosed and/or treated more than 20,000 ME/CFS patients among them—has developed a clinical case definition that provides a flexible conceptual framework based on the characteristic patterns of symptom clusters, which reflect specific areas of pathogenesis. The expert subcommittee of Health Canada selected the expert consensus panel. Authors include:

* Dr. Bruce M. Carruthers, lead author of the consensus document; co-author of the draft of the original version of the ME/CFS clinical definition, diagnostic and treatment protocols document; internal medicine.
* Dr. Anil Kumar Jain co-author of the draft of the original version of the ME/CFS consensus document, affiliate of Ottawa Hospital, Ontario.
* Dr. Kenny L. De Meirleir, Professor Physiology and Medicine, Vrije Universiteit Brussel, Brussels, Belgium; ME/CFS researcher and clinician; organizer of the World Congress on Chronic Fatigue Syndrome and Related Disorders; a board member of the American Association for Chronic Fatigue Syndrome; and co-editor of *Chronic Fatigue Syndrome: Critical Reviews and Clinical Advances* (Haworth)
* Dr. Daniel L. Peterson, affiliate of the Sierra Internal Medicine Associates in Incline Village, Nevada; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the International Chronic Fatigue Syndrome Study Group
* Dr. Nancy G. Klimas, Clinical Professor of Medicine in Microbiology/Immunology/Allergy and Psychology, University of Miami School of Medicine; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the federal CFS Coordinating Committee
• Dr. A. Martin Lerner, staff physician at William Beaumont Hospital in Royal Oak, Michigan; Clinical professor and former chief of the Division of Infectious Diseases at Wayne State University's School of Medicine; and ME/CFS researcher and clinician
• * Dr. Alison C. Bested, haematological pathologist; former head of the Division of Haematology and Immunology at the Toronto East General and Orthopaedic Hospital; affiliate of the Environmental Health Clinic and Sunnybrook & Women's College Health Sciences Centre, Toronto, Ontario; ME/CFS researcher and clinician
* Dr. Pierre Flor-Henry, Clinical Professor of Psychiatry, University of Alberta; Clinical Director of General Psychiatry and Director of the Clinical Diagnostic and Research Centre, both based at Alberta Hospital in Edmonton, Alberta, Canada; ME/CFS brain researcher
* Dr. Pradip Joshi, internal medicine, Clinical Associate Professor of Medicine at Memorial University of Newfoundland in St. John's, Canada
* Dr. A. C. Peter Powles, Professor Emeritus, Faculty of Health Science, McMasters University, Hamilton; Professor, Faculty of Medicine, University of Toronto; Chief of Medicine and Sleep Disorders Consultant, St. Joseph's Health Centre, Toronto; Sleep Disorder Consultant at the Sleep Disorder Clinic at St. Joseph's Healthcare, Hamilton, and Central West Sleep Affiliation, Paris, Ontario
* Dr. Jeffrey A. Sherkey, family medicine, affiliate of the University Health Network, Toronto, Ontario; and diagnosed with chronic fatigue syndrome nearly 10 years ago
* Marjorie I. van de Sande, Consensus Coordinator; and Director of Education for the National ME/FM Action Network, Canada

***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 at a pre-publication price of US $8.00 per copy plus $5.00 Shipping and Handling. (ISBN: 0-7890-2207-9). 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**
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About The Haworth Medical Press

Launched in 1991, The Haworth Medical Press focuses on specialty areas in clinical medical practice with special emphasis on pain and symptom control, oncology, geriatrics, home-based medical care, palliative care, and selected high exploratory areas in medicine such as chronic fatigue syndrome and environmentally related disorders. The Haworth Medical Press also includes specialty textbooks and clusters of clinical medicine handbooks for evolving medical specialties.

