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In Memoriam of Al Neilson Thank You

I would like to thank everyone who has communicated their condolences and sympathies on the passing of my dear husband, Al. I thank you for your emails and cards and would like you to know that your support and caring have helped me to be strong and have courage through this most difficult time of my life.

Sincerely,

Lydia E. Neilson, M.S.M.

Announcement

As I come to terms with the passing of my husband, Al, and the changes that have ultimately occurred as a result of this, I decided to step down as President of the National ME/FM Action Network.

I would like to announce the election of Margaret Parlor as the new President of our organization. Margaret is no stranger to our organization and has been one of

our Directors for approximately five years. She and I have closely worked together for that time and her goals and hopes for the ME/CFS and FM community also reflect my personal vision and those of our organization and I therefore feel she will make an excellent President and has already proven that in many ways.

I will stay on as Chief Executive Officer and Margaret and I will continue to collaborate and work together for the good of all.

Sincerely,

**Lydia E. Neilson, M.S.M.
Chief Executive Officer**

MEDICAL NEWS

Unprecedented Research Program

**By: PR Newswire
Dec. 3, 2008 03:00 PM**

CHARLOTTE, N.C., Dec. 3 /PRNewswire/ -- The four million Americans who suffer from chronic fatigue syndrome (CFS) have new reason for hope today with the announcement of an unprecedented research program to help identify biomarkers for the illness and improve diagnosis and treatment of CFS. The announcement was made by the CFIDS Association of America, which is funding the program, called the Accelerate CFS Research Initiative.

As part of this initiative, the CFIDS Association also announced today research grants totaling \$647,940 to six research teams in the U.S. and Canada.

"These awards represent a new approach to CFS research," said Suzanne Vernon, PhD, the CFIDS Association's scientific director. "Instead of each investigator working in isolation, we are building a network of researchers and a framework for data sharing

and collaboration not only among researchers who receive grants from the CFIDS Association, but among scientists worldwide."

Vernon, a microbiologist who helped pioneer the application of genomics to CFS, is now working to pioneer this new CFS research network and to direct the Accelerate CFS Research Initiative. "We were very impressed with the number and caliber of grant proposals we received this year, which signals a heightened level of interest in CFS research," said Vernon. "CFS, once shied away from by some researchers, is now considered a legitimate and challenging field of scientific inquiry."

The grant recipients are:-- Gordon Broderick, PhD, of the University of Alberta in Canada, who will study the immune and endocrine response in adolescent patients who became ill with CFS after contracting infectious mononucleosis, which is caused by the Epstein-Barr virus. By studying patients from the time they get infectious mononucleosis to the development of CFS and through the first 24 months of illness, the researchers hope to identify disease progression biomarkers, including those essential for early diagnosis.

-- Kathleen Light, PhD, of the University of Utah Health Sciences Center, who will investigate the mechanisms involved in chronic pain that afflicts 40%-70% of CFS patients. This study will determine whether receptors located on blood cells are increased and overactive in people with CFS and associated with increased pain sensitivity. Light theorizes that increases in specific receptors following exercise may be blood-based biomarkers for CFS and could lead to a medical test to identify CFS patients.

-- Marvin Medow, PhD, of New York Medical College, who will investigate how orthostatic intolerance, seen in many CFS patients, affects brain function. This study will examine if CFS patients have increased pooling of blood in the abdomen that results in reduced cerebral blood flow. Medow will also

investigate physiologic and oxidative stress changes associated with disturbance in blood flow. These results will help determine if alterations in blood flow affect brain metabolism.

-- Bhubaneswar Mishra, PhD, of the Courant Institute of Mathematical Sciences at NYU, who will use state-of-the-art bioinformatics and computational biology tools to create a computational model of CFS—a kind of "Google for CFS" that will be part database, part knowledge-base, part research network. This new resource will provide a "systems view" of CFS that accumulates published CFS literature and experimental data to disentangle complex relationships among reported findings and discover causes of CFS.

-- Sanjay Shukla, PhD, of Marshfield Clinic Research Foundation, who will use metagenomics to determine if the ratio of good to bad intestinal bacteria in CFS patients is altered, and whether this imbalance in gut bacteria may be responsible for triggering CFS symptoms. Recent advances in metagenomics have demonstrated the significance of altered gastrointestinal bacteria in illnesses like HIV, diabetes, Crohn's disease, inflammatory bowel disease and ulcerative colitis. Shukla theorizes that CFS patients also have an imbalance of good and bad intestinal bacteria, resulting in enhanced intestinal permeability—called leaky gut—allowing bacteria to move across the protective intestinal barrier and causing chronic inflammation and immune activation in CFS patients. This study will contribute to our understanding of the relationship between the human microbiome and CFS. It may also lead to new treatment options, including the use of probiotics.

