NATIONAL ME/FM ACTION NETWORK
Charitable tax no. (BN) 89183 3642 RR0001 ISSN 1205-786X
Quest Newsletter
www.mefmaction.com Quest # 87, Spring 2011 www.mefmaction.net

ME/CFS: The Research Frontier

Every truth passes through three stages before it is recognized. In the first it is ridiculed, in the second it is opposed, in the third it is regarded as self-evident

-Arthur Schopenhauer

Highlights of Dr. Daniel Peterson's presentation to medical practitioners: April 29, 2011, Calgary

By Anne-Marie Woynillowicz Kemp,
B.A., Dip.T., M. Ed.

Dr. Peterson began his presentation by describing ME/CFS as a complex scientific journey in research. Viral infections, endotoxemia, altered intestinal microflora, GI muscosal barrier dysfunction, cytokines and inflammation including low NK cell function, increased activation markers, oxidative stress, and mitochondrial dysfunction are a few of the possible markers found in patients with ME. There are no diagnostic tests available, however, there are definitive bio-markers for ME. Finding a diagnostic test is critical for the validity of the condition and to stimulate more treatment research.

RECENT RESEARCH

Currently there is much exciting research being published including the Schutzer et al. study that compared cerebrospinal fluid proteomes to differentiate ME and Post Treatment Lyme Syndrome (PTLS). Patient sets were 43 ME subjects that met the Fukuda Criteria, 25 subjects who met the CDC criteria for Lyme disease and had completed a minimum of three weeks of IV antibiotic therapy at least four months earlier, and 11 healthy controls. Using mass spectroscopy and liquid chromatography, the research team generated a comprehensive list of 30 000 peptides in the sample pooled from the subjects in each disease group. The results were as follows:

-738 proteins were found only in the ME subjects

-692 proteins were only found in PTLS samples

-724 proteins were only found in the normal controls.

Conclusions drawn from this study are that there are distinct sets of proteins that can distinguish ME patients from PTLS patients and normal controls. PTLS patients also have a distinct profile. Proteins relevant to specific neurological functions were lower in ME patients indicating that the brain is not functioning properly and proteins specific to immune function were markedly elevated.

Another study presented was the LEUKOTROPIC (living in white blood cells) HERPES VIRUS IN PATIENTS WITH POST INFECTIOUS FATIGUE, Knox et al., March 2011. The goal of this study was identification of chronic active herpes virus infections in individuals in order to prevent the misdiagnosis of "ME/CFS" and thereby justify new intervention strategies, such as antiviral therapy. All subjects met the CDC criteria for ME and had systemic signs and symptoms of an active, ongoing

See **FRONTIER** ***page 2***

Dr. Daniel Peterson speaks to medical practitioners in Calgary.

Contents

This newsletter is printed using 100% vegetable-based inks.

From* FRONTIER *page 1

infection. They also met the Canadian Consensus Criteria (CCC), Carruthers et al., 2003, which Dr. Peterson stated should be referred to as the "World Definition" for ME.

Below are the results of patients positive for the following:

HHV-6 (human herpes virus 6)	54/194	27.8%
HCMV (human cytomegalovirus)	71/249	28.5%
EBV (Epstein Barr virus)	79/153	51.6%

An association has been found between several critical human molecules such as the thyroid peroxidase protein and leukotropic human herpes viruses. This suggests a mechanism for the commonly reported finding of increased prevalence of autoantibodies in people with ME and strengthens evidence that autoimmunity can be triggered by infection. Furthermore, there is speculation that the immunosuppressive potential of HHV-6 may synergistically enhance the reactivation and replication of both CMV and EBV. Dr. Peterson added that beta herpes viruses are treatable.

ELEVATED LEVELS OF HHV-6 ANTIBODIES IN INDIVIDUALS WITH PSYCHIATRIC DISORDERS

HHV-6 antibodies in individuals with psychiatric disorders were discussed, Yolken and Dickerson, March 2011. This research showed that individuals with established schizophrenia had elevated levels of antibodies to HHV-6, which suggests schizophrenia can be treated with antivirals.

