NATIONAL
ME / FM
ACTION NETWORK

Quest

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Contents

Announcement

Introducing "The Journey"

Addition to Quest

We are pleased to advise that, commencing in this issue, there will be an added section to ***QUEST*** entitled ***The Journey,*** in recognition of those facing the daily struggles of ME/CFS and FM and its many challenges. We believe this section will be of interest to those interested in treatment options and support matters.

James (Jim) Deagle has joined our team as Editor-in-Chief of ***The Journey.*** Jim has worked in several news media and communications positions. Starting out as a reporter and editor for various community newspapers, he went on to lend his written communications skills to several Ottawa-area high tech firms, as well as the Standards Council of Canada and the 50th anniversary edition of the Canadian Tulip Festival.

Jim is the contact person for ideas and articles for ***The Journey*** and is a welcome volunteer with a fresh perspective. He can be reached via email at **mefm.jamesdeagle@yahoo.com** or by phone or fax at our organization's numbers.

Ottawa 2011 Conference Call for Papers

The IACFS/ME is calling for papers for the 10th International IACFS/ME research and clinical conference **"Translating Evidence into Practice**", hosted by the National ME/FM Action Network, and invites potential presenters to submit abstracts and/or workshop proposals for their next biennial meeting which will be held in **Ottawa, Ontario, Canada, September 22-25, 2011.**

Integrative conference themes will focus on fatigue, pain, sleep, pediatrics, cognition, and brain function in CFS/ME, Fibromyalgia, and related Illnesses (e.g., cancer fatigue). In addition, different sessions will address advances in assessment and treatment (from biological to behavioral), as well as new developments in virology, immunology, and neuroendocrinology.

Papers will be reviewed by the Conference Planning Committee for selection as an oral lecture, short oral presentation, or poster presentation. Professional workshop proposals will also be accepted. Attendees to IACFS/ME conferences are primarily biomedical and behavioral professionals, including clinicians, researchers, and educators. Papers should reflect this level of experience and expertise.

It is anticipated that this event will be accredited for continuing medical education for Category 1 CME (physicians), CNE for nurses, and CPE for pharmacists.

Please E-mail abstracts or workshop proposals, CV, and the two required presenter forms to **Brandon@iacfsme.org** no later than

March 1, 2011 for workshops,
March 15, 2011 for abstracts, and
July 15, 2011 for Late Breaking Communications (posters only).

The presenting authors will be contacted in April, 2011 and advised if submitted abstract(s) or workshop proposals is / are accepted with the type of presentation selected. Authors will be advised of the date and time of their presentation. If selected as a poster presenter, presenting author will be provided with specifications for presentation and display.

Questions regarding papers or the submission process should be directed to IACFS/ME Administrative Office, **Attention: Brandon Pacyna**;

E-mail: **Brandon@iacfsme.org**

Phone **847-258-7248**.

For complete details: see the IACFS/ME website at **www.iacfsme.org**

A Note on Registration for Conference

A number of people have asked about registration for the IACFS/ME conference (Sept. 22-25, 2011) in Ottawa.

We expect registration to open in May 2011 with options for early bird rates, regular rates and on-site registration. Currently, our Call for Papers is under way which closes in mid-March. Our conference planning committee will then review the submissions and select the conference speakers. This process takes about 4 weeks (including notification of presenters, completion of paperwork, etc). At that point, when we know what the specific content of the meeting will be, registration information will be posted on our website (**www.iacfsme.org**) and the National ME/FM Action Network (Canada) at

www.mefmaction.net. We expect to have highly informative scientific and educational

programs for both professional and patient meetings. We hope to see you there!

Thank you.

Fred Friedberg, PhD, President

IACFS/ME

XMRV – Where Do We Stand?

Four papers were just published in the journal of Retroviroligy while a 5th commented on them pointing out how easy it is to contaminate lab experiments involving the XMRV virus. The authors themselves disagreed on the interpretation of their data. One senior author stated that he just wanted to point out how easy it is to test positive for XMRV, even if the person is actually negative, if a tiny bit of the mouse DNA gets into the sample tested.

There is no need to get upset about these findings in the latest papers as it did not prove the other studies wrong. It only means that those testing the XMRV samples need to be extremely careful because of the possibility of contamination, something that researchers are very well aware of and don't need to be reminded of.

The way to look at the latest findings is that they are doing research and that no one would be going through all this trouble if they had actual proof that it doesn't exist.

Take pride in the fact that we are being taken seriously and research is ongoing. We know that both XMRV and MLV have been found. Scientists are hard at work to discover what these findings mean in regards to ME/CFS and what role, if any, it plays in the illness. Once that is established, the research on treatment can go full speed ahead.

Dr. Judy Mikovits, Director of Research at the Whittemore Peterson Institute on October 12, 2010 pointed out that the McClure et all studies were using simply PCR experiments while Lombardi et al and Lo et al were using four different methods of detecting XMRV as they understand the limitations of PCR technology and took rigorous precautions for contamination. Dr. Mikovits further stated that "….We have never claimed that CFS was caused by XMRV, only that CFS patients possess antibodies to XMRV, which integrates into human chromosomes and thus is a human infection of as yet unknown pathogenic potential."…."The coauthors stand by the conclusions of Lombardi et al. Nothing that has been published to date refutes our data."

[Ed note: view entire statement of Dr. Mikovits at http://www.eurekalert.org/pub_releases/2010-10/idso-nse101210.php]

Announcement

Additions to Medical Advisors

Eleanor Stein, MD, FRCP(C)

Dr. Stein is a psychiatrist and psychotherapist whose interest in the past nine years is in ME/CFS, FM and MCS. Dr. Stein runs a small, part-time private practice in Calgary, Alberta offering medical diagnosis and treatment, in addition to individual and group psychotherapy. She was recently appointed as a Clinical Assistant Professor in the Department of Psychiatry at the University of Calgary. Dr. Stein has organized CME medical conferences and public lectures and her research includes a study of autonomic nervous system function in ME/CFS. A paper on "Repeated exercise capacity in women with CFS", in collaboration with Dr. Brian MacIntosh, Faculty of Kinesiology, University of Calgary, is being prepared for publication. A study on the connection between XMRV and ME/CFS is in progress in collaboration with Drs Lorne Tyrrell and Michael Houghton and the University of Alberta and Dr. Graham Simmons at the University of California, San Francisco.

Gordon D. Ko, MD, CCFP(EM), FRCPC, FABPMR, FABPM

Dr. Ko is Medical Director, Physiatry Fibromyalgia Integrative Treatment clinics at Sunnybrook Health Sciences Centre, University of Toronto and the Canadian Centre for Integrative Medicine (Markham) and Assistant Professor, Department of Medicine, University of Toronto. His expertise integrates neuropathic pain medications, functional medicine, EMG-guided Botox and Ultrasound-guided Platelet-Rich Plasma injections for fibromyalgia and chronic back pain. Copies of his educational articles and media videoclips are available at www.DrKoPRP.com.
[Ed. Note: Dr. Ko is a member of the International Myopain Society]

NEW DEVICE MAY SEPARATE HUMAN DNA FROM VIRUS DNA

January 29, 2011
Carmen Chai, Postmedia News, at the *Ottawa Citizen* reports that a physics professor, Andre Marziali and his team at the Universitiy of British Columbia, Canada are working on a medical "tricorder" invention, a portable, battery-powered device, that can pinpoint the specific DNA signature of a virus. Very often researchers can't identify viruses due to the amount of human DNA in the backround. His team is still developing the technology by testing its accuracy and speed but anticipates the 'tricorder' may be available "as early as three years", depending on funding.

This device will be able to take samples from patients through such methods as blood tests or throat swabs that would be placed into the main instrument for real-time analysis. Dr. Low, chief Microbiologist at Toronto's Mount Sinai Hospital stated "… doctors are about 70& accurate when diagnosing patients during flu season, which is why the 'tricorder's' accuracy would be extremely beneficial." "....With 70 per cent sensitivity, you're misdiagnosing." Dr. Low further stated that aside from the common cold or flu, the 'tricorder' could quickly discover sexually transmitted diseases or other infections.

Fibromyalgia: Is It Real?

This introductory article is the first of a series of three papers on fibromyalgia. The subsequent two papers will focus on evidence-based treatments and newer emerging therapies to improve function and hope.