-- Dikoma Shungu, PhD, of Weill Medical College of Cornell University, who will use a brain scanning technique called magnetic resonance spectroscopy to confirm earlier findings that brain fluid of CFS patients contains significantly elevated levels of lactate, a substance important in metabolism.

Shungu's team will also investigate the reason for this phenomenon, exploring whether lactate levels are higher in CFS patients because their brains contain high levels of toxic compounds that cause a condition called oxidative stress (which could implicate chronic inflammation), or because mitochondrial dysfunction is causing malfunctions in the production of brain energy. If this study is successful, brain lactate levels could provide an objective diagnostic biomarker for CFS.

The Accelerate CFS Research Initiative was made possible by the successful completion of a yearlong, million-dollar fundraising campaign, the largest research campaign for CFS to date in the United States. The CFIDS Association has funded more than \$5.4 million in CFS research since 1987, making it second only to the federal government in CFS research spending.

"This was a real grassroots campaign, with most contributions coming not from major corporations or foundations, but from ordinary people whose lives have been affected by the illness," said Kimberly McCleary, president and CEO of the CFIDS Association. "Patients, their family, friends and doctors stepped up to give donations large and small to fuel the research initiative." "While support from individual American citizens is vital for research progress," McCleary noted, "more funding from the government, from biotech firms and from the pharmaceutical industry is desperately needed. CFS affects more Americans than many other well-known diseases, but receives far less research funding."

About the CFIDS Association of America

The CFIDS Association was founded in 1987 to stimulate high-quality CFS research, improve the ability of health care professionals to diagnose and manage the illness, provide educational information for patients and their families, and build widespread public awareness of CFS. The organization has invested more than \$26 million in research, education and public policy and is the largest

charitable funder and advocate of CFS research in the U.S.

To learn more about CFS, visit <http://www.cfids.org/cfs> and <http://www.cdc.gov/cfs/cfsdiagnosis.htm>

Vision Problems in CFS and Fibromyalgia

By: Jacob Teitelbaum, MD

In CFS/FMS, it usually reflects as blurred vision caused by rapidly changing visual acuity (ability to focus). People often note that they get an eyeglass prescription, only to have it no longer be accurate by the time they get their glasses made. This occurs because the fluid in your eyes and the lens in your eye, and the strength of the muscles which allow the lens and pupils to focus can change minute to minute as your thyroid and adrenal (and associated blood sugar) levels fluctuate. In fact, some doctors use the inability of your pupil to stay consistently constricted when a light is shined on your eyes as a measure of adrenal weakness. This is why in my book **From Fatigued to Fantastic!**, I recommend holding off on getting new glasses until ~ 2-3 months into treatment (especially with thyroid and adrenal support), at which time your vision will usually stabilize.

Another common problem is the gradual increase in "floaters" that one sees. These are common even in those without CFS, as the lens of the eye magnifies debris-like small blood cells. Unless there is a rapid "shower" of these going across your vision (in which case you should see the eye doctor immediately to look for a retinal tear), these "floaters" are generally benign and can be ignored. In CFS/FMS, people sometimes see strands that look like fungi, and which often resolve with the antifungal Diflucan (see **Candida — Eliminating Yeast/Fungal Overgrowth**). They are also not dangerous, but can be a marker of recurrent yeast issues.

Another major problem is difficulty with dry eyes and dry mouth (called "sicca syndrome"). This usually improves by avoiding medications (such as Elavil) which aggravate the problem, and taking **Fish Oil** and the **Energy Revitalization System** vitamin powder. Give these 6 weeks to work. In addition, for contact lens and dry eye induced irritation, using special eye drops containing vitamin A (a good example is **Viva Eye drops**) can be very helpful over time. Ophthalmologists have reported that using testosterone cream on the upper eyelids can also help in severe cases of dry eyes.

For those without CFS, other major eye problems include:

1. Cataracts
2. Glaucoma
3. Macular degeneration. In addition, it is estimated that 300,000 cases of macular degeneration (35% of cases), a leading cause of blindness, could be prevented simply by supplementation with antioxidants and zinc!
4. Floaters

References - **Article** at MedScape (free registration required).