About the *Journal of Chronic Fatigue Syndrome*
The *Journal of Chronic Fatigue Syndrome* presents original research, practical clinical management, case reports, and literature reviews that provide a comprehensive understanding of CFS. The journal is edited by Dr. Kenny DeMeirleir, organizer of the World Congress on Chronic Fatigue Syndrome and Related Disorders, co-editor of *Chronic Fatigue Syndrome: Critical Reviews and Clinical Advances* (Haworth), and a board member of the American Association for Chronic Fatigue Syndrome; and Dr. Neil Roland McGregor, author of a large number of published papers, conference presentations, and conference abstracts on chronic pain, chronic fatigue and chronic neurological diseases.

WHAT MAKES FOR A GOOD ASSESSMENT CENTRE?

Dr. Antonio Taverniti, B.Sc., D.C.,C.C.R.D

Many of the Functional Capacity Evaluations (FCE) and Functional Abilities Evaluations (FAE) that are performed are done incorrectly.

The key to reliable data is consistency of effort. Consistency of effort is determined mathematically and called the coefficient of variation (CV). The CV is usually assigned as 10 to 20% for healthy people depending on the research-based protocol. Most centres will arbitrarily use the lower 10% as their CV even though the research-based protocols ask for a higher CV to be used. This artificially portrays the client as giving an inconsistent effort.

The CV also has research-based protocols for the number of repetitions that should be used. Most of the protocols ask for tests to be repeated from three to six times. The more repetitions performed the more reliable the data. Most centres only do the test one to three times to save time i.e. money. This will reflect poorly on the person undergoing the evaluation. It will seem that an inconsistent effort was put forth.

Most centres will present the CV as a method for identifying whether the client put forth a maximal effort. These centres place doubt on the person's motivation and thus imply that the person is attempting to gain something from malingering.

The CV is only a mathematical tool to determine whether the data can be used. If the CV is too high that particular test result is to be discarded. It does not reflect maximal effort.

With regards to maximal effort most centres will concentrate on exposing the client to an excessive number of tests that are designed to catch one bad effort out of tens of efforts. They do not place the client into tests that are relevant to the purpose of the test; that is to determine someone's physical and/or mental capacity.

Also, most centres that use heart rate to monitor for maximal effort do not allow the client's post-effort heart rate to return to the resting heart. Thus, when the client is rushed through the tests, the computer program that only looks for change in heart rate during a test implies that the client did not give a maximal effort.

As well, the maximal effort tests are designed to determine only if someone gave a maximal effort. They can not tell if someone is not giving a maximal effort.

Furthermore, most centres expose clients to tests that are not valid for the individual being tested. Validity of a test implies that the content of the test reflects real life situations for the client. This is not the case for the majority of FCE and FAE tests. Most centres will only test gripping, lifting and carrying and sometimes pinching, pushing and pulling.

They will not test valid activities that are relevant to real life activities. These activities include walking, lifting, carrying, pushing, pulling, balancing, stooping, crouching, kneeling, climbing stairs, pinching, gripping, reaching in different planes, handling with one hand, bimanual handling, fingering with one hand, bimanual fingering, bimanual feeling, eye hand foot coordination, going from a standing to a sitting posture and vice-versa, tool use, and crawling.
Most importantly, the tests we use have normative research-based data that the scores can be checked against to generate an idea of whether the client could do any of these activities without experiencing undue hardship, fatigue and stress.

Most centres do not have this commitment to quality.

Some centres use equipment whereby the manufacturer supplies the database. This is not a research-based normative based database that has withstood scientific scrutiny. Rather, this is a database that the manufacturer has generated so that the buyer has something to report.

We have also witnessed centres that have changed the definition of disability that was set out by the original research. As an example, one centre changed the internationally accepted score of 100 ± 8% of the Industrial Standard for Method Time Measurements as the score that determines employability for that tested work activity to 1%. This implies that everyone tested, no matter how bad they were, would be employable. Thus, the test would find that all of the people that submitted to this test were employable. When in fact their scores reflected that they were not employable.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) clients report that they have good and bad days. Thus, it is possible that the client could be tested on a good day. The client then feels that it is not reflective of what he/she normally experiences and that, after the testing, he/she felt miserable and became bedridden. What we tell our clients that have undergone FAE and FCE testing is to write a detailed note with their signature and fax us informing us of this experience. This note then gets incorporated into the report, reflecting the fact that on good days when attempting to do too much, he/she will experience severe relapses.