Gordon D. Ko, MD, CCFP(EM), FRCPC, FABPMR, FABPM

Fibromyalgia syndrome (FMS), has generated considerable controversy in the past 20 years. The hallmark characteristic is chronic widespread pain. This is often accompanied by fatigue, non-restorative sleep, mood disorders and somatic symptoms. The challenges are multiple with an unknown pathogenesis, variable symptoms, unpredictable treatment responses and high prevalence rates (reported to be 2-3% in Canada, with females nine times more commonly affected than males).[1] The lack of an objective diagnostic laboratory test and of a gold standard of treatment further complicates management. This has resulted in physician insecurity in managing such patients. Medical school education regarding pain mechanisms and management is limited and extends to the postgraduate level as well.[2] This results in FMS being a frequently neglected, poorly understood and treated condition.

Scientific Basis for Fibromyalgia

Recent neurophysiologic studies including functional MRI (studying dynamic brain activity in response to pain stimuli) have provided validation of reported widespread pain in the absence of an identifiable physical abnormality (Figures 1 and 2).[3-6] These findings are currently available in the research setting only, and not yet available for general community use in diagnosing and following FMS patients.

Abnormalities in pain processing have been identified at various levels in the peripheral, central, and sympathetic nervous systems, as well as the hypothalamic-pituitary-adrenal (HPA) axis stress-response system.[3-8] Documented abnormalities include evidence of peripheral sensitization (pressure and thermal hyperalgesia), central sensitization (dynamic mechanical allodynia, and pinprick hyperalgesia with wind-up phenomenon and after-sensation), increased levels of substance P, glutamate and nerve growth factor in

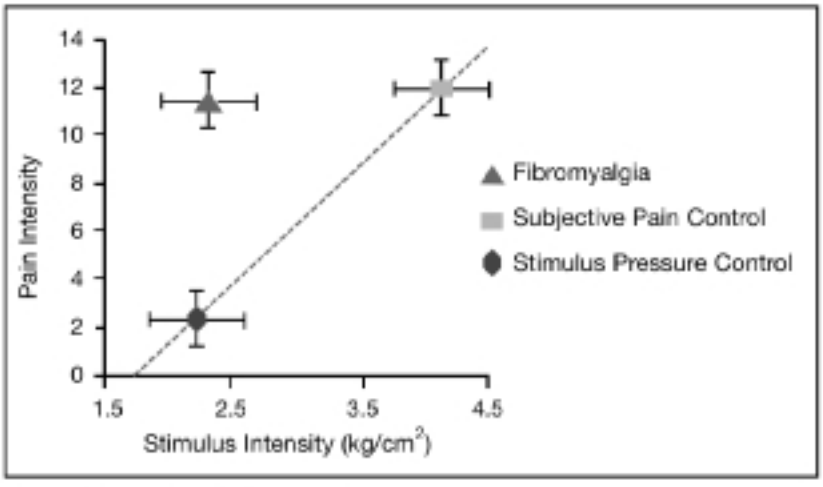

Figure 1: Pain Intensity vs. Stimulus Intensity[1]

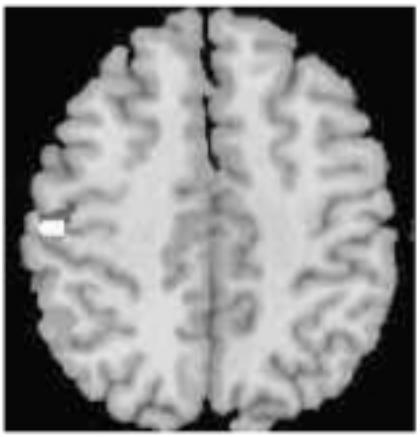

Figure 2: fMRI: Enhanced responses in somatosensory primary and secondary cortex, insula, putamen, and cerebellum[1]

Table 1
1990 ACR Classification Criteria[13]

History of widespread pain > three months
- Above and below waist
- Left and right side
- Must include axial spine

Pain in 11 of 18 tender points, palpation pressure < 4 kg
- Suboccipital muscle insertions
- Low cervical (C5 – C6 transverse processes)
- Upper middle trapezius muscles
- Supraspinatus origins (medial upper scapula)
- 2nd ribs (near costochondral junction)
- Lateral epicondyles (2 cm distal to them)
- Gluteal muscles (upper outer quadrant)
- Greater trochanters (2 cm posterior)
- Medial fat pad of knees (above joint line)

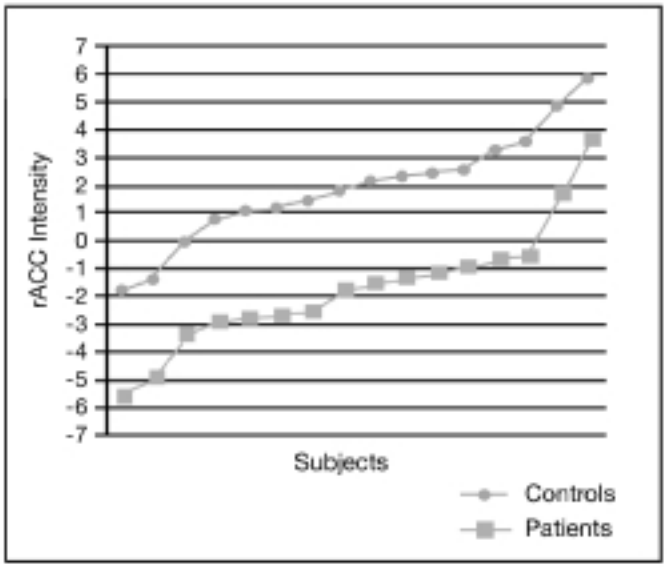

Figure 3: Intensity of Activation in rACC (the Origin of DNIC) During Provoked Pain[4]

the cerebrospinal fluid, and loss of descending noxious inhibitory control, or DNIC, (Figure 3). Recent research also points to interactions between peripheral, central bulbo-spinal and central cortical mechanisms with documentation on functional MRI and SPECT scan imaging of the CNS.[6,7]

Genetic factors may predispose some individuals to a dysfunctional stress response via the HPA-axis.[8] The odds risk ratio is 8.5 for first degree relatives.[9] In addition, there is epidemiological evidence that early life adversity such as the death of a mother, being in institutional care or family financial hardships are linked to chronic widespread pain in adult life.[10] These numerous interacting sensitizing factors may be the setting in which an inciting event such as a viral illness, accident (the odds are 13 times greater after a motor vehicle accident neck injury vs. a leg fracture),[11] or emotional trauma (reported in 31% of patients),[12] then becomes the trigger for FMS in some patients.

Dr. Ko is Medical Director, Physiatry Fibromyalgia Integrative Treatment Clinics at Sunnybrook Health Sciences Centre, University of Toronto, and the Canadian Centre for Integrative Medicine, Markham, Ontario; and Assistant Professor, Department of Medicine, University of Toronto, Toronto, Ontario

Diagnosing FMS in Clinical Practice

FMS should be positively diagnosed and no longer be seen as a diagnosis of exclusion. The 1990 American College of Rheumatology (ACR) diagnostic criteria were developed for research purposes and not purely as a diagnostic instrument (Table 1).[13] This older criteria require the presence of widespread pain for at least three months duration with the presence of at least 11 of 18 tender points in designated areas (Table 1). Tender points, the only physical examination finding used to help diagnose FM, indicate an overall reduction in pain threshold. They do not represent localized soft tissue pathology, and have been criticized for reliance on subjective interpretation. New ACR criteria are currently being reviewed to eliminate overreliance on tender points in favour of incorporating other clinically meaningful symptoms (sleep disturbance, fatigue, cognitive impairment) and somatic symptoms (depression, headache, irritable bowel) frequently present in FMS patients.[14] An about to be validated tool that the author has found to be very helpful in screening for FMS is the Fibromyalgia Moldofsky Questionnaire. A score > 11 is suggestive of FMS.