- [Read a study on Effective Treatment of CFS & Fibromyalgia.](#)
- [Signup for CD Workshops for health care practitioners.](#)
- http://www.endfatigue.com/web-newsletters/nl_45a_12-17-2008.html

*(Ed Note: This article first appeared in **Vitality101**, Dr. Teitelbaum's free newsletter and is republished with his permission. You can view this article at www.vitality101.com)*

Soy Kefir – A Novel Food Product With Implications for CFS and Fibromyalgia

**By Stan Kubow, Ph.D.^{1,3} and Dominique Garrel,
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Kefir is a probiotic milk drink that originates from the Northern Caucasus Mountains where it has been consumed for centuries and has been valued for numerous health promoting properties (Koroleva, 1988). Indeed, the term kefir derives from the Turkish word, keif, which can be translated as “feeling good” or “good feeling”. It is a popular beverage in Eastern Europe, Scandinavia, and numerous countries (Kroger, 1993) and is also sold in Canada and the US.

Kefir has been used traditionally for the treatment of a wide range of metabolic disorders such as atherosclerosis and cancer, gastrointestinal ailments including stomach ulcers and infectious diseases such as pneumonia, bronchitis and tuberculosis, when conventional medical treatment was unavailable (Koroleva, 1988). Controlled clinical trails involving Western science have yet to confirm the utility of most of the above clinical uses although there are Eastern European and Russian publications supportive of these health benefits. More recently, animal disease model and cell culture studies indicate that kefir and extracts of bioactive components of kefir exert a variety of biological activities that implicate significant health benefits. Studies have generally focused on modulation of the immune system, anti-proliferative and anti-tumorigenic effects against several forms of cancer and anti-microbial effects (Farnworth, 2005). Currently there are no

regulations on the sale of kefir or kefir extract as natural health products.

Kefir made by adding kefir grains to various milk products such as cow, soy, goat or other commonly consumed milks. Kefir grains are a soft white gelatinous mass that resembles small cauliflower florets and they contain a wide variety of probiotic bacteria (lactobacilli, leuconostocs, lactococci and acetobacteria) and yeasts. The grains contain clusters of microorganisms held together by kefir polysaccharides, which are produced by *Kefiranofaciens* and *L. kefir* bacteria. Kefir grains are not consumed as part of the final product as they are removed at the end of fermentation. The kefir grains ferment the milk, incorporating their probiotic microorganisms to create the cultured beverage.

The health benefits of kefir are partly dependent on the bioactive components within the food substrate itself that are acted on by the kefir microbes in the fermentative process. Thus, depending on the type of milk used (i.e., bovine, soy, goat, etc.) in the kefir fermentation, the types of bioactive substances such as peptides, polysaccharides, lipids components and other types of biomolecules will differ. The wide variety of bacteria and yeasts present in kefir is unique aspect of this probiotic beverage as normally probiotic foods such as yogurt contain only one or two probiotic bacteria. As each probiotic bacteria are typically demonstrated to produce their own specific bioactive molecules during fermentation, the array of biomolecules generated from the many microbes seen in kefir could produce a more biologically potent probiotic. Additionally, the microorganisms themselves (either live or dead) and their own metabolites could play a functional role in the proposed health benefits of kefir. It is thus likely that a combination of biofactors involving kefir fermentation by-products are involved in a synergistic manner to exert the systemic health benefits of kefir. It should be noted that recent studies have indicated that viable “live” bacteria are not

necessary to produce a significant biological effects as similar potency can be achieved with dead bacteria, depending on the biological outcome assessed (Mottet et al., 2004).

The kefir beverage made with soy has a tart, refreshing taste that is slightly acidic. Soy kefir product (SKP) is a concentrated dried form of soy kefir drink produced by a patent-pending fermentation process using kefir grains newly developed by KCLM Research in Nutrition, Montreal, Canada, a McGill University start-up company. It is currently being sold under the brand name of Liberation and is available via the websites of www.wykanta.ca and www.wykanta.com. There are many different geographical sources of kefir grain, which vary greatly in their microbial composition, which can lead to differing nutritional outcomes from the kefir-fermented product. SKP is produced using kefir grains with proven consistency from the All-Union Dairy Institute of Moscow, which has decades of experience in regulating kefir manufacture and development in Russia. SKP is formulated to concentrate the bioactive components of kefir in an easily consumable form but does not contain live bacteria or yeasts due to a heat-inactivation process used, which allows for a more prolonged shelf life. SKP has shown remarkable improvements in clinical studies of individuals suffering from pain and fatigue.

A double-blinded randomized controlled cross-over clinical trial was performed by the clinical research organization, Ethica Inc., that assessed the safety of SKP in human subjects. No adverse reactions as determined by examination of routine serum chemistry were shown, i.e., SMAC-24 - total bilirubin, creatinine, glucose, uric acid, sodium, potassium, BUN, chloride, CO₂, calcium, phosphorus, magnesium, total protein, albumin, alkaline phosphatase, AST, ALT, GGT, CK, LDL, cholesterol, HDL, triglycerides, iron. There were also no notable adverse events in heart rate, body weight, and urinalysis. No serious adverse events were observed although some mild adverse events

in terms of gastrointestinal events were noted; however, they were in a range of incidences of adverse effects that are very common in such studies. Probiotics such as the soy kefir powder of the present invention commonly show initially higher incidences of mild gastrointestinal upset that usually dissipate with more prolonged intakes.

