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IN MEMORIAM

AUDREY MacKENZIE June 4, 2007

By Margaret Parlor

It is with great sadness that we pass on the news of the death of Audrey MacKenzie, a wonderful friend to Canadians with ME and FM. Audrey died on June 4th in Toronto. She was 65 years old.

Audrey was originally from Springfield in rural Ontario. She entered and rose through the nursing profession. Around 25 years ago she fell ill. For two years she was virtually bedbound surviving on coffee and cigarettes. One day she found a treatment that helped and her condition improved somewhat.

She used this opportunity to reach out to others. She became active in the Ontario ME community. In 2000 she became President of The Myalgic Encephalomyelitis Association of Ontario. She stepped down as

President in 2006 but still remained interested and involved even in her last few days.

Here is a tribute written by Eleanor Johnston, one of her many friends and colleagues:

“Audrey May Cornish MacKenzie was an inspiration to so many whose lives she touched.

She was kind and caring, smart and wise and funny, frail but formidable, and fiercely determined to rise above any circumstances to accomplish anything to which she had set her mind.

It was our very good fortune that Audrey chose to apply her many talents, and that amazing will power and resourcefulness to advancing recognition of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and related environmentally-linked conditions, and to advancing appropriate care throughout the province, for people of all ages with these conditions.

Audrey saw the big picture and long-term goals as clearly as she saw personal situations and immediate needs. She worked diligently to address them all – educating, encouraging and supporting wherever she could, while constantly looking for opportunities, people who could help, and sources of funding.

Audrey was a master of the well-chosen word whether in creating the newsletter, doing funding proposals, or in speaking to politicians.

She was also good at understatement when it came to the extra health challenges she faced. We had so often seen how coffee, maybe a cigarette or two, and sheer determination had fuelled her to rise to challenges in the past, we expected that, on principle, she would keep working forever.

Audrey, we are very grateful for all the work you have done. We are even more grateful for your inspiration, your friendship and your impish laughter.”

The family has asked that anyone wishing to make a donation in Audrey's memory, please send it to:

The Myalgic Encephalomyelitis
Association of Ontario
P.O. Box 84522, 2336 Bloor Street
West
Toronto, Ontario, Canada
M6S 4Z7

MEDICAL NEWS

Where Have the Overviews Gone?

Second Printing and Mail-Out Completed

First, we would like to take this opportunity to thank doctor Bruce Carruthers and Marjorie van de Sande, for having volunteered to summarize the CFS and FMS Clinical Definitions and Protocols and to publish Overviews of those two consensus documents.

In our endeavor to advance the current understanding of ME/CFS and FMS, the National ME/FM Action Network has been working diligently to place Overviews in the hands of physicians.

We started with the Maritime Provinces and Territories because they have the least support. The National ME/FM Action Network is pleased to announce that we have just completed our 2007 mailing of Overviews to:

Throughout Canada

- **All Medical Schools** Heads of relevant departments
- **All University Medical Libraries**
- **Colleges of Physicians and Surgeons**
- **All Rheumatologists (FMS Overview)**

Saskatchewan, New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador, Yukon and Northwest Territories

- All physicians of Family Medicine

Alberta

- All physicians of Family Medicine
- All Neurologists
- All specialists in Community Health
- Specialists in Internal Medicine (Calgary)
- Nursing Schools (Calgary)
- All Cardiologists (ME/CFS Overview)
- All specialists in Infectious Diseases (ME/CFS Overview)
- All specialists in Clinical Immunology/Allergy (ME/CFS Overview)

Additional distribution of Overviews

British Columbia

- **The MEFM Society of BC** funded the distribution of Overviews to physicians of family medicine and neurologists in British Columbia. The MEFM Society of BC may be reached in Greater Vancouver at 604-878-7707 or BC toll free 1-888-353-6322, info@mefm.bc.ca www.mefm.bc.ca.

Quebec

- **Medical Schools Faculty –** thanks to the AQEM (Quebec ME Association) for distributing the ME/CFS Overviews
- **Medical Schools Faculty –** thanks to the Fédération Québécoise de Fibromyalgie for the distribution of the FMS Overviews.

