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Network Notice of Change of Address

Effective immediately, please note that the address of the National ME/FM Action Network is **#512 – 33 Banner Road, Ottawa, ON K2H 8V7**. The fax number has been changed to **(613) 829-8518**. The phone number will remain as **(613) 829-6667**.

In Memoriam of Al Neilson

By Philipa Corning, Vice-President

On August 18, 2008, Al Neilson passed away peacefully at 65 years of age after an 18-month battle with cancer. He is survived and will be much missed by his wife Lydia, his sons David and Stephen, daughter-in-law Julie, and his siblings – Skip, Eric and Marilyn.

He was a tall in stature and strong in nature. Indeed, he was a devoted and loving spouse, who always supported and encouraged Lydia in her endeavours as President of the National ME/FM Action Network. He was fiercely proud of each accomplishment that she achieved over the years. Even though, he always had a smile to share with people, his smile grew even wider when Lydia experienced a positive event or scored a victory.

Although he was compelled to stay at home due to a disability suffered in his renovating business, he kept himself fully occupied as a bookkeeper for the Network, musician, and gardener. To support the Network, he helped Lydia to keep the figures up-to-date on a daily basis. On Tuesday evenings, visitors at the house could not converse with Lydia, due to the band practice in the basement. Al was a guitarist and singer, and Tuesday night was his time to have his musician friends over for a regular jam session. In the summer, Al transformed the back yard into a paradise with flowers and the “Playa Margarita” (his above-

ground swimming pool). On a hot humid day, it was a pleasant place to sit under an erected awning with a cup of coffee, or cool off in the Playa. In addition, he loved to cultivate a small vegetable garden, which he fenced off to defend it from the local population of rabbits and wild turkeys.

This was one man who was compassionate and who had a marvelous sense of humour. He laughed easily, and always had a funny story to tell. Indeed, Al will be missed by many for as many reasons.

Dr. Bruce Carruthers receives another award

By Sherri Todd, Director for BC



Recently, well known and beloved British Columbia Doctor, Dr. Bruce Carruthers retired for the third and final time. During his two previous retirements, he returned to research and practice medicine, and continued to care for his patients. He also continued to be the medical advisor to our network.

When we learned he was retiring this time, the National ME/FM Action Network wanted to honor and recognize him for his distinguished service in the ME and FM community. His long standing

support for persons with ME and FM has made him a unique frontrunner in his acceptance and understanding of these two syndromes. His tremendous original research, investigation and the publication of what is now known as the ME and FM Consensus Documents, the TEACH-ME sourcebook for Teachers and Parents, and his never ending interest, care and compassion towards his patients, have truly made him an outstanding health professional.

On June 22nd, as BC Director on behalf of The National ME/FM Action Network, I had the great pleasure of attending his retirement party and presenting him with the special award that was created just for him. Dr. Carruthers was very pleased and most honored to have received this award!

The dedication on the award read.....

The National ME/FM Action Network

AWARD OF DISTINGUISHED MERIT

Presented to

Bruce M. Carruthers, M.D.,C.M.,F.R.C,P.(C)

**In Recognition and Appreciation
of his Distinguished Excellence
in Medical Practice, Courtesy and
Compassion Demonstrated in Patient Care;
and Exemplary Commitment to Furthering the
Understanding and Acceptance of ME/CFS and
FM.**

2008

LEGAL UPDATE

**Keays v. Honda—Supreme Court
upholds wrongful dismissal but
overturns awards of *Wallace* and
punitive damages**

By Hugh Scher

The Supreme Court of Canada unanimously upheld the trial decision awarding Kevin Keays 15

months' notice for the wrongful termination of his employment by Honda Canada. However, in a surprising 7-2 decision, the court overturned the awards of *Wallace* and punitive damages previously awarded to Keays and reduced his reimbursement for legal costs.

At trial, the trial judge had awarded 15 months' notice, together with an additional 9 months' notice for Honda's bad faith in the manner of termination of Keays. The trial judge further awarded \$500,000. in punitive damages and \$610,000. in legal costs on a substantial indemnity basis, together with a bonus premium. The awards of bad faith and punitive damages were based on Honda's unreasonable conduct in the manner of termination and its discrimination and harassment of Keays in his employment.

In particular, the trial judge found that Honda had engaged in a litany of acts of discrimination and harassment against Keays, had retaliated against him for retaining a lawyer to advocate on his behalf with respect to the protection of his human rights, and for unilaterally terminating his accommodation for his CFS disability. The award of punitive damages was based upon Honda's discrimination and harassment in employment contrary to human rights law, in the intimidation and ultimate termination of Keays in order to evade Honda's duty to accommodate under human rights law.