Two separate open label clinical trials have tested the efficacy of SKP in patients with either the Chronic Fatigue Syndrome or Fibromyalgia (Kubow and Garrel, 2008). Dr. Dominique Garrel at the Institut de recherches cliniques de Montreal (IRCM) carried out clinical research testing the health benefits of SKP for chronic fatigue syndrome subjects for 30 days. A subsequent USA-centered clinical trial involved patients with either chronic fatigue syndrome or fibromyalgia who were evaluated after 30 days and 60 days taking SKP. The latter research study was independently carried out by Oceanova, Quebec City, Canada and Douglas Laboratories, Pittsburgh, PA; a division of Atrium Biotechnologies, Quebec City. From the two above separate clinical trials, reported benefits of SKP included increased energy and vitality levels, significant pain relief and improved physical and emotional well-being.

Both of the above clinical trials utilized the SF-36v2 Health Survey, which is a FDA approved tool used in a wide variety of clinical areas ranging from cardiac rehabilitation programs and hip replacement surgery to the impact of medications on pain relief. The SF-36v2 Health Survey, is a highly validated, widely-used health status assessment tool that measures eight health concepts: physical functioning (PF) which defines limitation in physical activities because of health problems; limitation in role activities because of physical health problems (RP); bodily pain (BP); limitation in social activities because of health problems (SF); general mental health (MH); limitation in usual role activities because of emotional problems (RE); vitality (energy and fatigue) (VT); general health perception (GH). Scores for people at the top or bottom of a

scale can be interpreted by looking at the items and response choices that must be chosen to earn those scores. For example, someone at the top score of the SF-36 Physical Functioning (PF) scale does not have limitations in any of the SF-36 activities due to health. A person scoring at the bottom of the PF scale is very limited in all activities, including bathing and dressing. Physical Functioning (PF), Role Physical (RP), and Bodily Pain (BP) are primarily measures of physical health, while the other three scales are primarily measures of mental health. Research has demonstrated that scales associated with the physical health construct are sensitive to detecting the impact of physical health interventions (Ware and Kosinski, 2001). Similarly, scales that are the strongest measures of mental health are sensitive in detecting the impact of mental health interventions.

As case studies consistently showed improvements in several features of the chronic fatigue syndrome, i.e., weakness, lack of energy and strength, pain, and depressed mood, an open label pilot study was carried out by Dr. Garrel (Hotel Dieu Hospital de CHUM) to test the tolerance and effects of the product on a small group of chronic fatigue syndrome patients, most of whom also experienced chronic pain. Eleven patients with chronic fatigue syndrome received 56 pouches of 37.5 grams of product, to be taken as 1 pouch twice a day for 4 weeks. Patients answered the SF-36v2 Health Survey quality of life questionnaire before and after the 4-week treatment period. In the open label efficacy trial, two patients had to discontinue the treatment: one because of gastric pain after 3 days even though she said she had never felt so energetic from the time that she had the disease. She suggested that she wanted to try to take the product 1 or 2 days a week, as her improvements were so remarkable. The second patient had gastric discomfort and vomited at her first ingestion of the product. Increased satiety effects were also noted after the ingestion of the product. All other patients took the product for 4 weeks.

For the statistical analysis, a two-tailed Wilcoxon test was used. The results of the questionnaire are assembled into 8 scales and the average score for each scale before and after the treatment were compared.

The clinical trial conducted involving chronic fatigue subjects showed clinically important and statistically significant improvements in a variety of parameters tested by the SF-36v2 Health Survey including improvement in energy levels (VT), bodily pain (BP), energy and mood. Two scales, Bodily Pain and Vitality show differences with an alpha risk < 5% the accepted threshold in sciences and 4 other with an alpha risk \leq 12% which qualify them for “trend” because they are compatible with a true effect (and consequently have a good chance to be shown in a larger study). The clinical trial was extended from a two week to a four-week intervention, as there is evidence that the placebo effects typically fade after a two-week time frame. Hence, the placebo effect was therefore less likely as positive results were seen over the more extended period of four weeks. Vitality was particularly greatly improved, as a significant increase in the sub-scale measure of vitality in the SF-32v2 questionnaire scores was demonstrated with a 12.8-point increase over baseline measures. A 5-point increase is considered to be clinically meaningful (Rowbotham, 2001).

