Quest #38 October 1999

ME/FM CLINICAL DEFINITIONS/PROTOCOL - UPDATE

We are pleased to advise that on Wednesday, January 5, 2000 we have a meeting with the Director General of the Laboratory Center for Disease Control, and who will also represent the Minister of Health On the agenda for this meeting is a discussion of funding for a peer-review of the ME/FM clinical definitions and treatment protocols and funding for the dissemination of the information to the Canadian doctors.

The clinical definitions and treatment protocols are necessary because, to date, there are no standardized protocols followed across Canada. The 1994 ME definition established by the U.S. Centers for Disease Control is a research definition not a clinical one. Once a clinical definition has been established, it will give doctors the knowledge necessary to diagnose and treat.

The doctor in the following article reinforces our stand about the importance of standardized ME/FM clinical definitions and treatment protocols.

The National ME/FM Action Network would like to take this opportunity to congratulate all of you on the accomplishments we have been able to achieve as the result of our partnership with you. We can all look to the new millennium with optimism and hope.

Sincerely,

Lydia E. Neilson, President CEO

FROM: THE LYNDONVILLE JOURNAL Volume 1, Issue 6 - By: David S. Bell, MD

[Dr. David S. Bell is one of the pioneers of research on ME/FM and is featured in "Osler's Web" by Hillary Johnson. A paediatrician by specialty, Dr. Bell has been a leading figure in the field since the early 80's when, in the small town of Lyndonville, NY where he practices, a large number of people, including children, "came down" with ME/FM. As a Harvard graduate, Dr. Bell boasts impressive academic credentials and is the author of several books and numerous peer-reviewed research papers on ME/FM but apparently he prefers to work outside of the academic field, doing research on a shoestring budget and helping thousands of people with ME/FM around the world to live with this devastating illness. Jean Pollard, his office manager, is a member of his research team as is Mary Robinson, a US educator and parent. The National ME/FM Action Network is honoured that Dr. Bell has agreed to serve as the Senior Editor of our planned sourcebook for teachers working with children and youth with ME/FM. - submitted by Kate Andersen, Youth Consultant, National ME/FM Action Network.]

Symptom Variation: Illness or Host?