As there is no single routine lab test that confirms a diagnosis of FMS, it is recommended that only minimal testing, including a complete blood count (CBC),

Table 2
Modified Diagnostic Criteria 2010[14]

Patient must score 13 or more when the two categories are summed (with a minimum of 3 on the WPI):

Widespread Pain Index	Symptom Severity Scale
Presence of pain in any of the following 19 locations: • Jaw (right and left) • Shoulders (right and left) • Upper arm (right and left) • Lower arm (right and left) • Hips (right and left) • Upper leg (right and left) • Lower leg (right and left) • Neck • Chest • Abdomen • Upper back • Lower back ___/19 points	For each symptom, indicate severity over past week: 0 = no problem 1 = slight problems; generally mild or intermittant 2 = moderate, considerable problems 3 = severe, continuous, pervasive, life-disturbing ___ Fatigue ___ Waking unrefreshed ___ Cognitive symptoms ___ Somatic symptoms* ___/12 points *Somatic symptoms include: depression, headache, and abdominal pain

erythrocyte sedimentation rate (ESR), thyroid function tests (TSH), and creatinine kinase (CK), is done in the first instance. Other investigations (for rheumatic diseases or neurological disorders), or referral to a specialist should be driven by abnormal clinical findings.

Excessive and unnecessary testing may be detrimental to the well-being of patients by promoting an illness-centered focus and fostering a sense of uncertainty. Useful testing includes sleep studies, which should be done and interpreted by neuropsychiatry specialists with an understanding of the non-restorative sleep architecture disturbances seen in FMS (and not for simply ruling out sleep apnea). Quantitative Sensory Testing (QST, available at the CCIM drkoprp.com) goes beyond the traditional EMG-nerve conduction studies in being able to assess the slower pain conducting A-delta and C nerve fibres.

While a positive diagnosis of FM may alleviate patient concerns and is associated with reduced healthcare utilization and decreased investigations, many continue to question the validity of reported functional disability. A positive diagnosis also has medico-legal and work ability implications.[15] Dx

For a complete list of references, please see **www.stacommunications.com**

Take-Home Message

- FMS is a valid medical condition with pathophysiological functional abnormalities in the CNS (including functional MRI and neurophysiological studies demonstrating central sensitization and loss of DNIC)
- The poor understanding of the pathogenesis of FMS clinically leads to doubts about the validity of FMS complaints and results in physician insecurity and reluctance in caring for such patients
- FMS is not a diagnosis of exclusion; a positive diagnosis of FMS should be made without extensive and unnecessary investigations. A useful screening tool is the FMS Moldofsky Questionnaire
- The 1990 diagnostic criteria was based on widespread pain and tender points; the newer 2010 criteria will incorporate associated symptoms of non-restorative sleep, fatigue, and cognitive impairment as well as somatic symptoms (*e.g.*, headache, abdominal pain and depression)
- Minimal testing should be done in the first instance; other investigations should be driven by abnormal findings on clinical history and examination
- QST is an emerging assessment tool for identifying the pattern and distribution of pain
- Education of the patient, open discussion about his/her expectations ("What worries you the most about your symptoms?"), and identification of root causes ("What happened at the very onset of symptoms?") with subsequent management plan are required to provide validation and hope to patients

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Bond Symposium - Australia
December 3 and 4, 2010

A meeting of minds (and bodies)

By: Eleanor Stein, MD, FRCP(C)

I had the good fortune to attend as an observer (and reporter for Quest) a scientific symposium bringing together some of the top ME researchers in the world with leading neuro-immunologists. The symposium, held at **Bond University** in Queensland, Australia was sponsored by the **Alison Hunter Memorial Foundation**. The primary objective was to introduce ME to a group of leading neuro-immunologists to excite them about research opportunities in a field where so many large discoveries are yet to be made. Mission accomplished. It was a very exciting 2 days and many of the neuro-immunologists have expressed the intent to develop ME research programs.

The program was opened **by Dr. Nancy Klimas** (U of Miami and past president of the IACFS/ME). She summarized the immune defects found in ME: decreased cell mediated immune function (NK cells and killer T cells) on a background of overall immune activation. She emphasized a point which is becoming widely accepted that "challenge testing" is critical to uncovering the abnormalities in ME. Many of the immune abnormalities only become apparent after subjecting subjects to an exercise test or other "challenge". Similar challenges in healthy individuals make little difference. Therefore a challenge test is the best way to differentiate between a healthy person and one with ME. Dr. Klimas concluded by showing evidence that Graded Exercise Therapy is harmful in patients with ME since it increases inflammation (objective) and symptoms (subjective). At her new Miami treatment centre, Dr. Klimas uses maximal exercise testing routinely to determine patients' individual exercise tolerance.

Dr. Hugh Perry (Professor of Biological Sciences, University of Southamption UK) is an expert on inflammation and "sickness behavior". "Sickness behavior" refers to the biological response of an organism to infection or inflammation and has nothing to do with the person or mouse's motivation to get better. He explained how peripheral inflammation also causes brain inflammation. It was previously thought the blood brain barrier prevented such responses, but it's becoming clear there is active two way communication through both immune molecules (cytokines and chemokines) and neurotransmitters between the brain and the body. Dr. Perry's research in both animals and humans shows that in the presence of peripheral inflammation, diseases of the central nervous system such as Alzheimer's Disease progress much faster and that if the brain has been "primed" by a previous event such as infection, it is more susceptible to the otherwise subtle impacts of ongoing peripheral inflammation. Since many cases of ME are triggered by infection, this mechanism may be relevant. Dr. Perry stressed that measuring markers of inflammation in the periphery (ie blood) are not reflective of whether the brain is being affected.

Dr. Mary Ann Fletcher (University of Miami) summarized some recent research done in collaboration with Dr. Klimas and Dr. Gordon Broderick (University of Alberta) in which they are narrowing down the list of immune markers necessary for a diagnostic test for ME. The key markers include: Natural Killer Cell Number, dipeptidyl peptidase/CD26 cell markers and Neuropeptide Y. Dr. Fletcher echoed the theme already established by Drs. Klimas and Perry that "challenge tests" are required for accurate discrimination between ME and other groups with which it could be confused. Their group is doing a "good day / bad day" study seeing if immune markers vary within individuals with ME more or differently than in healthy individuals.

Dr. D.G O'Donovan, a neuropathologist from Cambridge UK reported on post mortem examination of the brain and spinal cord of four people with ME who died. All four cases showed abnormalities in the brain suggestive of dysfunction of the sensory and likely the

autonomic nervous system. Dr. O'Donovan thought these visible changes could be related to the pain and sensory sensitivity experienced by people with ME. He proposed setting up a specific ME brain and tissue bank in the UK to expand the sample and see if these findings are generally true for ME.

Dr. Olga Sukocheva a neuropathologist from Adelaide Australia reported on a post mortem of a severely ill individual who died from ME related complications. This brain showed many abnormalities including abnormally shaped astrocytes, glial swelling (swelling of the cells between the neurons), and presence of antigens of Coxiella burnetti in astrocytes (a type of brain cell). Coxiella is the causative agent of Q fever an infection known to cause a Chronic ME like condition. Coxiella was found in both the grey and white matter and in bone marrow, liver, lymph nodes and spleen. One wonders whether doing more biopsies and autopsies would reveal more evidence of infection in people with ME.

Dr. Dan Peterson (Internist from Incline, Nevada who will be speaking in Calgary, Alberta April 1 – 3 2011) reported on the prevalence of active infections in his patient population. Active Human Herpes Virus 6 (using viral isolation from blood cells) was found in 28%, active Cytomegalovirus (using viral isolation from blood cells) was found in 29% and Epstein Barr Virus (using the EBNA1 antigen assay) was found in 51%. The high rate of EBV is especially interesting as it is implicated in several autoimmune conditions including Multiple Sclerosis and autoimmune thyroid disease which may be more common in people with ME.

Ekua Brenu a PhD student working at Bond University with Drs. Donald Staines and Sonya Marshall-Gradisnik reported on ongoing research which has already garnered her PhD student of the year award at Bond University! Looking at a range of immune and neuropeptide markers in people with ME and healthy controls, Brenu and colleagues report: reduced CD8 (cytotoxic T cell) activity, decreased CD56 bright Natural Killer cell number and elevations of IL-10, IFN gamma and TNFalpha. Receptors for Vasoactive Intestinal Peptide were elevated in the ME group compared with healthy controls. This doesn't necessarily mean that VIP activity (which is critical for bowel motility) is increased as sometimes receptor numbers increase when molecule levels are decreased. They have research ongoing to understand the cause and role of the neuropeptide abnormalities further.

