Quest #37 August 1999

ME/FM CLINICAL DEFINITIONS/PROTOCOL - UPDATE

You may recall that we informed you in our last newsletter that we had presented the draft ME/FM clinical definitions and treatment protocols to the Laboratory Center of Disease Control and were informed that no monies had been set aside for ME/FM to do the peer review and dissemination of the information. We wrote the Minister of Health and the Director General of the LCDC asking for a meeting to discuss funding. We just received a reply from the Minister of Health that he is making arrangements with the Director General of the LCDC to meet with us on his behalf.

We will keep you advised when this meeting has taken place. Please help by forwarding a letter to the Director General advising how important it is that standardized clinical definitions be established for ME/FM. Be sure to also advise him that you support our Network in its Quest to bring these definitions to fruition. Address your letter to: **Dr. Michael Shannon, Director General, Laboratory Center for Disease Control, Tunney's Pasture, Postal Locator 0602C1, Ottawa, ON K1A 0L2 - Tel. (613) 957-0315 - Fax (613) 952-8189.**

TREATMENT WITH GANCYCLOVIR - By: Jeff Sherkey, M.D, , C.C.F.P.

In the Feb/Mar 1998 issue of Quest, Dr. Philipa Corning reviewed the work of Dr. Martin Lerner in his study of a group of CFIDS patients who he proved had a viral cardiomyopathy. You will be very interested to know, that subsequently to that article, a new antiviral drug, gancyclovir, was approved by the FDA, and Dr. Lerner treated 18 such patients with intravenous gancyclovir 5mg/kg I.V. every 12 hours for 30 days, while monitering blood parameters for potential problems to bone marrow, liver or kidney. The treatment was tolerated by all 18 patients without incident. 13 of the 18 patients, who, prior to treatment could not even do housework, were able to return to their former jobs. That is a success rate of 72%.

To follow further on this: Dr. W. John Martin has been lecturing for several years about a stealth virus which he has found in every CFIDS patient he has tested. The virus is present everywhere, but the brain is most susceptible to its effects of using the infected cells mitochondria and internal mechanisms for its own use and replication. Many of these patients were very sick and he did brain biopsies which showed vacuolization of brain cells. (Remember, these were extremely ill patients.) He now has refined his testing for the stealth virus by placing a patient's serum in a culture of healthy human fibroblasts. If the virus is present, it soon shows itself by turning the fibroblasts into vacuolated foam cells.

I recently sent my own blood to his lab for testing. The results were "strongly positive". Now, I have had CFIDS for six years. I am able to work full-time, but my life certainly is not what it was before I became ill. Dr. Martin gave me the name of two physicians in the U.S. who are using gancyclovir protocols , Dr. Jeff Kopelson in Brewster NY, and Dr. Ronald Kundargi in Los Angeles, CA.

I spoke to both of them last week. Their protocols differ slightly but they both send their patients' blood to Dr. Martin's lab for stealth virus testing, and if positive, they treat with 6 weeks of intravenous gancyclovir + various antioxidants etc. Both report 80% success rate.

I will be in Los Angeles for 5 days in early November. I am hoping to spend a day with Dr. Kundargi and observe how he administers the medication. He is an infectious disease specialist.Upon my return to Toronto, I will try the treatment on myself. The logistics of trying it on my patients are difficult. I hope I can enlist the help of an infectious disease doctor in Toronto, but I have my doubts. I encourage all members, and especially all doctors who are members of The National ME/FM Action Network, to check out Dr. Martin's website at http://www.ccid.org and print out and read all his publications there. By the way, ccid stands for The Centre for Complex Infectious Diseases. Dr. Martin also flatly states it is high time we dropped the name

Chronic Fatigue Syndrome etc. and called this illness a viral encephalopathy, which it clearly is.

This virus has dropped the genes that code for the antigens recognized by the immune system, and therefore gets bypassed by the immune system undetected, hence the name stealth. It has the uncanny ability to pick up genes from other viruses, bacteria, and even from the cell it is infecting. This would explain the many positive DNA PCR tests for mycoplasma, Lyme, etc. where antibiotics would be expected to work against these organisms but don't, because the PCR is picking up mycoplasma or Lyme DNA that has been incorporated into the virus.