Roughly 70% of the persons I see in the office have a pattern of symptoms that is "typical of" CFS. The remaining 30% have variations where doubt can be raised as to the diagnosis. This variation in symptoms is the main reason that most researchers see CFS as a variety of differing illnesses that produce fatigue as a symptom. Part of this is because of the current accepted definition of CFS, the CDC research criteria. These research criteria for CFS are just that - research criteria. They were not designed to help the clinician make the day to day diagnosis of CFS in the office. These criteria are intentionally restrictive. The purpose of this restriction is to create a small but homogeneous group of persons with a homogeneous symptom pattern that permits research. Without a good restrictive definition, it is impossible for one researcher to know what another is talking about in the medical literature. Unfortunately, this creates a big problem. Many clinicians, insurance companies, and governmental disability people will say that if you do not fit the research criteria you cannot have CFS. I do not think this is true. I know of many persons with CFS symptoms who do not fit the research criteria but are disabled. Clinical criteria for the practicing clinician need to be developed, but because of the political complexities, that will have to be delayed for a while. Is CFS one illness or many? Obviously this question cannot be answered at the present time, and the debate continues. But I feel that the vast majority have a single illness, rather than CFS being a mish-mash of a hundred or so different illnesses. The issue here is the debate of illness versus host. What exactly comes from the cause, and what comes from the host response? To look at this conflict, let us look at chicken pox. Chicken pox is an everyday, run of the mill, simple illness. Every clinician makes the diagnosis with ease. You see one chicken pox, you have seen a thousand. It is simple and it is one single illness. That is because it is an illness that affects a distant target organ - the skin. A five-year-old comes in with a fever and little blisters that look like a "dew drop on a rose petal". And that is exactly what a perfect chicken pox looks like (I have no idea where the chicken part comes in). There may be some minor variations. A child may have thirty pox or three hundred. Some pox (or poxes?) may get infected or scabbed over. Big deal, it is still chicken pox, one illness. The host (or person with the illness) does not affect it much. But wait. In some cases the host is critical and the illness can be different. Some people have chicken pox without a rash, or have a pneumonia, or worse yet, have a neurologic complication. Is it still chickenpox? Yes because we are able to culture the virus from the lung or brain and it is the same as the regular chicken pox in the skin. In CFS we do not have this luxury; the situation is different. Whatever CFS is, it affects a very central mechanism within the body, not an end organ like the skin. And this central mechanism, probably the brain, can manifest the symptoms of an insult very differently. With the brain, the same injury or illness causes a variety of symptoms. (Brain tumors, for example. The symptoms of a one-inch area of brain injury depend entirely upon the location of this injury. In one area, there may be minor if any symptoms. In another it might cause arm weakness, in another area, behavior or emotional symptoms). Let us suppose for one minute that a single neurotropic virus, one that affects brain tissue causes CFS. If this virus affects only a small part of the brain, the symptoms will be uniform (post-encephalitic Parkinson's). But if it affects more than one area, then a multitude of symptoms may result, with clear variations from person to person (Post polio syndrome). The issue is the competition between agent specificity and how the host responds to it (host versus illness). The enormous complexity of both genetic and environmental factors makes people different. By itself, this is an interesting discussion, and probably a good thing. But science would be easier if we were all clones. (We would probably get along better as well.) But the complexity of host response, differences in immunity, emotional vulnerability, and environment makes it so that the same injury may cause a variety of responses, particularly if that injury is a central or primitive part of the brain. In CFS, we can trace the symptoms to this primitive part of the brain where hormones are produced, where sleep and alertness are regulated, where blood pressure and heart rate are controlled, where pain is modified. One person with CFS may have asthenia as the worst symptom. Another pain is the worse symptom. Are these two illnesses or are they the same? The answer is seen not by looking at one or two symptoms, but by examining the entire symptom pattern. For now, it is reasonable to define CFS broadly without being picky. A clinical, symptom based diagnosis is appropriate, with the understanding that other fatigue causing illnesses have been excluded. The pattern of symptoms rather than the specific worst symptom defines the diagnosis. And this pattern may vary from person to person. I do not see this variation as due to differing illnesses. Rather I see the same illness having differing host responses. The roots of my bias are easy to spot. In Lyndonville, many persons developed severe fatigue and other symptoms due to something. Because this took place in an isolated rural community, I feel that it must have been a single event. I do not think that fifteen different causes of CFS hit all at the same time. For this reason, the variation of symptom severity and even emphasis must be due to host responses rather than cause. Two children in the same family become ill. One has acute onset, one gradual; one with fatigue as the worst symptom, one with headache. But it is too much of a coincidence that these would be different illnesses within the same family at the same time.

As an aside, the CDC has stated that CFS does not run in families. This is because all may not fit the CDC research criteria. But most clinicians feel that there is a clear familial component. If three family members develop chronic fatigue at the same time, host response is more likely to explain the differences in symptoms than the possibility of separate illnesses. At the time of the CFS "outbreak" in Lyndonville, there were those with viral infections that caused two months of fatigue. Lucky individual. And there were siblings who got full-blown CFS. My hunch is that it is the same initiating event expressing itself differently in separate individuals.

We will know the answer to host versus illness only when an underlying cause is known in a few persons. Then we can see if the others have evidence of the same underlying cause. This was the case with HIV infection. Some persons would have cancer, some bad pneumonias. Only when a specific initiating event was found was it possible to understand the full spectrum of HIV infection. So now we have to wait. We can create a definition, and start from there. It is my hunch that we will soon define appropriate subgroups of CFS. And it remains to be seen whether these subgroups are artificial or will accurately define different causes of CFS. But until this occurs, persons with CFS should not be denied appropriate diagnosis, treatment, or disability benefits if warranted. The definition of CFS now must be broad. Whether due to host response or initiating cause will be answered eventually with research. I am going to put my money on a few different initiating events causing a specific physiological injury in persons with varying host response. And I keep wondering why I am broke.

