Quest #48 June 2001

CONSENSUS UPDATE: By: Marj van de Sande, B. Ed., Grad. Dip. Ed,

Consensus Coordinator & Director of Education

The revised ME/CFS consensus clinical definition, diagnostic and treatment protocol document has been approved by the consensus panel. We have been looking into ways of publishing the ME/CFS consensus document and a Canadian Medical Journal is in the process of making some changes regarding submissions. However, the people making decisions are away for the month of August. We are just finishing writing a paper on the ME/CFS clinical definition that we are sending out to the consensus panel for their approval. Our goal is to be able to submit the paper in September. Once the paper is submitted, we will be able to concentrate on the FMS document. Key people have been away a lot this summer but should be back by September.

DIRECTOR OF EDUCATION HONOURED

Marjorie van de Sande, our Director of Education, was recently honoured by the "**Fibromyalgia Resource Group of Southern Alberta**" with an honorary life membership to that organization. This was in recognition of Marjorie's dedication and work she has done on behalf of fibromyalgia and myalgic encephalomyelitis patients. Her work as consensus coordinator for the definition/protocols documents is greatly appreciated by this organization. Marj said she was delighted to be asked to their executive committee dinner and was very touched by the award. Marj thanked the **Fibromyalgia Resource Group of Southern Alberta** for their ongoing support of all the projects of the **National ME/FM Action Network**.

NOW AVAILABLE - Sourcebook for Teachers of Children with ME/CFS &/or FM

By: Mary Ellen, Chairperson, TEACH-ME Task Force.

National ME/FM Action Network

We are proud to announce that our Sourcebook for Teachers is now posted on

the Youth and Parents' Pages at: **http://www.geocities.com/canadianyouthmefm/teachme.html**

The Sourcebook offers information and coping strategies for teachers who may have students suffering from

ME/CFS and/or FM. The Sourcebook will help teachers to develop practical approaches to developing modifications to

educational plans and the curriculum. The document is available NOW for parents to download and bring to their meetings with Boards of Education or Guidance Counselors who may be helping to arrange modified timetables for students this September.

Background To The SourcebookEvery day Canadian teachers are becoming aware of children and adolescents with ME/CFS and/or FM. It has not always been this way, partly because ME/CFS and FM have had a controversial history. Although the number of adults being diagnosed with these illnesses seemed to grow rapidly in the mid-eighties, official recognition of the illness in adults has been slow. Tragically, recognition of the prevalence and devastation of ME/CFS and/or FM in children has been even slower, leading to many heartbreaking situations. Fortunately, all that is changing. Research on

ME/CFS and/or FM has been increasing rapidly, including research on children and adolescents. We can expect that in the next few years we will understand these illnesses much better - in people of all ages. Meanwhile, there is much that the classroom teacher can do for a young person diagnosed with ME/CFS and/or FM.

Who Wrote This Book? - The authors of this Sourcebook are Canadian teachers, disabled with ME/CFS and/or FM, who are members of the **National ME/FM Action Network**. We developed a unique e-mail conference, known as TEACH-ME, in which we discussed ways that children with ME/CFS and/or FM could be provided with uninterrupted, high quality education. As people with ME/CFS and/or FM ourselves, we were devastated to imagine the effects of ME/CFS and/or FM on young people. As teachers, we remained unwaveringly committed to the importance of providing ongoing and enriching education to all children, no matter how ill or disabled. Yet, as adults who were homebound by the illness, we knew this could not be an easy task - for the young person or for the classroom teacher. We wanted to use our combined expertise in teaching and experience of the illness to help these courageous youngsters.

International Scientific and Real Life Expertise - We were very privileged to have the consultation of **Dr. David S. Bell**, a renowned paediatrician and the leading international researcher on ME/CFS and/or FM in children, and **Mary Z. Robinson**, a US educator, research assistant to Dr. Bell, co-author of "A Parent's Guide to CFS" and parent of two children with ME/CFS/FM. Our collaboration with Dr. Bell and Ms. Robinson enabled us to link our personal experience and teaching expertise with the most up-to-date and sound international research knowledge. Not only that, but Dr. Bell's and Ms. Robinson's knowledge of ME/CFS/FM is unique in that it has been acquired from following real families and children coping with this illness over many years. Assisting us to coordinate our efforts was **Kate Andersen**, the Youth Consultant for the **National ME/FM Action Network**, a university educator who has ME/CFS herself.