Dr. Joseph Burrascano Jr., the world-recognized expert on Lyme disease, has agreed that he is seeing Lyme-positive patients who do not respond as expected to antibiotics, and he has joined Dr. Martin's stealth virus task force.

If there are any M.D.s who are National ME/FM Action Network members and are infectious disease specialists who would like to collaborate with me on a clinical trial of gancyclovir, please e-mail me at sherkey@home.com. I ask that patients do not e-mail me, as I cannot accommodate you, let alone my present caseload of CFIDS/FMS patients at this time. I am writing this so as to give you hope that effective treatment may be around the corner.

Wishing you all a speedy recovery,

Jeff Sherkey M.D., C.C.F.P.

(a fellow-sufferer)

<u>NEVER EVER DISAPPOINT ANYONE</u> - <u>Fibromyalgia Sufferer</u> - By: Allan F. Chino, Ph.D.© 1999, Pain Institute of Nevada, 4500 W. Oakey Blvd., Las Vegas, NV 89102 U.S.A. Tel. (702) 878-8252

More than a few fibromyalgia sufferers have noted that emotional stress is a prelude to increased pain and fatigue. For example, how many times has this happened to you? The President's office calls and asks whether he might drop by for a last-minute visit this afternoon on his campaign swing through town-AND THERE'S A HUGE STACK OF DIRTY DISHES IN THE SINK! Or how about this one: Your chauffeur complains that the butler's staff is always parking too close to the garage and it's difficult for him to wash both the Rolls and the Bentley at the same time, as he prefers to do. And you take it upon yourself to mediate this most difficult-but all-to-frequent-dispute. Boom. A fibro flare. Happens all the time, right?

Well, perhaps there are other types of stressors which invade your world. But you get the idea. You may be surprised to know that the top 10 sources of stress involve not what's in front of your eyes, but rather what's behind them.

One example of what I mean is an unspoken belief that many have been taught over the course of their experiences in life: "I must never disappoint anyone." There are several popular corollaries of this assumption such as:

"I must always think of others before myself."

"If I don't do what's expected of me, I'm being selfish."

"I expect myself to do what others expect of me-even if it kills me."

"If I don't step in to solve the problem, no one will. It'll just be easier if I do it."

"If others are disappointed in something I've done-or haven't done-I've failed."

Chances are that one or more of these beliefs are familiar to you. But what do they have to do with the pain and fatigue of fibromyalgia? Don't individuals not suffering from fibromyalgia also hold these beliefs? Of course they do. But they don't have fibromyalgia! It seems that these beliefs, which are powerful influences upon behavior, can ultimately lead to physical changes in the nervous, endocrine, vascular, GI, and neuromuscular systems. Think about it. What happens to you physically when you realize that you're no longer able to keep up with the things in your life upon which you've always maintained a firm grip? When things start "falling apart," relative to your old, pre-fibromyalgia standards for personal performance? For many, a profound sense of anxiety and fear sets in. After all, maintaining order in your life may have always served to keep anxiety under control, especially for those who have been exposed to "disordered" environments earlier in their lives.

Just this morning a fibromyalgia sufferer proudly told me that she finally has decided to place her well-being higher on the priority list than the thin layer of dust on her end tables. Throughout her past experience with fibro flares, she always pushed herself to keep an immaculate house. This, of course, often resulted in increased pain and maybe an extra day or two in bed-time spent fretting about how she was neglecting her responsibilities! Over the years, she believed that keeping an orderly house was a way to maintain order in her life. It was an aspect of her life which was always under her control (unlike certain other aspects). Hence, when her pain and fatigue began to rob her of this sphere of control, she became fearful and pushed harder to get it back.

For those of you who recall the physiology of fear, you will appreciate the fact that her brain probably responded to these "emergencies" by flooding the bloodstream with stress hormones. Her immune function became stressed as a result. The peripheral blood vessels constricted, thus reducing oxygenation to the extremities and small muscles. GI motility increased. And as the "emergencies" continued, so did the physiological stress responses. She hurt more. She fell farther from her life-long personal expectations. She became more anxious and fearful. She pushed harder. Look up "vicious-cycle" in the dictionary. They refer you to her e-mail address.