In addition, the National ME/FM Action Network wishes to thank the following who generously contributed to the distribution of Overviews:

- Pfizer Inc. - $5,000.00 donation
- Lise Noël, a member - $3,000.00
- Dr. Kenny De Meirleir – for his generous donation of his time and expertise at his conference in Alberta

- Dr. Ellie Stein and the organizing committee of Dr. De Meirleir's Conference - for designating conference profits to the distribution of Overviews in Alberta
- FM-CFS Canada for transferring 1,000 FMS Overviews to the Network

The distribution of Overviews is a monumental task so we all need to work together. We are asking you to do whatever you can to help. Every time some Overviews are sent to doctors, it lightens the load for others. If you are able to make a donation or let family and friends know how they can help, please do. Donations to the United Way can be designated to the **National ME/FM Action Network, Charitable tax no. (BN) 89183 3642 RR0001.** Hundred per cent (100%) of donations designated to the distribution of Overviews go to that cause. Tax receipts will be issued for donations of $5.00 or more.

Please email Marj van de Sande at mvandes@shaw.ca with information regarding how many and where you send the Overviews. She will post the information on our website so we don't duplicate each others efforts.

Symptom or Cause? Trying to Correlate Immune and Sleep Deregulations in Chronic Fatigue Syndrome

Based on research reported in:
Van Hoof E, De Becker P, Lapp C, Cluydts R, De Meirleir K. Defining the occurrence and influence of alpha-delta sleep in chronic fatigue syndrome. *Am J Med Sci* 333(2): 78-84. 2007.

Summarized by Michelle Rank
Provisional PhD candidate in the Centre for Neuroscience at the University of Alberta

A well known symptom of ME/CFS is a disordered sleep pattern. Patients often report sleep related symptoms ranging from difficulty getting to sleep to frequent awakenings, and an overall non-restorative sleep. As part of the ME/CFS diagnosis process to exclude primary sleep disorders, many patients are no strangers to sleep labs and the polysomnographic investigations which help to characterize brain wave and biophysical changes during sleep. The polysomnographic recordings monitor electrical activity in the brain through electrodes placed on the scalp, and also use other sensors to measure heart rhythm, respiratory effort and body movements during a night's sleep.

Though previous research has long reported the sleep abnormalities common in ME/CFS[1], no specific underlying cause of them has been isolated. However, since the discovery of precise immunologic abnormalities and discrepancies associated with ME/CFS in the early 1990's by Suhadolnik and colleagues[1], researchers have often been quick to attribute one pathway in particular for the constellation of sleep abnormalities found in ME/CFS patients. Hyperactivation and deregulation of the 2-5A synthetase/RNase L antiviral pathway in ME/CFS patients is frequently reported in the scientific literature[1, 2, 3]. The increased activity of this pathway in ME/CFS patients, normally part of the antiviral defense mechanism in healthy cells and responsible for the regulation of cell growth and differentiation[4], leads to improper function of potassium channels and ultimately the inability of cells in the nervous system to function normally. The acquired potassium channelopathy associated with the exaggerated 2-5A synthetase/RNase L pathway activity is generally thought to be the culprit behind characteristic sleep disturbances in ME/CFS but this has never actually been directly investigated.

For the first time ever, a team of researchers from Belgium have finally explicitly investigated the correlation of immune parameters associated with the malfunction of the 2-5A synthetase/RNase L pathway to specific polysomnographic abnormalities found in patients with ME/CFS, and the results are not quite what many scientists and physicians expected.

