

Quest

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Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols

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ABSTRACT. Recent years have brought growing recognition of the need for clinical criteria for myalgic encephalomyelitis (ME), which is also called chronic fatigue syndrome (CFS). An Expert Subcommittee of Health Canada established the Terms of Reference, and selected an Expert Medical Consensus Panel representing treating physicians, teaching faculty and researchers. A Consensus Workshop was held on March 30 to April 1, 2001 to culminate the review process and establish consensus for a clinical working case definition, diagnostic protocols and treatment protocols. We present a systematic clinical working case definition that encourages a diagnosis based on characteristic patterns of symptom clusters, which reflect specific areas of pathogenesis. Diagnostic and treatment protocols, and a short overview of research are given to facilitate a comprehensive and integrated approach to this illness. Throughout this paper, "myalgic encephalomyelitis" and "chronic fatigue syndrome" are used interchangeably and this illness is referred to as "ME/CFS". *Journal of Chronic Fatigue Syndrome 11(1), 2003.* © 2003 by The Haworth Press, Inc. All rights reserved. Reprinted with permission from The Haworth Press, Inc.

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(The consensus document in **J of CFS 11(1)** is expected to be released the beginning of **February, 2003.**

Orders are being accepted.)

PLEASE CIRCULATE

NEWS RELEASE

**CANADA LEADS THE WORLD WITH A CLINICAL DEFINITION FOR MYALGIC
ENCEPHALOMYELITIS /
CHRONIC FATIGUE SYNDROME (ME/CFS)**

A Clinical Definition (clinical diagnostic criteria) for ME/CFS has been developed by an Expert Consensus Panel. Although created to standardize research, the American Centers of Disease Control (CDC) Definition is being used in Canada and most other countries to diagnose ME/CFS. There has been a growing demand for diagnostic criteria designed for a clinical setting. In response to a survey by the **National ME/FM Action Network**, doctors across Canada overwhelmingly concurred that a clinical definition, along with diagnostic and treatment guidelines, would be the most helpful items in diagnosing and treating ME/CFS patients. In addition to the clinical definition, the consensus document includes a discussion of the prominent symptoms, clinical practice diagnostic and treatment guidelines based on the best available research evidence, and an overview of research on ME/CFS. Dr. Bruce M. Carruthers of B. C., lead author, stated that "The Clinical Definition will enable clinicians to make an early diagnosis which may assist in lessening the impact of ME/CFS in some patients. 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."

A definition was developed and published in 1988 and later revised in 1994 under the aegis of the CDC. These definitions along with the Australian and Oxford, U.K definitions were developed to standardize research and not designed to be used for clinical settings.

The CDC definition requires that the patient must have persistent or relapsing fatigue that lasts more than six months and four of eight other criteria. One problem with this definition is that fatigue is a symptom of many diseases. By making other cardinal symptoms optional, it increases the diagnostic difficulty of distinguishing the pathological fatigue of ME/CFS from other fatiguing illnesses with overlapping symptoms.

The Expert Consensus Panel developed a clinical case definition that provides a flexible, comprehensive framework. More of the prominent symptoms are compulsory and symptoms that share a common region of pathogenesis are grouped together to give clarity and completeness. 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. The illness must persist for at least six months. Diagnostic exclusions and common co-morbid entities are also mentioned.

The Expert Consensus Panel felt that the Clinical Case Definition more adequately expresses the complexity of symptoms in a given patient's pathogenesis. It should reflect ME/CFS as a distinct medical entity and help distinguish it from other overlapping medical conditions in the absence of a definitive laboratory test. The eleven physicians, who made up the Expert Consensus Panel, have between them diagnosed and/or treated more than 20,000 ME/CFS patients. All authors approved the Consensus Document.

According to a large American study by Dr. Leonard Jason, approximately 422 per 100,000 people (approximately 150,000 Canadians) suffer from ME/CFS compared to 26 per 100,000 women who have breast cancer. ME/CFS is a severe illness that can be debilitating. There is no known cure. It often begins with a viral type infection such as an acute respiratory or flu-like illness. But instead of recovering, the person's health deteriorates and many other symptoms appear. A number of viruses have been studied but so far there is no conclusive support for any one pathogen causing the illness. Numerous studies have confirmed that there is a biochemical breakdown of one of the body's defense pathways used to fight

viruses, which supports the theory that ME/CFS is triggered by an infection. Other triggers and mechanisms are also being investigated.

The development of a clinical definition, and clinical diagnostic and treatment guidelines is a milestone in the fight against this complex and often debilitating illness!

