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CONTENTS

OOPS!... In our last newsletter, the article entitled "What's Up at FM-CFS Canada" incorrectly stated that the Consensus Panels updated the Overviews.

***Correction*: The Overviews were written and published by Dr. Bruce Carruthers and Marjorie van de Sande. They were not updated by the Consensus Panels.**

MEDICAL NEWS & VIEWS

The National ME/FM Action Network is Assisting a FMS Research Study

The development and publication of the Canadian Consensus Documents for fibromyalgia syndrome and myalgic encephalomyelitis/chronic fatigue syndrome were the fruition of years of lobbying by the National ME/FM Action Network.

Dr. I. Jon Russell and Dr. Stu Donaldson were members of the Expert Consensus Panel for FMS. They were introduced at the Canadian Consensus Panel Workshop and have communicated on a regular basis since that time. Dr. Russell and Dr. Donaldson have presented jointly at numerous conferences in the United States.

Dr. Russell and Dr. Donaldson have teamed together for a research study in FMS. We are excited that the Expert Consensus Panels' Workshop has resulted in members of the panel collaborating in important research studies.

The National ME/FM Action Network is very pleased to announce that we are providing financial assistance in support of this important research study.

Jon Russell, MD, Ph D, of San Antonio, Texas and Stuart Donaldson, Ph D, of Calgary are joining forces in an exploratory research study to examine numerous aspects of fibromyalgia including blood markers, spinal fluid, brain wave patterns and muscle activity.

Dr. Jon Russell is renowned throughout the world for his works in biochemical aspects of fibromyalgia. He has published extensively in refereed journals and in numerous textbooks. He is Editor of the Journal of Musculoskeletal Pain and a leading force in researching and lecturing on FMS.

Dr. Donaldson has studied the muscle activity and brain wave activity of fibromyalgia sufferers. His research shows that all fibromyalgia sufferers show abnormal muscle firing patterns affecting the entire body. Donaldson's research documenting the presence of different types of brain wave activity suggests the presence of subgroups with differing brain wave activity patterns.

The purpose of this study is to integrate the works of Dr. Russell and Dr. Donaldson to attempt to match blood and spinal fluid markers to the muscle and brain wave activity and to examine if these differ by subgroups. It is hoped this research will enhance a greater understanding of fibromyalgia syndrome and lead to markers, which would help in the diagnosis and treatment of fibromyalgia.

The National ME/FM Action Network wishes to congratulate Dr. Russell and Dr. Donaldson for initiating this innovative study.

Dr. Donaldson Receives Award

The National ME/FM Action Network extends our congratulations to Dr. Stu Donaldson, who received an award from the University of Alberta in recognition of significant contributions made by alumni over a number of years in their local community and beyond. Dr. Donaldson was recognized for his innovative work in surface electromyography, chronic pain and fibromyalgia. Dr. Donaldson, who received the award on September 28, commented, "I was actually stunned. I'm totally honoured, there are so many people doing so many good things."

The National ME/FM Action Network was Asked to Assist the Women Affiliate of the Canadian Health Network (CHN)

In a letter to our organization from CHN, they stated: "As a network contributor to the CHN and an expert in the area of fibromyalgia, we would like to ask for your assistance in reviewing the revisions and updates that we have made to the following FAQs: **What is fibromyalgia? How can I cope with fibromyalgia?**"

Marj van de Sande was pleased to review the CHN information about fibromyalgia and make some suggestions. We think their information is helpful for patients and look forward to seeing their new Frequently Asked Questions when they are posted on their website **www.canadian-health-network.**

Fibromyalgia, chronic fatigue syndrome and multiple chemical sensitivities. What do they have in common?

By Dr. Alison C. Bested

They are common poorly understood chronic multisystem illnesses that are newly recognized by the medical community and mainly affect women. Men and children can also be affected. They occur in 1.5 to three per cent of people according to the 2003 Canadian Community Health Survey. They cost the health-care system millions of dollars in health-care costs and the economy millions of dollars in lost wages. As a result of being chronic illnesses, this added burden often leads to family break-ups.

The following are summaries of the clinical definitions that describe these conditions.

Fibromyalgia (FM) is characterized by more than three months of pain on both sides of the body and at least 11 out of 18 positive tender points present on physical examination. Additional symptoms can also include: severe fatigue; sleep disturbance; neurocognitive problems including impaired concentration, reduced short-term memory, and difficulty multitasking; problems regulating blood pressure, irritable bowel symptoms; body temperature instability; and loss of adaptability to stress with anxiety or reactive depression.

The criteria that define Chronic Fatigue Syndrome (CFS) include the following: severe disabling fatigue and post-exertional fatigue; sleep disorder; muscle pain and headaches; problems with mental functioning such as impaired concentration, reduced short-term memory and difficulty multitasking; symptoms related to the autonomic nervous system such as low blood pressure and irritable bowel syndrome; autonomic neuroendocrine symptoms such as low body temperature, weight change and worsening symptoms of stress with anxiety and reactive depression; immune symptoms including ongoing sore throat and swollen glands, flu-like symptoms and new sensitivities to food, medications and chemicals; and persistence of the illness for at least six months in adults and three months in children. All other causes of the above symptoms must be ruled out before the diagnosis of CFS is made.