Using electroencephalographic (EEG) techniques, recording electrical activity in the brain, allows for characterization of what is happening in the brain during sleep. Normal sleep is divided into rapid eye movement (REM) and non-REM sleep, with non-REM sleep further subdivided into stages 1, 2, 3, and 4[5]. Delta waves, the large slow oscillating brain waves (2.5Hz or less) which are naturally present only in stages 3 and 4 of non-REM sleep, make up the deep sleep portion of a night's rest. Alpha waves, conversely, are smaller faster brain wave oscillations (8-12Hz) which normally occur during quiet wakefulness and disappear when sleep begins. EEG recordings in patients with ME/CFS have shown a reduction in sleep efficiency and time in REM sleep, as well as a longer sleep initiation[6]. A significantly lower percentage of deep, or stage 3 and 4, sleep is also characteristic of ME/CFS. Distressingly, ME/CFS patients also often suffer alpha wave intrusion in deep sleep, or alpha-delta sleep[6]. This effectively interrupts the deep restorative sleep obtained in stages 3 and 4, as the delta waves during these stages are constantly interrupted by bursts of awake-like brain activity resulting in a regression to a lighter sleep and ultimately feelings of fatigue. The deregulation consistently found in the 2-5A synthetase/RNase L pathway in ME/CFS patients has frequently been pointed to as the cause of this specific alpha-delta sleep anomaly. The Belgian researcher team explicitly tested this long standing hypothesis by correlating data obtained from sleep studies on ME/CFS patients with a limited number of immune parameters tested for in their blood samples. Specifically the researchers were looking at instances of alpha-delta sleep and for RNase L levels, NK-cells and T-cells in the blood samples (this enzyme and the other cells are implicated in viral immune responses and the RNase L level is thought to give a clear picture of immune deregulation). Could it really be that the immune deregulation ME/CFS patients are known to have are related to, and possibly the cause of, the unrefreshing sleep experienced?

The in-depth analysis of alpha-delta sleep in ME/CFS patients, not surprisingly, revealed results similar to those that have been reported in numerous studies since the early 1990s. ME/CFS patients show disturbed sleep continuity and a distorted sleep pattern, experiencing difficulty falling asleep and a high number of micro-awakenings per night. The 48 patients diagnosed with ME/CFS in the study group from Brussels slept an average of 5.5hrs, but spent nearly 30% of this time awake in bed. Though many of the patients in the study experienced alpha-delta sleep, no differences in the reported feelings of fatigue and unrefreshing sleep were found between patients with low or high alpha-delta intrusion. Alpha-delta intrusion percentages varied widely between patients in the study and alpha-delta sleep was found to be more common in ME/CFS patients *without* major depressive disorders.

When all the blood samples were analysed the patients in the study all showed a high RNase L ratio. The RNase L ratio is considered normal when it is below 0.5; any higher and this is considered an indication of deregulation in the 2-5A synthetase/RNase L pathway[7]. An overwhelming 87% of patients presented with an increased RNase L ratio. Unfortunately, the results of this Belgian study indicate that RNase L and the subsequent potassium channelopathy are not at all associated with alpha-delta intrusion in sleep. The study also revealed that none of the self-reported sleep problems or objective sleep parameters was associated with RNase L. So it would appear that the long believed hypothesis of deregulation of the 2-5A synthetase/RNase L pathway causing alpha-delta intrusion and other sleep abnormalities in ME/CFS patients is untrue. The study, although debunking a long held hypothesis, does not leave us completely empty handed. Even though the study questions RNase L as a biological gradient, it does further validate the existence of sleep latency problems and other sleep disturbances present in ME/CFS. It also leaves us with one additional piece of the ME/CFS symptom puzzle. It turns out, people suffering from high alpha-delta intrusion also experience significantly higher levels of anxiety. So because of the alpha wave intrusion in deep sleep, the full recuperative benefits of deep sleep are not obtained, leaving these individuals with higher anxiety levels.

Clearly this study points out the need for more vigilance when looking at commonly held beliefs regarding ME/CFS. Assumptions regarding diagnosis criteria and the causes underlying the many symptoms of the syndrome should never be made, and never be taken for granted. More research into the causal relationships of immune and sleep irregularities is clearly required.

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On The World Stage

1. In November 2006, the Centers for Disease Control & Prevention in the US formally announced recognition of ME/CFS as a biomedical condition and have started a multi-million dollar national education program for health care professionals and the public to increase awareness and improve access to appropriate treatment

2. At the International Association of Chronic Fatigue Syndrome (IACFS) biannual Conference in Fort Lauderdale Florida in Jan 2007 genetic research was presented that clearly shows the gene expression of people with ME/CFS to be different from that of healthy people.

3. ME was debated in the Norwegian parliament and the Health Minister pledged significant funding for research education and treatment of ME in Norway.

Local ME/CFS News

Dr. Ellie Stein, MD, FRCP(C) psychiatrist, from Calgary, presented keynote addresses at two international conferences and she was invited to present talks at both the Fort Lauderdale IACFS meeting January 2007 and a more recent meeting in Edinburgh, Scotland May 25 2007. Her topic was a review of the world research on behavioral interventions to support people with ME/CFS.