(Permission was granted to reprint this article which first appeared in the newsletter by Dr. David Bell "The Lyndonville News." This newsletter which is a joint effort of Dr. Bell, Jean Pollard, and Mary Robinson is written for people with CFS, or who have an interest in CFS . Each issue covers current research and theories, what is happening in his practice, and issues dealing with parenting a child with CFS. For a sample copy of the newsletter and information on how to subscribe please send an email to CFS-DSBELL@juno.com.)

REVIEW OF DR. CHENEY'S "GLUTATHIONE DEFICIENCY IN ME/CFS/CFIDS"

By: Philipa D. Corning, CD, B.Sc. (Hon), Ph.D.

[In this paper, any methods/supplements described were found successful in scientific experiments. Any measures are NOT proposed as medical cures, and readers are advised to consult a healthcare professional before trying anything. Furthermore, I caution all readers that what works for one person may not necessarily work for another. We are all biochemically unique.]

Dr. Paul Cheney - Research with Whey Protein

Dr. Paul Cheney is an eminent scientist and physician, who is well respected and held in high regard within the ME/CFS/CFIDS community for conducting studies on the cutting-edge of science in regards to this condition. Normally he sees patients who are very ill, because they have turned to him after other physicians have not been able to help them. In his recent preliminary study, he has found a method that works to some degree for all his very ill participants Basically, he found **all** these participants **deficient in glutathione,** whose abundance in the body is indicative of good health. By treating this deficiency with an undenatured whey protein, the participants in this study all felt better to varying degrees.

Normal Mechanism Gets Out-of-Control

Normally there is a pathway (referred to as the RNaseL pathway) that regulates protein synthesis within every cell of the body. If the system is highly activated, the production of all protein in the cell is decreased. Activation of this pathway reduces the synthesis of **all** cell protein, which includes intracellular **enzymes**. Of the many cell processes that normally depend on enzymes in order to operate are: the energy production cycle, the synthesis of hormones, the detoxification pathway and the immune response. Thus, disruption of these particular processes in the case of chronic fatigue syndrome could lead to the following situations occurring in the afflicted person's body:

1. reduction of the enzymes required for the production of energy resulting in fatigue;
2. decrease in enzymes needed for the synthesis of hormones leading to endocrine problems;
3. reduction of the enzymes necessary for the process of detoxification ending in the accumulation of toxins in the body; and
4. lack of enzymes in the immune system resulting in white blood cells that function poorly.

In the normal healthy cell, this RNaseL pathway plays a duel role:

1. the regulation of intracellular protein synthesis; and
2. an antimicrobial mechanism to rid the cell of intracellular pathogens such as viruses, mycoplasmas and small bacteria.

In CFS this pathway is up-regulated through the immune system becoming activated by an infectious agent, toxic substance, food allergy, etc. In the end, its activity and the associated reduction of intracellular protein lead to the complete disruption of cellular metabolism. Due to a lack of enzymes, the detoxification system easily becomes overwhelmed and so toxins accumulate. These harmful substances can cause structural damage within all cells of the body including the hypothalamus in the brain, the endocrine glands and the immune system resulting in their dysfunction. Toxins can also interfere with the few enzymes of the energy production cycle that have not fallen victim to the RNaseL pathway. The result is a cell and body in complete disarray.

Key Factor: Glutathione Deficiency

Dr. Cheney considers that this syndrome may represent:

1. an immune activation state (immune system constantly on hyper-guard);

2. with a disordered glutathione system.

Furthermore, he considers the deficiency of glutathione to be a **KEY FACTOR**. The glutathione system was particularly impaired in this syndrome. The lack of glutathione impacts on the function of the detoxification, the body's endogenous antioxidant and immune systems.

Glutathione

There are well over 40,000 published scientific research papers on the roles played by the molecule called glutathione in cells of the human body. Research indicates that glutathione is one of the most important molecules required in the body:

3. as a principal antioxidant deactivating unstable molecules called free radicals and assisting other antioxidants - vitamins A, C and E;

4. as one of the most important molecules in the detoxification system; and

5. as an immuno-enhancer for optimal function of the immune system.