The trial judge found that Honda's conduct justified punishment to the tune of \$500,000.00. Justice Goudge of the Ontario Court of Appeal would have upheld this award, while Justices Rosenberg and Feldman ordered that the \$500,000.00 punitive damage award be reduced to \$100,000.00. All judges at the Court of Appeal were unanimous in the application of the law relative to punitive damages, including the ability to grant an award of punitive damages based upon a breach of human rights law.

Despite these clear and unanimous rulings by the trial court and Court of Appeal, the Supreme Court of Canada engaged in an effective re-trial of the case effectively overturning almost every finding of fact made by the trial judge, including his findings relative to Honda's discrimination and harassment, Honda's bad faith in the manner of termination, Honda's retaliation against Keays for reason of his retainer of counsel, the nature of the position that

Keays held at Honda, and the impact of Honda's conduct on Keays.

The court went on to find as a matter of law that a punitive damage award could not be based upon a breach of human rights law and upheld an earlier 30-year precedent which prohibited courts from considering claims for remedies for discrimination based upon a violation of the Human Rights Code. The court held that all such claims had to be brought to the Ontario Human Rights Commission and that the Code provided a comprehensive scheme by which to deal with such claims.

It must be appreciated that in Ontario this is no longer the case as recent amendments to the Ontario Human Rights Code now expressly permit courts to hear and remedy complaints of discrimination contrary to human rights law where they arise concurrent with another cause of action such as a wrongful dismissal action, denial of benefits, or the infliction of mental distress.

Despite the fact that neither counsel or party asked the Supreme Court to address the issue of the law of bad faith in the manner of termination (*Wallace* damages), the court, on its own initiative, took it upon itself to address this issue and effectively overruled its earlier decision in *Wallace* which had previously held bad faith in the manner of termination could justify an extension in the notice period to employees upon the wrongful termination of their employment.

In keeping with an earlier ruling by the Supreme Court of Canada in *Fidler v. SunLife*, the court held that any damages for mental distress arising from bad faith in the manner of termination of employment are in the reasonable expectations of the parties to the employment contract and actual damages for mental distress can be compensated by way of an award of mental distress damages for breach of contract. As such, there was no need for an artificial extension of the notice period in order to address and remedy this kind of conduct.

This determination will make it much more difficult for employees to sustain claims to damages for bad faith in the manner of termination as it is now required for employees to demonstrate actual harm and damages in the form of mental distress. This will likely require employees to call expert medical evidence to justify their positions that they have suffered mental distress. It will also require

that employees seek out and obtain professional assistance in order to ensure that they have a basis to demonstrate actual harm as a consequence of bad faith in the manner of termination from employment. This will impose a significant practical and cost burden on employees who are seeking to sustain a claim of bad faith in the manner of termination.

With respect to punitive damages, the court has not entirely closed the door on such claims in the employment law context; however, they have made it significantly more difficult for a claim of punitive damages to be sustained in employment law and indeed, in the context of any breach of contract case.

The Supreme Court took the unusual step of effectively re-litigating findings of fact made by a trial judge. It is the usual course that findings of fact are accorded significant deference as the trial judge is the one charged to conduct a trial and to hear all witnesses, often over a number of days and years. In this case, the Supreme Court of Canada accorded no deference either to the findings of fact made by the trial judge, or to the unanimous decision by the Court of Appeal to uphold those findings of fact. As such, the Supreme Court has effectively said that 3 judges of the Ontario Court of Appeal and the trial judge were incorrect with respect to their findings of fact based on the evidence as only heard by the trial judge.

The Supreme Court did not accept arguments raised by Keays or by seven intervenors who were seeking an order that would have implied a term of non-discrimination into all employment contracts across Canada, or alternatively, would have created a new tort of discrimination as a separate cause of action. The Ontario Human Rights Code creates a new statutory cause of action in the manner described above in Ontario. This is not the case across Canada.

The court was obviously concerned that implying a term of non-discrimination into employment contracts, or creating a new tort of discrimination, would effectively limit the jurisdiction of human rights commissions across Canada and potentially increase the amount of litigation relative to discrimination claims. In any event, the court reversed the findings of fact made by the trial judge and upheld by the Court of Appeal that

Keays was discriminated against and thus found that there was no basis for an award of damages for discrimination, or for bad faith in the manner of termination in this case.

The court's decision represents a significant blow to workplace fairness across Canada. It significantly limits the remedies available to employees who are terminated, treated in bad faith and/or discriminated against in employment. It would appear that the tide is shifting away from the rights of employees and towards the rights of employers in a manner that is likely to make it more difficult for employees to sustain claims to damages beyond those related to reasonable and lawful notice upon a wrongful dismissal.

Note on Author: Hugh Scher is a partner in the law firm of Scher & De Angelis where he practices civil litigation with a focus on employment, insurance and human rights law especially in the area of disability rights. He serves as counsel to the National ME/FM Action Network, ME Ontario and Fibromyalgia Society of Ontario and has represented dozens of individuals from across the country with Fibromyalgia and Chronic Fatigue Syndrome in disputes with long-term disability insurers, the Canada Pension Plan, employers and Revenue Canada. Mr. Scher served as our counsel in the Lowe v. Guarantee Insurance (2005), O.J. (O.C.A.) and was counsel to Kevin Keays in Keays v. Honda.