Many credits must be given:

- The **National ME/FM Action Network**: for spearheading the drive for the development of a clinical definition, and diagnostic and treatment protocols. **Lydia Neilson**, President, has lobbied Health Canada for years to make this a reality.
- **Dr. Bruce Carruthers** and **Dr. Anil Jain**: who kindly donated their time and expertise to write the draft document. Dr. Carruthers also spent countless hours on the revisions and editing.
- **The Expert Consensus Panel** (**Dr. Carruthers, Dr. Jain, Dr. Kenny De Meirleir [Belgium], Dr. Daniel Peterson [USA], Dr. Nancy Klimas [USA], Dr. Martin Lerner [USA], Dr. Alison Bested, Dr. Pierre Flor-Henry, Dr. Pradip Joshi, Dr. Peter Powles, and Dr. Jeffrey Sherkey**): for their genuine concern for the ME/CFS patient, for donating their time and expertise to the development of the Clinical Definition and Clinical Protocols, and their determination to make the Consensus Document a reality.
- **Marjorie van de Sande**, Consensus Coordinator, (and Director of Education for the **National ME/FM Action Network**): for the countless hours she spent working with Dr. Carruthers and the other members of the Expert Consensus Panel, for compiling the consensus document, and getting information back and forth between the panel members.
- **Health Canada**: for the selection of the Expert Consensus Panel, and establishing the Terms of Reference for the panel.
- **Crystaal**: for sponsoring the Expert Consensus Panel Workshop.
- **James McSherry**: MB, ChB, CCFP, FCFP, FABMP, FAAFP, who was a member of the Expert Consensus Panel and participated in the review process, but was unable to attend the consensus meeting. We regret that Dr. McSherry has since passed away.
- **Kim Jones**: RNC, PhD, FNP, exercise physiologist, for her input in the exercise/treatment section.
- **Kerry Ellison**: OT (non-practicing), for her input in the patient management/ treatment and assessing disability sections.
- **Hugh Scher**: LLP, for his input in the assessing disability section.
- **All the members of the National ME/FM Action Network**: for their continuing encouragement and support.
- **The Haworth Press Inc.**: for bringing the publication of the ME/CFS Consensus Document to fruition.

Assessing Functional Capacity of Persons With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

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

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is an affliction that has altered the lives of 2 to 5 million individuals in the United States alone and approximately 150,000 Canadians (422 per 100,000). The difficulty of diagnosing this disease has created a misconception about its seriousness. The reality could not be farther from the truth. ME/CFS is a severe, medical condition that causes a wide range of physical and cognitive disabilities and its victims can be of any gender, race, age or class.

The symptoms that most sufferers report (not listed in their order of severity or occurrence) are as follow:

(*Diane Barrows, 1995*):

1. Debilitating fatigue;
2. Decreased memory for recent events-time sequence;
3. Decreased ability to attend tasks (i.e. work tasks, reading following conversations or television shows);
4. Decreased ability to complete numerical calculations;
5. Poor word finding ability;
6. Muscular pain, especially upper back or neck;
7. Joint pain (without edema or signs of inflammation);
8. Decreased muscular endurance or strength;
9. Panic or anxiety attacks;
10. Increase in symptoms following exercise;
11. Depression.

The Activities of Daily Living listed most frequently as being seriously affected or too difficult to perform are (*Diane Barrows, 1995*):

1. Working at previously performed job because of decreased memory, decreased cognitive ability, fatigue, pain and decreased endurance;
2. Completing self-care in a timely manner (under 2 hours);
3. Reading books and remembering what was read;
4. Watching television or movies and following story lines;
5. Participating in exercise, recreational or social activities;
6. Walking more than short distances;
7. Climbing stairs;
8. Performing housework;
9. Shopping;
10. Performing activities requiring sustained overhead reach such as washing, drying, setting or combing hair;
11. Driving.

The good news is that functional capacity can be measured after the onset of ME/CFS and compared to pre-onset levels in order to determine a sufferer's extent of disability. The goal of the Functional Capacity Evaluation (FCE) for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome patients is to objectively demonstrate the patient's current capacity for functional whole body activities and compare current capacity to the pre-morbid Activities of Daily Living (ADL) status and to the pre-morbid cognitive and physical job demands. An FCE usually takes six to eight hours to complete and includes both physical capacity and cognitive function testing.

During the physical and cognitive testing, the ME/CFS patient is observed for general fatigue while sitting and standing and while performing non-material and material handling activities, such as: joint range of motion, muscle strength, grasp strength, pinch strength, endurance, fitness status, walking, carrying, pushing a load, pulling a load, balance, stooping, crouching, kneeling, climbing stairs, reaching in many planes, material handling and non-material handling activities, fingering, gross and fine motor dexterity (GATB parts 8, 9, 10,

11 and 12), crawling, eye-hand-foot coordination, tool use, and going from a seated to standing posture (the accommodation offered to people who can not stand or sit for prolonged periods).