Multiple Chemical Sensitivity is a chronic condition characterized by symptoms that are reproducible with repeated chemical exposure. Very low levels of chemical exposure (lower than commonly tolerated), produce the patient's symptoms. The symptoms improve when the patient is removed from the chemicals. The patient responds to many chemically-unrelated substances. Symptoms involve multiple body symptoms but the most common symptoms include feeling dull or groggy, having difficulty concentrating, feeling "spacey", and having a stronger sense of smell than most people.

As you can see there is considerable overlap in these three conditions. As a result of public pressure, the Ontario government created the Ad Hoc Committee on Environmental Hypersensitivity Disorder chaired by Judge George Thomson. Their 1985 report stated that patients with Environmental Hypersensitivity (now called MCS) had significant health problems that required further research. The committee recommended that patients be treated with compassion and that a special clinic be funded as a bridge between patients, health professionals and researchers. The clinic opened in 1994 at Women's College Hospital and is now called the Environmental Health Clinic. When the clinic opened it also included an initial grant for a Research Unit connected to the clinic.

The clinic does not have a full time physician to service the province of Ontario. Time is divided by three part-time physicians who work at the Environmental Health Clinic one day a week. This out-patient clinic's mandate is to do a one time comprehensive patient assessment and a one time follow-up visit a few months later. The clinic is under funded and not able to service the whole province and has a lengthy waiting list. There is an ongoing health-care access problem with patients who have severe MCS and need hospitalization, as there are no in-patient beds available for this patient population in Ontario.

The exact causes of these conditions are not yet known. Fibromyalgia is commonly seen after physical trauma such as car accidents. Chronic Fatigue Syndrome is most commonly seen after a viral illness from which the patient does not recover. Multiple Chemical Sensitivity is most commonly seen after chronic exposure to low levels of chemicals.

So how are these conditions treated? At the Environmental Health Clinic we have developed the concept of "weed and seed". Weed out the bad habits of being sedentary, stressed out, eating junk food, drinking poor quality water, exposure to poor quality air and having poor sleep habits. Replace these with the "SEEDS" of health, which is short for the following:

Support: medical support for the patient - physical, emotional & spiritual; family, plus work place accommodation.

Environment: pesticide free food, water and better indoor & outdoor air quality.

Exercise: and Pacing of activities with appropriate rests.

Diet/Drugs: as needed for symptomatic relief of sleep and pain etc.

Sleep Hygiene: for better sleep quality.

In the last few years medicine has developed clinical definitions for the above conditions and research has begun to help unravel the mysteries of these illnesses. Preliminary genetic studies that were done through the EHC Research Unit showed that patients with MCS were "different from the controls in genetic polymorphisms in drug-metabolizing enzymes". This is a fancy way of saying that patients with MCS metabolize chemicals through their livers differently than normal people. This might help to explain why they are more sensitive to chemicals than most people - perhaps the chemicals hang around longer. More research is desperately needed in these areas.

The book ***Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia****, by Dr. Alison C. Bested, Dr. Alan Logan and Mr. Russell Howe was written to educate and uplift patients and their families.*

Alison C. Bested, MD FRCP, is a Staff Physician in the Environmental Health Clinic at The New Women's College Hospital. "Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia" is published by Cumberland House and is available at Indigo/Chapters,Amazon.editor@hospitalnews.com
[**Editor's note:** Re- published with authorization from Hospital News, July 2006/Your Health Source.

Post-Exertional Fatigue and Malaise – There is Hope!

By : Philipa Corning, Ph.D., B.Sc.; Odell Pui, B.Sc., Medical Laboratory Science; and Linda MacDonald, B.A., B.Sc. (Physical Therapy**).**
Reviewed by Dr. Bruce M. Carruthers, M.D., C.M., FRCP(C)

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a distinctive entity with many non-specific symptoms, including post-exertional malaise and fatigue. Its causes are still unclear. One of the keys to managing and developing novel means of therapy for this illness is an understanding of the possible molecular and genetic mechanisms responsible for the functional fatigue. Indeed, the main purpose of this present article is to explain some of the mechanisms that may be involved in fatigue and malaise following exertion for those afflicted with CFS (or PWCs – persons with CFS). Furthermore, the other purpose of this article is to prepare readers for articles on "Restorative Exercise for CFS", which are scheduled for the winter and Spring issues of Quest. An innovative approach was designed with this illness in mind, and has been researched by Staci Stevens, M.A. at the University of the Pacific. Presently, she and her team at the Workwell Foundation in Ripon, California are using this approach, and it has proven very beneficial to many of those afflicted with CFS (PWCs) in improving their health and level of function.