How Glutathione is Depleted in ME/CFS/CFIDS

As previously mentioned, glutathione levels in the body give an indication as to the individual's health status. In this syndrome, glutathione in the body can be depleted in the following ways:

1. increased free radical activity due to hyperactive immune response (free radicals are the weapons used by lymphocytes against pathogenic microbes), ingested environmental toxins, and normal metabolism just to mention a few;

2. high rate of lymphocyte (T and B cells) reproduction in a hyperactive immune system;

3. increased accumulation of toxins including pharmaceutical drugs that stress the liver's detoxification capacity;

4. highly activated RNaseL pathway uses mega amounts of glutathione; and

5. viral theft by activated latent viruses that have laid dormant in our cells and current viral infections steal host-cell selenium and in turn reduces glutathione synthesis (selenium is required for the production and activity of this protein).

Thus, it would seem beneficial to build up the body's supply of glutathione in order to improve the level of health and the quality of life of the person ill with ME/CFS/CFIDS.

Attempts to Increase Glutathione

In an attempt to raise the glutathione levels in the body, Dr. Cheney tried a number of conventional sources of glutathione: N-acetyl cysteine, methionine and cysteine. Unfortunately, none of the participants exhibited any signs of improvement. In his search for a better source of glutathione, he came across the whey protein concentrate (referred to as HMS90 in Canada and Immunocal in the United States) produced by Immunotec Research of Montreal, Quebec. This product was developed after 18 years of rigorous research and had won 7 pharmaceutical patents. Through research, this natural dietary supplement was validated to raise the body's glutathione levels. Dr.

Cheney decided to run a preliminary trial on this product.

Dr. Cheney's Study with HMS90/Immunocal

Dr. Cheney enlisted 8 participants in this preliminary clinical study using the whey protein concentrate from Immunotec Research. Each participant took two pouches per day for the first three months, and then for the last three months half were randomly chosen to take only one pouch per day. Each pouch contains about 9 grams of high quality undenatured bioactive protein. At the end of the trial, Dr. Cheney found the following results over the 6-month study period:

1. increase in well being of participants;

2. increase in participant level of energy;

3. lymphocytes which were non-responsive to foreign antigens were now effective against microbes;

4. level of free radical damage decreased to normal levels;

5. antibodies decreased to normal levels, which reflected a reduction in viral, etc.burden;

6. decrease in number of relapses;

7. reduced the population size of intracellular microbes by inhibiting their multiplication (this included viruses, mycoplasmas and small bacteria);

8. success was achieved for participants afflicted with multiple chemical sensitivities; and

9. two pouches per day produced the most beneficial results.

In some instances, Dr. Cheney reasoned that an individual might have to consume three packages a day. Thus, depending on the person the daily dose of the whey protein varied from 1 to 3 packages (9 to 27 grams).

How the Whey Protein Works

Glutathione is the naturally occurring protein that protects each cell, tissue and organ from disease, aging and cancer. And, like all proteins, glutathione consists of building blocks called amino acids. In order to build this protein inside each cell, the milk whey proteins are broken down in the digestive system, absorbed into the blood and then transported to the cells. Once inside the cell, amino acids are assembled into the protein glutathione. Of these amino acids, cysteine is rarely available in our diets as there are only trace amounts in certain foods, such as raw egg white, milk and meat.

These trace amounts are insufficient to ensure adequate synthesis of glutathione when the body is exposed to the environmental challenges of life today. HMS90/Immunocal contains a high concentration of this critical building block - cysteine, which gives glutathione its important bioactive properties. Unlike the other whey, Immunotec has developed a preparation process that involves the most advanced technology of microfiltration, ultrafiltration and drying aimed at preserving the delicate milk whey proteins in their natural forms. This process affords HMS90 its essential bioactivity.

Future Plans

Dr. Cheney's preliminary research has certainly proven that this therapy does indeed help ill people. In the near future, he will be conducting a larger formal study with this product to determine its true potential for improving the quality of life for individuals afflicted with the very debilitating syndrome.