The ME/CFS Profile

All of the ME/CFS patients report generalized debilitating fatigue that occasionally prevents them from donning and doffing clothing, eating or going to the bathroom. They state that it now might take nearly twice as long as it did before the onset of ME/CFS to shower and dress in the mornings, and that this self-care activity has to be divided into multiple short tasks with rest periods in between. Often, donning and doffing clothing and showering preclude all other activities for that day.

Almost all of the clients report that they get lost while driving. Some had to have family members come and lead them home. One client stated that after driving short distances she would often stop her car in parking lots where she slept for two hours before attempting to drive home. Clients state that driving is limited to physicians' appointments or infrequent but necessary trips to the market.

As a result of severe fatigue, many of the clients' lives revolve solely around their work, and they have only enough energy to drag themselves through the workday. They then spend each evening and weekend in bed in preparation for the next workday or workweek.

In ME/CFS patients, the resting heart rate is higher, but the maximal heart rate at exhaustion is lower, relative to healthy non-ME/CFS persons. The maximal workload and maximal oxygen uptake attained by patients with ME/CFS is almost half that achieved in healthy control subjects. Patients with ME/CFS show a significantly decreased exercise capacity. This could affect their physical abilities to a moderate or severe extent. Reaching the age-predicted target heart rate seems to be a limiting factor of the patients with ME/CFS in achieving maximal effort (*De Becker, Roeykens, Reynders, McGregor & De Meirleir, 2000*).

Along with the generalized fatigue, most ME/CFS patients report muscle weakness that is often difficult for the clients to pinpoint to specific muscles.

However, when questioned about weakness in regard to function, many ME/CFS patients complain of difficulty performing activities that require sustained overhead reaching, prolonged standing or walking, and stair climbing.

Electronic load cell muscle testing of gross muscle groups of the upper and lower extremities is assigned a numerical scale and used as follows: 0 – zero, 1 – trace, 2 – poor, 3 – fair, 4 – good, 5 – normal (*Kendall et al., 1971*). The majority of ME/CFS patients test in the good to normal range for short, singular contractions.

However, muscular fatigue is quickly noted when ME/CFS patients are asked to repeat the contractions several times. Poor muscular endurance, along with occasional muscle test scores that do fall below the good to normal range are most often observed in the shoulder and pelvic girdles. This observation is consistent with ME/CFS patient's perceived difficulties with activities like washing or drying their hair and walking up stairs (*Burrows, 1995*).

Patients with ME/CFS are weaker than sedentary and depressed controls and as unfit as sedentary controls. Low exercise capacity in ME/CFS patients is related to quadriceps muscle weakness, low physical fitness, and a higher body mass ratio (*Fulcher & White, 2000*).

Isometric strength testing is used during the FCE. Strength scores are compared to NIOSH's normative data (*U.S. Department of Health and Human Services, 1983*) to ascertain each patient's strength at the same time of his or her evaluation.

When Myalgic Encephalomyelitis/Chronic Fatigue Syndrome patients lose their ability to follow conversations, communicate, and/or participate in sports or recreational activities there is a history of social isolation.

Physical Testing

Both physical abilities and physical capacities are studied, and tests include, but are not limited to: joint range of motion, muscle strength, grasp strength, pinch strength, endurance, fitness status, walking, carrying, pushing a load, pulling a load, balance, stooping, crouching, kneeling, climbing stairs, reaching in many planes, material handling and non-material handling activities, fingering, gross and fine motor dexterity (GATB parts 8, 9, 10, 11 and 12), crawling, eye-hand-foot coordination, tool use, and going from a seated to standing posture (the accommodation offered to people who cannot stand or sit for prolonged periods).

Observations are made on the following: the ease and pattern of movement, the presence of tremors, trigger points associated with fibromyalgia, muscular atrophy, and the presence of syndromes that may accompany ME/CFS such as Carpal Tunnel Syndrome and chronic pain are observed and related.

To rate the ME/CFS patient's level of self-perceived pain, the Borg Pain Scale is administered with results ranging from 0 (no pain) to 10 (excruciating pain or pain that would require emergency room procedures). The patient's subjective pain statements, their description of daily living activities, and their facial expressions, may offer some indication of whether they are moderately impaired, severely impaired, magnifying symptoms or expressing inappropriate illness behaviour.