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MEDICAL NEWS

Definition and Aetiology of Myalgic Encephalomyelitis(ME): How the Canadian Clinical Definition of ME Works

By Bruce M. Carruthers, M.D., C.M., FRCP(C)

A perspective on the various definitions of ME and the process of discovering its aetiology has been taken. The importance of clinical guidelines has been emphasised to encourage clinicians to provide the clear descriptions of their individual patients required for proper clinical activity; diagnosis, estimation of severity of impact, prognosis, treatment, and rehabilitation. This individual knowledge is informed by general and (hopefully) publicly confirmed knowledge resulting from scientific research during the second person interaction which lies at the core of the clinical encounter. Both types of knowledge are essential.

Definitions of a medical disorder must serve two divergent functions; both necessary, yet mutually exclusive because of their fundamentally different observational contexts - one dealing with groups of patients who can be approached scientifically and the other with individuals in a clinical context.

Research definitions (1-3) provide researchers with (relatively) homogenous groups of patients to allow meaningfully isolated and controlled observations as they follow various hypotheses in the hope of confirming/refuting them. In the context of research, all knowledge is under review; both what is explicitly in doubt and what is supposed to have been confirmed. Thus the observational context is one of general uncertainty, but grounded in trust that the scientific method can generate reliable (third-person) knowledge, and one has to start somewhere. As each patient must be viewed as a member of a selected set, methodologically they cannot be viewed as individuals.

At the risk of exhibiting “anecdotalage”, I would like to argue that another context of observation is critical to the clinical endeavour, one that depends

on the anecdotal, viewpoint-including, first-person experience of a patient. This is not merely consideration of a list of symptoms. It uses what is regarded as established third-person medical knowledge (graded into several categories of certainty/uncertainty), and matches this knowledge with that being provided by the individual patient, in the certainty of her/his illness experience. These two types of (what is regarded to be) certain knowledge meet in a second-person interchange between physician and patient involving the basic clinical activities of individual diagnosis, individual prognosis, individual treatment and individual prevention (4), also including an assessment of its impact on the patient's individual life (degree of disease and disability, or deviation from the state of ease and ability which we call health).

The observational context of clinical activity is thus more complex and begins from the first-person viewpoint generated by the deictic (5,6) co-ordinates of the individual patient, which then meet the observational and empathic skills of the physician, as well as the generalised third-person coordinates of established public knowledge backed by various forms of evidence, in the doctor patient relationship within a second-person interaction. This knowledge then must be reapplied within the deictic co-ordinates of the individual patient, viewpoints and all. But this is “anecdotal” certainty, and hence irrelevant to science. But, however anecdotal, this clinical work is essential; the patient's unique clinical entity must be identified by being observed accurately and adequately within its proper context. The relevant variables to follow within the entity must be sorted out from the irrelevant ones, and similarly with those in its background. The symptoms and signs expressing this dynamic entity must be observed minutely to see how their qualitative and quantitative changes are developing. Interactions within and without the entity must be observed in order to find conciliant and causal chains to assign symptom priority. The individual effects of treatments must be observed and such effects may trump the statistical results of ‘evidence based’ treatments within the clinical context.

A primary clinical entity cannot be a static object. It is necessarily subjective in part (since it observes at least itself), and like the primary illness experience that participates in it, is an undivided, individual, as yet unnamed whole, and of the

nature of a real process, not to be confused with the set of concepts used to name and describe it (see problem of realism/nominalism(7)). Note that all of these clinical practices depend to a large extent on the assumption of the accuracy and adequacy of the patient's experience of illness as it unfolds under the observation of the physician. If the observational discipline of Western painting is based on the disavowal of deictic reference (8), then it is no wonder that clinical observation skills are atrophying. But it is the dynamic clinical entity, of necessity both subjective and objective, which orient the field of clinical activity, if clearly and adequately observed.