As we discussed all of this, she came to realize that the dust on her end tables came to symbolize her perceived inability to maintain control in her life. Her earlier environment had taught her that her needs were less important than those of others and that attending to them was a sign of selfishness. Her habit of being alert and responding to others' needs served to "keep the peace" and was, thus, strengthened (through a process called negative reinforcement which, by the way, is different from punishment). She was always "on duty" and never able to truly rest-especially while following her doctor's orders to stay in bed. Finally, she decided that her old strategy wasn't going to work anymore. She began tuning in to her own needs and responding to them. She concluded that her well-being and quality of life were simply more important than the amount of dust on the tables or than the decision of others to feel disappointed in her for taking care of herself. She broke the old rules-and was thrilled with the result. A burden was lifted. The guilt seemed more distant, less prominent. And the physical feelings associated with fear, shame, and inadequacy began to fade. Her pain has not disappeared, but her capacity to start living her life has taken some giant steps forward.

"Never, never, EVER, disappoint anyone" is terrible advice, whether it comes from others or oneself. Not only is it unrealistic, but it implies a belief system that serves to elevate one's vulnerability to chronic anxiety, physiological stress, and pain. It reflects the assumption that, no matter how bad things are, your feelings are less important than those of others. A bad mix-especially for the fibromyalgia sufferer. The good new is that old dogs can learn new tricks. Don't let anyone (especially yourself) tell you differently. It's never too late to stir things up a bit. Especially if the result is a more fulfilling, joyful life.

Q. & A. - DAVID S. BELL, MD, FAAP

Question: I am a 24-year-old postgraduate student with CFS. I have had moderate CFS for 5 years now. I have kept up my studies part time. I am wondering whether it would be considered good or bad medical practice to use central nervous system stimulants (judiciously and under medical supervision) during periods of relapse. For example the weeks of debility that follows an episode of the common cold, not during the infection but afterwards when the lassitude and debility set in. The lassitude after a cold is very distressing as well as incapacitating. I would classify this situation differently than a relapse precipitated by overexertion, where the use of CNS stimulants is probably highly inadvisable.

ANSWER: The use of stimulants in CFS is very appropriate when they work. The problem with very severe CFS is that they do not work and may make you feel worse. I have talked with three or four patients who felt that their CFS got worse because of stimulants. I tend to think that they were in a relapse that would have happened anyway and the stimulants made them feel worse, but did not necessarily cause their illness to be worse.

Healthy people use stimulants (coffee for example) judiciously. If they take too much they become frazzled and do not over do it the next time. CFS patients are very sensitive to stimulants in general, perhaps because of an increased adrenergic tone (The adrenaline system). That is the reason the heart rate is higher in CFS than healthy persons.

But if a stimulant helps, there is no harm to take it. (We are not talking of cocaine, by the way). Some CFS persons are helped by coffee, and they should use it judiciously. Amantadine, Ritalin, and other drugs may have a beneficial effect. CFS persons learn how to use stimulants quickly. For example, one person may take 1/2 teaspoon of a amantadine twice a day, while another takes it once every three days. This is not a one-dose-fits-all medication.

The drawback to stimulants is that they may worsen the agitation (being frazzled), and increase anxiety or interrupt sleep. But this can be overcome by starting with tiny doses. The main problem is that they do not create energy, so if there is a good response, it may be followed by a crash. I do not think this crash is dangerous. Common sense is the key. Find the middle ground with some increase in activity and not too bad of a crash.

By the way, cocaine is a very interesting cause of chronic fatigue, but not chronic fatigue syndrome. It is a tremendous stimulant, and causes severe chronic fatigue because it exhausts your norepinephrine stores (adrenergic). CFS is like cocaine addition without the cocaine or the initial high. Doesn't seem fair.

[Ed.note: Reprinted with permission - Source Lyndonville News, September 1999, Volume 1, Issue 5]

FIBROMYALGIA - THE PATIENT'S ROLE

By: David Saul, M.D.

Fibromyalgia (FM) affects over 150,000 people in Ontario alone. Women outnumber men by a ratio of 2:1 and the average age at diagnosis is between 45 and 55. The condition consists of diffuse muscular and joint pain, often with significant stiffness and fatigue. Sleep is disturbed, depression is common and both memory and concentration abilities are often severely impaired. Standard treatments consist of aerobic exercises as well as sleeping and pain medications. Most patients report only transient and limited improvement (if any) in pain and fatigue and the condition tends to last for several years.