Organization of Cellular Work/Activity

The body is organized around the functional unit known as the cell, which consists of two distinct regions: the nucleus, which is surrounded by a viscous fluid known as the cytoplasm containing specialized structures where cellular work or activity is conducted. Although cellular work takes place in the cytoplasm, the information that directs that activity is contained in molecules called DNA located in the nucleus. The molecules of DNA are divided into segments called genes. Each gene controls the production of one specific protein, and protein production takes place in the cytoplasm. The information contained in the gene is copied into a molecule called RNA, which passes out of the nucleus and into the cytoplasm where it controls the production of a specific protein. Each protein either becomes a part of cellular structure or performs cellular work/activity. This entire process from gene to the production of a specific protein is called "gene expression".

Energy Production Systems within Cells

To carry out cellular activity, cells require energy. All cells of the body have two different types of energy production systems to provide that energy – aerobic and anaerobic.

Aerobic Energy - The aerobic energy system produces energy with the presence and use of **oxygen** supplied by breathing. Aerobic activities are ones of endurance, and require a steady supply of energy over an extended period of time. Some examples of aerobic activities are: everyday functions including digestion, sleeping and thinking; and in terms of traditional exercise, walking, running marathons, climbing, dancing, house work, etc.

Anaerobic Energy - The anaerobic energy system produces energy **without** the participation of oxygen. Anaerobic activities use energy for one maximum effort over a short period of time, or for a series of short maximum efforts interspersed with periods of rest. Examples of anaerobic activities are: running for the bus, sprinting in running and swimming, weight lifting, football plays, etc.

Diminished Energy Production in CFS

For most daily activities, healthy people utilize the aerobic energy system. This system is the one that is damaged and thus impaired in CFS. Research into CFS has produced evidence of various types of impairment of the aerobic energy production. As a result in CFS, the anaerobic energy production system starts to take over when the aerobic energy system cannot supply energy quickly enough to maintain activity. Three of these possible impairments will be discussed in this article.

First of all, since the early 1980's, research has presented evidence of mitochondrial damage. Mitochondria are tiny structures located in the cytoplasm of the cell that are responsible for the aerobic production of energy. They are often referred to as the "energy factories" or "powerhouses" within the cell. More recently, research has provided evidence of dysfunctional genes involved in aerobic energy production (**second impairment)**, and evidence of an abnormal molecule called "RNaseL" (**third impairment**) associated with reduced exercise capacity. These pieces of research give explanations for the inability of PWCs to undertake even normal daily aerobic activities. They also explain why these individuals crash into a state of exhaustion that cannot be relieved by rest after a bout of more classically recognized forms of aerobic activity. Once PWCs are exhausted, the aerobic system which is impaired takes hours and in many cases days to be replenished. For some, it takes years of convalescing due to the accumulative effect.

Impairment of Aerobic Energy Production in CFS

Reduction in the capacity to produce energy aerobically, results in the lack of energy and in the increased post-exertional fatigue of CFS.

(1) *Mitochondria* - According to Dr. Robert Cathcart[1] and Dr. Paul Cheney[2] who have been treating CFS patients and doing research on this illness since they first encountered it at Incline Village in Lake Tahoe in 1978 and 1983 respectively, there is mitochondrial damage in the case of CFS. According to Dr. Cathcart, such damage may be caused by viruses, bacteria, toxins, overload to chemicals, allergic reactions, free radicals, etc. Since the mitochondria (located in the cytoplasm of each cell) are the "powerhouses" of the body, damage to them leads to a significant reduction in aerobic energy production and subsequent increase in fatigue in CFS.

(2) *Genes and Enzymes* – Remember from the text above that genes are located in the nucleus of a cell. Their correct function ensures that needed types of proteins (enzymes) are produced in the cytoplasm. The production of the protein is referred to as "gene expression. If the proteins are correctly produced, gene expression and the resulting cellular activity are normal. In CFS patients (PWCs), gene expression has been found to be altered relative to normal individuals in "control" groups (individuals used as a basis for making a comparison). The genes affected include potential contributors to the syndrome. It is difficult to determine whether the altered gene expression is due to genetic inheritance or caused by environmental factors, as evidence is still controversial.

Some pieces of research suggest the role of genetic inheritance in altered gene expression in CFS, for example, in some twin studies a familial component has been indicated. [3, 4] Furthermore, Sullivan et al [5] found that no definition of fatigue-related illness had more of a genetic correlation. Therefore, a genetic component in CFS seems very likely.