If such clarity and adequacy are not achieved, several types of smudging may result. In other words, if the generalisations from the medical model are too generic, they have no chance of adequately meeting the patients' illness experience, and much relevant data may be overlooked and/or misinterpreted. Thus the move from a more specific clinical concept such as ME or Fibromyalgia to a more generic concept such as Chronic Fatigue Syndrome or Chronic Pain Syndrome entails missing a lot of the information that makes the syndrome as a name match the syndrome as an experience. The syndrome as an experience is a coherent entity whose parts run together as a process - as the word syndrome indicates etymologically - and whose causal interactions are sensed directly in the mode of causal efficacy (9). This entity arises against a background which is treated as a nonentity for the purposes of the observation. Thus the attempt to organise clinical activity around a nonentity, such as in Somatization Disorder and Munchausen Syndrome(10,11), where diagnosis depends on the absence of an entity, may interfere with proper clinical activity by importing a misplaced forensic attitude towards a patient's illness experience, discounting or distorting its relevance. The move towards ignoring the distinctions between primary and secondary which designate sensed causal directions within a clinical entity, whether applied to depression, anxiety, infection or fibromyalgia, add to the confusion and impede the elucidation of a properly dynamic clinical entity. The widespread use of the holistic biopsychosocial model of disease (12-14) without any distinction between a clinical entity and its background encourages the "drowning" of clinical entities by risk factors which can proliferate endlessly in a nominalist fury

without orientation as to their state of relevance or lack thereof with respect to a real entity (7).

The Canadian consensus case definition and diagnostic protocol for ME (15) has been influenced by the clinical method of Sydenham (16), which is to provide a fuller and richer framework to fit the patient's illness experience into a framework that is specific and complete enough to match the patient's experience, yet consonant with the large body of public and confirmed results that have been obtained by the research activity stimulated by earlier definitions. It tries to be more adequate to the clinical activity that each patient's unique clinical situation demands. It facilitates a precise and adequate observation of the unique clinical entity arising in a patient in contrast to its contextual background. This is necessary to orient clinical activities, to guide the quantification of the events, both syndromal and contextual, which may be of particular relevance, as well as sorting out their causal direction and priority. It tries to remain close enough to be adequate to the illness experience of the patient and thus invariant to the changes in interpretation of this experience as science evolves over the years (16). Unless a disease entity is 'eliminated' by better understanding and better technology, it will continue to require clinical attention, whatever we hypothesize its 'natural kind' to be.

To improve clinical observation, the Canadian definition and diagnostic protocol lays out a number of regions of patho-physiological dysfunction, as necessary components of the syndrome of ME, but the particular expression of symptoms within each region is contingent between individuals, and their specific pattern is left open to be decided by clinical observation of the individual and later diagnostic classification. These component regions include fatigue, which must be severe and prolonged and of a certain dynamic pattern (delayed, prolonged reactive), and significant dysfunction must be observed in the following realms - sleep, pain, neurological/cognitive, and at least one of the following 3 realms - autonomic nervous system, neuroendocrine, and immune system. This approach facilitates the identification of the patient's individual clinical entity or syndrome, how its parts fit together and interact, as well as its impact on the patient's life - seen as disability and disease - and leading to a more accurate and

adequate diagnosis. It allows estimates of the clinical course and prognosis, decisions regarding treatment, estimation of the treatment effects, and search for successful preventive and rehabilitative strategies. With its flexible combination of necessary and optional features, the definition allows the diagnosis to fit the patient rather than the other way around (as with Procrustes, an innkeeper from Greek mythology who stretched the guests to fit his bed!).

The possible aetiology of ME is under scientific observation. This is done by experiment and by controlled observation. Many observers are following various lines of investigation and observation as to the aetiology of ME, which we are all following with interest.

There are some problems. A hypothesis is a cognitive structure necessary to organise one's experimental efforts. When rigorously tested independently and often enough, your hypothesis can be regarded as tentatively confirmed. But within the context of research, you should work to disprove your hypothesis. As noted by Sydenham (16), to arrange reality to save it can cause much error. I quote "In writing the history of a disease, every philosophical hypothesis whatsoever, that has previously occupied the mind of the author, should lie in abeyance. This being done, the clear and natural phenomena of the disease should be noted - these and these only. They should be noted accurately, and in all their minuteness; (...) No man can state the errors that have been occasioned by these physiological hypotheses. Writers, whose minds have taken a false colour under their influence, have saddled diseases with phenomena which existed in their own brains only; but which would have been clear and visible to the whole world had the assumed hypotheses been true."

The opposite problem of importing a context of doubt into the clinical arena, which is heavily dependant on deictic certainties, can result in the disruption of the second person clinical observation structure and subsequent clinical practices, as observed with the "smudge" diagnoses mentioned earlier.

The problem of cultivating a holistic view without adequately structuring the field with a proper clinical entity can lead to great confusions of relevance, where contextual and syndromal

features are confounded with no way of clinically quantifying their relative impacts. Choose the right kind of entity or you may end up only considering background factors with no clinical entity left that they are the background of - see the fate of the Cheshire cat in Alice in Wonderland, where the cat fades, leaving only the smile! (17)

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[Ed. Note: Dr. Carruthers is the Co-Author of the Canadian Working Case Clinical Definition & Treatment Protocols for ME/CFS and FMS, the Co-Author A Clinical Case Definition and Guidelines for Medical Practitioners, An Overview of the Canadian Consensus Document. Marjorie I. van de Marjorie I. van de Sande, B. Ed., Gad. Dip. Ed, is the Co-Author. Dr. Carruthers has been practicing medicine for over 30 years].