Also, it is important to get tested on a good day as this reflects the best a client can be. Thus, even on a good day, flexibility, strength and endurance, when compared to normative data, demonstrate that the client is significantly weaker than non-ME/CFS people are.

The problem with ME/CFS is that the clinical symptoms of the disease are not enough to document disability. Thus a Functional Ability Evaluation (FAE) is performed. The FAE documents why you cannot do something. This will document the losses in strength, flexibility (range of motion) and endurance. Losses in range of motion and strength are objective proof of your impairment.

The Functional Capacity Evaluation (FCE) documents what you cannot do. This will document activities of daily living and disabilities. Losses in your ability to carry out activities of daily living are considered an impairment. Losses in your ability to carry out work related abilities are considered a disability.

Together, these two types of assessments provide documentation for the impairments and its resultant disabilities.

[Ed. Note: See also QUEST 55 - Dr. Taverniti's article about assessing functional capacity of persons with ME/CFS. Dr. Taverniti is on our National Doctors' Roster]

COGNITIVE BEHAVIOUR THERAPY (C.B.T.)

By: Philipa Corning, Ph.D., Bs.C., Vice-President

Insurance companies are aggressively promoting cognitive behaviour therapy as a treatment of choice for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). According to the Canadian edition of *Time Magazine* in January 2003, this therapy is simple, quick, practical,goal-oriented and cheap.
Insurance companies keep referring to an article in the British Medical Journal (BMJ) entitled "
All you need is cognitive behavior therapy" (volume 324, pages 288 – 290, 2 February 2002). However, what is involved in this type of therapy, and what does this much referred-to-article say about the value of cognitive behavior therapy?

What is it?

Although cognitive behaviour therapy is one of the dominant approaches used in psychotherapy today, it was pioneered in the early 1960's by psychiatrist Dr. Arron Beck. Cognitive models at that time theorized that "emotional upsets are caused not directly by events, but by mediating processes of our perceptions and interpretation of events. Psychological problems are seen to be a result of our reality distortions about a situation or ourselves, or to be based on faulty reasoning or poor problem solving. Sometimes our perceptions help us and sometimes they harm us."

Rather than exploring the patient's psychological history with the time-consuming and cumbersome Freudian psychoanalytical methods, Dr. Beck designed a quick, pragmatic and focused approach aimed on attaining results. Thus, cognitive therapy attacks the symptoms of anxiety and depression by "coaching" patients on how to think about their lives more clearly (according to the Time Magazine article).

In traditional psychotherapy, there is little dialogue exchanged between therapists and patients. Normally, therapists sit and listen to their patients ramble on while asking only a few probing questions. In contrast, cognitive behaviour therapy is collaborative - the patients are equals and information is shared. In addition, cognitive therapists talk to their patients and give guidance – they point out the patients' misconceptions, and advise these individuals on ways of seeing their lives more clearly. During each session, cognitive therapists follow the same method, so it is standardized. According to the same Time Magazine article, this therapy is remarkably effective for treating depression, and its success is backed by statistics. Because a course of treatment takes about 6 – 8 sessions, and there are 5,000 cognitive therapists in Canada, insurance companies love this therapy; it is cheap, quick, and accessible.

What does this article in the BMJ tell us?

Information Attractive to Insurance Companies: According to this article, the Department of Health in Britain indicates that cognitive behaviour therapy may be used for depressive disorders, panic disorder, agoraphobia, generalized anxiety disorder, post-traumatic stress disorder, bulimia and chronic fatigue. Furthermore, it states that this therapy is efficient, is relatively easy to learn and deliver, and produces good results in many instances.