The Voices of Young People with ME/CFS/FM and their Parents. Young Canadians with ME/CFS and/or FM themselves, and their families, made special contributions by sharing their real experiences. We thank them enormously for enriching this project.

Finally, we'd like to thank **Kate Andersen**, the Youth Consultant for the **National ME/FM Action Network**, whose expertise, talent and dedication made this Sourcebook possible and whose original vision inspired us all to use our limited energy for such a worthy cause.

"EFFECTIVE TREATMENT FOR CHRONIC FATIGUE SYNDROME, MYALGIC ENCEPHALOMYELITIS AND FIBROMYALGIA (CFS/FMS/ME) DEVELOPED!" -

By: Jacob E Teitelbaum MD

We are very excited to report that that day has arrived!

The lead article in the upcoming edition of the Journal of Chronic Fatigue Syndrome is titled "Effective Treatment of Chronic Fatigue Syndrome and Fibromyalgia -- the Results of a Randomized, Double-Blind, Placebo-Controlled Study"! After decades of hard work by hundreds of researchers in the field, we have progressed to the point where effective treatment is now available for these illnesses! In our study, over 90 percent of patients improved with treatment.

In the average patient, after two years of treatment, the average improvement in quality of life was 90 percent. Pain decreased by over 50 percent on average. Many patients no longer even qualified for the diagnosis of CFS or fibromyalgia after treatment!

That the vast majority of patients improved significantly in the active group while there was minimal improvement in the placebo group proves two very important things. The first is that these are very treatable diseases. The second is that anyone who now says that these illnesses are not real or are all in your head are clearly both wrong and unscientific. A new day is dawning in how CFS/fibromyalgia will be treated. It is important to recognize that these syndromes can be caused and aggravated by a large number of different triggers. When all these different contributing factors are looked for, and treated effectively, patients improved significantly and often get well! Although it will take a bit of time for the news to get out to your doctor, this is also happening. Many news organizations have expressed interest in the story -- which will be released August 5, 2001. We invite you to help us in getting the word out.

What is causing these illnesses? - As we noted above, CFS/FMS/ME is not a single illness. Our study has shown that it is a mix of many different processes that can be triggered by many causes. Some of you had your illness caused by any of a number of infections. In this situation, you can often give the time that your illness began almost to the day. This is also the case in those of you who had an injury (sometimes very mild) that was enough to disrupt your sleep and trigger this process. In others the illness had a more gradual onset. This may have been associated with hormonal deficiencies (e.g. low thyroid, estrogen, testosterone, cortisone, etc.) despite normal blood tests. In others, it may be associated with chronic stress, antibiotic use with secondary yeast overgrowth, and/or nutritional deficiencies. Indeed, we have found well over 50 common causes of, and factors that contribute to, these syndromes.

What these processes have in common is that most of them can suppress a major control center in your brain called the hypothalamus. This center controls sleep, your hormonal system, temperature, and blood flow / blood pressure. When you don't sleep deeply, your immune system also stops working properly and you'll be in pain. When we realized this, the myriad symptoms seen in CFS/fibromyalgia/ME suddenly made sense. It also gave us a way to effectively treat you!

Four main categories of problems need to be treated.