CMX001-CIDOFOVIR PIM CONJUGATE is an antiviral drug in phase 3 trials. By linking a lipid to the phosphonate group of cidofovir, a drug has been formed which is able to cross the intestinal wall and penetrate target cells before being cleaved to free the antiviral, cidofovir. Improved potency has been demonstrated in preclinical studies. In cell culture assays, CMX001 is significantly more active than cidofovir against double-stranded DNA viruses including:

-orthopox viruses (variola, monkepox, vaccinia, cowpox and ectromelia)

-herpes viruses (CMV, herpes simplex virus (HSV)-1,and 2, HHV6,-8, varicella zoster virus(VZV), Epstein Barr virus (EBV)

-multiple adenoviruses.

Dr. Peterson suggested that CMX001 is an almost perfect drug as it only needs to be administered orally 2 times a week. This makes it much more accessible than the current intravenous options for the human herpes viruses.

APOPTOTIC SERUM DNA TESTING

Apoptosis is a natural process of self-destruction (programmed cell death) in certain cells that is determined by the genes and can be initiated by a stimulus or by removal of a repressor agent. In March, 2011, Chronix Biomedical filed a provisional US patent application jointly with Hemispherx Biopharma, Inc on a blood test for ME. Chronix is developing disease-specific biomarkers based on DNA fragments that are released into the bloodstream by damaged and apoptotic cells.

The Chronix Biomedical blood test for ME is limited to investigational use because it has not been evaluated by any regulatory agents yet. It is expected that this test will be 100% accurate and that it will be inexpensive.

XMRV

XMRV is proving to be highly controversial and is providing much healthy debate and research. Xenotropic viruses originate in mice but can only infect cells from another species. Most retroviruses, especially members of the gamma retrovirus genus, can induce tumors as a consequence of integrating their viral genome into the host cell chromosome and activating proto-oncogenes (a normal gene that has the potential to become an oncogene).

To date, there have been at least 21 studies of XMRV research in ME. Two studies, Lombardi et al, October 2009 and Lo et al, September 2010, have supported XMRV in ME. Nineteen studies have not found a link to XMRV. These include Erlwein et al., January 2011, Groom et al., February 2010, Hong et al., September 2010, Heinrich et al., October 2010.

There are suggestions that some test kits were contaminated.

NEW RESEARCH DIRECTIONS FOR ME

Currently there are two large studies for ME. The first is at Columbia University, headed by Dr. Ian Lipkin. Dr. Lipkin is internationally recognized for his work with SARS. He is responsible for discovering SARS and is credited with saving millions of lives, especially in China.

The ME world is truly fortunate that Dr. Lipkin has agreed to do two studies on ME. Through viral assays for known and unknown pathogens, Dr. Lipkin will be looking for all human viral pathogens. As well, there is a study of 240 post SARS patients from Toronto, Canada. These patients are being tracked and approximately 6 to 8% developed identical symptoms to ME.

Dr. Peterson is involved with the second large study which is being conducted at Bond University, Gold Coast, Australia. This research study is looking at Natural Killer (NK) cell phenotype and functional study. Currently, the team is applying for permission to do spinal fluid tap for a viral assay on ME to determine the cause of NK cell dysfunction.

At this time, Dr. Peterson recommends measuring of NK function for diagnosis of ME as it is the most reliable marker for ME.

THE FUTURE

Significant strides are being made in research due to registries and biobanking. Nosology is the branch of medicine dealing with the classification of diseases, which traditionally was built using signs and symptoms. Now, nosology can be based on gene expression and is improved with clinical markers, lab markers and biotech markers. Because all disease could be redefined from a molecular perspective, patient outcomes will improve.

Translational medicine allows researchers and clinicians to work together. Future direction of the translational model will ensure there is large scale clinical data gathering through multiple international sites involving patient and provider. It will allow biospecimen collection with connection to a clinical database with RNA expression, DNA sequencing as well as other molecular testing. There will be focus on chronic and syndromic diseases such as ME.

The future looks promising.

REFERENCES

Schutzer SE, Angel TE, Liu T, Schepmoes AA, Clauss TR, et al. (2011) Distinct Cerebrospinal Fluid Proteomes Differentiate Post-Treatment Lyme Disease from Chronic Fatigue Syndrome. PLoS ONE 6(2): e17287. doi:10.1371/journal.pone.0017287

Knox K et al. Systemic Leukotropic Herpesvirus Infections and Autoantibodies in Patients with Myalgic Encephalomyelitis-Chronic Fatigue Syndrome. 7th International Conference on HHV-6 and 7. March 1, 2011. Reston, VA.