Dr. Kenny De Meirleir (Free University of Brussels and private practice) looked at immune markers in a group of ME patients who are positive for the XMRV virus. Compared to population norms (there was no control group reported) the XMRV positive patients showed decreased T cell numbers, NK numbers and elevated levels of C4a (a part of the complement inflammatory cascade also reported by Dr. Ritchie Shoemaker to be elevated in people with mold exposures, lyme disease and other known causes of ME like syndromes), elastase and CD14 (a marker for lipopolysaccharide). These latter three markers are strongly suggestive of changed or increased growth of bacteria in the small bowel, something Dr. De Meirlier continues to believe is an important component of ME. He proposes that certain types of dysbiosis e.g. increased growth of enterococci and streptococci in the bowel can be identified by the presence of hydrogen sulphide (H2S) in the urine. Test kits for urinary H2S levels are available from Dr. De Meirleir's office. Dr. De Meirleir believes that the elevated levels of H2S found in people with dysbiosis impairs mitochondrial function and slows bowel transit time causing the severe nausea and constipation suffered by some patients with ME.

Dr. Richard Kwiatek (radiologist, Adelaide) expanded on findings presented by Dr. Barnden from his group at the 2009 IACFS. They measured autonomic function using 24 hour blood pressure and heart rate monitoring and brain MRI using voxel based volumetry to look at the size of various parts of the brain. Overall brain volume was not different between the patients with ME and the healthy controls.

This differs from the 2005 report of de Lange et al who reported decreased brain volume in patients with ME. The Adelaide group did find some compelling correlations between autonomic function e.g. resting pulse pressure (the difference between the systolic and diastolic blood pressure numbers, a measure I find very useful clinically) and HR while asleep and changes in brain volume in the brainstem – the part of the brain which controls the autonomic nervous system.

Dr. Barrie Marmion, the world's preeminent Q fever researcher presented a summary of the work of the Adelaide Q Fever Research Group from 1993-2008. They have shown in both humans and animal models that Q fever, once thought to be an acute illness only, causes chronic ME like symptoms in 5 – 15% of those affected. Symptoms include: night sweats, photophobia, alcohol intolerance, disturbed sleep and cognitive function. Sound familiar? They have developed a model to explain this previously unknown (and still actively disbelieved by some) condition. Some people, likely with certain genetic predisposition have a defect in clearing the Coxiella antigen at the time of acute infection. This causes immune stimulation and cytokine dysregulation which alters genetic expression causing the long term symptoms. Dr. Marmion's group has proven this by finding antigen complexes in tissues (not in blood) of people who have been ill for up to 15 years after the acute infection. Interestingly, although antibiotics are the treatment of choice for acute Q fever, they don't improve symptoms of chronic Q fever. One has to rectify the immune defects to see improvement.

Dr. Anne Boullerne (University of Illinois) studies Multiple Sclerosis, specifically an animal model of MS called Experimental Allergic Encephalomyelitis in which an MS like syndrome is stimulated in experimental animals by exposure to certain antigens such as myelin or myelin basic proteins. The field of MS has benefitted from a long history of brain autopsies which show inflammatory, autoimmune changes. This brain inflammation requires some permeability (leaking) of the blood brain barrier. Interestingly it has been shown in Lupus, another autoimmune conditions that the BBB only becomes leaky when subjects are stressed in some other way. The BBB is hypothesized to be leaky in ME but confirmation is hampered by the difficulty of studying BBB function in living humans. Again the need for an animal model and for "challenge tests" rather than random measurements arises.

Dr. Doug Feinstein (University of Illinois) studies CNS disorders including MS and Alzheimers disease with a focus on brain inflammation. Noradrenaline is a neurotransmitter integral for mood and energy. Several of the newer antidepressants impacting neuropathic pain increase noradrenaline levels. Feinstein has found that noradrenaline is a natural anti-inflammatory. In experimental animals, increasing noradrenaline levels decreases brain inflammation and decreases pain. It also helps maintain the integrity of the blood brain barrier. Dr. Feinstein is experimenting with various drugs that increase noradrenaline levels(e.g. droxidopa, atomoxetine) to improve cognitive function and brain autopsy findings in animals with alzheimer's disease.

Dr. Doina Ganea (Temple School of Medicine, Philadelphia) is an internationally renowned scientist of neuropeptides. These are the molecules which direct communication from the brain and central nervous system to the periphery (nerves and immune system). Neuropeptides such as vasoactive peptide (VIP) and pituitary derived adenylate cyclase activating peptide (PACAP) play an active role in the development of immune tolerance. Immune tolerance is the body's ability not to react to every antigen it sees e.g. itself. VIP and PACAP also have significant anti-inflammatory effects and have been used therapeutically in animal models of inflammation including collagen induced arthritis and experimental autoimmune encephalomyelitis (the animal model of MS). Neuropeptides seem like a potential therapeutic tool, but Ganea cautions that these molecules are unstable and cause side effects.

Nevertheless, nasal VIP is being used experimentally by some clinicians for patients with ME like syndromes. The role of neuropeptides in ME is certainly an area ripe for further investigation.

Dr. Monica Carson (University of California at Riverside) another internationally known neuroimmunologist presented on the impact of the chemokine CCL21 on the immune system. This chemokine is produced in the brain by neuron cells when injured or infected primes the peripheral Tcells to react more strongly when needed. In mice genetically modified to have high CCL21 levels, autoimmunity is more common. This priming activity which is often triggered in the first place by an infection (eg. toxoplasma gondii) may provide an explanation as to why in some conditions such as ME immune activation continues long after an infection seems to have abated

Dr. Donald Staines (Bond University, Queensland) has developed a hypothesis his group is now testing that neuropeptides may play an integral role in ME. He believes that due to molecular mimicry (where the body mistakes an infecting agent for one of its own molecules because they look so similar) people with ME have an autoimmune response to their own neuropeptides such as VIP and PACAP. If these molecules or their receptors are damaged by the body's own immune response, Staines believes this could explain many of the symptoms of ME. His group incuding Sonya Marshall-Gradisnik, Ekua Brenuu and Mieke Van Driel are currently testing these hypotheses in patients with ME.

On the second day of the conference we discussed common ground and potential research collaborations between the ME and Neuroimmune researchers. The following press release was drafted to summarize conclusions and intentions of the Bond University Symposium. We have called it the "Bond Manifesto".

"ME – Cardboard Case Collapses"
Bond University Symposium sheds light on the body mind connection.

In 1996 a committee of the British Colleges of Physicians, Psychiatrists and General Practitioners published a report that set the plight of ME (Myalgic Encephalomyelitis) sufferers back 14 years. The report dismissed for lack of evidence all extant biological hypotheses for ME. According to then Lancet editor Dr. Richard Horton in a 1997 editorial in the British Newspaper Observer, the committee (heavily stacked with psychiatrists) built a "cardboard case" against the idea that ME is an organic disease of the brain. Sadly this report was influential beyond the borders of the UK and perpetuated the untruth that ME is a psychological or psycho-social condition. This belief has prevented many patients from accessing care for their debilitating physical symptoms.

15 years on, a report of 4 brain autopsies of persons deceased with ME show evidence of "organic brain disease" visible under a microscope. At the same meeting, December 3 and 4, 2010 at Bond University in Queensland where these findings were presented, other researchers presented irrefutable evidence of immune abnormalities and infectious connection in a majority of cases. It seems the case of the Royal Colleges and others who have authoritatively dismissed ME as a modern psychosocial fad has collapsed.

The missing link in the quest for a fuller understanding of ME may come from the field of neuroimmunology. **Dr. Donald Staines** of Bond University in Queensland, Australia believes the connection between the body and brain dysfunction in ME may be tiny molecules called neuropeptides. His group has just published findings of increased receptor numbers for vasoactive intestinal peptide in ME patients. At the recent Bond University Symposium, international experts in neuroimmunology explained how there is constant two way communication between the brain and the immune system and a problem in either place could lead to a chronic neuroimmune dysregulation causing many of the symptoms of ME.

The group of neuroscientists, researchers, specialist and primary health physicians have released a manifesto summarizing their agreement on several points which may come back to haunt the Royal College committee.

- The label ME (Myalgic Encephalomyelitis) reflects the current science and clinical symptoms of the condition. The label ME should be used in preference to CFS (Chronic Fatigue Syndrome) which ignores the plethora of serious symptoms other than fatigue and doesn't reflect the severity of the disorder.