What is the patient's role in fibromyalgia treatment? From my experience in helping patients decrease their pain and increase their energy, there are some general strategies, which can point FM patients in the right direction - the road to recovery.

- *Look for the right doctor.* Not all doctors are sufficiently knowledgeable about FM. Some cannot establish the diagnosis appropriately and as a result, effective treatment can be delayed.
- *Be careful of hucksters.* Some people might try to take advantage of the desperation felt by FM patients by promoting unproven, expensive and sometimes valueless treatment.
- *Be proactive.* Learn everything you can about FM - causes, treatments and newer research. Try different nutritional and exercise programs. Explore what alternative medicine has to offer for relief of symptoms.
- *Don't get discouraged.* If a treatment strategy doesn't work, don't give up! Wait for a bit and try it again later on, or move on to something new. Frustration and depression is common with FM so, hang in.
- *Look for a support group*. Many patients feel better sharing their experiences, both positive and negative with a support group. If there is no group in your area, consider starting one yourself.

FM is a frustrating syndrome for both the patient and the doctor. However, I have found that by using a comprehensive approach, there can be substantial and long-lasting improvement. I've seen it.

[Ed. note: About the author: Dr. Saul is a family doctor working in Scarborough for over 22 years. He has a special interest in helping patients with FM and CFS. Dr. Saul can be reached for a consultation at (416) 298-1303 or (416) 789-4343].

LOOKING FOR TWINS WITH CHRONIC FATIGUE SYNDROME OR FIBROMYALGIA:

Do you know anyone with CFS and/or FM who has a twin? We are studying the immunologic, virologic, and genetic differences between twins--one or both with CFS and/or FM. We currently have over 300 sets of twins in our registry.

Please write **DEBRA BUCHWALD, M.D**., Harvorview Medical Center, 325 Ninth Avenue, Box 359780, Seattle, WA 98104 U.S.A. or call (206) 521-1935 and speak with Megan Belcourt. You can also visit our website at: http://weber.u.washington.edu/-dedra/twins.html

For more information or other videos etc. contact: Dolly Curtis, 35 Flat Rock Road, Easton, CT 06612 U.S.A. Tel. (203) 372-4511 - Fax (203) 372-4511 - Web: www.dollycurtisinterviews.com

FAMILY MEMBERS' (LACK OF) RIGHTS - By: Douglas E. Faulkner, Séguin, Landriault & Lamoureux, Barristers & Solicitors, 1110-141 Laurier Ave. West, Ottawa, ON K2P 5J3 - Tel. (613) 236-9141 - Fax (613) 236-0980 - E-mail: dfaulkner@seglaw.com

As Fibromyalgia and Chronic Fatigue Syndrome sufferers know, the family members of the person who is ill pay a significant price as well. The family's financial security is likely affected when the ill person is no longer able to work. Other family members must perform the household tasks that their disabled member used to do. That person is apt to become depressed, withdrawn, angry or all of the foregoing. The pain and exhaustion suffered by the disabled person wears them down and those around them. These illnesses strike at the heart of the whole family and not just the disabled person in isolation. And because of the persistence of the symptoms of Chronic Fatigue Syndrome and Fibromyalgia, the long term effects of the illness can be devastating for the ill individual and the loves ones around.

This is not 'news' to CFS/FM sufferers and their families but it continues to be news to the Ontario court system. Pursuant to the Family Law Act of Ontario, Section 61, family members of a person injured by the 'fault or neglect' of another person are entitled to recover monies for their out of pocket expenses caring for or replacing services provided by the injured family member as well as a sum for the 'loss of care, guidance and companionship' the family sustains because the disabled person is so often radically altered by their situation. As a lawyer representing several CFS/FM sufferers, I frequently see the terrible exacerbation of the disabled person's situation when benefits are (often capriciously) terminated by their disability insurer. The additional distress caused by the increased burdens imposed on the family are like a pebble tossed into a pool; every member of the family feels the ripples.