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Shin, Clifford H. Absence of XMRV and other MLV-related viruses in CFS. J. Virol. Doi:10.1128/JVI.00693-11. Published online ahead of print on 4 May 2011.

Moldofsky H & Patcai J. Chronic widespread musculoskeletal pain, fatigue, depression and disordered sleep in chronic post-SARS syndrome; a case-controlled study. BMC Neurol. March 24 2011;11:37.

Ottawa 2011 Conference: We're up and running!

Registration is now open for the September IACFS/ME Conference in Ottawa (www.iacfsme.org).

We invite you to the conference and welcome your participation at this truly unique international gathering of scientists, clinicians, educators, and patients. The ME/FM Action Network, under the able leadership of Lydia Neilson, is hosting the conference and providing valuable resources that can come only from a strong and vital patient advocacy organization.

Why should you attend? Perhaps the most important reason is the educational and supportive experiences that you will have at this meeting. You will learn about the current status of ME/CFS research, including the debate over the XMRV retrovirus in ME/CFS.

The patient meeting will bring together world experts on the illness who will address causation, coping, pathophysiology, fibromyalgia, medications, management of activity intolerance, and legal aspects of disability. And there will be a special breakout session for parents of children with ME/CFS. The patient conference will conclude with a Q and A session so that your concerns can be directed to our expert panel of speakers.

The supportive experiences of the conference involve meeting and networking with other people who are ill or affected by the illness. It is easy to feel isolated when you have an illness that is disbelieved or dismissed by so many. In the conference, you will have the opportunity to interact with others who share your challenges and difficulties. Perhaps Karen Ficano said it best in her excellent and inspiring article about her experiences at an IACFS/ME conference:

"I met men and women I really liked. We had wonderful conversations. We watched each other light up with new ideas and a better understanding of ourselves. We were creating relationships through this disease, not because of this disease, and these relationships happened at lightning speed."

Your participation and support will help to make this conference the success we would all like it to be. Strong scientific advocacy by our organization is one important path to increased biomedical research funding for this persistently under-funded illness. And more research leads to advances in understanding causation, developing new treatments, and ultimately curing this debilitating condition.

In summary, we are asking for your support for this unique and important gathering. More information on the conference and online registration may be found at: www.iacfsme.org

Thank you!

Fred
Fred Friedberg, PhD
President

[Ed. Notes: To receive a hard copy of the registration forms, please contact the National ME/FM Action Network and we will be pleased to mail or fax it to you; Karen's story, "You Think I should Do What??? Go To the Conference???" *can be viewed at www.mefmaction.com or to receive a hard copy, please contact the Network]*

"We were creating relationships through this disease, not because of this disease, and these relationships happened at lightning speed."

-Karen Ficano
from "You Think I Should Do What??? Go to the Conference???"

Protein controls brain inflammation

May 3, 2011

Aquaporin-4 , a new-found protein in the brain, may play a key role in brain inflammation, or encephalitis. This discovery is the first to identify a role in brain inflammation and opens doors for new drug development that treats brain inflammation and other conditions at a cellular level rather than treating the symptoms.

Dr. Alan Verkman, a senior researcher from the Department of Medicine and the Department of Physiology at the University of California, San Francisco, states that "Our data suggest that inhibition or down-regulation of aquaporin-4 expression in brain and spinal cord may offer a new therapeutic option in diseases such as multiple sclerosis, neumyelitis optica and other conditions associated with neuroinflammation."

The scientific experiments with mice indicated significantly reduced brain inflammation in the mice that did not produce aquaporin-4. Dr. Verkman found that aquaporin-4 deletion causes the brain to be less susceptible to inflammation, involving differences in astrocyte reaction to stress suggesting that using drugs or other agents that target this protein may be effective for treating a variety of conditions associated with brain or spinal cord inflammation.