- The Canadian Consensus Criteria published in 2003,(Carruthers et al, 2003) should be used in preference to the Fukuda or other criteria as they are more specific and avoid confusion between ME and other conditions. The Empirical Revision of the Fukuda criteria published in 2005 (Reeves et al, 2005)should specifically be avoided as the criteria allow inclusion of an alarming number of people who don't have ME.

- In the absence of approved drugs for ME, "off label" use of drugs as necessary to treat symptoms and perpetuating factors should be allowed and endorsed.

- Since ME is a serious condition sometimes causing death, there is a need for an international post mortem protocol building on work being done at the Cambridge Tissue Bank UK. If one doesn't look for "organic brain disease" one is unlikely to find it.

- There is a need for national ME registries (similar to national twin registries) enrolling those with active disease and those in remission to facilitate research and establish prognosis.

- Future research directions should include:

    - Neuroimaging to better understand the organic brain dysfunction in ME
    - Validation of existing biomarkers and development of new ones
    - Study the role of immune and gastrointestinal function in ME
    - Develop experimental models including animal models
    - Long term follow up studies of people with ME

The Bond University Symposium has stimulated new, exciting research collaborations between ME researchers and established neuroimmunologists to further the existing knowledge base.

References:

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Reeves, W.C., Wagner, D., Nisenbaum, R., Jones, J.F., Gurbaxani, B., Solomon, L., Papanicolaou, D.A., Unger, E.R., Vernon, S.D., & Heim, C. (2005) Chronic fatigue syndrome – a clinically empirical approach to its definition and study. BMC.Med. 3:19. 19

Soya Kefir Implication for people with ME/CFS and FM - Update

Dr. Kubow et al of the School of Dietetics and Human Nutrition, McGill University, Montreal wrote in our Fall 2008 and Fall 2009 issues of QUEST on the implications of Soya Kefir on CFS and Fibromyalgia pain. Dr. Kubow

advises that The Wykanta site no longer is selling Soya Kefir. Please direct your enquiries to:

Stomo-phlebo

Centre Stomo-phlebo Montreal, 3545, Berri, Montreal, QC H2L 4G3 Canada

Delivery can be made to the pharmacy of your choice.

Telephone: **1-800-823.7573**

If you live in the U.S.A. or elsewhere, please contact Stomo-phlebo at

info@stomophlebo.com.

What is Soya Kefir?

Soya Kefir is a patent-pending powdered extract of a soy-based Kefir drink newly developed by KCLM Research that has shown remarkable improvements in clinical studies of individuals suffering from pain and fatigue. It is formulated to concentrate the bioactive components of Kefir in an easily consumable form.

Clinical Research Studies

Clinical research testing the health benefits of Soya Kefir was carried out for 30 days by Dr. Dominique Garrel at Institut de recherches cliniques de Montréal (IRCM). Statistically significant improvements were shown for Bodily Pain and Vitality (energy and fatigue) in the study at IRCM.

A USA-centered clinical trial involved patients who were evaluated after 30 days and 60 days taking Soya Kefir.

From the two above separate clinical trials, reported benefits included :

-Significant pain relief
-Increased energy and vitality levels
-Improved physical and emotional well being

There is ongoing scientific research regarding the health properties of Soya Kefir at McGill University, the Université de Montréal and North Carolina State University.

[Ed. Note: For more information or questions on Soy Kefir, please contact KCLM Research in Nutrition or call at **1-877-693-1121** or visit **www.soya-kefir.com**]

NEWS SNIPPETS

- Ms Laura Williams of The Canadian Pain Coalition announced that the Government of Canada will be adding National Pain Awareness Week to their Calendar of Health Promotion Days on the Health Canada website. They will also be linking to the National Pain Awareness page on the Canadian Pain Coalition website.

[Ed Note: For details view: **http://www.hc-sc.gc.ca/ahc-asc/calend/index-eng.php** and **http://www.canadianpaincoalition.ca**]

- Elizabeth R. Unger, Ph.D., MD has just been appointed Chief of the Chronic Viral Diseases Branch (CVDB) at the U.S. Centers for Disease Control & Prevention (CDC). She was previously the acting chief. She currently leads research and public health studies encompassing molecular pathology of both human papillomavirus (HPV) and chronic fatigue syndrome (CFS) programs in CVDB.

- Dr. Fred Friedberg, President, of IACFS/ME contacted Dr. Unger requesting answers as to 1) will she continue to use the empiric definition of CFS which is only used at CDC; 2) will she conduct new biomedical studies, particularly in the areas of virology, immunology and molecular biology; 3) will she engage external scientific and professional communities as in the past she had been dismissive of their

input and 4) requested that as a good faith gesture she would hold the meeting of scientists and clinicians at the CDC which was promised in the 5-year plan issued more than 18 months ago. The IACFS/ME is keeping a close watch on developments as is the ME/CFS community.

Conference Update 2011

Please accept my heartfelt thanks on behalf of the National ME/FM Action Network with our fundraising. It is heart-warming to see the inventive ways you have come up with for raising money for this vital event.

I also would like to remind you to send us your list of doctors and other professionals you wish us to put on our information list so that we can invite them to the conference. You can do so by email or snail mail or fax.

This is the chance we have been waiting for: bringing awareness and knowledge to illnesses which have not had the recognition any chronic illness should have.

Lydia

Newsletters/Conferences/Books/ Reports, etc.

Conference Announcement
April 1-3, 2011

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) - Diagnosis and Management: The Basics and Beyond

Location: The Blackfoot Inn, 5940 Blackfoot Trail SE Calgary, Alberta

Dr. Daniel L. Peterson, MD
Internal Medicine Specialist, 27 Years Clinical Experience with ME/CFS

Clinical Case Conference with Dr. Peterson and Dr. Ellie Stein

Bring a challenging file to get advice from the experts.

Registration limited to ensure maximal participation

Date: Friday April 1, 2011, 1:00 - 4:30 pm (room to be announced)

Fee: $ 75

Networking Dinner

Date: Friday April 1, 2011, 7:00 - 9 pm (room to be announced)

Dinner Speakers: Dr. Peterson and a member of the U of Alberta/U of Calgary XMRV research team

Topic: XMRV in ME/CFS - Is this newly discovered retrovirus an innocent bystander or central player?

Fee: $ 45

Continuing Medical Education Program

Date: Saturday April 2nd, 2011

Registration: 8:30 – 9:00 am

Workshop: 9:00 am – 5:00 pm

CME: This program has been reviewed by The College of Family Physicians of Canada and is awaiting final accreditation by the College's Alberta Chapter. This program has been approved for RCPSC Section 1 - 3.5 hours and Section 3 - 2.5 hours.

Learning Objectives: This program includes small group interviewing practice with pre and post self assessment

1. To list and elicit the diagnostic criteria for ME/CFS

2. To evaluate and support patient self management

3. To identify common reasons for failure of patients with ME/CFS to progress

4. To perform a diagnostic work up on a patient with ME/CFS

5. To implement a treatment strategy for patients with ME/CFS

Fee: $140 ($170 after March 15, 2011)

$100 for registered students (please provide proof of student status)

Includes Overview of the Canadian Consensus Guidelines for the Diagnosis and Treatment of ME/CFS, program syllabus, refreshments at breaks and lunch

In support of the IACFS/ME research and clinical conference in Ottawa, Canada "*Translating Evidence into Practice*" September 22 - 25, 2011, proceeds from these events will be **donated** to its host, the **National ME/FM Action Network,** a registered Canadian charity for ME/CFS and FM.

Book Review

The Sound of a Wild Snail Eating
By: Elisabeth Tova Bailey

Elizabeth, ill with severe ME/CFS, received the unexpected gift of a snail from a friend. The snail was given a home in a terrarium at her bedside and she observed its adventures, telling its story as well as her own. Her observations of the snail are stunning and you will never look at a snail the same way again after reading this book. While the book focuses on the snail, the backdrop is the experience of illness and her reflections on this subject are equally moving.

At first, Elisabeth did not think much of the snail's arrival, but she started observing the creature during a severe relapse in her illness and became aware that the life of her snail was not really so different from her own. Her experience is echoed by many who are ill with ME/CFS "When the body is rendered useless, the mind still runs like a bloodhound along well-worn trails of neurons, tracking the echoing questions: the confused family of *whys*, *whats* and *whens* and their impossibly distant kin *how*."