Calgary Research Study Pending

Dr. Brian MacIntosh, Department of Kinesiology at University of Calgary and **Dr. Ellie Stein** are planning a study in collaboration with a fatigue research group at the **University of the Pacific in Northern California**. The study is currently before the ethics committee for approval. Dr. Staci Stevens and colleagues at University of the Pacific have published preliminary evidence that ME/CFS may be differentiated from the healthy state and from other illnesses by submitting patients to a standard exercise test two days in a row. They will test the hypothesis that people with ME/CFS show a decline in work the second day despite maximal effort whereas others do about the same or even show a small training effect on day two. They are expanding the study to see whether they can measure fatigue in small muscle groups as well as the cardiovascular system. If this is true, then people could be tested without putting them through the effort of an exercise test (only 12 minutes but at maximal effort).

Dr. Stein is accepting calls from potential research subjects (in the Calgary area) for this two day protocol. Eligible participants will have a diagnosis of ME/CFS plus experience significant exertional malaise. Also they need healthy people the same age and gender who are healthy but sedentary. The protocol involves approximately 1 hour of time on day one and 30 minutes on day two. Each day will include a maximal exercise test which lasts 10 - 12 minutes. Ph: (403) 287-9941 FAX: (403) 287-9958

[*Ed. Note: Thanks to Dr. Stein for her assistance in keeping us up to date*.]

LEGAL NEWS AND VIEWS

Supreme Court Agrees to Hear Appeal in Keays v. Honda

By Hugh R. Scher

On March 17, 2005, the Ontario Superior Court of Justice released its landmark ruling in Keays v. Honda. Following a thirty day trial, the Court awarded two years' pay in lieu of notice for the wrongful dismissal by Honda of an employee with Chronic Fatigue Syndrome. The Court found that Honda engaged in significant bad faith and discriminatory conduct in the accommodation process by disciplining Kevin Keays for his disability-related absences from work; failing to offer him timely accommodation for his disability despite the existence of a program for that very purpose; imposing upon Keays a discriminatory note requirement as part of the accommodation process which had the effect of increasing Keays' absences, imposing a burden upon him not imposed on other employees "with mainstream" illness and which defied the nature of Keays' CFS disability. The Court further found that Honda engaged in significant bad faith by subjecting Keays to biased and insensitive medical assessments; withholding from Honda's doctor significant aspects of Keays' medical file; grossly misrepresenting the advice received from Honda's medical practitioners in an effort to bully and intimidate Keays into meeting with a further Honda physician; demanding that Keays attend for a further medical assessment which the trial judge found was intended to set him up for termination; refusing to clarify the purpose of the proposed medical assessment despite repeat requests from Keays and his counsel; refusing to communicate with Keays' counsel in his efforts to resolve the accommodation issue; subjecting Keays to inappropriate remarks and conduct from co-workers and managers who ridiculed his disability and refused to address

Honda's discriminatory conduct in violation of Keays' human rights. The Court also found that Honda abused its power and authority by permitting its medical and legal advisors to act contrary to professional standards in an effort to bully and intimidate Keays.

As a consequence of Honda's discriminatory and bad faith conduct, the Court awarded Keays punitive damages in the amount of $500,000.00, the largest ever punitive damages award in Canadian employment history. The Court further awarded reimbursement for Keays' legal costs in the amount of $610,000.00.

Honda appealed to the Ontario Court of Appeal and on September 29, 2006, the Court of Appeal released its decision in which the Court unanimously upheld the award of two years' notice including a nine month increase in the notice as a result of Honda's bad faith in the manner of termination. Justice Goudge, who wrote for unanimous Court on all other issues, would have upheld the $500,000.00 punitive damage award. The majority of the Court reduced that award from $500,000.00 to $100,000.00, claiming that the trial judge erred in finding that Honda's misconduct persisted over a period of five years, that Honda's in-house counsel violated the rules of professional conduct, that Keays was not viewed as a problem associate and thus that Honda did not benefit from the termination of Keays' employment.