[Ed. Note: For article, see http://bit.ly/mBiHNu - Source: Federation of American Societies for Experimental Biology]

IACFS/ME 10th International Research & Clinical Conference

Translating Evidence into Practice
September 22-25, 2011
Ottawa, Ontario, Canada

AGENDA - Professional

Highlights

Latest Research on XMRV/MLVs
The case FOR Human Gamma Retroviruses (HGRV) in CFS/ME
The case AGAINST Human Gamma Retroviruses (HGRV) in CFS/ME
Debate
Fibromyalgia: Are Tender Points Necessary?
Research
New findings: Blood XMRV Working Group on Blood Safety
Latest findings
immunology
virology
genomics
brain and neuroendocrine function
pediatrics
exercise physiology
Clinical Practice Sessions
Difficult Clinical Cases
IACFS/ME Clinical Practice Guidelines: A New Primer
Professional Workshops
Treating Sleep, Pain and Fatigue in ME/CFS Patients
Fibromyalgia Theory, Assessment and Practice
Behavioral Assessment and Treatment of ME/CFS
Pediatrics and CFS/ME
Exercise Intolerance: Guide to Management and Treatment
How to Apply for Grants

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.

AGENDA - Patients & General Public

September 22nd, 2011

Highlights

New Developments in Possible Causes of ME/CFS
New Research on What Helps People Cope with ME/CFS
Fibromyalgia: Current Status
Breakout Session: For parents of children with ME/CFS
Legal Aspects of Disability
Latest Research on the Pathophysiology of ME/CFS
Effective Management of Activity Intolerance
New Developments in Pharmacologic Treatments
Invited Speakers:
Anthony Komaroff, MD
Nancy Klimas, MD
Leonard A. Jason, MD
Charles Lapp, MD
Lucinda Bateman, MD
Rosamund Vallings, MB, BS
Hugh Scher (Attorney)
Annette Whittemore, WPI

For further information or registration for the conferences, please visit: http://www.iacfsme.org and http://www.mefmaction.com

[Ed. Note: If you would like a registration form to be sent to you by mail, email or fax, please contact the National ME/FM Action Network]

BC Ministry of Health approves $2-million clinical and research study

March 30, 2011

VICTORIA: Ryan Jabs, Media Relations Manager for the British Columbia Ministry of Health, announced a $2-million provincial clinical and research study for a variety of complex chronic diseases, such as chronic lyme disease, fibromyalgia, and chronic fatigue syndrome, with screening, diagnosis and treatment.

Mr. Jabs stated there are a variety of debilitating complex chronic diseases where the cause is unknown and can be difficult to treat and diagnose but where it is strongly suspected that an infectious agent may play a role. Due to recent advances in gnome science, new techniques may help to diagnose previously difficult illnesses such as ME/CFS, FM and Lyme Disease, and as a result the Ministry of health Services requested the Provincial Health Services Authority (PHSA) to present options for a clinic for patients with complex symptoms, possibly related to an underlying infectious disease.

Mr. Jabs indicated that British Columbia is taking a leading role within Canada by working with patients and family physicians from across the province in providing care as well as performing research. The clinic will take referrals from family physicians or other health care providers for patients with symptoms of these chronic illnesses, with the goal of helping patients by accurately diagnosing their conditions, providing treatment and helping with ongoing symptom management.

The clinic will also include telehealth capabilities, provide consultations and information to physicians and health care providers from all across the province which will coincide with the Province's research study

See **CLINICAL** *page 6*

CFS - A Neuroimmunolical model

April 5, 2011

Recent developments in understanding the uniqueness of the brain may provide an explanation of the pathology of CFS.

Researchers argue that CFS pathogensis lies in the "influence of peripheral inflammatory events on the brain and the unique immunophysiology of the central nervous system "(CNS). There's evidence that CFS patients have a relative immunodefiency that predisposes them to poor early control of infection leading to chronic inflammatory responses to infectious insults.

SV Arnet and colleagues of the School of Biology, Australian National University, support the hypothesis that CFS is a disease of long-term inflammatory processes of the brain and state they will provide an investigative framework that could be used to justify the use of anti-TNF biological agents as a reliable and effective treatment approach to CFS.