Disability insurance contracts have long been described by the courts as "peace of mind" contracts; ones specifically entered into to protect the peace of mind and reduce the stress of the purchaser of the insurance. As such, the courts have also been prepared to impose punitive or exemplary damages upon insurance companies where benefits were terminated for insufficient reasons. Once again the Courts in the West are leading the way. In a case called *Warrington v. Great West Life* The British Columbia Court of Appeal awarded Mr. Warrington, a Fibromyalgia sufferer, both punitive and aggravated damages. The trial judge had reasoned that a contract of disability insurance is one that requires the 'utmost good faith' and 'fair play in every dealing' and that Great West Life had not lived up to those legal standards in its dealings with Mr. Warrington. The Court of Appeal agreed and confirmed that the breach of this duty of good faith was a separate wrong perpetrated by the insurance company upon Mr. Warrington, separate and apart from its breach of the paper contract of disability insurance. That separate wrong warranted the punitive damage award. Aggravated damages, also called damages for mental distress, were also justified in circumstances where the insurer was aware or ought reasonably to have been aware that the insured was actually entitled to receive his benefits. The loss of benefits forced the family onto social assistance and a reliance upon the charity of friends with understandable distress and humiliation that the judge also determined was worthy of monetary compensation.

The correctness of that decision was recently re-affirmed by the British Columbia Court of Appeal once again in a 1999 decision entitled McIsaac v. Sun Life Assurance.

The effect of the decision from the point of view of family members of CFS/FM patients is that the courts have now determined that the breach of the "peace of mind" duty is a separate and actionable wrong different from the failure to pay benefits. That is the usual definition of what comprises "fault or neglect" under Section 61 of the Family Law Act, an actionable wrong. But the courts of Ontario have yet to import the forward thinking of courts in other jurisdictions in Canada to permit Ontario family members to be compensated for the 'ripple effect' that happens within the family unit when the insurer wrongfully terminates benefits. If you are the spouse or parent or child of a person with Fibromyalgia or chronic Fatigue Syndrome who has had their insurance benefits terminated, you know the impact that has on your home life, your relationship with the disabled person, your financial stability and your own emotional stress levels. If your family member had suffered a broken wrist from a slip on a banana peel at the local grocery store you would be properly compensated for those losses. But because your family has been injured by the callous behaviour of an insurer insurer the Ontario justice system has yet to recognize the impact that has had on the family members of the insured and has failed to recover for them the benefit of the law they would receive if the injury had been inflicted differently.

Persons living with Fibromyalgia and Chronic Fatigue syndrome have been struggling against the ignorance displayed by the insurance industry, the medical industry and the court system for decades now. This is one more element of that struggle, one more battle in the war to be won! If you have a claim proceeding at the present, you may want to discuss with your counsel the possibility of amending your claim to seek compensation for your family members. Certainly some day a judge in Ontario will make the right decision. But not if we don't persist in demanding equal justice from the system.

The MMPI: ITS VALIDITY IN ASSESSING PEOPLE WITH CFS - By: Faith E. Hayman, LLB

[Faith E. Hayman is a lawyer practicing in Vancouver who represents clients with chronic illnesses and can be reached at (604) 683-9621 or by mail at: 202-650 West Georgia Street, Box 11547 Vancouver Centre, Vancouver, BC V6B 4N7. Ms Hayman would like to acknowledge the assistance of Dr. Peter Joy, Psychologist, in writing this article]

In 1994, a trial judge in Alberta decided that a woman in her 40's who claimed damages for injuries sustained as a consequence of a motor vehicle accident, did not suffer from fibromyalgia. Instead, relying heavily on defence experts who interpreted the results of MMPI testing, the trial judge concluded that the plaintiff had an obsessive, compulsive personality with a hysterical conversion disorder. Unfortunately, there was little psychiatric or psychological evidence tendered by the plaintiff to challenge the defence experts.

This decision, *Mackie v. Wolfe,* reflects a serious problem which people with CFS/ME may face when asked to take psychological tests so that some third party can diagnose or clarify the cause, nature and/or extent of their illness.

The problem lies in the interpretation of the "Minnesota Multi-Phasic Inventory" (MMPI), updated in 1989 and called the MMPI-2.2. The MMPI is the most frequently used and extensively validated test instrument in clinical psychology. It is also easily subject to misinterpretation when administered to a person who suffers from an illness which is associated with physical symptoms of unknown origin, such as CFS or Fibromyalgia.

To see how, we need to first understand the MMPI's design and normal usage.

What is the MMPI?