The pain scales include, but are not limited to: Numeric Pain Scale (*Borg*, 1982), Oswestry Pain Questionnaire (*Fairbanks, Couper, Davies O'Brien*, 1980), Neck Pain Questionnaire (*Vernon, Mior*, 1991) and the Ransford Pain Diagram (*Ransford, Cairns & Mooney*, 1976).

Physical tests include, but are not limited to, tests for: range of motion (AMA 4th Ed. Guides to Impairment), manual strength (*Kendall, Kendall & Wadsworth*, 1971), static strength (*Blankenship*, 1989), dynamic strength (*Snook & Ciriello*, 1991), Canadian Aerobic Fitness (*Canadian Society for Exercise Physiology*, 1996), Jamar Dynamometer grasp strength (*Niebuhr & Marion*, 1987). Testing for Maximum Voluntary Effort and Validity are also conducted during the FCE (*Blankenship*, 1989).

The strength scores provide insight into the patient's current strength versus probable strength as ascertained from subjective pre-morbid work and ADL capabilities.

In a study, 66% of women and 56% of men that completed isometric testing scored in the sedentary physical demand level. Less than 1% of the women and fewer than 2% of the men scored above the light physical demand level. On the basis of the patient's pre-morbid work and recreational histories, higher ratings were expected (*Diane Barrows*, 1995).

Cognitive Testing

Cognitive abilities assessed in the FCE for ME/CFS includes, but are not limited to attention, memory, numerical processing, reasoning, abstract thinking, judgment, and general intellectual thinking. The objective for the FCE is to identify the perceptual and cognitive deficits in order that the patient's potential for a successful return to work can be determined.

The patient is asked to give a detailed description of his job(s).

he patient also completes a subjective functional capacity checklist regarding his pre-morbid activities of daily living, home maintenance activities, caregiver activities, infirmed caregiving activities, work and recreational activities.

With the data collected the patient is assigned a physical demand level and/or a cognitive aptitude as defined in the Dictionary of Occupational Titles (DOT 1991) and/or National Occupations Classification (NOC). The data is compared against the patient's demonstrated physical and cognitive abilities to the characteristics (as defined by the DOT or NOC) of workers in the same or similar occupations.

Comparisons of the FCE findings based on clinical observation, comparative data and accepted normative data determine the patient's capacity to perform physical and cognitive activities.

The FCE demonstrates or clarifies the ME/CFS patient's self-perceived effects of the disease, and its associated disabilities in relation to the objective findings.

The FCE demonstrates whether the ME/CFS patient's current capacities allow him to safely and successfully return to his pre-morbid essential job tasks of a previous occupation.

The FCE also assists in determining whether the ME/CFS patient requires vocational rehabilitation, referral to a work-conditioning program or continued medical leaves of absence.

Aptitude tests simulate essential cognitive job tasks that are required for successful employment. They include, but are not limited to: General Aptitude Test Battery (1986 *Edition of the Manual for the General Aptitude Test Battery*, Canadian Edition).

The aptitude test scores are then compared to the scores of healthy populations in the same or similar occupation. Other than re-norming standards to reflect modern Canadian application, the GATB itself has remained relatively unchanged in theory and application since its inception (*Sandra Beggs*, 2000).

Demand Level (Dictionary of Occupational Titles. 1991) and/or the National Occupation Classification (Human Resources Development Canada) is used to define a job's cognitive aptitudes and physical requirements.

What's Next?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome's Etiology remains unresolved. Most ME/CFS patients over time do improve, however, a substantial proportion remains functionally impaired.

With the advent of more sophisticated diagnostic and testing formats, and the growing recognition of the severity of the effects of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, there is increased optimism for easier access to treatment, services and health benefits for sufferers.

[Ed. Note: Next Issue will include another article by Dr. Taverniti: WHAT MAKES FOR A GOOD ASSESSMENT CENTRE? Dr. Taverniti will discuss details explaining the ways in which many Assessment Centres are performing incorrect F.C.E.'s and F.A.E.'s]

TELEVISION BROADCAST - Dr. Richard L. Bruno highlights similarities of ME/CFS and Post-Polio Sequelae

"Health on the Line", a nationally broadcast, hour-long medical discussion program aired on the Discovery Health Channel which is a digital channel, delves into the debilitating illnesses of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and/or Fibromyalgia (FM) and sheds light on a theory that attempts to link them to the Polio virus. Host Avery Haines welcomes Doreen Van Gijn, a person who has had ME/CFS for over ten years, to discuss the symptoms of her illness and well-known broadcaster from ChumCity tv, David Onley. David was a victim of polio when he was three and now has been diagnosed with Post-Polio Sequelae, an illness that has a disturbing similarity to ME/CFS. **Dr. Richard L. Bruno** weighs in with his theory that the illnesses are indeed linked. Dr. Richard L. Bruno, author of "The Polio Paradox", is Chairperson of the International Post-Polio Task Force, an Associate Professor at New York's Mount Sinai School of Medicine, and Director of The Post-Polio Institute, the International Centre for Post-Polio Education and Research and the Fatigue Management Programs at New Jersey's Englewood Hospital and Medical Center and was a speaker at the **National ME/FM Action Network's** Symposium in June 2002. This episode aired at 11:00 am and 6:00 pm on Tuesday, October 8 and 7:00 am Wednesday, October 9, 2002. The episode will begin airing on the **Life Network** in **January 2003**. We will keep you posted.