Information Not Attractive to Insurance Companies: Later the article discusses limitations of this therapy. It suggests that several aspects of cognitive behaviour therapy are open to question:

- The foundations upon which the therapy is built are not as secure as some of it supporters believe;
- There is still much to learn about its impact on the long-term psychiatric illness that it is used to treat.

- It is proven effective in the laboratory, but there is no body of evidence on its effectiveness in the real world.
- Its effectiveness has not been compared with another form of psychotherapy.
- There are signs that leading therapists in this discipline are beginning to question aspects of the therapy and recognize some of its limitations.

Then, the article in the BMJ indicates that the reason cognitive behaviour therapy may be so popular is because of its research and marketing strategy, and not because it is superior to other psychotherapies.

<u>Why this article in the BMJ should NOT be used by insurance companies as a remedy for ME/CFS</u>

First: This article only mentions chronic fatigue on a list of psychological disorders, leaving the impression that it refers to Chronic Fatigue Syndrome / Myalgic Encephalomyelitis, which it does not. The words ' chronic fatigue' are not inter-changeable with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis. Although chronic fatigue may be caused by certain specific problems in the central nervous system, it is not the same illness as ME/CFS. ME/CFS is a physical illness that may or may not have a secondary psychological component such as depression. Just like with cancer, or heart disease, secondary depression may play a role in all chronic illness as people struggle to adjust to coping with disability.

Second: Cognitive behaviour therapy has its limitations. It is not a cure-all approach, and has not been proven effective in the real world. In addition, some of the leading therapists in the field are beginning to question it.

Summary:

In the eye of the insurance industry, the BMJ article supports their belief that cognitive behavior therapy is a cheap and effective method of treatment for chronic fatigue. The flaw in the insurance industry's premise is that ME/CFS is a different illness with an organic basis. Just as with cancer and heart disease, patients with ME/CFS cannot be cured by improvements in their reasoning skills, perceptions or problem solving skills.

ME/CFS & FM AND THE PROBLEM WITH "MULTI-DISCIPLINARY HEALTH SERVICES CLINICS"

Richard R. Evenson, Evenson Bundgard Flynn *Lawyers*

In recent years, disability insurers have increasingly adopted a new approach in respect of disability income claims based on conditions such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM). This approach involves the use of "Health Services Clinics".

The Health Services Clinics (HSCs) used by disability insurers are typically privately-owned and privately-run operations which provide "multi-disciplinary" or "inter-disciplinary" assessments of disabled individuals. These assessments usually include medical, behavioral and psychiatric evaluations. In addition, the HSCs provide "multi-disciplinary" treatment programs that are said to be based on the results of the assessments and, the HSCs claim, will result in significant improvement in the degree of disability.

A common scenario is as follows: the disability insurer refers the claimant for a "multi-disciplinary" assessment by a HSC. Typically, the claimant is already in receipt of disability benefits and is approaching or at the point where the contractual definition of "Disabled" is about to change from one defined in terms of the claimant's ability to do his or her own occupation to one defined in terms of ability to do virtually any occupation. In directing the claimant to submit to the HSC assessment, the disability insurer relies on the terms of the insurance policy which obligate the claimant to comply with insurer-ordered medical assessments or examinations. The HSC assessment typically involves an internist, a physiatrist, a psychiatrist, a psychologist, perhaps a kinesiologist, and especially in cases of FM, a rheumatologist. The assessment usually takes several days – perhaps over several weeks- and may involve a visit to the claimant's home. A complete psychiatric assessment is taken, including the patient's history since childhood and a listing of all possible stressors in the period just prior to, and during, the period of disability.