Honda sought leave to appeal to the Supreme Court of Canada on the following issues:

a. Are courts permitted to award punitive damages for breach of human rights legislation?

b. Is it appropriate to use principles developed in insurance cases when assessing punitive damages in employment matters?

c. When can a trial judge conduct independent research and must his independent findings be put to a witness?

Keays cross-appealed based on the following issues:

d. Whether the Court of Appeal erred by reducing the trial judge's award of punitive damages based on discrimination without providing further redress for Honda's discrimination because of the Supreme Court of Canada's holding in *Seneca College of Applied Arts and Technology v. Bhadauria,* [1981] 2 S.C.R. 181?

e. Whether the Court should revisit its decision in Seneca College and recognize a separate cause of action for discrimination and harassment?

f. Whether the Human Rights Code should be incorporated into the terms of individual employment contracts, particularly where Code protections are expressly included as a contractual term?

g. Whether and how the principle of proportionality should apply to balance the quantum of compensatory and punitive damage awards based on the same discriminatory conduct?

h. Whether the overriding and palpable error standard of review should be integrated with the rationality standard of review applicable to awards of punitive damages and whether the Court of Appeal erred by failing to apply the overriding and palpable error standard of review in the present case?

The Supreme Court is presently scheduled to hear argument of this matter on **February 20, 2008**.

While the entire judgment is under appeal at the Supreme Court of Canada, argument is sure to focus on the issue of whether or not punitive damages should be awarded based upon a finding of discrimination; whether the Court should reinstate the full $500,000.00 award, and whether or not Courts should now be permitted greater jurisdiction to adjudicate complaints of discrimination which were previously considered to fall under the exclusive jurisdiction of human rights tribunals.

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

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Chronic Pain? - Disability Claim Denied

By Alf Kwinter, Senior Partner
Singer, Kwinter.

From the perspective of a personal injury lawyer who represents only Plaintiffs, there is probably no greater challenge than the disability claim of a person suffering from chronic, disabling pain where there is no “objective” evidence to support the condition. Anyone involved in the treatment of pain knows that one can suffer unremitting pain and be totally disabled from working yet not have objective evidence to support the complaints. Establishing this condition to an insurance company for purposes of obtaining monthly disability benefits can be a very difficult task.

Insurance companies understandably approach these claims with a great deal of skepticism. Firstly, there is often no objective evidence such as an X-ray, MRI, CT scan or other tests to confirm the patient's complaints. Even a condition such as fibromyaglia, while recognized by rheumatologists (although not so quickly recognized by some other specialties) is often seen by insurance companies as a suspicious condition and insurers often do not readily accept the "pressure point" test as an objective measure of disability. Certainly the main evidence that a person is suffering from chronic pain is the word of the sufferer. To an insurance company which is being asked to payout many thousands of dollars often over a period of many years, the word of the claimant alone is simply not enough.

How To Support the Claim

The first question I ask a chronic pain client is "Does your family doctor confirm your disability?" Such support is essential. After all, it is the family doctor who has usually seen the patient on numerous occasions and very often has known the person for many years and will be most familiar with the patient's medical history. The family doctor will have had an opportunity to have seen the patient when he or she was not suffering from this condition and can compare the patient's conduct, behavior and presentation both before and after. A sympathetic and understanding family doctor who supports the claim is a must.

Specialist Referrals

Unfortunately, the family doctor's opinion, as essential as it is, will usually not be sufficient to satisfy an insurer. Insurance companies often see the family doctor as an advocate for the patient, and will very often discount the family doctor's opinion. While this in no way diminishes the importance of the family doctor's support, it is important that the patient be referred to a specialist to confirm the diagnosis that supports the claim of total disability. Here again, the family doctor must be understanding and knowledgeable of these types of conditions. This is important not only to support the claim but also to know what specialist to refer the patient to. Usually, patients suffering from chronic pain will be referred to such specialists as physiatrist, psychiatrist or rheumatologist. If there is a referral to an orthopaedic surgeon, it would usually be made not to confirm a diagnosis but for the purposes of eliminating any possible orthopaedic injury or condition. As with the family doctor, referral to a specialist who understands and treats chronic pain is most important. This is particularly so as the insurer will most certainly have the claimant seen by a doctor of its own. In many cases, such a doctor will often be someone who is skeptical of chronic pain. I often see reports making statements such as "there is no objective evidence to support this disability", "there is pain magnification", "and secondary gain".