[For more information on Immunocal/HMS 90, Contact: **Darleen Mills (613) 258-5474 -**

E-mail: dlmills@docuweb.ca - Web: www.docuweb.ca\immunocal]

PAIN MANAGEMENT AND TREATMENT - BY: Mark Baily, B.Sc., M.D., D.A.A.P.M.

Management of chronic pain has always been one of the most challenging tasks for physicians. Chronic pain often leads patients into a downward spiral of physical debilitation, increasing analgesic use and depression. The Headache Treatment Clinic is a facility specializing in the treatment of chronic head, neck and facial pain as well as fibromyalgia.

In an effort to meet the patient's diverse needs, we offer the patient a comprehensive rehabilitation program, assist in breaking the chronic pain cycle and maintaining a pain-free state. Ongoing communication is provided to the family physician in developing, organizing, and implementing a treatment plan which is developed after a thorough medical assessment and the treatment is individualized for the patient.

Our clinic provides:

1. Pharmacological management to provide optimum relief while preventing analgesic misuse. Drug withdrawal techniques are employed whenever necessary;

2. Nerve blocks have been proven to be very effective in the treatment and control of chronic head and neck pain. This procedure is a powerful tool in breaking the pain cycle and often results in long-lasting relief. In our experience, nerve blocks will result in significant pain reduction in 60-70% of chronic headache patients;

3. Trigger point injections in conjunction with active and passive physiotherapy is an effective method we employ to treat myofascial pain;

4. Chiropractic, alone or in conjunction with other forms of therapy, is often a useful treatment for certain types of headache and chronic pain;

5. The Synaptic 2000 is a new electronic pain management device approved by Health and Welfare Canada. The concept behind this new device employs a neuromolecular biological technique that releases neurochemical substances in the brain (endorphins) to combat pain and inflammation. It is the only device on the market that uses high frequency stimulation to induce local analgesia, deep anestheria and increased circulation. This device in the management of acute and chronic pain is showing encouraging results;

6. Referrals to local facilities offering: a) Physical modalities and therapy; b) Active rehabilitation with muscle strengthening; c) Work hardening; d) Psychological counseling and relaxation training; and e) Biomechanical and temporomandibular joint (TMJ) assessment and treatment.

All services including nerve blocks, trigger point injections and the Synaptic 2000 are fully covered by OHIP (Ontario Health) and Workers' Compensation. Other services, such as chiropractic may be partially covered by OHIP and WCB or by third party insurance and motor accident benefits.

Patients that would benefit from referral include those suffering from chronic headaches including tension, migraine, post-traumatic, medication induced, menstrual associated with or without neck pain; and anyone whose quality of life has been affected by their chronic pain conditions, including those patients suffering from fibromyalgia.

[Ed.note: Dr. Baily and his Associates can be reached at the Headache Treatment Clinic in Toronto at: (416) 699-8843 or Brampton at (905) 451-7241]

WINNING THE FIBROMYALGIA CASE -

By: Richard M. Bogoroch, Esq., Bogoroch & Associates, 150 King Street West, Suite 1707, Toronto - Tel. (416) 599-1700 - Fax: (416) 599-1800 -

E-mail: info@bogoroch.com

Few medical diagnoses has engendered as much controversy as fibromyalgia. Among doctors, lawyers and health care professionals, lines have been drawn as to the existence of this condition. As a lawyer who represents fibromyalgia survivors and their families, I can tell you that the legal and medical dispute is unhelpful. Fibromyalgia sufferers and their families live with its consequences every day. Lives and careers have been shattered and families disrupted because of fibromyalgia. There is no doubt that this condition exists, and there is no doubt that people who suffer from fibromyalgia are entitled to compensation and, in the context of disability claims, payment of disability benefits in accordance with the terms of the policy.

Fibromyalgia sufferers need to know that they are not alone, that there are lawyers that not only have experience in representing fibromyalgia sufferers, but are committed to seeing that justice is done. The purpose of this article is to inspire and empower those who are suffering from this terrible condition and to let them know how their claims for compensation can be won.