On the other hand, changes in gene expression may also be a result of environmental factors such as bacterial and viral infections.[6, 7, 8, 9] Persistent viral infection is known to be a feature of CFS.[10] Gene expression changes as part of the body's immune response to fight against such infections. However, the mechanisms by which viral infection leads to gene dysregulation are unclear. Viruses replicate in a host by taking advantage of the cell's own machinery, that is, DNA in the nucleus, mitochondria, and other molecules and structures in the cytoplasm. One of the genes found to be up-regulated in CFS is EIF4G1, a component of the protein complex that various viruses have diverted from the cell machinery to the manufacturing of their own viral proteins.[10]

Regardless of the contributor's origin – inherited or environmental, recent exciting research has made a major genetic breakthrough in CFS. In 2005, Dr. JR Kerr[11] and Dr. J Gow[12], both British researchers, conducted and published their independent research findings. Their research teams identified genes that controlled cellular protein production pathways that were up-regulated (more active than normal) or down-regulated (less active than normal) in PWCs. In Dr. Kerr's research some of these identified genes play important roles in the mitochondrial function. Indeed, he indicated: "the involvement of such genes does seem to fit with the fact that these patients lack energy and suffer fatigue". In other words, genes that are down-regulated and are involved in the production of energy by the mitochondria would lead to reduced energy production and increased fatigue. In addition, genes that are up-regulated may be involved in cellular activities that are a drain on the amount of energy available to the cell. This could result in increased fatigue as well. Unfortunately at this point, such consequences of up-and-down-regulated genes are only hypotheses, and further research is required to provide the detailed information to fully understand the roles played by up- and down-regulated genes.

(3*) Abnormal RNaseL in CFS*

During recent years in CFS research, a great deal of attention has been focused on a viral activated pathway within cells of the body. Drs Paul Cheney, RJ Suhadolnik and R. Podell have identified a molecule called RNaseL that is abnormal in CFS patients, and have connected its presence with increased fatigue. [13, 14, 15, 16, 17]

RNaseL – When a virus infects cells of the body, it basically hijacks these cells and forces them to produce new viruses which includes viral protein. This directs the cell's enzymes away from their normal performance in the cell including the production of energy, thereby increasing an individual's level of fatigue. When viral infection occurs, an antiviral pathway called "RNaseL" is activated. This pathway produces an enzyme called "RNaseL" that destroys RNA, the molecule which is now controlling the synthesis of viral protein. Therefore, the purpose of the RNaseL pathway is to prevent viral protein from being produced, and in this way stop the virus from reproducing. In CFS this pathway is up-regulated when the immune system is activated by an infectious agent, toxic substance, food allergy, etc. This up-regulation may be due to faulty gene regulation.[18] In the end, not only is aerobic energy production decreased, [13, 14] but also the RNaseL pathway is activated, which leads to a further drain on the cells' energy stores. Of course many of these consequences of the abnormal RNase-L production remain hypothetical and need to be worked out in more detail.

Weight of RNaseL Molecule – Normally, the RNaseL molecules produced in the cells are designated as 80, 42 and 37 kDa RNaseL. The acronym kDa stands for kilodalton, which is the weight of a molecule. A higher number indicates a higher molecular weigh. Researchers found that there were increased amounts of all three forms (80, 40, and 37 kDa) in CFS patients. [13, 14, 19] However, in addition in PWCs, there is an abnormality resulting in the buildup of an abnormal low molecular weight form of RNaseL (37 kDa) that is not otherwise found in normal "control" individuals.[20] Furthermore, the total RNaseL activity is also increased in PWCs.[21] This abnormal molecule is potent in its activity [22] and it rapidly recycles, thus using extraordinary amounts of ATP (the energy storage molecule produced by the energy production systems within the cell). [13, 14]

Impact of Viral Infection and RNaseL – As a result of viral diversions of cell enzymes and RNaseL activity, huge amounts of ATP (energy) are used up, leaving little energy left for other cellular activities. Thus, it is a reasonable hypothesis that PWCs have a significantly impaired aerobic energy production system because of this excessive use of ATP and, therefore, feel excessive fatigue as a result.

Conclusion

The abnormal exercise response in CFS patients, with the symptoms worsening after exertion, can be due to a number of factors[7]. However, in this article we have focused on three specific ones – mitochondrial damage, dysfunctional genes, and abnormal RNaseL, and the possible roles that they might play in the impairment of the aerobic energy production system.

There is evidence of reduced aerobic capacity and impaired aerobic energy production in PWCs. The most commonly used measure of an individual's cardiovascular functional capacity and aerobic fitness is called the aerobic "V_{O2max}". It is defined as the maximal rate at which oxygen can be taken up and utilized for exercise. It is measured in units of L/min or can be expressed per kilogram of body weight. As an individual exercises over a prolonged period of time or at an increasing rate, there will be a point where oxygen consumption will level off; this is known as V_{O2max}. This index is a composite of 1) the ability of the lungs to extract oxygen from air and deliver it to the blood; 2) the ability of the blood to deliver the oxygen to muscle tissues; and 3) the ability of the muscle to utilize the oxygen for energy-producing pathways. In CFS, exercise capacity and V_{O2max} decrease. In fact, PWCs show a reduced aerobic exercise capacity compared with control individuals in each of the following measurements: peak VO_2, peak heart rate, exercise tolerance, and exercise duration. [23, 24, 25] Furthermore, the symptoms worsen after exertion.