Anecdotally, three of Dr. Garrel's patients with chronic fatigue syndrome have now been taking SKP for more than 3 years now and they feel that they cannot endure without the product. For two of the patients, the SKP is very important for their pain relief whereas for the other patient the SKP is essential for vitality.

In the second clinical trial carried on in a US medical clinic, patients suffering with moderate intensity from chronic fatigue syndrome and fibromyalgia were recruited with symptoms of prominent fatigue and widespread muscle and joint pain. Patients were followed for 60 days and SF-36v2

questionnaires were filled at baseline, and after 30 and 60 days of treatment. A total of 18 patients completed the study with 10 patients at 20g and 8 patients at 30 g. Statistical analysis aimed at comparing treatment groups at any time point to their baseline values by use of a two-tailed paired t-test.

The study appeared to show a time and dose relationship to the SKP regimen.

No statistically significant change occurred at 30 days with the 20 g dose with only scales of bodily pain and physical function showing a tendency to improve with scores of 9.1 and 7.0, respectively. On the other hand, with the 30 g dose after the 30-day intake, all scores had improvements greater than 5 points over baseline, ranging from 7.4 for general health to 23.6 for social function and 20.1 for vitality. Statistically significant effects were observed for bodily pain, role physical and role emotional, with major improvement in scores over baseline by 17.2, 22.2 and 23.2, respectively.

At 60 days of treatment, the 20 g dose for the first time showed statistical improvements over baseline in physical function, role physical and bodily pain, which had increases of 7.5, 15.6 and 15.9 over baseline. Vitality showed a non-statistical improvement of 6.9 with the 20 g dose. The 30 g dose at 60 days showed similar findings that were observed at 30 days, with all scores above 5 points and statistically significant increases in role physical, bodily pain and role emotional, and an 18.1 increase in vitality scores over baseline values. The study thus indicated that greater efficacy was observed with the 30 g vs. 20 g dose although improvements were noted in the 20 g dosage with greater length of treatment. Importantly, the major clinically relevant increases in scores over baseline were maintained over a more prolonged 60-day period of intake signifying no major diminution of effect.

The scientific rationale and mechanisms of action for energy improvement with SKP are unclear but are likely multi-factorial. Chronic

fatigue syndrome has been associated with higher serum angiotensin-converting enzyme (ACE) levels, which has been suggested to reflect damage to the vascular endothelium (Lieberman and Bell, 1993). Hence, a part of the efficacy of SKP in chronic fatigue might be related to its demonstrated ACE inhibitory activity (unpublished data), which has been well demonstrated for other fermented soy products (Kinoshita et al., 1993).

Several supplementation trials have indicated that branched chain amino acids (BCAA) can contribute to combat fatigue and to improve mental and physical performance in athletes (De Lorenzo et al., 2003; Blomstrand et al., 1997). Soy protein is one of the best sources of BCAA and fermentation increases the quantity of soluble proteins. Hence, the digestibility and bioavailability of BCAA from soy kefir would be significantly enhanced to provide a significant enhancement in BCAA uptake. An imbalance in the ratio of free tryptophan to BCAA with relatively low blood levels of BCAA has been implicated as a possible cause of acute physiological and psychological fatigue (central fatigue) during exercise (Gastmann and Lehmann, 1998) and the chronic fatigue syndrome (Georgiades et al., 2003).

Amongst the putative bioactive ingredients in SKP are substantial amounts of isoflavones. Soy isoflavones have been shown to decrease inflammation, which recently has been indicated to play an important role for inducing fatigue (Collado-Hidalgo et al., 2006). The half-lives of isoflavones are about 4 to 8 hours suggesting that maintenance of effective plasma concentrations can be achieved with regular daily consumption of SKP (Manach et al., 2004). In addition to isoflavones, soy kefir likely contains a host of components that may be involved in the medicinal effects including polyphenolic compounds such as lignans, saponins, phytic acid as well as other bioactive molecules such as sphingolipids and branched chain fatty acids, which might exert cumulative biological effects.

In conclusion, clinically significant improvements in chronic fatigue syndrome patients and fibromyalgia with the soy-derived SKP product is an exciting new approach for treatment of the fatigue associated with this group of patients, particularly since no effective treatment exists by conventional medicine. Future studies are being directed towards a better understanding of the mechanisms of action using animal models.

For more information on SKP: visit www.wykanta.ca or www.wykanta.com or send your questions to admin@kclmresearch.com or call toll-free 1-800-953-0081

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Book Reviews

I- Cellular Hypoxia and Neuro-Immune Fatigue: Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, Fibromyalgia, Orthostatic Intolerance/Dysautonomia, Multiple Chemical Sensitivities, Chronic Lyme Disease.