Ottawa Moves on Allergy Labelling Law

News from Allergic Living magazine

Health Minister Tony Clement announced recently that legislation will be moving forward requiring the food industry to label, clearly and plainly, any priority allergens among the ingredients listed on food packages.

The announcement follows a campaign in which almost 4,000 individual Canadians e-mailed a form letter to Prime Minister Stephen Harper requesting

that these important regulations, long delayed, be passed into law. The staff at *Allergic Living* magazine extends our sincere thanks to all of you who took the time to send that letter, posted at AllergicLiving.com. Clearly, your voices have been heard, and this grassroots campaign, involving individuals from St. John's to Victoria, has proved a success. Dr. Charles Frankish, president of the Canadian Society of Allergy and Clinical Immunology, was on hand for the announcement in Ottawa. The CSACI, Anaphylaxis Canada, the AAIA, the AQAA and the Canadian Celiac Association, have been instrumental in the development and lobbying efforts for the new labeling regulations. These organizations sent a group letter to the prime minister, urging the regulations finally be passed after years of discussion.

Thankfully, their entreaties and yours have been heard. The regulations still have to pass a couple of regulatory stages to become law. But the Health Minister clearly signaled the government's intent to pass the labeling legislation and to increase the level of food safety for Canadians with food allergies and celiac disease. Health Canada is asking food companies to start complying with the new regulations as soon as possible.

At *Allergic Living*, we are committed to the goal of reasonable accommodations for the growing population of people living with allergies and asthma. The success of this campaign shows the strength of our community when it works together. We look forward to working with all of you on other important initiatives.

Sincerely,

The Staff of Allergic Living magazine

What Do You Know? The Science of CFS: CFS Myth-busting Quiz 2008 – continued, Part 2

By Linda MacDonald. B.A., BSc Physical Therapy

Refer to Spring Issue of Quest 2008 for part 1 of the Mythbusting Quiz

Chronic fatigue syndrome (CFS) is a common and disabling condition affecting hundreds of thousands of Canadians. The cause is still unknown. Research has identified damage to the central nervous system, immune system and impaired gene function in CFS patients. Despite such international advances in the knowledge of the clinical and scientific basis of CFS, there remains no proven cure, no standard treatment,

and many questions, which remain to be answered.

In Canada CFS is also known as ME - myalgic encephalomyelitis, although even this is not a simple discussion point. To avoid confusion, "CFS" in this article refers to ME/CFS in keeping with the terminology used in the 2003 Canadian Consensus Guidelines for the Diagnosis and Treatment of ME/CFS.

For diagnosis and treatment guidelines, and lists of symptoms for CFS, fibromyalgia or similar conditions, please visit the National ME-FM Action Network at www.mefmaction.net. Become a member and you will receive the newsletter, Quest, for science education and support updates.

What do you know about CFS? May 12 is National ME (CFS) –FM Awareness Day in Canada and most people know someone who is ill with CFS. So we challenge you to take the rest of our Myth-busting Quiz...

7. "CFS is a serious illness."

Answer: True

CFS is a serious, disabling and chronic organic (ie. physical, not mental) disorder.

International expert Daniel Peterson is on record as stating about CFS: "In my experience, (it) is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages."

"The Centres for Disease Control (the US federal agency charged with the containment of diseases and known internationally as the CDC) designates {ME/CFS} for funding status as 'A serious legitimate diagnosis CDC PRIORITY 1 disease of public health importance.' " According to US statistics provided by the CDC, only 4% of patients had full remission (not recovery) at 24 months.

American researchers found that the quality of life is particularly and uniquely disrupted in CFS and that all participants related profound and multiple losses, including loss of jobs, relationships, financial security, future plans, daily routines, hobbies, stamina and spontaneity. Activity was reduced to basic survival needs for some subjects. The researchers found that the extent of the losses experienced by sufferers was devastating, both in number and intensity.

With the direct economic costs added, 2007 research estimates that CFS costs the U.S. economy 19-25 billion dollars a year. American CFS researcher Leonard Jason used the updated CFS population estimate for the USA - 8 million - as the basis for the economic cost calculations.

Australian researchers found that patients with this disorder had more dysfunction than those with multiple sclerosis. The degree of impairment is more extreme than in end-stage renal disease and heart disease, and that only in terminally ill cancer and stroke patients was the sickness impact profile (SIP) greater than in CFS.

The severity and disability in CFS are greater than in congestive heart failure, acute myocardial infarction (heart attack), multiple sclerosis and type 2 diabetes.

Few people have been reported to die directly from CFS. Nonetheless, given the paucity of research into deaths due to CFS or related complications, and the inconsistent use of internationally accepted guidelines of diagnosis, it is difficult to know if people with CFS are dying from CFS-related causes. UK doctors reported in 2001 that, "ME is rarely listed as the cause of death, although after decades of illness, death from end-organ damage (mainly cardiac or pancreatic failure) is known to occur."