Elisabeth became more and more cut off from her human world because her illness limited her physical participation in life. The snail's world became her world and she considered the needs of its survival as tantamount with her own. To help her with her quest, she started reading scientific information on the snail and even consulted experts and became fascinated by the snail's wanderings and discoveries. She learned what it liked to eat, what the best conditions were for it to thrive and was thrilled when she observed it laying eggs. She later discovered she may be the first person to write down her observations of a snail revisiting its eggs after they'd been laid.

Elisabeth's observations of the snail helped her through setbacks in her illness. Her book breaks through the barrier and mystery of ME/CFS so that people who would not normally be interested in reading about illness become fascinated by her beautiful writing and prose and introduces us to the fascinating and tiny world of a snail.

Elisabeth with this book showed us that she is not only a talented writer but a survivalist and shows us that no matter how small a creature you are, you matter.

To Order:
Tel. **905-475-9126** Fax: **905 475-6747** Toll Free **1-800-387-4333**
Email:**info@t-allen.comhttp://www.thomasallen.ca/site/index.aspx**
Or: **http:www.wortleyroadbooks.com**

[Ed. Note: For more details see **http://www.elisabethtovabailey.net**]

The Journey

Life & Living with ME/CFS and FMS

Issue # 1 **Published by the National ME/FM Action Network** **Winter 2011**

Should You Get the Flu Shot?

Doctor advises careful consideration

Flu season is now well underway, and with it comes the usual debates for and against getting the flu vaccine. People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) may wonder if their condition potentially raises the stakes.

Dr. Alison C. Bested, a medical advisor to the National ME/FM Network, is advising patients to consider several factors when deciding whether or not to get the flu vaccine. In a recent announcement, she pointed to several factors that should be considered in any decision.

- "If you are allergic to eggs, you should not get a flu shot as the vaccine contains egg protein."

- "If you had the vaccine in the past and did not have any problems with it, then probably you would tolerate it this time."

- "If you have never had it before, then the first question is whether you need it. If you are totally isolated in your own home and your caregivers and family are very aware that they should not come to visit you or care for you if they are ill, then your risk of exposure is minimal."

- "If you go outside the home, then you could take the following precautions. Take a disposable paper mask with you if you have to visit public places e.g. doctors' offices, church, stores. If anyone is coughing then put your mask on immediately so that you do not breathe in viral particles. Try to keep your hands off of your face, especially after coming into contact with another person (e.g. shaking hands) or an object just used by another person (e.g. a pen) so that you do not transfer viruses from your fingers to your eyes and nose. These are easy entry routes for viruses into your body."

For those who decide to go ahead with vaccination, Dr. Bested advises proceeding with caution. "I recommend starting with an injection of one third the usual adult dose. If there are no side effects, then the same dose can be repeated in a month's time, and the same again after one further month."

In addition to her work with the National ME/FM Network, Dr. Bested is the Haematological Pathologist Staff Physician and Medical Specialist Liaison for the Environmental Health Clinic at Women's College Hospital Toronto, Ontario.

Bringing M.E. Awareness to City Hall

Brockville M.E. Association photo

Brockville M.E. Association President Betty Cirne went to Brockville City Hall to talk about M.E. awareness, and presented Mayor David Henderson with a special t-shirt to commemorate May 12. For more May 12 events coverage, see pages 4 and 5.

On funding discrepancies and tongue-tied editors

By James Deagle
Editor-In-Chief

Welcome to the first issue of *The Journey*, a new section of *QUEST* aimed at chronicling the stories of people living with (or affected by) Myalgic Encephalomylitis and Fibromyalgia.

The past few months have been a learning curve for Your's Truly, as I have been tasked with gleaning all I can about the medical basis of ME and FM, as well as the various social and political issues surrounding them. (And despite how far I have come my pronounciation of 'encephalomyelitis' is still a work in progress.)

One of the key areas of interest for me is the friction where the social implications of ME and FM rub up against the medical realities. This friction is demonstrated when you look at the Federal funding for ME and FM compared to other diseases. According to figures released by the Canadian Institutes of Health Research (CIHR), ME and FM affect more than 300,000 Canadians each, and combined have received a total of $6,453,852 since December 2007 for 24 studies. Compare that with HIV/AIDS, which affects 63,000 Canadians, and in the same time period has received $342,111,092.00 for 1240 studies. On a per-person basis, that works out to $5,430.33 per HIV/AIDS patient, versus $14.49 and $2.41 each respectively for Fibromyalgia and Myalgic Encephalomylitis.

While the above is not to diminish the challenges faced by those with HIV/AIDS, the reality is that as diseases go, it has better political connections and plenty of showbiz clout.

As National ME/FM Action Network President Margaret Parlor pointed out in a recent statement, “health research funding is not equitably distributed. Fibromyalgia and Chronic Fatigue Syndrome receive very little funding, expecially considering their prevalence and the burden of illness.”

Such discrepancies indicate that we have a long way to go in bringing ME and FM into the forefront of the public's imagination and further up the government's list of funding priorities. This is (in part) why we decided to call this section *The Journey*. I'd like to thank Lydia Neilson, CEO and Founder of the National ME/FM Action Network, for inviting me to come along for the ride.

* * *

One thing I'd like to note is that all of the work you see here was done with Free and Open Source Software (FOSS). While this may seem a little off-topic at first glance, I believe FOSS can be of tremendous value to those involved with support groups who happen to publish their own newsletters or else need a software solution on the administrative side of things.

In a nutshell, FOSS is (usually) free of charge, and is always free of the usual restrictions that encumber propietary offerings. With FOSS you can simply download it from the 'net, install it and never look back, as well as not worry about any prohibitive End User License Agreements. As they say in the FOSS world, think 'free' as in 'freedom', not 'free' as in 'beer'.

Specifically, I'd like to acknowledge and thank the developer communities behind the FreeBSD 8.1 operating system and the *OpenOffice* suite of productivity tools, as well as various graphics and desktop publishing programs, including *Scribus*, *Inkscape* and *GIMP* (the GNU Image Manipulation Program).

For further information on free software and why software freedom matters, visit www.fsf.org.

Send all submissions, including articles, pictures and letters to the Editor to:

mefm.jamesdeagle@yahoo.com

U.S. study: tai chi may ease fibromyalgia symptoms

Results encouraging, though larger trials needed, says NCCAM

By James Deagle
The Journey

Tai chi is widely regarded as a martial art that carries with it many health benefits. A recent study by the U.S. National Center for Complementary and Alternative Medicine (NCCAM) shows that these benefits may also extend to those with fibromyalgia.

In "A randomized trial of tai chi for fibromyalgia", researchers led by Dr. Chenchen Wang worked with a total of 66 fibromyalgia patients across two control groups – one that merely received wellness education and practiced stretching exercises, and one that practiced tai chi twice a week for 12 weeks, in addition to practicing at home with a DVD. The results were published in *The New England Journal of Medicine*.

The study found that the tai chi group experienced a much steeper decrease in the total Fibromyalgia Impact Questionnaire score than the other control group, and had a better improvement in sleep quality, mood and quality of life, with no adverse events reported.

Public domain image

In an official statement in response to a query from *The Journey*, NCCAM said the study was admitedly small, and that generally small studies need to be confirmed in larger trials. NCCAM further stated that certain criteria need to be met before larger trials can go ahead. "Whether an additional study would be conducted would depend on many factors, such as availability of funds, whether a researcher has submitted a grant proposal for such a project, and the evaluation of the application through rigorous National Institutes of Health (NIH) peer review."

NCCAM said that so far no governmental response to the study, either from departments or individuals, had been received.

As one of 27 institutes of the NIH, NCCAM is the U.S. Government's lead agency for researchng complementary and alternative medicine (CAM), and defines its mission as being to "explore CAM practices in the context of rigorous science, train complementary and alternative medicine researchers, and disseminate authoritative information to the public and professionals."

PEI Health and Wellness Minister salutes FM/CFS Awareness Day

By James Deagle
The Journey

Chronic Fatigue Syndrome and Fibromyalgia were formally recognized in the Legislative Assembly of Prince Edward Island (PEI) on May 13 when Health and Wellness Minisister Carol Bertram acknowledged Fibromyalgia and Chronic Fatigue Syndrome Awareness Day.