These types of impairments to the aerobic (requires oxygen) energy production system, although very different from one another, all decrease the aerobic capacity of the PWC, and at the cellular level they would leave the cell little option except to possibly increase its reliance on anaerobic pathways, which do not use oxygen and are also less efficient.

Hope

Fortunately, the anaerobic energy system can regain its energy production relatively quickly. It is clean running except for the accumulation of lactic acid (a byproduct) in the muscles. Lactic acid can be removed by rest or very mild exercise (eg, body builders rest in between repetitions of working with weights, and runners do mild walking at the end of a sprint). Therefore, on a theoretical basis, the new type of approach called "restorative exercise" makes sense, ie, a person that has an impaired aerobic energy production system, should be able to use the anaerobic system and do anaerobic types of activity with appropriate build-in rest periods.

According to the ME Society of America (a research-information and advocacy group in the United States), "when the capacity of cells to take up and release oxygen is impaired, the body shifts to anaerobic metabolism".[26] Therefore, the practice of "restorative exercise" offers hope that PWCs can regain some function and improved health through a well designed, personalized program of non-aerobic or anaerobic exercise.

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LEGAL NEWS & VIEWS

Court of Appeal unanimously upholds Trial Judgment but majority reduces record quantum of Punitive Damages

***Keays v. Honda Canada Inc.*, 2006 CanLII 33191 (O.C.A.).**

By Hugh R. Scher

The Ontario Court of Appeal has released its decision in *Keays v. Honda Canada Inc.* The Court unanimously upheld all of the legal principles set out and relied upon by the trial judge to justify his award of damages for wrongful dismissal, Wallace damages, punitive damages and costs. Honda is considering an appeal to the Supreme Court of Canada.

The Court unanimously upheld the finding of two years notice for Mr. Keays, including a nine month extension in the notice period for Honda's bad faith in the manner of termination (*Wallace Damages*). The Court further upheld the legal costs award on a full indemnity basis together with a premium bonus, but reduced the premium bonus from $155,000.00 to $77,500.00 thus bringing the total cost award close to the $610,000.00 originally granted, inclusive of interest and $35,000.00 costs for the appeal.

With respect to punitive damages, the Court was split with Justice Goudge holding that the entire $500,000.00 should be upheld along with the balance of the trial judgment. However, two Justices of the Court ruled that the punitive damages award should be reduced from $500,000.00 to $100,000.00. The basis for their decision was the suggestion that the trial judge's finding of fact related to a protracted corporate conspiracy on the part of Honda was not supported by the evidence and that the award was disproportionate to Honda's high handed conduct.

The Court unanimously held that Honda's conduct was planned and deliberate and designed to intimidate and ultimately terminate the employment of a particularly vulnerable employee and that Honda was aware of its continuing duty to accommodate, thus justifying an award of punitive damages. The Court concluded that an award of punitive damages was necessary and appropriate to punish Honda for its outrageous conduct and to deter other employers from engaging in such high-handed behaviour.

This decision has significant implications for people with disabilities and particularly people with Chronic Fatigue Syndrome and Fibromyalgia. The Court held that "it is important that the accommodation process display more open-mindedness and less prejudgment if the disabled are to be accorded the dignity and equality to which they are entitled."

The Appeal Court set a new standard for employers acting in the accommodation process requiring that they act reasonably, honestly, open-mindedly and in good faith, failing which they may be held liable in damages, including punitive damages.

The Court of Appeal also established the important principle that an employer who seeks a better, more efficient workplace by instituting a structure that gives employees' responsibilities more equal worth, cannot expect to entirely escape the consequences of that fact when reasonable notice periods are assessed.

As noted by the Court, the need for this large employer, and indeed all employers, to take seriously their responsibilities in accommodating employees with disabilities is very important. "This is, if anything, more true for employees whose disabilities may be seen by some as outside the mainstream and therefore not genuine."

"The accommodation process must be approached in good-faith, openly, and sensitively if the dignity and equality of disabled employees is to be respected as required by the law and morality." An employer must be deterred from engaging in subterfuge to wrongfully terminate a disabled employee in order to escape these responsibilities.

The decision has significant implications for employers in the accommodation process to fairly and reasonably assess employee claims for accommodation, particularly where the nature of the disability is invisible and not readily demonstrated by objective medical information.

The Court of Appeal has recently applied a similar standard to independent medical assessors. In *Lowe v. Guarantee Insurance* (2005), O.J. (O.C.A.) and *Worthman v. Assessmed Inc.*, 2006 CanLII 7038 (ON S.C.D.C.), the court held that IME assessors could be held liable in damages where they act in a biased, bad faith manner.