1--Disordered sleep. Most patients with these illnesses find that they are unable to get 7-8 hours of deep sleep a night without taking medications. In part, this occurs because hypothalamic function is critical to deep sleep. Unfortunately, many of the most common sleep medications actually aggravate the sleep problems by decreasing the amount of time spent in deep sleep. For patients to get well, it is critical that they take enough of the correct sleep medications to get 7 to 9 hours sleep at night! These medications include Ambien (zolpidem), Desyrel (trazodone), Klonopin (clonazepam), Xanax, Soma (carisprodol) and, if you don't have Restless Leg Syndrome, Flexeril (cyclobenzaprine) and/or Elavil (amitriptyline). In addition, natural remedies that can help sleep include valerian (160-480mg), Kava (125-375mg-do not use if you have liver disease), passionflower (100-300mg), lemon balm (80-160 mg), 5-HTP (100-300mg), melatonin (3/10-1mg) and wild lettuce. Some patients find that over-the-counter antihistamines such as doxylamine (unisom for sleep) or Benadryl can also help. In the first six months of treatment, it is not uncommon to sometimes need to take even six to eight different products simultaneously to get 8 hours of sleep at night. After 6-18 months of feeling well, most people can come off of most sleep (and other) medications. I'm starting to believe that, to offer a margin for safety during periods of stress, it may be wise to stay on 1/2 to 1 tablet of a sleep medication for the rest of your life. Your doctor may initially be uncomfortable with this. Nonetheless, our experience with over 2000 patients and 2 research studies have found this approach to be safe and critical to people getting well. When one recognizes that CFS/FMS is a hypothalamic sleep disorder -- not poor sleep hygiene -- this approach makes sense. Otherwise, it is as if your doctor would immediately try to stop blood pressure or diabetes medicines every time the patient was doing better! Issue six of my newsletter discusses treatment of sleep in great detail.

2--Hormonal deficiencies. The hypothalamus is the main control center for most of the glands in your body. Most of the normal ranges for our blood tests were not developed in the context of hypothalamic suppression or these syndromes. Because of this (and for a number of other reasons) it is usually necessary, albeit controversial, to treat with thyroid, adrenal (very low dose cortef; DHEA), and ovarian and testicular hormones -- despite normal blood tests! These hormones have been found to be reasonably safe when used in low doses. Growth hormone has also been shown to be helpful in fibromyalgia. We don't use it because, unfortunately, it can cost over $15,000 a year and is given by injection. Fortunately, there may be a cheaper way to raise your low growth hormone. Most growth hormone is made during deep sleep. This may be another reason why getting 7 to 9 hours of deep-sleep a night can be critical!

3--Unusual infections. Many studies have shown immune system dysfunction in FMS/CFS. Although there are many causes of this, I suspect that poor sleep is a major contributor. The immune dysfunction can result in many unusual infections. These include viral infections (e.g. –HHV-6, CMV, and EBV), parasites and other bowel infections, infections sensitive to long-term treatment with the antibiotics Cipro and Doxycycline (e.g. mycoplasma, chlamydia, lyme's, etc) and fungal infections. Although the latter is controversial, both our study and another recent placebo-controlled study found treating with an antifungal to be very helpful with the symptoms seen in these syndromes.

4--Nutritional supplementation. Because the western diet has been highly processed, nutritional deficiencies are a common problem. In addition, bowel infections can cause poor absorption, and the illness itself can cause increased nutritional needs. The most important nutrients include: a) vitamins -- especially the B vitamins (most at 25-50 mg/day), vitamin B12 (50-3000mcg/day), antioxidants (e.g. -- vitamin C and E). b) Minerals -- especially magnesium, zinc, iron, and selenium. c) Essential fatty acids and d) amino acids (proteins). There is a product that contains most of these and many more in the proper dose in 1&1/2 scoops of a powder taken daily. Deficiency of a critical antioxidant, called glutathione, may be a major problem in these syndromes and could account for most of the symptoms. Taking it by mouth is not effective as it gets digested in the stomach. It can be raised inexpensively, however, by taking NAC 500-1000mg/day and vitamin C (500-1000 mg/day). There are many other nutrients that also can be very helpful.

What other new approaches are being developed?

Happily, 85 to 90 percent of our patients improve significantly by treating the problems that we have discussed above. There are many other treatments that can also be very helpful.

1--Dr. J. Goldstein's protocol. Dr. Goldstein focuses on medications that are rapidly active in the brain. Remarkably, in a subset of patients, some of these can reduce or eliminate the symptoms within 45 minutes. He uses over 80 different medications, testing them sequentially, to see if they will help patients. My favorite ones to try include Nimotop (nimodipine) 30 mg, naphzoline .1% eye drops, TRH eye drops, and oxytocin 10 units by IM injection. These are fairly safe, and the effect is usually seen within 45 minutes. Issue five of my newsletter discusses Dr. Goldstein's protocol in great detail.