B.C. LIBERALS PLAN MAJOR CUTS TO DISABILITY BENEFITS

In his Political Connections Column in the Georgia Straight Newspaper for October 3-10, 2002. Bill Tieleman wrote an article discussing the implications of the 20% of disabled people who will now lose disability benefits as a result of the B.C. Ministry Human Resources plan to have disabled people reassessed. Please go to our website and click on DISABILITY to read an edited summary of this article summarized for us by **Diana Inselberg** and also see there the response letter written by **Sherri Todd**, our **BC Director and Youth Ambassador for the National ME/FM Action Network**.

UNQUALIFIED NEUROPSYCHOLOGISTS WRITING INDEPENDENT MEDICAL EXAMINATION (I.M.E.) REPORTS

On October 28, 2002, our Manager of Special Projects sent the following letter to the Registrar of the College of Psychologists of Ontario:

I am writing to you on behalf of the **National ME/FM Action Network**. We are a registered, Canadian charitable organization dedicated to helping people with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM) through support, advocacy, research, education and the publishing of our bi-monthly newsletter, QUEST. As well as to thousands of individuals, hundreds of doctors and lawyers experienced in ME/CFS/FM, our newsletter goes out to over 450 support groups across Canada.

Over the last several years, the **National ME/FM Action Network** has become increasingly concerned with the number of complaints we receive from our members who have been subjected to unfair IMEs generally and insurer sponsored psychological assessments in particular. Our growing alarm prompted us to establish a method of tracking these complaints. Further, we have encouraged people who have raised concerns with us in terms of unfair IMEs to bring their concerns to the appropriate College in a formal complaint.

We are writing to you today to express two serious concerns:

First, we are concerned with the frequency of neuropsychological IMEs written by psychologists who are not approved by the College to practice in this specialty area;

Second, we are concerned with the CPO's apparent tendency to dismiss complaints of this nature with minimal, if any, censure.

We are aware of the Ontario Health Regulation that addresses the issue of competence to practice in specialty areas and are also familiar with the related Principal #3 of the College's professional standards. It is our understanding that when a psychologist begins to practice in a new specialty area and declares competence, she/he is obligated to inform the College. At this point her/his qualifications are reviewed for College approval.

Many of our complaints arise from what are perceived to be unfair neuropsychological assessments. Some of these have been directed toward the work product of Dr. Hemendra Shah. For example, only a week ago we became aware of yet another member of our organization who was sent to Dr. Shah a couple of years ago for a neuropsychological assessment. She has since complained to the CPO and you have initially sought to resolve the complaint with a letter of apology from Dr. Shah. Hers is not the only complaint we are tracking that arises from neuropsychological assessments written by Dr. Shah nor is hers the only one that you have sought to dispose of in this way. We chose Dr. Shah as an example of systemic problems partly because so much has already been said in the mainstream media using him as an example of this widespread problem. We are aware that Dr. Shah continues to await a Disciplinary Hearing to address several allegations of his failure to adhere to professional standards which were referred by the Complaints Committee in late 1999. One of the allegations is failing to limit the provision of his psychological services to his demonstrated areas of professional competence. As has been said, this case was widely reported in the press and your comments

to Steve Buist, journalist at the Hamilton Spectator with respect to the state of Dr. Shah's qualifications were similarly reported.

Further, we are aware that the Health Professions Appeal and Review Board have thoroughly reviewed the issue of Dr. Shah's qualifications and have issued a decision which states that he is unqualified to practice neuropsychology and that in so doing he undermines the integrity of the IME system in Ontario. Yet the College has allowed him to continue. If you have read the HPARB decision you will know that all of the work Dr. Shah has done at AssessMed since his hiring in early 1996 has been of the "neuropsychological variety." Given the allegations drawn up by your Complaints Committee, the HPARB decision that addresses Shah's lack of qualifications and your own statements in the press on this subject, we wonder why you insist on permitting Dr. Shah to do insurer sponsored neuropsychological assessments.