So aligned are some insurers with certain doctors that in a city the size of Toronto, where there are numerous doctors readily available to perform examinations, an insurer will wait months to have a specific doctor see the claimant for what is commonly misdescribed as "an independent" medical examination.

Surveillance

Probably the most effective and often used "weapon" of insurance companies in disability claims is surveillance. Following the claimant around to observe his or her activities, photographing the person, and taking videos of the person's activities can be very effective in challenging a disability claim. Most people suffering from pain, while unable to maintain full-time employment, are usually not confined to their bed or home but will go about their day to day activities albeit at a slower pace. Very often, such persons are in great pain and under heavy medication. By following a person around and video taping his or her activity the insurer will compare what the person is doing with what he or she is reporting to the treating doctors. Very often there will be a significant discrepancy in the complaints and the activities. If you are telling your family doctor that you can stand for only 15 minutes but are seen on a video walking around a Home Depot store for 45 minutes, this can cause a significant problem in the case. Similarly, if someone is seen engaging in strenuous activities while at the same time claiming that he or she can lift only very light loads, this can cause great difficulty in proving a claim. Where credibility is so important, I recommend to clients that they be cautious as to what activities they are engaging in. Certainly I would never suggest that anyone purposely curtail their activities. What I advise clients is that they should not do anything 'heroic' or strenuous which if observed on a video tape might make one seriously wonder if the person was disabled. I ask the client to imagine he or she sitting on a jury and watching such a tape. Would a person helping their neighbour move furniture likely be considered disabled?

Of course, the insurers have heard all the usual excuses when the claimant is confronted with such surveillance. "I really paid for that Mr. Kwinter, I was in bed for the next week", or "Mr. Kwinter they don't realize I was on 5 Tylenol 3's when I did that". The bottom line is, there is a good chance you are being watched. If you are presenting a claim for disability based on chronic pain, govern yourself accordingly.

Conclusion

Disability claims for chronic pain are difficult claims. Insurance companies will often fight these claims hoping to discourage the claimant from proceeding or perhaps force the claimant into a low settlement by putting up a strong defence. With appropriate legal advice, strong medical support, and provided the claimant's credibility is not seriously compromised, these claims are usually resolved - most often in the client's favour.

National Doctors' Roster – Addition

DR. JAN VENTER, MD Diagnosis & Treatment for ME/CFS and FMS
Old Orchard Medical Clinic
#11 – 4429 Kingsway
Burnaby, BC V5H 2A1

Tel. (604) 431-6585 Fax (604) 431-0274

National Lawyers' Roster

Congratulations!

The National Post newspaper has, in the Financial Post section a subsection called the Legal Post. From time to time this section selects a segment of the legal community and provides a listing of the best lawyers in that particular category. Recently they have highlighted **Personal Injury lawyers**. We are pleased to share the following information:

Bogoroch and Associates is pleased to announce that **Richard Bogoroch** has been named by the National Post newspaper as **one of The Best Lawyers in Canada for personal injury and medical malpractice litigation**. Bogoroch and Associates will work very hard to remain worthy of this honour. This listing can be found on page 16 of the Financial Post section in the April 18th, 2007 issue of the National Post.

[*Ed note:* ***Mr. Richard Bogoroch*** *has been on our National Lawyers' Roster for quite some time.*

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Toll Free 1.866.285.6927
Fax (416) 961-6760
www.singerkwinter.com

Books/Newsletters

'SACRED SPACE' By Elizabeth Bailey, Reflexologist and Reiki Healer: ISBN 9 781425 98041

Sacred Space is an enlightening and empowering self-help guidebook. This uplifting book includes the story of the journey and life programme that enabled both Elizabeth Bailey and her son, to cope with and recover from ME/CFS, and is written with a heartfelt 'can do' approach to healing and recovery. In her book Elizabeth shares her experiences and the valuable lessons she has learned, and provides advice and encouragement on a moment-to-moment, day-to-day basis towards coping and recovery. The book includes practical advice on relaxation, meditation, nutrition, and suggestions for improved sleep patterns, gentle exercise, and how to cope with the psychological side effects that long-term illness can bring to both sufferers and their families.