2-guaifenisin, a safe and inexpensive medication, has been found, when used for an extended period, to decrease pain in some patients. Although a well-done study by a wonderful researcher (Dr. Robert Bennett) showed no benefit from this medication, many patients have written to me saying that they found it to be helpful and another study is being developed. Unfortunately, one must avoid anything with aspirin/salicylates or the treatment will not work. This is much harder than it seems. It is a treatment that I have only rarely needed to use. Issue eight of my newsletter describes this treatment in detail.

3-heparin -- the body's blood clotting systems seem to be over activated in these syndromes. Oddly enough, this can result in easy bruising. It also seems to cause problems with getting nutrients out of the blood vessels and into the tissues with they are needed. About half of my patients that use the blood thinner heparin twice a day by injection get significant relief of their symptoms. Unfortunately, there are potential risks and side effects that are life threatening. Because of this, I have only needed and been willing to use heparin in a very few patients. Interestingly, some physicians have noted that long-term antibiotics work better in these syndromes when they are combined with heparin.

4-there are many other treatments available as well. Although space does not allow for a full discussion of these in this article, I discuss them at length in the next edition of my book, which will be available

August 5th 2001. My From Fatigued to Fantastic newsletter allows me to continue to update readers as new information comes out. It usually comes out to 2-4 times a year.

How do I make my pain go away?

Pain is one of the easier problems to treat! If usually will improve dramatically and then go away if you get the eight hours of sleep at night I discuss above, take B vitamins with magnesium, take thyroid hormone, and treat the underlying yeast infections. Aspirin family medications (including ibuprofen) are not very effective for most patients. I avoid Tylenol because it can markedly deplete the critical antioxidant (glutathione) that we discussed above. The medications I find to be most helpful for pain include Celebrex (celecoxib) and Skelaxin (which are not sedating) and Neurontin, baclofen, and Ultram which can be sedating. There are many other medications and other effective ways to treat pain as well. These can be used to help keep you comfortable while we go after the pains underlying causes. Issue seven of my newsletter will teach you and your doctor how to make your pain go away.

How do I go about getting well?

My best-selling book "From Fatigued to Fantastic" has been dramatically updated, and will be available August 5th, 2001. It will supply you and your physician with all the information that you need to get treated effectively. It also contains the full text of our, double-blind, placebo-controlled study which proves that effective treatment is now available.

Because determining which treatments are needed by any given individual and then teaching them how to use them can be very difficult and time consuming (even for doctors that are very skilled in treating these syndromes -- a new patient visit in my office usually takes at least four hours of my " one on one" time), I've created a sophisticated computer program on my website (www.endfatigue.com) that is like a computerized CFS/FMS specialist! The good thing about it being a computer program is that it has both the time and ability to guide almost everyone with these syndromes back to health! It can:

A -- elicit a very detailed medical history

B-- supply a prescription for you to be able to get the lab testing you need

C-- create a complete and thorough medical record of your case for your doctor or other health professionals

D -- analyze your symptoms and lab results to determine what the likely factors are (in order of probability) that contribute to your case. It also screens for many other medical problems and symptoms unrelated to CFS/fibromyalgia. This is critical. Because it is common to have so many symptoms associated with these illnesses, it is easy to ignore symptoms that may come from other, possibly dangerous, problems

E. -- Determine which treatments are most likely to be helpful in your case. These are listed in order of priority. Although some treatments are prescription, most of them are natural remedies. Because of this, a large part of your treatment can be started on your own!

F-- supply detailed information on the underlying conditions contributing to your illness and how to use the treatments.

In addition, our website also contains:

1 -- copies of both of our research studies demonstrating effective treatment for these illnesses. The first one, published in 1995, was an open (not placebo-controlled) study in which over 90 percent of patients

improved. The second, soon to be published study is the placebo-controlled study I've discussed above. Feel free to make copies of this study for your physicians, friends, and for anybody in the news media you think might be interested.

2 -- a referral list of over 700 health care professionals (with an area for patient comments) who asked to be listed. If you have (or are) a good health care provider who uses a significant part of our protocol, please encourage them to go on our site and add their name to our list. Because we do not know many of the health care professionals who asked to be on our list, please add your comments about the ones you are familiar with. This will help to let people know who are the "diamonds" versus the "lumps of coal". I am now developing workshops for health care professionals (both physicians and non-physicians) who would like to learn my protocol in more depth. Please let us know if you are a health care professional and would like to be on our mailing list (those on our referral list are automatically on our mailing list).