The Keays case represents an unprecedented award of punitive damages for discrimination and harassment in an employment case and if the totality of the award is considered, it amounts to approximately $900,000.00.

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 insurance, employment, 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 is counsel to Kevin Keays in Keays v. Honda.

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Mediating Disability Claims

By: J. Roy Nickerson, B.A., LL.B.

When a disability insurer refuses to pay disability benefits, the only recourse available to the victim is often litigation – Sue The Bastards!

In this process, the victim is further victimized by exposure to the "adversarial system", which is far removed from anything they've ever experienced in the past, and is completely divorced from anything they've seen on television.

No matter how determined a claimant is to have his or her day in court, the process, before one even has a hint of a trial date, is extremely drawn out and tiresome, even with a motivated and talented legal advocate and usually includes the following:

- Complicated documents have to be prepared with input from the claimant in what is known as a breach of contract action;
- Examinations for Discovery have to be completed, which would include an emotionally draining and sometimes physically painful in-depth inquiry into all of the claimant's medical history;
- Insurance examinations by unsympathetic, skeptical, if not downright cynical medical practitioners have to be endured;
- Lengthy and complex vocational or psychological tests may also have to be endured.

While all the above is happening, the claimant's medical practitioners, upon whom the claimant will depend at trial to give important evidence on their behalf, may be losing interest in the case and may become more and more reluctant to answer the letters and phone calls of the lawyer, let alone be enthusiastic about the prospect of appearing in court. The claimant's treatment may even be put in jeopardy.

Obviously, the claimant is motivated to settle a case as soon as possible, even if compromises have to be made.

Fortunately, the uncertainty of a large claim, usually including a claim for punitive damages, motivates insurance companies to settle as well.

One way to speed up the process is mediation. Mediation is the introduction of a knowledgeable and independent stranger to the process, well before trial, who attempts to bring the adversaries to common ground.

Besides the obviously advantage of speeding up the receipt of money by a deserving claimant, there are other advantages to mediation:

- The disability insurer can usually be persuaded to agree to pay for the cost of a mediator. Mediators don't come cheap as they are usually very knowledgeable and personable individuals.

- The parties have input into who will mediate. They do not have input in who will judge their case in a courtroom.
A trial can be an all-or-nothing proposition. Worse yet, a loss at trial can see the loser being saddled with devastating court costs.

- Mediation usually takes place in the comfort and privacy of the mediator's meeting room.

- There is no "point of no return" in a mediation – "no deal" is an option in mediation. In a trial, the judge has control and, if an inherent weakness crops up in the case, the claimant's options are limited to capitulation or the greater risk of forging on to an inevitable loss.

Remember, one thing they never ever talk about in television trials is the specter of court costs. On TV, the loser walks away with nothing. In real life, the loser can walk away with insult added to injury: the insult being the insurer chasing the claimant for ruinous court costs. These may amount to thousands of dollars a day for the insurer's defense team, as well as the unpalatable specter of paying the horrendous fees of an insurance doctor for minimizing the claimant's illness or condition.

This is a bigger risk than a lot of people anticipate, because of a lack of appreciation on the concept of "onus of proof". A claimant is obliged to prove, on a balance of probabilities, his or her claim and that requires evidence from committed, compassionate, and competent medical practitioners functioning in an overburdened medical system. A claimant is also usually represented by a single lawyer taking on a team of insurance lawyers.

Even though the stakes aren't as high in a mediation, that doesn't mean the procedure should be taken lightly. The claimant and the lawyer should be as well prepared for mediation as for a trial. Every concern of the other side which can be intelligently addressed will result in an improvement in the final offer. You do not have to like the other side's position but you have to understand it. More progress will be made by confronting the weaknesses in the claimant's case than by trumpeting the strengths. The insurer already knows those strengths or they wouldn't be prepared to settle.

Also, be prepared to be confronted by credible sounding contrary arguments that may not have been anticipated. If they sound ridiculous, don't waste time saying so, spend time showing it.

If the surveillance video shows scenes which are inconsistent with the claimant's disability, then more will be accomplished in a frontal attack on why and how the video distorts reality than repeating the contents of a favourable medical report.

If a credible insurance doctor states a claimant is able to perform light inside work, which contradicts a treating physician's contrary opinion, don't dwell on that contrary opinion. The insurer would be more persuaded by being shown that "light inside work" doesn't exist in the claimant's environment or that the claimant is untrained to do that kind of work long enough to earn a reasonable income.

Mediation allows for the mediator to meet with individuals from both sides, separately. The more reasonable the claimant sounds, the more helpful the mediator may be in encouraging the insurer to make a reasonable offer.

It's a waste of time to attend mediation without knowing what a reasonable offer is. The claimant should have a goal and it should not be an inflexible bottom line. If the claimant shows up with no goal, other than to find out what the insurer's bottom line is, he or she won't find it.