Author: David S. Bell. Livermore, CA: WingSpan Press, 84 pp. \$14.95 (Amazon)

Reviewed by: John Prescott DVM PhD, Professor, University of Guelph.

Despite the horrendous title, this is an excellent and well-written self-published book by David Bell, a U.S. physician well known for his contributions to

clinical aspects of Chronic Fatigue Syndrome (CFS). He comes across in the book as a slightly crusty but eminently wise family doctor, who is very “pro-patient” and extremely knowledgeable about the symptomatology of CFS. Most CFS patients would be delighted and lucky to have him as their doctor. Where Dr Bell excels is his exceptional knowledge of the illness, and particularly of its clinical or biological characteristics. He tries to weave this into a story, that can be understood by an intelligent and educated reader, integrating what we know about the clinical manifestations of the illness with what is known or speculated about its causes.

The strength of the book is that Dr Bell has a unifying hypothesis about the cause of CFS and related illnesses, and that he truly understands what must be explained when we finally know how CFS happens. The litmus test of whether any new theory of CFS is correct is that it has to be able to explain all its many symptoms. For example, there’s quite a lot of research going on into the significance of low cortisol levels in CFS patients. So far this explains almost nothing about the symptoms, and might turn out to be almost irrelevant to understanding CFS, one of the many blind alleys of current CFS research. According to Dr Bell, based on fairly sound evidence, the pathology of CFS is in every cell of the body and relates to “cellular hypoxia”, a dysfunction of being able to produce adequate energy through oxidative phosphorylation at the cellular (mitochondrial) level. How this happens is unclear, but appears to relate to persistent low-level immune activation because of persistent chronic viral infection and/or an inability to switch off chronic cytokine (immune system messengers) over-production, with excessive production and impaired degradation of nitric oxide with the result of poisoning the cellular energy packet (ATP). That’s a long sentence, but this in general terms explains the central feature of CFS, which is of course severe “fatigue”.

The weakness of the book is that, although Dr Bell is an astute clinician, he is definitely not a research scientist, so that some of his explanations of the precise cellular or biochemical bases of his explanations or speculations are poor. As he himself says, “The problem of a clinician dabbling in basic science is the lack of perspective and judgment that is gained by a lifetime studying a subject.” In these days of intense specialization,

however, finding scientists with the breadth and depth of understanding of infectious disease, immunology, biochemistry and physiology etc required to understand a complex illness such as CFS is at best difficult. This family doctor has an insight unavailable to many scientists. His stimulating book should be read by every researcher working in the field of CFS for its unifying view of CFS. It would be an inexpensive book for CFS patients to give to their doctors or relatives wishing to understand this serious and still poorly understood illness.

II - *Cure Unknown: Inside the Lyme Epidemic*

Author: Pamela Weintraub, St. Martin's Press \$30.95, 408 pages

Reviewed by: Margaret Parlor

Exploring the roots of the Lyme controversy

Pamela Weintraub was already an accomplished science journalist when she moved with her family to a pastoral hamlet not far from New York City. This, she declares, was the worst mistake of their lives. She, her husband and their two sons would become very ill with Lyme disease. Lyme disease is complex, debilitating, multi-system illness transmitted primarily by ticks, and infected ticks were endemic to that area. Lyme disease is also, she found, an illness steeped with controversy.

Ms Weintraub describes how she took her very ill son to numerous doctors over the span of five years looking for diagnosis and treatment. “By April of 2000” she reports “we had exhausted whatever establishment medicine had to offer our boy. From the infectious disease expert at our local hospital to our personal paediatrician to a range of specialists in the great teaching hospitals of Manhattan, there was no answer for, and no interest in, our wounded son.”

At the suggestion of an acquaintance, she contacted a Lyme disease support group. “Mona was just the sort of support-group person our paediatrician had emphasized it was important to avoid. But after the paediatrician and his minions, including a dozen high-powered Manhattan specialists, suggested Jason's illness was all in his head, it was Mona I believed.”

Ms Weintraub soon realized that other Lyme disease patients, as well as a number of practitioners and academics, had rejected the establishment approach and “crossed the line.” The hostility between patient community and the establishment shocked her. As a journalist, she set out to explore the roots of the controversy. She interviewed hundreds of people and read numerous studies. She wove the information into this fascinating book that reads as smoothly as a thriller.

The establishment view, she found, is that Lyme disease is rare, hard to catch and easy to cure. As she examined the evidence for this view, it crumbled before her. “The more I looked into it, the more I concluded that the very scaffolding of Lyme science was flimsy as a house of cards.”