Even more curious is the CPO production of an "advisory" to its members regarding, among other things, competence in the context of neuropsychological insurer sponsored assessments - an advisory you seem to resist applying to Dr. Shah. Shouldn't the College have long ago issued an interim suspension that would require Dr. Shah to limit his practice to those areas in which he is approved? Had the College done so, our organization would not continue to receive complaints from people who have been sent to him and who have subsequently lost their insurer benefits solely on the basis of his neuropsychological reports. Beyond that, we wonder why the College is inclined to dispose of these complaints from our members by seeking to resolve the matter with a letter of apology or perhaps mediation. Whether or not these complainants are aware of the state of Dr. Shah's qualifications in neuropsychology and have explicitly included this issue in their letter of complaint is irrelevant – the College is well aware and yet seems intent on not pursuing the issue of his incompetence.

Are we to conclude that the position of the College is that Dr. Shah has permission to continue to produce neuropsychological assessments outside his demonstrated areas of competence as long as he is willing to write a letter of apology on those occasions that he is caught? Is this approach to incompetence adequate from the perspective of public trust and public safety? We are not asking you to comment on particular cases. We do want you to know that we are tracking these complaints relating to Dr. Shah and other members of your College not listed to practice neuropsychology. From our vantage point, it appears the College is much more interested in protecting Dr. Shah, and others who ignore CPO professional standards, than it is in protecting the public. Please explain why the College continues to allow unqualified psychologists to practice neuropsychology and why complaints against them as a result of these assessments are so easily dismissed by the CPO. We look forward to a reply at your earliest convenience.

GROUP OR JOINDER ACTIONS : By: Lou Ferro, Barrister & Solicitor - The Whitten case has opened the door to the reform-minded plaintiffs who wish to bring lawsuits to change how the insurance system presently adjusts claims. Whitten is very clear in its support for encouraging private attorney general (PAG) lawsuits that bring to the attention of the Court unlawful or unfair conduct that results in bad faith claims practices. Such cases normally seek to attract punitive damages to punish and denounce and deter the conduct of the insurer.

There are many ways to start a bad faith claim for punitive damages. The most popular and most used method is to have an individual policyholder bring an action in bad faith for his own claim and allege the insurance company treated him or her unfairly. The most important limitation on this lawsuit is that it is difficult to prove that the behaviour of the insurance company was "Standard Operating Procedure" and a recognized claims practice of the insurer in all claims. The Whitten case is the prime example of a single isolated act of bad faith that attracted a million dollars in punitive damages and the conditions for repeating that kind of success are outlined in the case itself.

The second most readily available approach is to launch a class action claiming unfair claims practices that result in bad faith design of claims processing systems. However, recent court decisions have made this kind of lawsuit a very risky matter indeed. Lawyers are going to be reluctant to start class action lawsuits because

in one case a failed certification proceeding resulted in a court order of costs against the plaintiffs in excess of \$185,000. As I understand class action proceedings, lawyers agree to indemnify the clients for any costs incurred that are unsuccessfully recovered. In that case the law firm may be responsible for the costs of the failed proceeding. I am not sure there are many law firms in this province now willing to entertain class action lawsuits that have ground-breaking or unique points of law to argue. In my view, the class action proceeding may have been dealt a death blow by these recent cases.

However, there is a new and interesting approach that may be taken known as the Joinder Action under Rule 5 of the Rules of Civil Procedure in Ontario. Generally, the Rule allows for the joining of claims by multiple plaintiffs in the same proceeding against any defendant where the plaintiff assert claims arising out of the same transactions or occurrences or series of transactions or occurrences where it appears there is a common question of law or fact and the joining of the plaintiffs would result in or promote the convenient administration of justice.

The future, I believe, is in the Joinder Action because group actions by plaintiffs not only spread the cost of litigation over many plaintiffs but also have the structural advantage of bringing to court multiple examples of instances of bad faith conduct arising in a claims environment that tends to, by the very nature of the allegations, bring home to the Jury that the defendant, in fact, has repeated what are alleged to be illegal acts over series of files thus strengthening the case that in fact it may be standard operating procedure or systemic in nature.

Systemic or institutional bad faith claims have yet to be widely accepted and litigated in Canada but have been brought successfully in the United States. The most striking example of a systemic or institutional bad faith claim is the case of Campbell vs. State Farm which is now on its way to the United States Supreme Court. In that case, the plaintiff was successful in showing State Farm's claims practices included all manner of sanctioned behaviour that was illegal and promoted and endorsed by upper and middle management as a way of turning the claims process into "profit centers". The recent Dateline show on Unum Provident can be seen as one example of a systemic approach to denying claims that takes away the individual discretionary power normally vested in the adjuster. When management comes in and has "round tables" and brings targets for closing files to the table and forces doctors and adjusters to meet certain targets irregardless the merits of the claims, then we have what is known as an institutional or systemic claims practice that is founded on bad faith principles.