Flexibility is the key to a successful mediation. Most cases deal with various components: past benefits, possible future benefits, the taxable position of both benefits, and punitive damages. The last item is almost impossible to obtain but it still causes the insurer to be concerned about the prospects of bad publicity, if there's an adverse result at trial. Usually insurance policies entitle the insurer to deduct CPP benefits and sometimes disability benefits can be reinstated to the claimant on the understanding that the claimant will strenuously pursue their CPP benefits.

Most mediations end with a settlement with both parties feeling that they conceded more than they had to. That is not a bad thing. In the end, both parties benefit from the inherent value that "certainty" adds to any dispute.

[**Editor's note**: *Mr. Roy Nickerson is a Senior Litigator & Victims' Advocate, who practices law in Alberta at Nickerson Roberts Holinski & Mercer, Barristers & Solicitors, 1901 Toronto Dominion Tower, 10088 – 102 Avenue, Edmonton, AB T5J 2Z1 – Tel. (780) 428-0041 Fax: (780) 425-0272 – Email: rnickerson@nrhmlaw.com – Web: www.nrhmlaw.com]*

National Lawyers' Roster - Addition

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The National ME/FM Action Network has a New Website!

The National ME/FM Action Network would like to thank **Bob van de Sande**, Marj's son, for building us a new website. Instead of taking a planned break, Marj van de Sande, our webmaster, spent much of the summer developing a new menu and content and programming several hundred new pages and links. She has endeavoured to make the website as user-friendly as possible.

Our new website has the same address <u>www.mefmaction.net</u> and general look but it has lots of new features.

- **New Menu:** We now have a menu under our logo at the top of the page, which gives the general categories. The various sections for the chosen category will appear in the left-hand menu. In addition, there is a **site map** link located at the bottom of each page.
- **Patients' Corner:** We have added a "Patients' Corner" to allow more input from patients. It is hoped that members will visit the Patients' Corner often. Please contribute to this area.
    - **Faces:** We want to personalize these illnesses – patients are not statistics but are real people. Please send us your picture and your story about having ME/CFS or FMS.
    - **Writers' Wings:** Writing and sharing can be therapeutic. We encourage patients to send us their creative writings – poems and short prose. Because patients tire quickly, please keep your poem/prose to approximately one or two pages. There are three topic categories. **Soaring Flights** is uplifting or inspirational writing or seeing the beauty in little things. Sometimes being ill can change your view on things. **Pivitol Points** is looking at something from a different perspective. **Upside Down** is for humourous writing.
    - **Painted Wings:** Painting or drawing can be very rewarding for patients. Please send us a picture of your art work to post in the Patients' Corner.
    - **Timely Tips:** Have you found something that helps you cope with these illnesses? Share your tips so that they may help others.
    - **Moving Moments** and **Chuckles** are the last two sections of our Patients' Corner. Reading about illnesses is heavy reading and sometime you need a break. The inspirational writing and humorous items in these two sections are not necessaraly written by patients but are intended to give you a cognitive break. We welcome items that would be appropriate for these sections that are not copyrighted.
- **Youth Corner:** Often young people with ME/CFS and FMS feel isolated and want to hear about other kids with these illnesses. We have expanded our Youth Corner to make it more kid-friendly. We are delighted that Sarah Lacy, age 18, has kindly agreed to be our Youth Corner Assistant. The Youth Discussion Board will be opening soon.
    - **Young Faces:** We want all young people with ME/CFS and FMS to send us their picture and their story.
    - **Creative Voices:** Writing can be rewarding. We are asking young people - 25 years and younger - to send us their poems and prose, approximately 1 to 2 pages.
    - **Artistic Expressions:** We would like to feature the artwork of young people with ME/CFS and FMS. Please send us a picture of your artwork.
    - **Our Voice – Articles:** Young people with ME/CFS and FMS can send us short articles about how to cope with these illnesses.
    - **Our Voice – Discussion:** Kids can discuss their ideas about the illnesses with other kids. The youth discussion board will be opening soon.
    - **The remainder of the Youth Corner provides information for Parents and Educators.**

- **Caregivers:** This new section of our website provides helpful information for caregivers.
- **Notice to Online Members:** We have discontinued the "Members Only" area of our website because it was too time consuming. All members will receive Quest by mail. The information that was in the "Members Only" area is now accessible to everyone. However, there is a one-year lapse between when Quest is published and when it is entered into our "Quest Library" in consideration to our paying members.
- **Libraries:** Our newsletter **"Quest", Legal and Research Libraries** and **search engine** are now accessible to all. These libraries have a wealth of information in them. The case law summaries for the remainder of 2005 and 2006 are now posted. The National ME/FM Action Network would like to thank David Lackman, barrister and solicitor, of Lackman Firestone Law Offices (416-364-0020) for having a case law search done on our behalf, not only this year but for the past several years.
- **Support Groups:** In addition to our directory of support groups, we have expanded the information about support groups. We are also pleased to post support group information and notices of meetings and events in this area.
- **Media:** Our new media section is designed to provide a place where the media can make a quick stop to obtain basic information about FMS and ME/CFS and other pertinent information.
- **Under Construction:** We still have lots to do so please be patient.