In the vast majority of cases, the HSC assessment produces a comprehensive, multi-paged report which often contains at least the following primary conclusions:

1) There is no clearly-definable, objectively-demonstrable underlying disease process or pathology to account for the claimant's ongoing discomfort and disability. Put another way, the degree of discomfort and disability claimed by the patient is in excess of that which can be accounted for solely on the basis of a clearly-definable underlying disease process or pathology.
2) The claimant's definable medical status is such that there are no specific activities which would be medically contra-indicated – in the sense that such activities would place the claimant at increased risk of harm or damage by virtue of engaging in such activities.
3) The claimant shows evidence of a psychological condition or abnormality which is contributing to his or her claimed discomfort and disability, and which should be addressed by cognitive behavioral therapy. A number of specific stressors can be identified in the claimant's life – past and present- which typically produce the psychological condition or abnormality discerned. (In addition, there is often a finding that the claimant has poor "sleep hygiene", which is causing ongoing physical and emotional tiredness; and which should be addressed by altered sleep habits.)
4) The claimant is a candidate for a comprehensive multi-disciplinary treatment program which can be provided by the HSC itself. This treatment program will involve cognitive-behavioral therapy, pharmacological intervention, and general physical re-conditioning. Through participation in this treatment program, the claimant, within four to six months, will very likely realize a significant improvement in his or her level of functioning and will be able to return to work, as well as resume many other activities lost since the onset of the disability.

Following the completion of the assessment procedure by the HSC and the production of the assessment report, the claimant is directed by the disability insurer to participate in the treatment program recommended by the HSC. The claimant has little choice in the matter because failure to participate in the program will be seen by the disability insurer as non-compliance with the claimant's obligations under the disability insurer's policy and will result in termination of the claimant's disability benefits.

In the majority of cases, the "multi-disciplinary treatment program" provided by the HSC consists of little more than a graduated exercise program. Typically, within four to six months following the commencement of the treatment program, the claimant is directed to commence a rehabilitative return-to-work program.

Analysis

The approach outlined above (hereinafter the "HSC Approach") is based on dubious premises and gives rise to erroneous conclusions. In addition, the HSC Approach outlined above is inappropriate and in many cases could be harmful to individuals disabled by ME/CFS and FM.

The fundamental premise of the HSC Approach to the treatment of ME/CFS and FM appears to be that in most cases of chronic disability, the initiating disease process or pathology has resolved, but "non-disease" factors or variables have taken over and become the primary source of the patient's discomfort and disability. The majority of these non-disease factors, it seems, are psychological; and thus fall under the inclusive label of "illness behaviour". Additionally, existing conditions such as dysthemia, depression, anxiety, etc., may have pre-disposed the patient to illness behaviour. Physical de-conditioning (attributable to the initial disease and/or the subsequent illness behaviour) and disturbed sleep, are other non-disease variables seen by proponents of the HSC Approach as contributing to false disability.

Because conventional medicine has no definitive diagnostic procedure for ME/CFS or for FM, and because these illnesses, so far, have no definable and objectively-demonstrable underlying disease pathology, and, further, because they often seem to develop following an illness such as the flu, or a traumatic accident such as a car crash, ME/CFS and FM fit neatly into the premise or theory underlying the HSC Approach. It is not at all surprising that the HSC assessment, which utilizes conventional diagnostic techniques and procedures, finds no clearly-definable, objectively-demonstrable underlying disease process or pathology to account for the patient's ongoing discomfort and disability. Also, where there is no definable underlying disease pathology, it is easy to conclude that various treatment modalities are not "contra-indicated"; i.e., the patient will not cause harm to himself or herself by virtue of engaging in any particular activities.

The fact that conventional diagnostic techniques do not find a clearly-definable, objectively-demonstrable disease process or pathology in patients suffering from ME/CFS or FM does not mean that the patient does not experience real and debilitating pain and discomfort that is physiological as opposed to psychogenic. Historically, this has been the case with numerous diseases or syndromes. There was a time when multiple sclerosis had no "clearly-definable, objectively-demonstrable underlying disease process or pathology" and was thought to be largely psychosomatic. We now know that MS is a serious and disabling physiological illness.