The MMPI consists of a test booklet with over 500 statements (called "items") which the person writing the test is required to decide are either true or false, as applied to that person. The test is designed to assess the **psychiatric** state of the person by eliciting information relevant to the following categories:

Scale #	Name	Description
1.	Hypochondriasis	Abnormal concern over bodily health
2.	Depression	Depressed phase of manic depression
3.	Hysteria	Hysteria or histrionic personality
4.	Psychopathic Deviate	Characteristics of young delinquents under court-ordered assessments

5. Masculinity-Femininity Characteristics of gay invert males; soldiers and female airline employees

6. Paranoia Paranoid state, paranoid condition, paranoid schizophrenia

7. Psychasthenia Inability to resist maladaptive actions or thoughts (obsessive-compulsive)

8. Schizophrenia Schizophrenia

9. Hypomania Mild to moderate mania (a type of affective disorder characterized by euphoric mood, excessive activity, impaired judgment and sometimes psychotic symptoms etc.)

10. Social Introversion Characteristics of high and low-scoring female college students

In addition to these categories, the MMPI has a number of "validitiy" scores which indicate how open and honest the person was in answering the questions.

Once the person completes the test, it is scored by registering each answer in at least one, and sometimes two or three of the above categories. The test results produce what is called a "profile" with a visual summary of important personality information, plotted on an easy-to-read graph. The higher the score in any category, the more prominent those psychiatric traits are thought to exist in the person.

Why is the MMPI so popular?

The MMPI is popular for a number of reasons:

- .it is perceived to provide an objective evaluation of an individual's personality characteristics, symptom patterns and personal attitudes;
- it is easy to administer;
- it is cost effective since it takes very little professional time to obtain the necessary information; and
- the test can be computer scored. There are 6-8 computer programmes on the market which assist in the interpretation of various MMPI-2 profiles.

Can the MMPI be used to accurately diagnose CFS?

The usefulness of the MMPI in shedding light on a diagnosis of CFS is affected by one major factor: ***the MMPI is based on the assumption that a person is physically healthy.***

Several of the statements in the MMPI relate to the person's physical state. Some examples are:

- I am troubled by attacks of nausea and vomiting
- I am in just as good physical health as most of my friends

The MMPI was originally designed to assess physically healthy individuals who, when asked the above questions, would tend to answer F and T respectively. The intent of questions such as those above was to identify people who were physically healthy but who suffered from a psychiatric state that made them think they were ill.

Difficulties arise when people with "genuine" or organic physical problems write the MMPI. In response to the above questions, they may answer T and F, opposite answers to those of a healthy person. Their answers would register as elevations on scale 1 (suggesting a psychiatric state of hypochondriasis) even though they were responding truthfully and accurately and in a manner consistent with a "normal" person who was ill.

If the MMPI is scored without regard to the physical state of the subject, or on the assumption (possibly mistaken) that the person is physically well, there will be artificial and inaccurate elevations in the profiles of psychiatrically normal, but physically ill, people. In an article in Arthritis and Rheumatism entitled Elevated MMPI Scores for Hypochondrasis, Depression and Hysteria in patients with Rheumatoid Arthritis Reflect Disease Rather than Psychological Status, it was noted that "The MMPI has been extensively validated in hundreds of individuals with and without psychological disorders, but not in subjects with somatic diseases." The article concluded that the "widespread use of the MMPI has led to clinical interpretations of increased levels of hypochondriasis, depression, and hysteria in individual patients with RA and other chronic diseases. Our findings suggest that such interpretations are not valid for RA patients and, possibly, are not valid for patients with other diseases."

The profiles which tend to be consistently elevated as a result of physical pain are scales 1, 3, 4, 7 and 8. Because depression is a common product of pain states, scale 2 also tends to be elevated in subjects suffering from injuries or physical illness.

There is one further point to note: the standard method of scoring an MMPI results in double and triple-counting of some answers, thereby increasing the misrepresentation. Approximately 40% of the items on the MMPI are designed to be scored more than once. The maximum number of times any item is scored is 6. Scales 1 and 3 overlap on 20 items.

Many of the items on scales 1 and 3 relate to somatic complaints which, as described in the previous section, are susceptible to misinterpretation. When they are double and triple counted, the distortion is even more exaggerated. In an editorial in the Journal of Rheumatology in 1984, Dr. Hugh A. Smythe, Professor of Medicine and Chief, Division of Rheumatology at the University of Toronto noted: "Because of double or triple counting, these 19 questions, together with 13 more pain-related questions that appear on one scale only, contribute a total of 59 positive scoring points toward the possible maximum raw scores, a built-in bias towards a "neurotic" score of up to 38%".