Conclusion

CFS-related disabilities can be compared to those resulting from MS, early stage Alzheimer's, heart disease, diabetes and AIDS. Furthermore, prolonged physical illness increases the risk of developing severe depressive illness. However, the disabilities and symptoms related to CFS are largely invisible and therefore subject to misunderstanding. In the worst stages the patient is housebound and may be bedridden, adding to the invisibility of the illness. If the patient makes it into public on his or her best day of the year, she may be

told she “looks great” by onlookers.

People with CFS have greatly decreased quality of life and the current support for CFS research is scarce. Suffering is great, social empathy is low. Suicide rates are high and are said to be the most common cause of death in ME (CFS) and to be related to the current climate of disbelief and rejection of welfare support.

In 2003 the Canadian Consensus Guidelines for the Diagnosis and Treatment of ME/CFS were published. They are the work of a Health Canada-selected International Expert Consensus Panel who had collectively assessed more than 45,000 CFS or fibromyalgia (FM) patients. (FM is a disabling pain syndrome clinically related to CFS.) The panel reached 100% consensus, and these documents have since been lauded internationally by CFS clinicians and researchers. Electronic copies can be obtained at www.mefmaction.net/physician resources.

The United Nations World Health Organization, the Canadian Consensus Guidelines, and the Ontario Medical Association state that ME (CFS) is a neurological illness. (W.H.O. diagnostic code: ICD-10. G.93.3).

8. “People with CFS are just tired because they are out of shape and they would surely get better if they would just exercise.”

Answer: False

Exercise cannot cure CFS. Physical exercise often exacerbates the symptoms that characterize CFS, resulting in a post-exertional relapse that can last for 24 hours or more. The Canadian Consensus Documents identify post-exertional malaise (PEM) as a hallmark indicator of CFS.

Research findings suggest that **non-aerobic** exercise (such as weight training), carefully tailored to the stage and severity of the CFS patient, may be more suitable for maintaining strength than aerobic exercise (walking, swimming, cycling), which could precipitate a relapse by further taxing impaired pathways.

However, “it is a myth that patients with CFS can be cured by exercise, but it is also a myth that no one with CFS can ever benefit from some physical activity. For some patients, a carefully monitored program incorporating paced and non-fatiguing activity can be used to strengthen and condition muscles. But it is worth noting that Black, O’Connor, and McCully (2005) recently found that with an average 28% increase over baseline levels of daily physical activity over for a four week period, patients with CFS indicated they had worsening overall mood, muscle pain intensity and time spent each day with fatigue.” - IACFS website 2008 – statement on exercise in CFS.

9. "People disabled with CFS have access to all the services, assistance and rights already available to meet the needs of disabled citizens in Canada."

Answer: False

Canadian CFS patients face many roadblocks in the quest for needed assistance of all kinds.

The diagnosis of CFS is based on clinical criteria and critically depends on exclusion of other physical diseases, or psychiatric illness. In Canada, the testing recommended on page 19 of the Canadian Consensus Guideline Overviews is rarely carried out or completely known by physicians. The typical CFS diagnostic period of 5 years disadvantages those patients applying for medical or disability leave, since deadlines for supplying documentation of illness can rarely be met by patients awaiting CFS diagnosis. The patient is obliged to pay for laboratory or other CFS specific tests offered only in other countries, with no guarantee that once the results are available, these (Health Canada-recommended) tests will be acknowledged or understood by the insurance company or other recipients.

The various definitions of disability remain open to diverse interpretations, and this, plus the lack of adherence to a gold standard leaves the patient floundering to prove permanent disability – or to prove illness at all.

Lack of implementation of the Health Canada-recommended baseline diagnostic standard (The Canadian Consensus Guidelines for the Diagnosis and Treatment of CFS) has allowed insurance companies and government disability bodies to ignore findings, rendering the process of proving illness next to impossible. The situation is such that in many cases, no evidence which could be presented by any doctor or lab has been accepted. This equates to a categorical dismissal of CFS as a disabling illness. The financial, personal and social spin-offs of this situation are ubiquitous and easy to imagine.

To complicate matters, CFS patients are in the most severe stages by the time they reach out for help and in many cases, filling out a form, making a phone call, or attending an appointment is very difficult or impossible.

Then there is the innate extra expense of being a CFS patient. Private Canadian CFS clinics typically extra-bill for services because the provinces do not cover most CFS-specific tests or procedures/methods, and there is no government body which periodically reassesses this. The result is a default situation of private health care for CFS, with little mainstream care available. This limits access for the many with CFS who have been unjustly denied disability benefits, have lost all former resources and income, and now live below the poverty line on a fixed income.