3-- a list of support groups. Please let us know if you would like to add your group to our list.

4--a question, answer, and comments area.

5--. A section or you can vote for which of over 200 treatments helped or didn't help. You can also see how others voted, and their comments.

6 -- an area where you can see chapters and articles from my From Fatigued to Fantastic book and newsletters (and order these).

7 -- a shop where you can order supplements books and newsletters

8 –an area where you can add your name to our e-mail mailing list. Every few weeks, we send out updated information on CFS/FMS/ME and their effective treatment

9-- articles of interest, and more.

The purpose of our web site is to supply, in one place, all of the resources that you need in order to get well.

How can I get treated if I don't have much money?

Although some of the treatments for these syndromes can be very expensive, it is often possible to do the treatment protocol in an affordable manner. For example, although we charge US$160 to do the website computer program, we make it available at a discount or for free to those who cannot afford it. The key tests that are needed include the blood count (CBC), ESR, general chemistry, free T4 level (thyroid test), vitamin B12, iron, and DHEA-S level. Although many other tests can be very helpful, one can often rely on symptoms alone to make the other treatment decisions. The following medications and supplements can be found fairly inexpensively, and will often be helpful. The foundation vitamin powder can be adequate for basic nutritional support. Flexeril and Elavil, although more likely than some other medications to cause side effects, are inexpensive. Desyrel and Klonopin, in generic form, are also reasonably priced. These four can be very helpful for sleep, and your doctor is likely to be comfortable prescribing the first three of these. Thyroid, cortef, DHEA, and estrogen, can also be found for a fairly low price. For infections, nystatin and tetracycline are also inexpensive. Most drug companies offer medications for free to those who cannot afford them. I am currently working on an article that will help guide people on how to get medications they cannot afford. Although many of the other treatments can often be very helpful, these inexpensive ones may be enough to help you get well.

In last 20 years, my associates and I have had a wonderful time in our quest to make the possibility of effective treatment available for everyone with CFS, &FMS related problems. Finding effective treatment, doing the research to prove its effectiveness, writing a book that teaches people how to get well (and their doctors how to treat them), and creating the web site educational program that can help you tailor a treatment program for your specific situation has fulfilled this goal! You have no idea how joyful this has made me, and my associates! Our next job is to get the word out to the many millions of people suffering worldwide- these illnesses are treatable! Once you have effectively used our protocol (or even before), please e-mail us on our website if you would like to help us get the word out. Your help is very appreciated!

At this time, you now have all the tools you need to get well! We wish you all God's blessings and our best wishes in reclaiming vibrant health!With appreciation for all you've been through, **Jacob E Teitelbaum MD**

[Ed Note**: Dr. Teitelbaum** is a board certified internist and director of the **Annapolis Research Center for Effective CFS/Fibromyalgia Therapies**. Having suffered with & overcome these illnesses in 1975, he spent the next twenty-five years creating, researching, and teaching about effective therapies. His office is in Annapolis, Maryland **(410-573-5389).** He lectures internationally. He is also the author of the best-selling book" From Fatigued to Fantastic!" His web site can be found at: _ **HYPERLINK "http://www.endfatigue.com" __www.endfatigue.com_.]**

NEW CANADIAN RESEARCH PUBLISHED IN MEDICAL

JOURNAL IN JULY 2001

Chronic fatigue syndrome: neurological findings may be related to blood-brain barrier permeability. **Med Hypotheses 2001 Jul;57(2):231-7 Bested AC, Saunders PR, Logan AC. Environmental Health Clinic, Sunnybrook and Women's College, Health Sciences Centre, Toronto, Canada PMID: 11461179**

(Editor's Note: The next issue of QUEST will contain a full article.)

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Introduction -

There can be but few physicians remaining these days who have not been approached by their patients, their patients' lawyers, insurers, or benefits agencies such as the Canada Pension Plan, to address requests for information, documentation and assessments concerning disability.

This article is directed primarily to medical professionals. The opinions expressed are those of a lawyer practicing almost exclusively in the area of injury and disability law, representing claimants. The article will focus on the role of physicians in the injury and disability claims process, and how physicians might best view and carry out certain administrative and professional responsibilities toward their patients in a medical-legal or benefits-based setting. Much of what is said regarding physicians, however, may apply equally to other health disciplines which also become involved in the claims process, such as therapists and rehabilitation specialists.