A major difficulty in the diagnosis – and indeed the treatment – of ME/CFS and FM is that each case may not be homogenous in origin. While medical science still has much to learn about the etiology of ME/CFS and FM, enough is presently known to establish that these conditions are physiologically-based and not psychological conditions. Given this knowledge, to find on the basis of conventional diagnostic procedures that ME/CFS and FM sufferers have no underlying organic disease process or pathology, is to advance an erroneous conclusion. Further, to state, on the basis of that erroneous conclusion, that the patient's definable medical status is such that there are no specific activities which are medically contra-indicated, is not only to advance a further erroneous conclusion – but perhaps an unhealthy one as well. It is well-documented that certain activities can exacerbate the symptomatology associated with ME/CFS and FM and prolong a patient's recovery.

By relying on the results of conventional diagnostic procedures, the HSC Approach incorrectly diminishes the effect of ME/CFS and FM and excludes these conditions from consideration as independent causes of disability. This is a serious flaw in the HSC Approach. Any treatment approach which virtually dismisses a patient's ME/CFS and/or FM as a major cause of the patient's discomfort and disability, cannot be expected to produce a valid treatment program.

Further, having found that there is no objectively-demonstrable physiological disease process to account for the patient's ongoing discomfort and disability, the HSC Approach has opened the door to the finding that the apparent cause of the patient's disability is largely psychological (e.g. illness behaviour, depression, anxiety, poor sleep habits, etc.). Reasoning of this sort incorrectly sees *results* of the patient's chronic disability as *causes.* Many ME/CFS and FM sufferers experience reactive or secondary depression or dysthemia as a result of being chronically disabled. Further, it is well-known that ME/CFS and FM adversely affect the ability of the sufferer to obtain undisturbed and restorative sleep.

To summarize, the problems in the HSC Approach can be stated as follows: relying on the lack of evidence (as determined by basic conventional diagnostic procedures) of a physiological disease process or pathology to conclude that there is no organic condition causing the patient's discomfort and disability (and to play up the role of non-disease factors such as "illness behaviour"); relying on the lack of evidence of an physiological disease process or pathology to conclude that no specific activities are medically "contra-indicated"; concluding that the patient's disability can be attributed primarily to psychological causes, and that the presence of outside stressors is diagnostically significant, when, firstly, such stressors are ubiquitous in present-day life and, secondly, given the chronic disability of the patient, it is to be expected that he or she will develop reactive psychological conditions or abnormalities; and, concluding that a treatment program consisting primarily of a graduated exercise program will bring about improvement of a degree sufficient to allow the patient to return to work.

Finally, it is arguable that the HSC, in carrying out both the assessment *and* the treatment program, has a serious conflict of interest. Clearly, insofar as the HSC stands to make more money if the claimant participates in the HSC's treatment program, the HSC has a pecuniary interest in the outcome of the assessment it conducts. Discussion of this topic, however, is perhaps best reserved for another, separate article.

[Ed. note: Mr. Evenson is on our National Lawyers' Roster]

COLLEGE OF PHYSICIANS & SURGEONS OF ONTARIO PASSES POLICY POSITION ON THIRD PARTY REPORTS

By: Mary Ellen, Manager of Special Projects

Readers will remember that in our Communications #43, August/September 2000 issue of Quest, we announced the completion of guidelines for medical examinations by non-treating physicians which were adopted by the College of Physicians and Surgeons of Alberta. We are now pleased to advise our members that in November 2002, the College of Physicians and Surgeons of Ontario (CPSO) released their own policy position on third-party reports. That is the good news. The bad news is that new CPSO guidelines are much weaker than Alberta's.

Consider some of what is explicitly stated in the Alberta guidelines:

1. The physician should be wholly objective and impartial;
2. The physician should clearly declare qualifications;
3. The physician can perform assessments only within one's area of expertise;
4. The physician must avoid demeaning or judgmental comments in reports;
5. The physician should not disparage other professionals (physicians or non-physicians);
6. The physician must base opinions on the best scientific evidence available and not on a personal belief system.