In my experience, it is not unusual to have overly aggressive Vice Presidents of claims set "production" targets and file-closing processes that are designed to encourage the termination of benefits and the triggering of a litigated response by the policy holder. In many cases, the policyholders simply accept the fact they have been terminated and do not seek the advice of a lawyer. One presumes the number of policyholders who do nothing is very high because this form of conduct in illegally denying claims is very prevalent. There must be an economic advantage in simply denying claims and waiting for the policyholder to take action. Most of them likely never do. The ones that do make it into the court system then have to move along an adversarial process that can at times be difficult and the insurer counts on this "trial by ordeal" in order to scare people away from litigation.

However, there is great comfort in the group or joinder action because all of the plaintiffs are sharing the load and they all come to Court all with the same story. They are all complaining of the same conduct. All of them are equally supportive of each other's facts and an attack of their credibility can rarely be a successful tactic on the part of the defendant. It is one thing to challenge the credibility of one plaintiff but quite another yet to challenge the credibility of fifteen or twenty people who all come to Court all with the same story, all against the same defendant.

What do you need to start a Joinder Action? There should be at least fifteen or twenty common plaintiffs, that is, people who have all been treated the same, more or less, by the same defendant. So, for example, if an insurance company is fond of using one particular insurance doctor because of the results they

get, then all of those individuals who were seen by that individual doctor can sue not only the doctor but the insurance company for either negligence in the administration of the benefit or punitive damages for the setting up of the bogus insurance medical examiner.

Our firm has been doing research in this area and while it has not been done before, nevertheless, the legal theory is there to support the Joinder of claims and I believe it can be successful. However, the defendant is likely going to argue that the claim should not be joined because it brings an unfair advantage to the plaintiffs. On the other hand, the plaintiffs will argue that the very nature of the allegations in the Statement of Claim require that multiple plaintiffs be joined in order to prove the facts that are being claimed in the Statement of Claim. While there has been very little activity in the insurance marketplace in this area, there are many other cases that have proved the principle of joining multiple plaintiffs.

However, before a law firm would consider the start of such a lawsuit, it would have to be satisfied the strict conditions of the Rule are met including the common interests of the plaintiffs against the same defendant, similar facts and issues of law as between all of the plaintiffs and the single defendant and that the proceeding would be the most convenient or prudent course of conduct in bringing the case to trial.

Meritorious claims can be made successfully against insurance companies, adjusters and or other agents of the insurers such as insurance medical examiners and these claims will likely reduce the impact of the recent prophylactic decisions in the class action proceedings environment.

[Editor's Note: If you are interested in becoming part of a Group or Joinder Action against a particular IME doctor/ psychologist, assessment centre, insurance company, etc., please contact **Mary Ellen** at **(905) 831-4744** or email her at marye@pathcom.com. Once we see where the interest lies, we will determine where to begin.]

IME UPDATE - By: Mary Ellen, Manager - Special Projects - 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, Canada Pension Plan (CPP), or Workplace Safety & Insurance Board (WSIB, formerly known as Workmen's Compensation Board) to act now by doing the following:

1. 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 on record
AND

2. If you feel that your evaluation was biased:

(Did the evaluator believe that people can be disabled to the point where they are unable to work? Did the evaluator have the latest scientifically based research about the organic nature of your illness? Does your evaluator regularly treat patients disabled with your illness or only do assessments for insurance companies?)

OR, if you feel that your evaluator was unqualified to do the evaluation,

(Was he/she a specialist in an area that is appropriate to your illness? Does the regulating body, such as the College of Physicians and Surgeons or College of Psychologists approve of this doctor doing assessments in this area of specialty?)

OR, if you feel that you were treated disrespectfully,

(Such as being accused of malingering or being called any other names of disrespect such as "manipulative", "deceptive", "cunning" or spoken to in an abusive tone or with abusive language)

OR, improperly threatened to comply with the assessment,

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.

Colleges of Physicians and Surgeons and Colleges of Psychologists, and Colleges of Physiotherapists etc are now looking into the issue of a fair IME. Please send your letter of complaint. Your letter WILL make a difference. We must keep up the pressure to ensure better treatment for disabled people who must undergo these assessments. Please help yourself and others by writing your letter.

Please continue to fill out our confidential 7 question Registry Submission Form about your experience with an IME or FAE and continue to send us copies of your letters of complaint to the Colleges of Physicians and Surgeons, Colleges of Psychologists or whatever regulatory body is appropriate.