Physicians are Central in the Claims Universe. The injury and disability claims field is "physician-centric". To the extent that an individual's entitlement to compensation or benefits is dependant upon confirmation of injury or medical disability – as is normally the case – it is the physician whose information and opinion has the potential to steer the ultimate direction of the claim. Whether a motor vehicle injury claimant "suffers a substantial inability to perform the essential tasks of her employment" as a condition to receiving no-fault income replacement benefits under the Statutory Accident Benefits Schedule, is a determination made largely on the basis of the available medical evidence. Whether a long-term disability benefits claimant "is in a continuous state of incapacity due to illness which prevents him from performing the essential duties of his own occupation" as a condition to receiving "own-occupation" benefits under a typical LTD policy, is a determination made largely on the basis of the available medical evidence. Whether a Canada Pension Plan claimant suffers from a "severe and prolonged disability" as a condition to receiving CPP disability benefits, is a determination made largely on the basis of the available medical evidence. While other types of evidence may also be necessary to support a claim, such as current employment information, the central issue usually seems to involve the proof of disability.

Understanding and Supporting Patients' Claims - To a patient who has suffered injury or disability and the consequent impairment of lifestyle or income security, her benefit claim is one of the most important things in her life at that time. She is in pain, feeling emotionally frustrated and financially insecure, possibly getting the "run-around" from her insurer or a benefits agency, and the last thing she needs to hear is the insurance claims handler telling her that her own physician has either failed to respond to requests for information or has responded in such a way that the insurer is compelled to deny the claim.

When asked by a patient, insurer or agency for information concerning the patient – such as the completion of a medical questionnaire, disability certificate or narrative report – the physician should understand the importance in providing a prompt, fair and thoughtful response. Before responding, however, it is important that the physician also have some understanding of the particular disability criteria involved, be it the criteria for LTD entitlement, CPP entitlement, or otherwise. The criteria can usually be obtained by simply asking the patient (or her lawyer) to provide, for example, a copy of the insurer's definition of "disability" or "totally disabled" that will invariably be found in the LTD benefits booklet or contract, or a copy of the Canada Pension disability benefits brochure (which is also readily available online at the Human Resources Development Canada website).

It is also important for the physician to understand the patient's occupational demands. A physician cannot possibly certify whether the patient is or is not totally disabled from performing her essential job functions, if the physician has little or no understanding of the patient's job description, requirements and demands. Taking a little time with a patient (or employer) to discuss these matters will go a long way toward promoting a greater understanding of whether or why the patient is unable to return to work, or to engage in certain activities, or to function without modifications to the home or work environment. In that way, the likelihood of fair and accurate medical reporting to the party responsible for the benefits determination is bound to be enhanced.

Similarly, an early, "rosy" prognosis is a formula for potential disaster for the patient's claim if, in fact, it should turn out that the patient is legitimately continuing to experience disabling symptoms well beyond the prognosticated period of recovery. I cannot overstate the frequency with which an insurer has "reminded" counsel that his client's own physician stated in the Disability Certificate that, within the specified number of months, the patient would make a complete recovery or be capable of returning to unrestricted employment. I can only conclude in such cases that the physician, while perhaps well-intentioned and obviously optimistic, was unduly myopic or naive about how a claims handler would seize upon the early prognosis and turn it against the patient-claimant. It may be fairer and in the patient's interests, particularly when reporting at the initial stages of the claim, for the physician in making the requested prognosis, to avoid expressions of undue optimism. This can be done by frankly indicating, for example, that the prognosis is currently "guarded", or that it is simply "too early" to provide a fair and realistic prognosis, as the case may be, at least until such time as a more definitive statement regarding the patient's future course can fairly and reliably be made.

Assisting Patients by Challenging Insurer Medicals - Automobile and disability insurers are in the business of assessing injury and disability claims. Once we understand that insurers are commercial entities that are driven by profit, are accountable to their shareholders, and maximize dividends by concerning themselves with ratios between claim pay-outs and premium dollars, then we understand that insurers may be approaching the assessment of disability differently than perhaps would the claimant's own physicians.