"Chronic Fatigue Syndrome is a real and severe disease which impairs its victims in their ability to work," said Bertram. "It takes perfectly healthy people and makes it difficult for them to function at all."

"Many Canadians are affected by these diseases, for which there is not yet an effective treatment. I hope that ongoing research will continue to unravel these difficult and perplexing diseases."

"I hope that ongoing research will continue to unravel these difficult and perplexing diseases."

-Hon. Carolyn Bertram
Legislative Assembly of PEI, May 13

She also acknowledged the importance of the people and organizations within the ME/FM community. "Today I want to commend the National Action Network and the many volunteers in self-help and mutual aid groups here in PEI and across Canada. These individuals provide information, advice and reassurance to those afflicted by these syndromes."

Her office was subsequently asked by *The Journey* whether her government officially declare May 12 to be ME/CFS Awareness Day in PEI, and also whether or not the Province would fund the participation of a PEI doctor at the IACFS/ME International Research & Clinical Conference being hosted by the National ME/FM Action Network in Ottawa in September 2011. Her office not comment on either matter.

A similar query was met with no response or acknowledgement from Leader of the Opposition Olive Crane.

ME/CFS and FMS Awareness Day

The People, Events and Activities of May 12, 2010

By James Deagle
The Journey

Various support groups across Canada and around the world celebrated ME/CFS and FMS Awareness Day this past May 12. And as you'll see from the following round-up, each did their part to get the message out in their own unique ways.

The Fibromyalgia Support Group of Winnipeg (FSGW) got the word out on the street – literally. For the entire month of May, the organization had an ad emblazoned on one of their city's "Community Relations Bus".

As the organization's Karen Klos explained to *The Journey*, "the Community Relations Bus is a city bus that runs ads free of charge to organizations or groups in Winnipeg," and added that the ads typically run for a full month and change routes so that all areas of the city are covered. In addition to the free coverage on either side and the back of the bus, the program also provides free artwork and designs for the ads. "After the first time running it," said Klos, "we adopted their design as our logo as we liked it so much."

The success of the Community Relations Bus is evidenced by the response it garnered. "Of the calls or emails we received from the ad," said Klos, "I believe all were from people who had been diagnosed with Fibromyalgia, or their friends or family members. None had heard of our organization previously, and were very interested in hearing what we have to offer."

ME Society of Edmonton photo

Dolores Wiart, Interim President of the ME Society of Edmonton, presented Dr. Gordon Broderick with her organization's 2010 Florence Nightingale Award. Dr. Broderick was recognized for his CFS research.

Speaking to the overall importance of May 12, Klos concluded that "most people who are newly-diagnosed are feeling very desperate and confused, and need education and support."

The awareness-raising efforts got underway early as the Brockville (Ontario) ME Association and its supporters participated in the Mayor's Community Walk in April. The walk encourages residents of Leeds & Grenville to collect pledges for the community organization of their choice. According to the Brockville ME Association, they doubled their pledge amounts over the previous year. The group stood out with their banner as well as their distinctive blue and white turtle shirts.

Brockville ME Association President Betty Cirne spoke at a Brockville City Council meeting about ME/FM awareness, and presented Mayor David Henderson with his very own blue and white turtle shirt. According to the association, Cirne's talk had an impact on councillor Henry Noble, who commended her on a job well done.

Mary Fairbairn, of the Brockville ME Association,

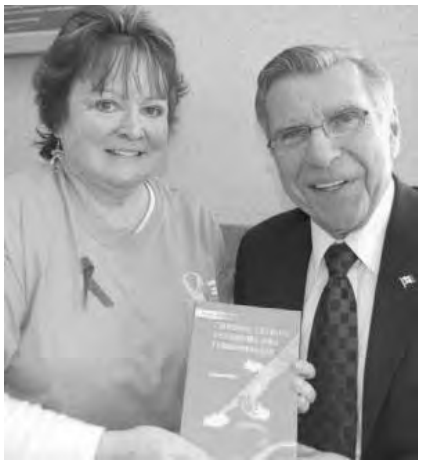

Photo by R. Comfort, Morrisburg Leader

Mary Fairbain, of the Brockville ME Association, presented MP Guy Lauzon with Dr. Alison Bested's book, Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia.

Brockville ME Association photo

Brockville M.E. Association President Betty Cirne went to Brockville City Hall to talk about M.E. awareness, and presented Mayor David Henderson with a special t-shirt to commemorate May 12. For more May 12 events coverage, see pages 4 and 5.

presented Stormont-Dundas-South Glengarry MP Guy Lauzon with a copy of the book H*ope and Help for Chronic Fatigue Syndrome and Fibromyalgia*, by Dr. Alison C. Bested of the Women's College Hospital. This meeting didn't go unnoticed by the local media, as it garnered coverage in the *Morrisburg Leader*. Fairbairn told *Leader* reporter Rebecca Comfort that those living with ME "need more people with important names to become aware of this," adding that "it's wonderful to have the support of our MP. This is the first time that someone other than a sick person has listened to me."

Lauzon was quoted as saying "I can't make any promises about the results, but I can guarantee that I will try. If one person gets diagnosed because we took the time to listen, we all benefit."

The ME Society of Edmonton named Dr. Gordon Broderick its 2010 Florence Nightingale Award Recipient for his significant contribution in the fields of education, awareness, research and volunteerism regarding Myalgic Encephalomyelitis. Dr. Broderick is the sole Canadian among six reaserchers funded by the CFIDS (Chronic Fatigue / Immune Deficiency Syndrome) Association of America.

In his speech at the presentation, Dr. Broderick spoke to the obvious need for awareness of Chronic Fatigue Syndrome among those in the medical profession. "To be honest, I was struck by the magnitude of the illness' impact, and how poorly understood it still is. I was also saddended by the stigma often associated with this illness and how poorly equipped physicians are to recognize this as a very real physiological disorder."

Dr. Broderick's current work concerns biomarkers for early detection, as well as objective diagnosis and early detection of Myalgic Encephalomyelitis. His recent papers have modelled how the brain, endocrine and immune systems are altered by CFS.

Also in attendance was Dr. Flor-Henry, as well as Andrea Kreitz and Landon Berger, two University of Alberta medical students whose work with Dr. Broderick was funded by a special $3,000 grant.

Over at the University of Alberta Hospital there was a display by FIBROFREE, Edmonton's Fibromyalgia Guaifenesin Recovery Group, which promoted awareness of Fibromyalgia, the Fibromyalgia Treatment Center in Marina del Rey, California, and the Guafenesin protocol. (This protocol is an experimental, three-part treatment that has had some anecdotal evidence of success, if not empirical proof of its effectiveness.) Nevertheless, FIBROFREE's Cheryl Kowaleski has said that the Guaifenesin protocol "is changing the lives of many of our 160 members.")

See* ROUND-UP *page 6

This ad graced Winnipeg's Community Relations Bus, which ran free of charge for an entire month on various routes throughout the city and also included graphic design at no charge. The Fibromyalgia Support Group of Winnipeg has since gone on to adopt it as their official logo .

Health research funding not equitably distributed

Fibromyalgia and Chronic Fatigue Syndrome are serious illnesses. Statistics Canada data show that over 300,000 Canadians have been diagnosed with each illness and that patients with these illnesses experience very high levels of disability, disadvantage and unmet needs. (This was documented in our special issue of *QUEST* Spring-Summer 2009.)

There is a great need for health research into these illnesses. The Canadian Institutes of Health Research (CIHR) is the federal agency that is the primary source for health research funding in Canada. How much has the CIHR invested in research into Fibromyalgia and Chronic Fatigue Syndrome?

Both the U.S. National Institutes of Health and the Australian National Health and Medical Research Council publish spreadsheets showing how spending is distributed among health topics.

By Margaret Parlor
President,
National ME/FM Action Network

CIHR does not publish such a spreadsheet. However, CIHR maintains two databases that describe the studies that have been approved for funding and it provides a keyword search function. A knowledgeable user can generate such a spreadsheet.

Since December 2007, CIHR has approved 6.240 studies worth over $1.5 billion. Only six studies worth $5.6 million refer to Fibromyalgia. Only four studies worth $800,000 refer to Chronic Fatigue Syndrome.

To increase transparency and accountability, CIHR should publish a spreadsheet showing how it distributes funding among health topics so that this information is available for public discussion.