Sacred Space by Elizabeth Bailey is available to order directly from ***www.authorhouse.co.uk*** and ***www.authorhouse.com*** (USA), and through most leading book retail outlets online, or in-store worldwide. The guidebook is also available to order with Amazon globally. The price guide is $14.49 U.S. funds.

NETWORK NOTES

IME/FAE Registry Submission

The **National ME/FM Action Network** continues to urge those who have attended an **Independent Medical Examination (IME)**, **Functional Abilities Evaluation (FAE)** or any other form of assessment at the request of an insurance company, Canada Pension Plan (CPP) or Workplace Safety & Insurance Board (WSIB) to fill out our 7-question, confidential, **Independent Medical Examination Registry Submission Form** so that the names of the doctors and healthcare professionals who evaluated you can be put on record. Patients, doctors, lawyers, advocates, support groups wishing to receive a copy or copies of the Form, or to inquire about specific IME doctors, please contact: **National ME/FM Action Network** – Or download the Form from our website at **www.mefmaction.net**

MEMBERSHIP: $25.00 per year, which includes quarterly newsletters
Payment can be made by CHEQUE, VISA or MASTERCARD.
Do not email credit card information.
NATIONAL ME/FM ACTION NETWORK
3836 Carling Ave., Nepean, ON K2K 2Y6, Canada
Tel/Fax: (613) 829-6667 E-mail: ag922@ncf.ca
Web: http://www.mefmaction.net

RESOURCES

Consensus Documents

Complete Original Consensus Documents :

FMS Consensus Document US$24.95

"The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners".
Haworth Press, 2004. (soft cover book)
ISBN: 0-7890-2574-4
Phone: **800-429-6784** Fax: **607-771-0012**
Email: ***orders@haworthpressinc.com***
Online: ***http://www.haworthpress.com/store/product.asp?sku=5342***

ME/CFS Consensus Document US$14.95

"MyalgicEncephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols". *Journal of Chronic Fatigue Syndrome,* Vol. 11, No. 1, 2003. Haworth Press 2003/2004 **ISBN:** 0-7890-2207-9
Phone: **800-429-6784** Fax: **607-771-0012**
Email:***orders@haworthpressinc.com***
Online:***http://www.haworthpress.com/store/product.asp?sku=4958*** **CFS46**

Overviews of the Consensus Documents:

Fibromyalgia Syndrome, 24 pp, 2006
Chronic Fatigue Syndrome, 20 pp, 2006

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

ME/CFS DVD Resources

Prices include shipping & handling

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

  Canadian Consensus Guidelines for Diagnosis, Assessment and Treatment of ME/CFS -What they are and how to use them.
    - Research Update
    - Diagnostic Work Up and Treatment Algorithm
    - Case Examples and Discussion
    - CD of Slides
- **Dr. Kenny De Meirleir : Patients' lecture $25.00**
- **Dr. Pierre Flor- Henry's lecture**: **$20.00**
  qEEG studies (current density source) & psychophysiological studies (very technical)
- **Dr. David Bell's lecture: $25.00** (emphasis on chronic orthostatic intolerance)

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

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

Network Resources

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

Quest Collections

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

Quest Collection I: presently out of print
Quest Collection II (1999 – 2003): $38.00

TEACH-ME: A Sourcebook for Teachers (Second Edition): $22.00 *Discount on bulk orders*
With Dr. D. S. Bell, Dr. B. M. Carruthers and the TEACH-ME Task Force (teachers with ME/CFS and/or FMS)
This educational resource book will enhance teachers' and parents' understanding of ME/CFS and FMS in young people, and assist educators in developing educational modifications and programs.

The Canada Pension Plan Disability Benefits Guidelines: $7.00.

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

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

The Legal Disability Manual includes sections on: FMS and ME/CFS Overview; The Medical Report and Expert Witnesses; Independent Medical Examinations; CPP Disability Benefits, Disability Insurance and Other Legal Articles; Case Law; Psychological Factors, Tests, and Treatments; and

Research Abstracts. Many of the articles have been written specifically for the **National ME/FM Action Network** by lawyers and doctors. Our new Canada Pension Plan Disability Benefits Guidelines are also included in the Legal Disability Manual. This manual is a must for those in litigation.

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. Discuss medical treatments with your personal physician.