Added to this is the scarcity of CFS doctors on top of the current shortages of doctors nation-wide (Alberta for instance is short about 1000 family doctors for any condition, according to a 2007 estimate.) Canadian CFS doctors have waiting lists as long as three years, and many are no longer taking new patients. Diagnosis of CFS remains inefficient and diagnostic times average 5 years. Patients should be aware that a Health Canada recommended (Rnase-L) blood test is available through Redlabs USA. In many cases it provides a quick clear diagnosis of CFS. Patients should urge their provincial health authorities to provide access to and coverage for this test.

Few CFS patients are healthy enough to travel to other countries to try the protocols used there. However, our universal health care offers them no CFS-specific options, despite availability at least on a clinical trial basis elsewhere. Provincial governments do not yet fund federally-recommended CFS blood tests, nor are there any government departments or watchdog ethics organizations monitoring and implementing updates to current default protocols of omission.

There exist only a handful of CFS clinics across Canada. The result: half a dozen overloaded extra-billing clinics for 340,000 patients, many of whom are bed ridden or housebound and unable to travel.

When these medical and health care basics are not working, the government, justice system and society at large do not receive the input required to include the needs of CFS patients in existing social, justice or educational programs, provide services, monitor and update policies to include CFS needs, launch inquiries, or change situations which are not working.

Lack of access to medical and health care for CFS patients is an in-depth, multi-faceted issue which already required immediate federal and provincial government attention 20 years ago. By now, it is a well-silenced and global crisis of exclusion, of unprecedented magnitude for any illness in the developed world.

This situation is not unique to Canada. « In the USA, more than 80% of CFS/ME patients have not found a provider expert enough to make a diagnosis, let alone treat their illness. It is a gaping hole in our health care system, and is true across the globe. Our patients are falling into this chasm. The lack of providers with any training in this field guarantees that this will remain the single biggest issue facing our patients. As investigators, it deprives us of our subject population and skews the population we do study to those patients that can overcome the barriers of our health care systems to seek expert care. All in all, this is simply

unacceptable.» - introductory letter on <http://www.iacfsme.org/> by Nancy Klimas, M.D. President, International Association for CFS/ME (IACFS/ME) 2008.

Hope

There have been recent improvements to aspects of the CFS disability status in Canada, such as the addition of criteria to the Disability Tax Credit application which acknowledge disabilities related to severe CFS. However, much remains to be done to ensure access to CFS healthcare and to disability, human and civil rights at the national standard.

10. "People usually get better from CFS, it's just a matter of time."

Answer: False

Most people with CFS will have it for the course of their lifetime, despite using all available symptomatic treatments and complementary medicine.

Though the severity of the syndrome may vary extensively throughout one's life, the rates of relapse following remission are relatively high. Children and adolescents have a higher rate of improvement to closer-to-normal function, though why this is so is not clear.

We may well find that CFS is not one illness stemming from one cause, but a group of illnesses which result in similar clinical pictures.

The general consensus from research suggests patients have about a 6% chance of recovery – however, follow-up studies of rates of relapse are presumably unknown. For those who remain sick, illness severity can be high and quality of life can be greatly diminished. Life span is shortened by at least 10 years. CFS clinicians agree that early diagnosis is an important factor in how severe the CFS becomes. Optimal management can at least prevent progression to housebound, dependant, and bedridden states.

Biomedical research is pointing to viral and environmental chemical damage to gene function...so we should not be surprised by the words of CFS genetics researcher Jonathan Kerr, who notes that the specific treatment of virus infections could provide more benefit than is currently being given credit for:

"There is no specific treatment for CFS other than the much-underutilised approach of specific treatment of virus infections. Current priorities are to understand the molecular pathogenesis of disease in terms of human and virus gene expression, to develop a diagnostic test based on protein biomarkers, and to develop specific curative treatments."

Viral or other infectious epidemics which resulted in a percentage of the affected people subsequently developing CFS are well documented. The immunological research continues but like all CFS research is grossly under-funded worldwide.

The 2007 identification of 7 subtypes of CFS based on gene impairments and clinical picture (symptom range) may assist researchers in determining if recovery is a subtype-dependant phenomenon.

Dr. Paul Cheney, 30-year-long American CFS researcher, identifies 3 stages of CFS – and has added a 4th stage recently. Stage 3 patients are housebound and unable to function independently. Stage 4 is the bedridden or severely ill state. Identification of stages of CFS is an important aspect of care still not widely anticipated.

10. popular myths - Conclusion

A full understanding of the causes and course of CFS will involve cutting edge research – requiring “cutting edge” public and private funding. Will Canadian medical researchers rise to the challenges set by the international community of biomedical researchers of CFS? Inspiration and political will starts with education.

CFS remains largely invisible both medically and politically in Canada. Many myths are left unchallenged. Pass around this myth-busting quiz – inform the media. Patients with CFS need champions from among the healthy, socially-concerned, and scientifically-educated members of society.