One study, used to justify the importance of a positive blood test, supposedly shows that people with Lyme disease almost always test positive. In fact, the study used circular logic, defining Lyme cases as those where the person had already tested positive to the same test. This ignores many studies which have shown that the test misses many cases in the first place. Another study was used to show that doctors were regularly treating Lyme disease when they had insufficient evidence for a diagnosis. The study was based solely on hospital records, ignoring files at doctors offices where additional evidence of the illness could be found. Another study is used to show that long-term antibiotics are ineffective for all chronic cases. This study was based on a small and distinct sample of patients who had previously failed to respond to antibiotics.

After learning that her son's paediatrician had failed to diagnose a number of Lyme cases, the author reported him to the state's Department of Health.

The complaint was rejected. The author concluded that “[n]ot treating Lyme disease, even for years, even if the case was so classic it belonged in a textbook, even if the patients became disabled, and even if they were children, violated no medical code in New York State.”

Instead, she notes, “ it was treating the disease aggressively, comprehensively, and beyond the narrow guidelines accepted by insurance, that brought on censure and risk. On the day I sent the complaint, seven of just eleven physicians still

willing to treat late-stage, disseminated Lyme disease beyond the narrow guidelines were under investigation in New York State.” She traces a number of investigations brought against doctors and shows how this casts a chill on the community.

This book is a plea for open-minded thinking about Lyme disease. The illness model that the medical establishment has adopted for Lyme disease is incomplete and out of touch with reality. As a result, patients can be caught in the situation where doctors deny their illness and prevent them from receiving the treatments, accommodations and supports they need. While the book is U.S.-focused, this message applies equally in Canada where infected ticks have been spreading Lyme disease for years, where the restrictive guidelines are the norm and where doctors who treat aggressively draw the attention of the establishment.

This book also challenges us to consider the health system's track record on newly identified conditions. Lyme disease is not the only case of a flawed illness model. In their early days, AIDS was considered a gay disease, Autism Spectrum Disorder was attributed to lack of maternal warmth, and Chronic Fatigue Syndrome was attributed to distorted illness beliefs. Even the poison ivy rash was once attributed to gardener's hysteria. It can take decades for flawed models to be corrected, leaving patients in conflict with the medical system which is supposed to be helping them. Ironically, it can be difficult to access research money when research is most needed because of the lack agreement on a framework. As the author shows, when there is tension between the patient and medical community around an emerging illness, it is easy and convenient to suggest that patients are somehow at fault. Reality is much more complex.

Slides for All Oral Presentations at the 1st Alberta Symposium on Disabling Fatigue in Chronic Illness

Available for viewing at:

<http://www.ucalgary.ca/cfs/node/35>

The username is: cfs2008 (case sensitive)

The password is: cfs2008 (case sensitive)

FOR: Podcasts of the CME course for physicians (October 24 & Nov 7) and the Public Lecture (Nov. 9th) go

to: <http://podcast.med.ucalgary.ca/groups/cfs/weblog/>

There are ten podcasts. Double click on the "play" arrow for the podcast you wish to view. If you do not have Quicktime on your computer, you will be prompted to load it. To stop and start while watching the podcast click on the small "play arrow" next to the speaker icon (bottom left). Some people can fast forward or back by clicking and moving cursor to little ball at bottom of screen and hold and slide forward or back. I cannot get this feature to work.

itunes format for podcasts are also available in itunes format which download onto your computer and are easier to manipulate. To launch itunes click on the "**subscribe in itunes**" icon to the right of the first podcast. You will be prompted to "**choose an application**". Choose "**itunes.exe**". If you don't have "**itunes**" on your computer you will be prompted to load it. Once in itunes, click on the view icon at the top right, then click the horizontal bar icon next to it. This will list all the podcasts available. Double click on the rotating arrows icon at the far right of each podcast to load it on your computer. It takes several minutes to load each one but you can load about 3 at a time without crashing the system. Once loaded, the podcast can be viewed by double clicking on the line of the podcast you wish to view. **Happy Viewing**

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University Education from Home

How can you continue your education when you cannot get to class? The answer may be to have the class come to you through distance learning.

A number of institutions provide distance learning, but there are two Canadian universities which are based on the "open" concept. These universities try to make education as accessible as possible. They have minimal admission requirements, they transfer credits from other universities, they will consider giving credits for prior work experience, and they accept students anytime throughout the year.

Athabasca University (AU) advertises itself as Canada's leading distance-education and online university: It currently serves about 37,000 students per year, following a period of rapid growth which saw student numbers double over a six-year period. Some 260,000 students have registered in AU's individualized courses and programs since the University was created by the Government of Alberta in 1970.