Important: Please send your picture and story, your creative writings, artwork and tips to post! Others would love to read you poem and prose and view your artwork. Check the submission guidelines on our website and send your submissions to Marj at **mvandes@shaw.ca**

Patients, please get involved. We need your input - let's hear from you! Your voice is our voice!

Sarah Lacy – Website Youth Corner Assistant

The National ME/FM Action Network is delighted to welcome Sarah Lacy as our Website Youth Corner Assistant. She is providing ideas to make the Youth Corner more kid-friendly.

When Sarah was struck with ME/CFS at age 12, she was the top of her class in a gifted bilingual program, did ballet 12 hours a week and had been accepted into the National Ballet summer school. Read her story and the article that was in the St. Catharines newspaper on our website.

Overviews Update

There has been excellent response to the Overviews, not only in Canada but around the world.

Translations

Dr. Carruthers and Marj van de Sande have given permission for the following translations:

- **French :** ME/CFS Overview - **L'Association québécoise de l'encéphalomyélite myalgique** [Québec] The translation is complete and is being reviewed.
- **German:** ME/CFS Overview - **Fatigatio** [Germany] The translation has been done and is presently being reviewed.
- **Spanish:** ME/CFS and FMS Overviews The ME/CFS Overview has been translated and reviewed. The translation of the FMS Overview is in the review process.
- **Danish:** ME/CFS Overview - **Danish ME/CFS Association.** The translation has been delayed due to illness.
- The translations of the Overviews will be posted on our website

Permission to Reprint the Overviews

Please note that all printings of the Overviews in North America and countries not listed below must go through Marj van de Sande. If you would like to place an order or purchase the Overviews please contact Marj van de Sande - mvandes@shaw.ca Please send comments regarding the Overviews to Marj.

The following organizations have been given permission to reprint the Overviews and have agreed that other organizations in their country can place orders through them.

ME/CFS Overview

- **United Kingdom** - East Anglia ME Patient Partnership
- **Australia** - Alison Hunter Memorial Foundation
- **New Zealand** - ME/CFS Nelson

Where Did the Overviews Go?

- **Canada** – 9,000 copies of each Overview were printed
- **Republic of Ireland**

All Primary Care Physicians (over 2500) and over 100 consultants were sent a copy of the ME/CFS Overview compliments of the Irish M.E./CFS Support Group.

- **Republic of Ireland**

The Irish M.E. Trust sent a copy of the ME/CFS Overview to 500 Consultant Physicians.

- **Norfolk Suffold and Cambridgeshire, United Kingdom –** 10,000 copies printed All primary healthcare practices in Norfolk Suffolk and Cambridgeshire receive a copy of the ME/CFS Overview compliments of Dr. Terry Mitchell, MA, MD, FRCPath, Consultant Haematologist. Head of Norfolk and Suffolk ME/CFS Service, NHS Clinical Champion for ME/CFS in Norfolk, Suffolk and Cambridgeshire, Honorary Consultant, The National ME Centre. The Overview will also be provided to patients who receive a referral to his clinic.

- **Solihull & South Birmingham, United Kingdom**
  All general practitioners and members were sent complimentary copies of the ME/CFS Overview by the Solihull & South Birmingham Support Group. They plan to extend this to other areas of Birmingham.

Website Notice to Online Members
We have discontinued the "Members Only" area of our website because it was too time consuming. All members will receive their newsletter by mail.

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**

MEMBERSHIP: $25.00 per year, which includes quarterly newsletters
Payment can be made by CHEQUE, VISA or MASTERCARD.
Do not email credit card information.
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

RESOURCES

Consensus Documents

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
"MyalgicEncephalomyelitis/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**

New 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**

- **Dr. Pierre Flor- Henry's lecture**: **$20.00** qEEG studies (current density source) & psychophysiological studies (very technical)

- **Dr. David Bell's lecture $25.00** (emphasis on chronic orthostatic intolerance)

Payment: must be by **check** 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 <u>National ME/FM Action Network</u> 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 II (1999 – 2003): $38.00

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.

The Canada Pension Plan Disability Benefits Guidelines: $7.00.

New up-dated 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.

Legal Disability Manual: **$60.00**
Approx. 400 pages *Editor: M. van de Sande*

The Legal Disability Manual includes sections on: FMS and ME/CFS Overview; The Medical Report and Expert Witnesses; Independent Medical Examinations; CPP Disability Benefits, Disability Insurance and Other Legal Articles; Case Law; Psychological Factors, Tests, and Treatments; and Research Abstracts. Many of the articles have been written specifically for the **National ME/FM Action Network** by lawyers and doctors. Our new Canada Pension Plan Disability Benefits Guidelines are also included in the Legal Disability Manual. This manual is a must for those in litigation.