The College of Physicians and Surgeons of Ontario has failed to address any of these fundamental issues. As a result, general practitioners can continue to state that they "specialize" in an area of medicine even though they are not recognized as "specialists" by the CPSO. This is a long way away from clearly stating one's qualifications. The failure to address these tactical semantics allows some IME doctors to continue to inflate their credentials in a deliberate effort to mislead not just claimants, but to fool arbitrators and judges as well.

For whatever reason, the CPSO has taken the position that each of these issues need to be dealt with on a case-by-case basis. For practical purposes this means that the responsibility falls on the patient to spot these kinds of problems and then bring them to the attention of the College in a formal complaint. Beyond that, these conspicuous omissions raise another more disturbing question: since the CPSO prefers to consider each of these concerns on a case-by-case basis it logically follows that the College must think that in some cases it is permissible to inflate credentials, demean patients and disparage attending physicians, and perhaps even base a medical conclusion on a personal belief system rather than best scientific evidence. To be willing to revisit these concerns over and over again as specific complaints arise must mean that in some unidentified circumstances the College would overlook these kinds of abuses. We are left to wonder just what exactly those circumstances would be.

So, as has been said, the good news is that there are now guidelines in Ontario which address IMEs. The bad news is that the CPSO might just as well have not bothered. The point of guidelines is, after all, to avoid the need to “reinvent the wheel” over and over again. Aren’t guidelines, by definition, intended to avoid repeated time-consuming case-by-case considerations of minimal expectations regarding standards of professional practice? Apparently the CPSO doesn’t think so.

NATIONAL PROTEST DAY AGAINST UNFAIR INSURER-SPONSORED MEDICAL ASSESSMENTS

Mary Ellen, Manager for Special Projects

Too many of our members across Canada continue to have their insurance benefits denied or terminated by insurers who routinely commission IMEs with unqualified or underqualified health professionals who hold prejudicial beliefs against claimants. For example,
some insurer doctors believe people with ME/CFS and/or FM are nothing more than "middle-aged women looking for early retirement packages". Given the stonewalling by the provincial governments on this serious issue and their continued refusal to restore integrity to the IME system, the National ME/FM Action Network is tentatively planning a protest rally to be held at Queen's Park in Toronto, Ontario on Monday May 12, 2003, National ME/FM Awareness Day. Depending on the response we receive from support group leaders and members across the country it may be necessary for logistical and organizational reasons to reschedule to a later date if by doing so we can increase our turn-out. We are hoping for at least 400-500 people to participate in this long - overdue, public appeal for fairness. Perhaps we can arrange protests at the provincial government buildings in each province across Canada to occur on this day. The proliferation of bias/bogus IMEs must be brought to a halt. Support Group Leaders and individuals willing and able to participate are asked to contact Mary Ellen, Manager of Special Projects at **marye@pathcom.com** or by telephone at **(905) 831-4744** as soon as possible so we can assess how best to proceed.

IME/FAE Registry UPDATE

The **National ME/FM Action Network** is urging all people who have attended an independent medical examination, functional capacities evaluation or any other form of assessment at the request of an insurance company or Canada Pension Plan (CPP) or Workmen’s Compensation Board to act now by doing the following:

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 and the DAC or assessment centre can be on record, AND If you feel that your evaluation was biased, we urge you to write a short letter of complaint to the regulatory body in your province and send a cc. National ME/FM Action Network.