British Columbia has also had an open university since the 1970s. It became part of Thompson Rivers University based in Kamloops, B.C in 2005. TRU offers 400 courses in 57 programs (including secondary school completion) through its distance learning branch. It currently has about 16,000 distance students.

Both universities accept students from across Canada and around the world and the degrees they grant are recognized degrees.

I asked the Office for Access to Students with Disabilities (ASD) of Athabasca University whether their university would be a good option for Canadians with ME/CFS or FMS. The following is extracted from the reply I received.

"The ASD Office has assessed and provided accommodations for students with ME or FM since its inception. These students initially contacted our office for accommodation through a variety of sources and with a number of different educational objectives.

Some students were already attending Athabasca

University when they were diagnosed. Many students have been referred through our colleagues at other postsecondary institutions, government and community agencies, and through medical or healthcare professionals. Still others have contacted Athabasca University and our office as a result of their own research.

Their educational goals have spanned the range from enrolling to: pursue a degree or diploma through distance education; complete a course or a few courses as a visiting student until they can return to their own University; take an individual course for personal interest and to keep their mind active.

While I cannot provide you with any statistics or any testimonials, I can advise there have been a number of students who have been identified with FM or ME who have successfully achieved their educational objectives, although in some cases it has taken longer than originally expected.

Distance education is not for everyone. To assist students to determine if they are ready to pursue an education at AU the Counseling and Advising Services have prepared the following online self-assessment:

<http://amiready.athabascau.ca/index.html>. A number of additional self-help tools are available online for students to determine their preparedness for specific subject areas, to plan their programs, and/or to help decide on a career path:

<http://www.athabascau.ca/counselling/assessyourself.php>

We certainly advise students about the need to address distance education courses as though they were courses in a traditional school or as a job that they would attend whereby they will need to ensure that study times are scheduled. The difference is that with distance education one has the flexibility to schedule study sessions in a manner that fits with their individualized needs.

Our office will assist students to develop a study plan that fits with their accommodation requirements. We also encourage students to take advantage of the resources AU offers to facilitate communication with their peers toward developing a sense of being part of a learning community and feeling less isolated within their studies. We also encourage students to contact us or the

Counseling Services if they are struggling to make progress.

ASD provides appropriate, individualized accommodation and support services to eligible students with disabilities. Such accommodations might include a reduced course load, extended time to complete assignments or courses, assessments and training for assistive technology, and exam accommodations. The ASD Office also provides students with information and support to apply for student funding and grants to cover the cost of disability supports such as assistive technology. Student information is maintained in a strictly confidential manner, in accordance with freedom of information and protection of privacy guidelines.

It is our greatest belief that the services that ASD offers contribute to making AU a viable option to students with disabilities who require accommodations and who may otherwise be unable to attend a traditional University program.”

You can learn more about Athabasca University at www.athabascau.ca, and about Thompson Rivers University at www.tru.ca. (Ed. Note: Thanks to Brenda Moore of Athabasca University and Marj Huntley and Jennifer Read of Thompson Rivers University for their input)

National Lawyers' Roster – Addition

ROBERT H. LITTLEJOHN- Initial consultation free
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Quest Collection III – 2004-2008 now available

We are ready to go to print with our latest collection of a compilation of our medical and legal articles which appeared in our newsletter 'QUEST' between 2004 to 2008. Please reserve your copy now by sending us your cheque as soon as you can so that we may know how many we need to print and reserve. Cost: **\$38.00 each**

RESOURCES

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

"Myalgic Encephalomyelitis/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.

Version française : Abrégé du Consensus sur le SFC: \$5.00, – (NEW/NOUVEAU), payable par chèque seulement, à AQEM

Commander à AQEM, 7400 Boul. Les Galeries, bureau 410, Anjou, (Québec), H1M 3M2, Tél. Montréal : 514-369-0386; (à l'extérieur) : 1-877-369-1689 sans frais; site web : www.aqem.org

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**

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 National ME/FM Action Network 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

Quest Collection III (2004-2008) Will be published shortly – orders accepted now: \$38.00 NEW

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.

TEACH ME: (traduction française): Guide de référence pour l'enseignement aux élèves souffrant d'EM/SFC et/ou de la FM. \$22.00, 120 pp. NEW/NOUVEAU

The Canada Pension Plan Disability Benefits Guidelines: \$7.00.

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.

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

PLEASE NOTE CHANGE OF ADDRESS AND FAX NUMBER

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

#512 – 33 Banner Road, Nepean, ON K2H 8V7.

. Tel: (613) 829-6667 Fax: (613) 829-8518 E-mail: ag922@ncf.ca

Web: <http://www.mefmaction.net>

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