Because of these and other problems with the MMPI, psychologists Helmes and Reddon wrote: ?By any standard, the MMPI and MMPI-2 are inefficient instruments. The use of the clinical scales on either instrument requires substantial experience and sophistication by the user. Much of that sophistication is necessary only because of the many pervasive conceptual and operational weaknesses that we have itemized....In conclusion, assessment devices are fallible instruments and should not be taken for granted. Users of personality tests need to be cognizant of the issues and to appraise the underlying system behind their interpretations of test results."

Dr. Linda Iger, a psychologist in California, has gone further. She analyzed the MMPI scores of a number of CFS patients and developed a CFS profile. While such a profile cannot be treated as diagnostically determinative of CFS, it can be used to indicate that a person's MMPI score is more consistent with a diagnosis of CFS than with a diagnosis of a psychiatric illness.

In any MMPI administered to someone with CFS, it is necessary to clarify what causes elevations on the test. The answers which produced elevations (called the "endorsed items') should be individually examined to see whether they were responses to questions concerning physical symptoms, and if so, whether those physical symptoms are consistent with a diagnosis of CFS. This does not answer the question of the cause of the physical symptoms. It does, however, provide a basis for determining the impract of these symptoms on the person's psychological profile.

Conclusion:

The MMPI provides a great deal of potentially useful information about a person's thoughts and feelings. For anyone who suffers from CFS, however, a proper interpretation of the MMPI score must take into account the person's physical symptoms. If it does not, then the conclusions drawn from the MMPI may be significantly misleading.

References:

1. Machie v. Wolfe, (1994) A.J. 467 (Alta.Q.B.); 2. All future references to the MMPI include the MMPI-2 unless otherwise stated; 3. Pincus, Callahan, Bradley, Vaughn and Wolfe: Elevated MMPI Scores for Hypochondriasis, Depression, and Hysteria in patients with Rheumatoid Arthritis Reflect Diseases Rather than Psychological Status. Arthritis and Rheumatism, Vol.29, No. 12, 1986; 4. Smythe: Problems with the MMPI, Journal of Rheumatology, 11:4, 1984; 5. Helmes and Reddon. A perspective on Developments in Assessing Psychopathology: A Critical Review of the MMPI and MMPI-2. Psychological Bulletin, Vol.113, No. 3, 453-471, 1993; 6. Iger. The MMPI as an Aid to Chronic Fatigue Syndrome Diagnosis, Chapter 52, The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 1992.

[Ed.note: This article first appeared in "The Disability Reporter" Nov/Dec.1998 and has been reprinted with the permission of the author. To subscribe to "The Disability Reporter" call: (613) 237-2296 or write to CAL, 401-200 Elgin St., Ottawa, ON K2P 1L5 Web: http://home.istar.ca/~gcamcal/cmaweb.htm]

ATTENTION: ALL 450 SUPPORT GROUP LEADERS/CONTACT PEOPLE ACROSS CANADA -

By: Mary Ellen, Manager - Special Projects

As you know, the National ME/FM Action Network is collecting information from people across Canada with ME/FM who have been requested by their insurance companies to undergo an Independent Medical Examination or Functional Abilities Evaluation (I.M.E. or F.A.E.).

Within the next two months, please contact Mary Ellen, either by sending an email, a short letter or by telephoning her to let her know how your people are responding to the Independent Medical Examination Registry Submission Form.

Do your people find this an important project? Why?

How many of your people are having difficulty receiving benefits from their private insurance company?

Are certain doctors' names repeatedly coming up, who are being used by the insurance company to perform an I.M.E. and then write a report that is used as a basis to deny or terminate benefits?

Are certain insurance companies and then these reports being used as a basis to terminate benefits?

Are certain insurance companies terminating benefits more often than others?

Have you been able to publicize the Registry Submission Form at support group meetings? In a newsletter? On a Website?

At the local doctors' offices; Chiropractors' offices; Physiotherapists'' offices; massage therapists' offices; aquatherapy classes; health food stores; and lawyers' offices?

Do you need any more copies of the confidential, seven-question Registry Submission Forms?