We would be pleased to help you write your letter if you have difficulty writing short letters because of limited energy or cognitive problems.
To receive a copy or copies of the simple, confidential, 7 question Registry Submission Form, please Contact: **Mary Ellen**, Manager of Special Projects, Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON., L1V 6P7
Phone or fax: (905) 831-4744 - Email: **marye@pathcom.com** - Or download the Form from our website at
www.mefmaction.net/medexam.html

ANNOUNCEMENT - By: Eleanor Stein MD, FRCP(C), Calgary, AB Tel. (403) 287-9941

Re: Chronic Fatigue Syndrome, Fibromyalgia, Multiple Chemical Intolerance & Related Disorders

I am writing to advise you of a **new service** designed specifically for people with **cognitive difficulties** secondary to **Chronic Fatigue Syndrome, Fibromyalgia, Multiple Chemical Intolerance and Chemical and Mold Exposure or any combination of the above.**

This testing protocol has been several years in the making and is the result of a **multidisciplinary effort** between myself (**Dr. Ellie Stein**), **Gerard Alberts, Chartered Psychologist; Diana Monea, Optometrist; Anne Wooliams, Audiologist and Matt van Olm, Pulmonary Physician.**

The **objective** of the testing protocol is to **objectively measure the cognitive and sensory dysfunction experienced by people with the above disorders**. The protocols are based on those used now in the United States by Kaye Kilburn MD and Nancy Didriksen PhD, both of whom have been generous with their time and expertise to assist us in getting started.

The testing itself will take approximately **15 hours** of **in person assessment time with 5 different professionals**. We are able to organize referrals for out of town clients if booked far enough in advance. It would be difficult to schedule all of the assessments in less than a full week and probably 10 days would be more realistic especially for clients with energy limitations. All clients will receive a **written report** summarizing the findings of each specialist, recommendations arising from those findings and can then discuss the report at an in person follow up session. For out of town patients this feedback could be done by phone.

In addition to providing a clinical assessment we will be accumulating data (without identifying information) for research purposes and further learning about these yet poorly understood disorders.

Our Multidisciplinary Team:
Ellie Stein MD FRCP(C) is a psychiatrist with expertise in Chronic Fatigue Syndrome, Multiple Chemical Intolerance and related disorders. The objective of Dr. Stein's medical assessment will be to confirm diagnosis, identify additional medical or psychiatric disorders, assess current treatment and make treatment recommendations.

Gerard Alberts M.Ed. C.Psych. of Alberts & Associates is a chartered psychologist with extensive experience in psychometrics, including cognitive testing and other aspects of psychological evaluation. Alberts & Associates will be the central point of contact for clients seeking information and/or testing, and will conduct the cognitive testing, compile the multidisciplinary findings and meet with the client to provide feedback.

Other team members include:
Dr. Matt Van Olm (pulmonary specialist
Dr. Diana Monea (optometrist)
Ms Anne Wooliams (audiologist)

FOR MORE INFORMATION CONTACT:
Alberts and Associates and ask about the new cognitive testing for effects of chemical or mold exposure, Multiple Chemical Intolerance, Chronic Fatigue Syndrome and Fibromyalgia - Tel. (403) 254-8400 - E-mail: albertsg@shaw.ca

[Ed note: Dr. Stein is on our National Doctors' Roster and will be writing an article about the new cognitive testing in our next newsletter]

PROPOSED AMENDMENTS TO DISABILITY TAX CREDIT (FORM T2201) WITHDRAWN

In August 2002 the Federal Department of Finance announced that it was considering amendments to the Income Tax Act which would further limit who would qualify for the Disability Tax Credit. Due to the outpouring of the disability community, the controversial proposal was withdrawn and new consultations have taken place for a revised proposal. The deadline for these submissions was January 17, 2003. We await to see whether the new proposals will help or hinder applying for this Tax Credit.

INTER-GROUP/CONTACT COMMUNICATION

The **Fibromyalgia Society of Ontario** is hoping to host a conference to take place the first part of August 2003. It will be held in **Brockville** with everything happening under one roof at the Grenville Co-Ed Boarding School. Funding is being sought so that costs for accommodation and food will be under $100.00 per day. To get an idea of how many would be interested in attending please call our toll free number at **1-866-552-5515** and leave a message.

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