It has been said that litigation is "not a tea party". For that reason, a fibromyalgia sufferer must ensure not only that he or she is prepared to see the case to conclusion, but that his or her counsel is tenacious and will do what is necessary to see that justice is done.

There are three factors required to win the law suit: preparation, preparation and preparation. There is no substitute for the hard work and diligence required of counsel to ensure that the fibromyalgia sufferer is properly briefed for the litigation process, but also to ensure that the appropriate experts are employed to help educate the trier of fact (either judge or jury), about the nature of fibromyalgia and the effects on the fibromyalgia sufferer.

How is this accomplished? Case selection is obviously very important. The cases which have the greatest chance of success are those cases in which the Plaintiff (that is the person suing) has a good work history and is a credible historian about his or her past ailments and conditions and illnesses. Few people, particularly fibromyalgia sufferers, have unblemished medical histories. Indeed, in the real world, very few people have had "pristine" medical histories. Most of us have had some ailment, condition, illness or disability at one point in time in our life. That does not mean to say that just because someone has a pre-history of disability or periods of time off work that they are not to be believed; all it means is that the evidence must be documented, collected and disclosed. Credibility problems arise when the trier of fact comes to the conclusion that the Plaintiff has not been "up front" about his or her disability. For that matter, it is essential that the lawyer taking on the case do a complete investigation about the client's medical history and obtain clinical notes and records from the treating physicians. It is a truism to state that any law suit or any claim for compensation involves an intrusion into the privacy of the fibromyalgia sufferer. Unfortunately, if one is suing or claiming compensation, one's life becomes to a certain extent an "open book" and pre-existing medical records are producible. The reason is to safeguard the integrity of the system and to ensure that people who claim are legitimate, and one way to test that is by requesting and obtaining clinical notes and records from the treating physicians.

Once that is obtained and appropriate disclosure made, one would think that the insurer would pay the claim. Because there are many doctors today who don't believe in fibromyalgia and deny its very existence and legitimacy, insurers rely on these doctors to deny payment of disability benefits due and owing. It is in that case where we become involved.

We examine the claim, we carefully interview the client and we obtain all of the records. We will then, as a general rule, retain an expert, someone who is skilled in fibromyalgia and knowledgeable about the medical literature that has developed, to examine our client and prepare a report regarding the medical condition of the client. Our client will be sent to these physicians for the purpose of assessment, not treatment, and the report will be used in the law suit that we commence on behalf of our client.

Case preparation, attention to detail and selection of the right expert are the essential ingredients in winning the fibromyalgia case. I prepare my cases from the time the client comes in the door. Our trial preparation begins immediately. Most cases do indeed resolve before trial but in order to achieve the best result, you not only sometimes have to proceed to trial but you also must prepare the case as if it is going to trial, and that is what we do. We have found over the years that by thorough preparation, attention to detail and a commitment to client service, we are able to achieve just results. Fibromyalgia sufferers and their families must know that there are lawyers who are prepared to fight for the rights of fibromyalgia sufferers and their families and will work hard to ensure that a just result is achieved.

[Ed. Note: Mr. Bogoroch has moved and started his own firm, Bogoroch & Associates, with a support staff of 11 people, and aims to provide fibromyalgia and chronic pain sufferers with the best possible service. They do not charge until the case is concluded, and handle cases throughout Ontario]

BOOKS/NEWSLETTERS/REPORTS/VIDEOS ETC.

Complementary & Alternative Health Practices & Therapies - A Canadian Overview - The York University Centre for Health Studies - 410 pages. For a copy, please contact York University Centre for Health Studies at: Fax (416) 736-5986 - E-mail: ychs@yorku.ca

NATIONAL LAWYERS' ROSTER: ADDITION

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URGENT! URGENT! URGENT!

This time of year, the National ME/FM Action Network seems to get an increase in the number of phone calls from desperate people across Canada whose private insurance company has terminated their disability benefits as a result of the report of an Independent Medical Examination (I.M.E.) or Functional Abilities Evaluation (F.A.E.) in spite of the fact that the person is too ill to work. If you hear of such people, please let them know that our organization wants to help.