A common practice of insurers in a given claim, is to arrange one or more medical assessments by practitioners of their choosing. Insurers like to refer to these undertakings as "Independent Medical Assessments". Whenever someone has to remind me that they are "independent" by labeling themselves as such, I become naturally curious if not skeptical. In any event, decisions to accept or deny claims are often made on the basis of these assessments. A claim denial that follows such an assessment may lead the claimant to consult with her physician, her lawyer, or both. I would actively encourage any physician who questions the report made by the insurer's medical advisors to unhesitatingly respond in kind, either by forwarding to the insurer a reasoned, narrative report identifying the specific areas of concern, inaccuracy or disagreement, or by referring the patient to an appropriate specialist who may be better positioned to address or challenge the medical findings or conclusions made on behalf of the insurer.

Similarly, situations may arise where the insurer is seeking to have the claimant submit to excessive assessments or to be placed in a program of rehabilitation that, in the opinion of the claimant's primary physicians or other health practitioners, is inconsistent with the therapeutic regime or goals that have been clinically established for the patient. In such cases, the physician is well within her rights – some might say duty-bound – to intervene in the process, with the assistance of the patient's counsel if necessary, by informing the insurer of any potential harm or regressive effects that the insurer's proposed plan may precipitate. The patient's physician, rather than the insurer, should be exercising the ultimate authority to control the course of rehabilitation. Such intervention will not only help maintain a workable balance between the various interests; it will go a long way toward reaffirming the patient's trust and confidence in his physician that portends a more successful medical and insurance outcome.

Cooperation with Counsel - Cooperation between a client's physician and lawyer is essential to the advancement of the claim. In my own practice experience, difficulties in dealing with physicians who have assessed or treated my clients are generally rare. Most respond reasonably promptly to requests for clinical notes, records and narrative reports. On occasion, however, requests may go unanswered, which could have unfortunate result of delaying the processing of the client's benefits claim. In most such cases, polite reminders and follow-up correspondence will usually suffice. In others, further inducements may be required, including advising the physician of the adverse impact her conduct may be having on the patient's claim or advising of the patient's option of involving the professions' regulatory body. None of this, of course, should have to be necessary.

Counsel's requests for information may also be met with the physician's demand for advance payment of her invoice. While such a demand is permissible, the patient (who often is not able to work and earn income because of the very injury or disability that brought her to the physician in the first place) may not be financially able to pay for the documents requested. Although some physicians are amenable to working out satisfactory payment arrangements, including accepting a written undertaking that guarantees payment by an agreed date or out of the proceeds of the settlement of the patient's insurance claim, others insist upon immediate payment from the lawyer or patient. Supporting a patient in his claim should encompass a level of financial cooperation from the physician that facilitates the advancement of the claim and lessens the patient's anguish. Physicians should appreciate that lawyers practicing in the personal injury and disability field frequently refrain from charging their clients fees until the claim is settled, in recognition that to do otherwise would place too difficult a financial burden on the client.

Summary and Conclusion - The old adage "an ounce of prevention is worth a pound of cure" applies as much to insurance and benefits claims practices as to health maintenance practices. The prevention element, directed to helping the patient avoid an undue denial of benefits, is in ensuring that the patient's claim-related needs are addressed effectively by:promptly responding to requests for medical information and other documentation in support of patients' claims; rendering reports and disability certificates to insurers that are useful to the assessment of claim, in that they are fair, realistic in their recovery and return-to-work prognostications, and based upon an understanding of the patient's occupational demands and limitations; ensuring that statements made about the patient's functional capacities address the specific disability criteria in issue; challenging insurer proposals for treatment and rehabilitation that are viewed as inconsistent with the primary therapeutic goals set for the patient; making appropriate specialist referrals where necessary; and, being flexible and making allowances for the patient's inability to pay up-front for services relating to her benefits claim.

The stress and anxiety that is eliminated when the claims process operates smoothly because the above-noted considerations are kept in mind, may have the tangential effect of speeding the recovery process and restoring the patient's function even sooner than anticipated.