To receive a copy or copies of the simple, confidential, 7 question Registry Submission Form, please Contact: Mary Ellen, Manager of Special Projects - Phone or fax: (905) 831-4744
Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON., L1V 6P7
Email: marye@pathcom.com Or download the Form from our website at www3.sympatico.ca/me-fm.action/medexam.html

NATIONAL DOCTORS' ROSTER - ADDITION

***Antonio Taverniti, B.Sc., D.C., C.C.R.D.,**
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Toronto, Ontario M4V 2G7,
Tel. **(416) 975-2633** or e-mail cmed@on.aibn.com
Clinical Director of **Comprehensive Medical Diagnostics & Evaluations, Inc. (CMED).**
Able to perform a fair FAE and/or FCE for people suffering with ME/CFS and/or FM.

NATIONAL LAWYERS' ROSTER - ADDITION

Lou Ferro, Barrister & Solicitor
1 King Street West, Suite 903
Hamilton, ON L8P 1A4
Telephone: **905-522-8702** - Fax: **905-522-9728**
E-mail: lou@lawpac.net - **Auto Accidents Only**

WEBSITE'S "MY STORY" UPDATE:

Be sure to check out our latest addition to "My Story" Submissions on our website. Bernard Miller, suffering from ME/CFS, FM and MCS, was the subject of a recent t.v. documentary describing the deliberate cover-up by the United Nations, the Canadian government and a building owner. All refused to take responsibility for his illness even though he was exposed to chemicals in the workplace while working for the UN in its Montreal-based agency. No one is willing to take responsibility and pay Bernard Miller disability benefits in spite of the fact that documentation exists proving that toxic chemicals were measured in the air, negative health effects were attributed to these chemicals, and warnings and advice were given on action to remedy the problems long before Bernard Miller and others became disabled. Bernard Miller won a three-year court battle for the right to sue the Canadian government and the building owner although the UN is immune to the laws of Canada and can't be sued. Preparation for the actual trial is almost complete. Bernard Miller is determined to win his court case in order to protect other people. We wish him luck and await the outcome of his court case with bated breath.

To access Bernard's story go to our website at www.mefmaction.net, click "Active Projects", click on 'My Story' link, Quebec Story No. 1.

Please submit your own personal stories of problems with insurance issues. Your story will be published under the province in which you live. We do not mention your name or the name of the insurance company, unless you request otherwise.

BOOKS/NEWSLETTERS/VIDEOS ETC.

*** THE POLIO PARADOX: What you need to know – Uncovering the Hidden History of Polio to Understand and Treat “Post-Polio Syndrome” and Chronic Fatigue** – Cost: **\$43.00** Canada, International: **\$46.00**.

***Video on National ME/FM Action Network’s June 15, 2002 1st Annual Symposium on Parallels Between Post-Polio Sequelae, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia** - Cost: **\$30.00**

***Available through the National ME/FM Action Network**

PAYMENT METHODS AVAILABLE: BY CHEQUE, VISA OR MASTER CARD

OUR WORLD:

HUMOUR: AN ESSENTIAL DAILY NECESSITY

CONSTANT UPS & DOWNS OF SYMPTOMS - BODY IMITATING STOCK MARKET (Lorraine Legendre, Ottawa)

NEW WEBSITE ADDRESS

We have finally secured a new domain name which is shorter and easier to remember. The old website address (<http://www3.sympatico.ca/me-fm.action>) will still be valid, but more and more, we will be advising the use of the new URL. Please take note and bookmark for your own records: **<http://www.mefmaction.net>**

“QUEST COLLECTION” BOOK - FIVE YEARS: 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 i.e. medical, legal etc. We have kept the **cost** of the book to a minimum at **\$20.00** each which includes shipping and printing. Please make **your cheque payable to the National ME/FM Action Network** and let us know how many copies you would like.

TEACH-ME - Sourcebook for Teachers. We are proud to announce that the hard-copy of **our 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 FM, is now available. Price \$22.00 (includes S & H) – Discount on bulk orders. Cheques payable to the **National ME/FM Action Network**. Please also see our youth and parents’ pages on our website at: **www.mefmaction.net**

LEGAL/RESEARCH PACKAGE - Medical and Legal Information on ME/CFS and/or FM, a resource for lawyers, advocates, doctors and patients. Please make **cheque payable to Marj van de Sande** in the amount of **\$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 - Tel/Fax: (403) 547-8799. E-mail: mvandes@telus.net**

MEMBERSHIP: \$25.00 per year which includes bi-monthly 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>

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