Thank you to all of the local support groups who added the I.M.E. Registry Submission Form to their newsletter in the past few months. Your support in reaching people about this important project is appreciated. Please continue to remind your members how important it is for them to spread the word to anyone appropriate. Your endorsement of this project and of our reputation for confidentiality and advocacy work often make the difference as to whether or not someone feels comfortable contacting us. This time of year, many insurance companies seem to increase the number of requests for people to see an independent medical examiner or attend a functional abilities evaluation and we need to keep our records accurate about which doctors are being used for these purposes. Please help us to work towards seeking insurance reform, which is long overdue. We need strong statistical evidence of the serious problem in order to be successful. Our goal is that disabled people be truly protected when they need financial support from their private insurance companies. These people have paid premiums for years. They deserve to be treated fairly when they are unable to work.

To get a copy of our simple, 7 question Registry Submission Form, please 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

<u>ASK A LAWYER</u> - Mary Ellen submits questions on behalf of our members -

Answers by: Douglas Faulkner, Esq., Barrister & Solicitor, Séguin Landriault & Lamoureux, Barristers & Solicitors, 1110-141 Laurier Ave. W., Ottawa, ON K1P 5J3 - Tel.(613) 236-9141- Fax: (613) 236-0989 - E-mail: dfaulkner@seglaw.com

QUESTION: Are people required to go through an I.M.E./F.A.E. with someone other than a medical doctor?

REPLY: The right to require an I.M.E. is always set out in the contract of insurance. That policy is established by the insurance industry without reference to the medical industry. And as the individual who contacted you discovered by reading his own policy, the parties entitled to perform the I.M.E. are spelled out in the contract. They vary from insurer to insurer and from policy generation to policy generation. The disabled party's policy in 1994 may have read "qualified physician" but now reads "or other health care professional as determined by the insurer" or words to that effect. The company and insured are bound by the words of the policy in effect at the time the application was accepted and if the insured had been receiving benefits under the 1994 wording, the company could probably in that case not demand an assessment by anyone other than a medical practitioner. Of course, the conflict escalates as soon as the insured refuses to undergo ANY assessment suggested by the insurer. The insured must be prepared to do battle if the intention is to confront the insurer on this issue because the usual approach is to terminate benefits now and discuss later.

QUESTION: A lot of insurance companies do not provide a copy of the contract to the insuree. I know that when legal action is taken, the lawyers for the insurance companies know it cannot be withheld, but a lot of people would like to know how to pry it out of them before this point.

REPLY: The insured has an undisputed right to obtain a copy of the policy of insurance as they are a significant party to that legal agreement. The company cannot legally deny the insured a copy, nor can they satisfy the insured's rights by providing one of their glossy little booklets that merely outline the policy. The insured, if covered by a group policy can also obtain a copy from the employer or, if unionized, from the union representative. The policy clearly sets out the terms and conditions upon which the insured and insurer must base their legal relationship. It is completely inappropriate for the insurer to refuse to provide a copy to the insured of a document containing terms and conditions largely determined by the insurer but binding on both parties. Not only does the insurer in that case have the primary power in setting the terms and conditions, they would appear to calculatedly attempt to ensure that the other party to the contract remains ignorant of what it is that has been agreed to and what the insured may have paid for many years running! This sort of callous and high-handed behaviour should lead to an award of punitive or exemplary damages though that is rare. Which is all to say, DO NOT TAKE 'NO' FOR AN ANSWER FROM THE INSURER ON THIS ISSUE.

QUEST COLLECTION BOOK - FIVE YEARS:

By popular request, the National ME/FM Action Network has just published an easy to read book consisting of a collection of important articles which have appeared in our 'QUEST' newsletters over the years. Many people have wanted easy access to certain medical or legal articles and we are pleased to announce that this book has now been completed. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We believe that anyone who is involved in the ME/FM community will want a copy of this book consisting of over 100 pages of information. This may also be a good book for you to purchase and give to the professionals in the medical/legal community.

We have kept the **cost** of the book to a minimum at **$20.00** each which includes the cost of 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.

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**

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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