NEW CANADIAN RESEARCH PUBLISHED IN MEDICAL JOURNAL

Chronic fatigue syndrome: neurological findings may be related to blood-brain barrier permeability. **Med Hypotheses 2001 Jul;57(2):231-7 Bested AC, Saunders PR, Logan AC. Environmental Health Clinic, Sunnybrook and Women's College, Health Sciences Centre, Toronto, Canada PMID: 11461179**

(Editor's Note: **The next issue of QUEST will contain a full article**.)

INTER-GROUP/CONTACT COMMUNICATION:

The Myalgic Encephalomyelitis Association of Ontario is hosting a Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Information Session.

Date: Wednesday, September 12, 2001

Location: Auditorium (main floor) of Women's College Hospital, Toronto, 76 Grenville Street (between University Ave and Bay Street, Nearest subway stop is: Queen's Park on the University Subway Line.

Time: Door opens at 12:30PM

Speakers: 1-2 PM - Lawyer, Russell Howe

2-3 PM - Alison Bested, M.D. F.R.C.P. (C) and Alan C. Logan ND

2-3 PM - Will be a question and answer period

If you have a medical question, please bring it with you and it will be collected upon your arrival.

OOOOOOPS!

KATE ANDERSEN: Her correct telephone number is **(604) 732-6030** and the

E-mail address: **kate_andersen_uivc@yahoo.com** or **canadianyouthmefm@yahoo.com**

SMALL BUSINESS ENTREPRENEURS WARNED ABOUT DIFFICULTIES

COLLECTING LONG-TERM DISABILITY BENEFITS -

By: Mary Ellen, Manager - Special Projects

The July issue of CanadaOne Magazine: The free online magazine for small businesses in Canada featured an article by Elaine Sambugaro entitled, "Life's a Risky Business. Can you Afford to get Sick? An in-depth look at the ins and outs of shopping for disability insurance (DI)"

As well as offering consumers advice on how to purchase a policy, the article highlighted the difficulty that many disabled individuals have in collecting their benefits:

"Lydia Neilson, President & CEO of the National ME/FM Action Network says that the number of legitimate claims that have been denied by insurance companies since 1998 is alarming.

"Neilson says that their office has been overwhelmed by telephone calls from disabled individuals who cannot collect DI. She says that the one thing they have in common is that they were denied benefits because they failed an independent medical examination conducted by physicians known to be affiliated with a specific insurer.

" 'It's not a gift,' Neilson said. 'These people paid premiums in the unlikely event that they get disabled. When they're diagnosed with cancer or liver disease or heart disease, look what happens. It's immoral'

"The **National ME/FM Action Network** has been gathering nation-wide information about physicians involved in writing reports that result in legitimate claims being terminated by insurance companies."

Please help us continue to find opportunities to raise public awareness about this serious situation by passing out our IME Registry Submission Form to anyone who may have attended an independent medical examination or functional abilities evaluation requested by a private insurance company, Canada Pension Plan or Workmen's Compensation. Please show our Form to anyone who may come into contact with these people such as doctors, lawyers, chiropractors, massage therapists, dentists, naturopaths, aquafitness instructors, acupunturists, support group members, etc.

To receive a copy or copies of the simple, confidential, 7 question Registry Submission Form, please Contact:

Mary Ellen, Manager of Special Projects, Phone or fax: (905) 831-4744 -

Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON., L1V 6P7 -

Email: marye@pathcom.com

Or download the Form from our website at: **www3.sympatico.ca/me-fm.action/medexam.html**

OUR WORLD: DISORIENTATION: BRAIN IMITATING WEATHER ‘UNDER THE INFLUENCE’

CRYING: WATERING THE DESERT OF DESPAIR IN VIEW OF GREENER PASTURES Author: Lorraine Legendre, Ottawa.

<u>QUEST COLLECTION BOOK - FIVE YEARS:</u> By popular request, **the National ME/FM Action Network** has published an easy to read book consisting of a **collection** of important articles which have appeared in our **‘QUEST’** newsletters over the years. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We have kept the **cost** of the book to a minimum at **$20.00** each which includes shipping and printing. Please make **your cheque payable to the National ME/FM Action Network** and let us know how many copies you would like.

<u>LEGAL/RESEARCH PACKAGE</u> - **Medical** and **Legal** Information. 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**

MEMBERSHIP: $25.00 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

E-Mail:ag922@freenet.carleton.ca

WEB: 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.