Health reasearch funding is not equitably distributed. Fibromyalgia and Chronic Fatigue Syndrome receive very little funding, especially considering their prevalence and the burden of illness. CIHR's mandate includes “building research capacity in under-developed areas”. Research into CFS and FM are truly underdeveloped. There is a need for proactive efforts to build research capacity for these illnesses.

From* ROUND-UP *page 5

The South Okanagan FM-ME Support Association hosted Kelowna Sleep Specialist Dr. Ronald Cridland, who spoke of the benefit of proper sleep in addressing Fibromyalgia pain. According to the organization's Sheryl Ann Wilson, Dr. Cridland “believes that sleep can do a lot to assist in the betterment of the pain of Fibromyalgia and has worked with persons with Fibromyalgia for over a decade.”

After a recent postponement due to a blood poisoning in her leg, Sherri Todd spoke to an MEFM support group in Vancouver on May 17 about her own history, and gave an update on the National ME/FM Action Network's projects. (Sherri is the organization's Director for British Columbia.)

At the Ontario Legislature on May 12, the Myalgic Encephalomyelitis Association of Ontario (MEAO) and its supporters were on hand – both in the Legislature gallery and in front of Queen's Park – as various MPPs acknowledged and introduced several ME/FM support groups from across the province and spoke about the importance of awareness.

Announcements

The Myalgic Encephalomyelitis Association of Ontario (MEAO) has a new web site and email address, as follows:

Web: www.meao.ca
Email: info@meao.ca

The Seaway M.E./FM Self Help Group (in Cornwall, ON) now has a new President, Louise McLellan. Please direct all queries and congratulations to pmclellan2@cogeco.ca.

"If you grit your teeth and show real determination, you can do anything."

-Charlie Brown

'Lightning Process' boasts 3-day cure for ME/CFS

Critics claim controversial treatment is scientifically unproven

By James Deagle
The Journey

Lightning Process (LP) is a somewhat new treatment on the ME/CFS and FMS landscape, and like any new treatment whose propents herald miraculous results, it also has its share of detractors.

Trademarked as by British osteopath Phil Parker as *Phil Parker Lightning Process®*, the treatment purports to cure ME/CFS – as well as a host of emotional conditions – in three days flat through life coaching and the teaching of various movement and posture techniques. The treatment involves teaching practitioners to take control of their body's "Personal Emergency Response" (PER), which produces adrenaline, noradrenaline, dopamine, cortisol and DHEA (dehydroepiandrosterone) when there is a perceived threat. LP is therefore seen by some to be predicated on the theory that ME/CFS is caused by the overproduction of adrenline, and that therefore the condition can be cured by retraining the brain to produce endorphins rather than adrenaline when there is no apparent threat.

So far, any evidence for the effectiveness of LP has been anecdotal. The official website presents a few examples of success, including that of "Elaine", who suffered from CSF for more than 20 years before attending an LP course. "I can't believe how well I have now become and able to do so many of the things I used to enjoy," she says in her testimonial. She further relates that post-LP, she was able to ski four out of five days on a recent ski trip, compared to the previous year, when wasn't able to ski at all.

In another testimonial, "Katrina" relates that "since the course my life has changed dramatically," and that she is now doing "full days at school, which involves being up early and up to five hours of lessons in a day," followed by frequent dining out, as well as socializing often until 11 p.m.

Despite the above, however, LP has generated some controversy. As Mary-Jane Willows, chief executive of the UK Association of Young People with ME, told the *Daily Mail* (C*ould ME be caused by too much adrenaline?*, January 9, 2007): "While we have heard of members who have been helped by undertaking the Lightning Process and are thrilled for them, we are aware of others for whom the outcome was less than positive. We cannot recommend this therapy or others for children where there is no clinical data or research available."

The *Daily Mail* article also quoted Dr. Neil Abbot, director of operations at ME Research UK, who expressed doubt about the perceived central premise of LP, saying he would "like to see some evidence that there is an adrenaline rise in ME sufferers, and if there is, whether lowering adrenaline induces a 'lightning' cure." Dr. Abbot added that the "only thing that will create general acceptance of the principles and treatment techniques applied by LP will be large-scale tests."

Besides being scientifically-tested, others have doubts about the organizational structure surrounding the treatment. Dr. John Greensmith, of the British advocacy group ME Free For All, told the CBC in an April 18, 2008 broadcast that he had reservations about the fact that LP trainees frequently go on to become practitioners, saying that to him it all sounded like a "pyramid scheme.". He also called LP's claims "extravagant", and that its proponents' logic is that "if patients get better, they claim the success of the treatment, but if they don't, they say the patient is responsible."

Treatment creator speaks out

In an interview with *The Journey*, Parker defended the treatment against the above criticisms, and said that when he started looking at ways to help people struggling with chronic illness, "I never imagined that finding simple and rational solutions, which have made such a difference in the lives of quite a few people and their families, would create such debate and in some cases unreasonable comment."

Addressing the lack of scientific evidence behind LP, Parker noted that "one of the reasons why complementary research is uncommon is that it is a very expensive and time-intensive endeavor. Therefore, research in the area of health is usually delivered by academically-funded research teams in Universities or linked to the huge budgets of the drug companies. These resources are completely out of the league of most independent organizations."

See* LIGHTNING PROCESS *page 8

Exercise caution when posting materials online

Insurance companies now cruising social media sites for incriminating pictures and info

A recent article in the *Ottawa Citizen* demonstrated a good reason to be very careful about you post on social media sites such as Facebook (*Insurance companies reading social-media sites*, by Shan Li, McClatchy-Tribune News).

The article points out that insurance companies now read their customers' profiles on Facebook and other similar sites, and that what may seem innocuous to you could be reason enough for them to withhold your benefits. One example given was a woman on depression leave who posted pictures of herself on a beach and hanging out in a pub.

From those photos alone, and without consulting her doctor, her insurance company arbitrarily decided she was ready to work again and no longer needed her benefits.

Although this article was written about insurance companies, this also applies to employers, prospective employers, investigators and anyone else who needs information on you. Don't post anything anywhere that can hurt you.

From* LIGHTNING PROCESS *page 7

He added that he and proponents of LP have been very fortunate in that due to the anecdotal evidence, large numbers of people have been attending LP courses, (2,500 last year alone), and that the significant changes seen by clinicians in a large enough percentage of trainees has stimulated requests from patients and patient groups to evaluate LP. Parker's hope is that this sort of success will lead to a Randomized Controlled Trial (RCT) into the treatment's efficacy, though this process could take five to 10 years to produce results.

Meanwhile, rather than waiting for an RCT to run its course, his organization is gathering its own research, including surveys of trainees, an outcome measures project that is already in progress, as well as an additional outcome measures project that was due to start shortly after this issue of *The Journey* went to press.

Parker dismisses what he sees as a misconception about – and excess emphasis on – the role of adrenaline.

"Lightning Process does not suggest that ME/FM is due to the overproduction of adrenaline," he said. "The research indicates that there are no hard and fast rules about adreanal gland/HPA hormones in ME/FM. Some studies find high, others low, and some normal.

"My hypothesis is that, based on the signs of chronic malfunction of the immune and neurological system present in sufferers of ME, the disruption of sleep patterns, digestive function and energy levels, it is reasonable to suppose that there is some dysfunction of the hormone production by the Andrenal gland/HPA. Note not high or low, but dysfunctional." He added that this hypothesis is independently supported by the findings of Dr. Bruun Wyller in Norway and Dr. Perrin in the UK.

And finally, Parker addressed certain accusations about his organization's motives.

"We have asked the psychologist Dr. Greensmith to stop making unfounded opinions on this point a number of times. The LP is not in any way like pyramid selling, and it is disingenious to suggest so. It is run as any professional body, with codes of ethics, CPD programs and supervision for practitioners." He added that the numbers show that the LP program "would make a very tiny pyramid."

"Each year less than one per cent of the people who take on LP training decide to become practitioners, many of whom were ill with ME and had always promised themselves if they ever found a way out of this illness they would love to spend some time helping others."

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The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents entitled Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols and The Fibromyalgic Syndrome: A Clinical Case Definition for Practitioners.

Overviews can be ordered from Marjorie Van de Sande via email at mvandesande@shaw.ca or by regular mail at 151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 Canada, or from the NATIONAL ME/FM ACTION NETWORK Or may be viewed on our website at www.mefmaction.net

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