It is crucial for Mary Ellen to know how this insurance issue is affecting people all over Canada. We need to be sure that we are in fact receiving a balanced view of the situation based on the Forms and inquiries that we are receiving daily. The information will benefit us all!

CONTACT: Mary Ellen, Manager of Special Projects: Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7; Telephone/Fax: (905) 831-4744; E-mail: marye@pathcom.com.

NATIONAL DOCTORS' ROSTER - ADDITION:

DONALD G. SEIBEL, MD Diagnosis/Treatment ME/FM

Callingwood Medical & Musculoskeletal Centre **Tel. (403) 487-2770**

6807 - 177 Street **Fax (403) 487-4204**

Edmonton, AB T5T 4K3 **E-mail: callmed@telusplanet.net**

FRANK ADAMS, MD, FRCP(C) DAAPM Diagnosis/Teatment ME/FM

Specializing Disorders of the Brain Tel. (613) 530-2909

797 Princess St., Suite 411 Fax (613) 530-2000

Kingston, ON K7L 1G1

NATIONAL LAWYERS' ROSTER - ADDITION:

JEFFREY WM. STRYPE ONE HR. FREE CONSULTATION FREE

SMITH LYONS **JWStrype@SmithLyons.ca**

Barristers & Solicitors **www.smithlyons.ca**

Suite 5800, Scotia Plaza

40 King St. West **Tel. (416) 369-4578**

Toronto, ON M5H 3Z7 **Fax: (416) 369-7250**

BOOKS/VIDEOS/NEWSLETTERS ETC.

EVIDENCE OF GLUTATHIONE DEFICIENCY IN CFS & CASE STUDIES - Paul Cheney, M.D., Ph.D. - VIDEO - 2 hours $24.95 U.S. To obtain a copy contact: Tree Farm Communications Inc. - Product No. EM 92-08V - (425) 868-0464 -

Fax (425) 868-2495 Web: www.treefarmtapes.com

LYME DISEASE VIDEOS - Produced by Dolly Curtis Interviews, 35 Flat Rock Road, Easton, Connecticut 06612 U.S.A. Tel/Fax: (203) 372-4511 - Web: www.dollycurtisinterviews.com

"Ira Maurer - The Lyme Disease Lawyer on Legal Issues of Lyme Diseases - 60 Mins. - *$35.00 U.S.

"Newer Understanding of Lyme Disease" Lecture & Slide Presentation w/Sam T. Donta, MD - 120 Mins. *$35.00 U.S.

"Update on Lyme Disease Treatment" w/Steven E. Phillips, MD - *$30.00 U.S.

"The Treatment of Chronic and Neurological Disease" w/Kenneth B. Liegner, MD, PC, and Janice Kochevar, F.N.P. *$35.00

***Shipping Charges: $3.00 U.S., each additional tape $1.00 U.S.**

QUEST COLLECTION - FIVE YEARS:

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

In response to many requests, the National ME/FM Action Network is pleased to publish a collection of highlight articles from its first five years of operation. It is hope that bringing these various articles together into one booklet will be of assistance to our reader. For ease of reference, these articles have been grouped into three sections according to their focus. Please make cheque **payable to the National ME/FM Action Network - Cost: $20.00**

LEGAL/RESEARCH PACKAGE - Please make **cheque payable to Marj van de Sande** in the amount of **$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 - Tel/Fax: (403) 547-8799 - E-mail: vandesam@cadvision.com**

OUR WORLD:

WEAKNESS: Like lifting an ant that feels like an alligator.

POOR EYESIGHT: Like wearing someone else's prescribed lenses.

MEMBERSHIP: $20.00 per year includes bi-monthly newsletters

Please make cheque payable to:

NATIONAL ME/FM ACTION NETWORK

3836 Carling Ave., Nepean, ON K2K 2Y6 CANADA

Tel/Fax: (613) 829-6667

<u>E-Mail:</u> ag922@freenet.carleton.ca

<u>WEB</u>: http://www3.sympatico.ca/me-fm.action/

DISCLAIMER: The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for information on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia. Some of the information contained herein is intended to help patients and their physicians make informed decisions about their health. However, the NATIONAL ME/FM ACTION NETWORK does not dispense medical advice or endorse any specific medical hypothesis or product and assumes no responsibility for any treatment or action undertaken by its readers