For access to the 2003 Canadian Consensus Documents for Diagnosis and Treatment of CFS for the Health Canada guidelines for the diagnosis and treatment of ME/CFS and fibromyalgia at www.mefmaction.net – select: Physician Resources.

How did you score? x/10

1/10 – Special thanks for learning so much about CFS! Feel free to pass that info along!

2-5/10 There are sooo many other facts about CFS... visit www.mefmaction.net for more!

6-7/10, you likely have CFS but are too sick to complete quizzes so you missed a few points.

8-9/10 – you get the gold star for CFS awareness!!

10/10 – you probably wrote the 2003 Canadian CFS consensus documents for diagnosis and treatment!

Linda MacDonald is the Assistant Science Director and Manager of Government Relations for the National ME-FM Action Network. She has been a physical therapist for stroke patients, an English as a second language teacher, a Canadian folk musician, a university graduate student in experimental phonetics, and is now housebound indefinitely and unable to work due to ME/CFS, multiple chemical sensitivity and fibromyalgia.

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RESOURCES

Complete Original Consensus Documents

-FMS Consensus Document - US\$24.95

"The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners".

Haworth Press, 2004. (soft cover book)

ISBN: 0-7890-2574-4

Phone: 800-429-6784 Fax: 607-771-0012

Email: orders@haworthpressinc.com

Online: <http://www.haworthpress.com/store/product.asp?sku=5342>

-ME/CFS Consensus Document US\$14.95

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

Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004

ISBN: 0-7890-2207-9

Phone: 800-429-6784 Fax: 607-771-0012

Email: orders@haworthpressinc.com

Online: <http://www.haworthpress.com/store/product.asp?sku=4958> CFS46

Overviews of the Consensus Documents:

Fibromyalgia Syndrome, 24 pp, 2006

Chronic Fatigue Syndrome, 20 pp, 2006

can be ordered from Marjorie Van de Sande at mvandesande@shaw.ca or at 151 Arbour Ridge Circle NW, Calgary AB T3G 3V9.

Version française : Abrégé du Consensus sur le SFC: \$5.00, – (NEW/NOUVEAU), payable par chèque seulement, à AQEM

Commander à AQEM, 7400 Boul. Les Galeries, bureau 410, Anjou, (Québec), H1M 3M2, Tél. Montréal : 514-369-0386; (à l'extérieur) : 1-877-369-1689 sans frais; site web : www.aqem.org

ME/CFS DVD Resources

Prices include shipping & handling

- **Dr. Kenny De Meirleir - Physicians' full day workshop \$80.00. This includes 4 DVDs and a CD**

Canadian Consensus Guidelines for Diagnosis, Assessment and Treatment of ME/CFS -What they are and how to use them.

- Research Update
- Diagnostic Work Up and Treatment Algorithm

- Case Examples and Discussion
- CD of Slides

- **Dr. Kenny De Meirleir : Patients' lecture \$25.00**

Payment: must be by **cheque** or **money order** payable to **Marjorie van de Sande**

Mail it to her at **151 Arbour Ridge Circle NW, Calgary AB T3G 3V9.**

Network Resources

The following resources can be ordered from the National ME/FM Action Network. Prices include shipping and handling. Cheques should be made payable to the National ME/FM Action Network or you may pay by VISA or MasterCard.

Quest Collections

By popular request, the **National ME/FM Action Network** has published two collections of important articles which have appeared in 'QUEST' newsletters. The articles in each five-year collection have been grouped into sections according to their focus.

Quest Collection I: presently out of print

Quest Collection II (1999 – 2003): \$38.00

Quest Collection III (2004-2008) Will be published shortly – orders accepted now: \$38.00 NEW

TEACH-ME: A Sourcebook for Teachers (Second Edition): \$22.00 *Discount on bulk orders With Dr. D. S. Bell, Dr. B. M. Carruthers and the TEACH-ME Task Force (teachers with ME/CFS and/or FMS)*

This educational resource book will enhance teachers' and parents' understanding of ME/CFS and FMS in young people, and assist educators in developing educational modifications and programs.

TEACH ME: (traduction française): Guide de référence pour l'enseignement aux élèves souffrant d'EM/SFC et/ou de la FM. \$22.00, 120 pp. NEW/NOUVEAU

The Canada Pension Plan Disability Benefits Guidelines: \$7.00.

Guidelines have been designed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. It will help you understand the criteria, important items to include and walks you through the various steps of the process.

NETWORK NOTES

IME/FAE Registry Submission

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: **National ME/FM Action Network** – Or download the Form from our website at www.mefmaction.net

PLEASE NOTE CHANGE OF ADDRESS AND FAX NUMBER

MEMBERSHIP: \$25.00 per year, which includes quarterly newsletters

Payment can be made by CHEQUE, VISA or MASTERCARD.

Do not email credit card information.

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