[Ed. Note: Arnet SV, Alleva LM, Korossy-Horwod R, Clark IA]

Bond Symposium Australia - clarification

Dr. Eleanor Stein wishes to clarify the report of the Bond Symposium Dec 3/4/10 that was printed in the Winter 2010 issue of *QUEST*. She states as follows:

"The short essay *ME - Cardboard Case Collapses* was written by Dr. Stein and is her opinion only, not approved by the Bond Symposium attendees. The bullet points of the Bond Communique which follow that essay had not gone through final approval at the time of printing. The final approved communique can be read at:

http://www.bond.edu.au/research/research-at-bond/events/BD3_014159

Since the communique was made public in early March 2011, the International ME Research Collaboration (IMERC) has generated interest from other scientific groups wishing to join and the network is already generating research ideas." Elleanor Stein MD FRCP(C)

New MEA funding for ME/CFS research

March 31, 2011

United Kingdom: The ME Association (MEA) has announced that its trustees have approved funding for a new research study investigating the role of transcription factors in ME/CFS. The peer-reviewed research will be carried out by Dr. Abhijt Chaudhuri, Professor Peter Behan, Professor John Gow, Professor Chris Hillier and Simone Hutchinson at the Glasgow Caledonian University.

Transcription factors are complicated proteins that act at a cellular level and are released in a cascading fashion following harmful stimuli, such as infections, trauma, exposure to toxins etc. and form a key part of the body's initial defensive response. They assist in the process of 'switching on' genes and the activities they control.

The researchers will be investigating blood samples from four separate groups:

- People with well-characterized ME/CFS: Professor Behan will be doing the clinical assessments;
- Healthy Controls;
- People from Professor Gow's research into gene expression; and
- Blood samples obtained from the CFIDS biobank facility in the United States.

The study is expected to take a year to complete and if significant abnormality in transcription factors is confirmed, it could lead to further research and therapeutic interventions.

[Ed. Note: More information on the Ramsay Research Fund can be found at MEA: www.meassociation.org.uk/?page_id=1086]

From* CLINICAL *page 5

to examine these illnesses in depth. The clinic and research study is expected to start running by the Fall 2011.

Minister of Health, Michael de Jong states "Chronic Lyme disease, fibromyalgia, and chronic fatigue syndrome can seriously affect people's quality of life and cause immense pain and suffering. By taking a leading role, I hope that B.C. can help to positively impact patients across the country by studying these illnesses and learning ways to help patients manage their symptoms."

[Ed. Notes: For more information, contact: Ryan Jabs, Media Relations Manager, Ministry of Health - Tel: 250 952-1887 or view www.gov.bc.ca/connect

For more information on Lyme Disease, please see QUEST #77 - Spring 2008, or visit the Canadian Lyme Disease Foundation at www.canlyme.com Tel. 250.768.0978]

XMRV: Where are we at?

JAPAN

To evaluate the risk of XMRV infection during blood transfusion, Japan screened three populations: healthy donors, patients with prostate cancer (PC) and those with CFS against antibodies of XMRV proteins in freshly-collected blood samples. Researchers also examined blood samples of viral antibody-positive patients with PC and both antibody-positive and antibody-native patients with XMRV DNA.

The results indicated that none of the individuals in the three tested populations retained strong antibody responses to multiple XMRV proteins. Occasionally XMRV genes in plasma and peripheral blood mononuclear cells were detected but failed to isolate an infectious or full-length XMRV.

Researchers concluded that their data showed no solid evidence of XMRV infection in any of the three populations which implies there is no association between the onset of PC or CFS and XMRV infection in Japan. However, due to lack of adequate human specimens and positive controls in Ab screening and limited sample size, it does not allow them to draw a firm conclusion.

[Ed. Note: Rika Furuta, Takayuki Mlyazawa, Takeki Suglyama, Hirohiko Kuratsune, Yasuhiro Ikeda, Efiii SataNaoko, Misawa Yasuhito, Nakatomi Ryuta Sakuma, Kauta Yasuf, Kouzi Yamaguti, Fumiya Hirayama. Credits/Source: Retrovirology 2011, 8:20. Published 2011-03-18]

U.S.A.

Although critics are still banking on anti-HIV drugs, new research is dashing the hopes for many ME/CFS patients. Some patients diagnosed with ME/CFS were prompted to begin taking potent anti-IV drugs which has been discredited by subsequent research.

Cancer biologist Robert Silverman, a key researcher at Cleveland Clinic's Lerner Research Institute who worked on XMRV studies linked to CFS and prostate cancer told the *Tribune* his lab was working to determine if contamination occurred as virologists who had examined work by Dr. Silverman and others raised serious questions about contamination. "I am concerned about lab contamination, despite our best efforts to avoid it," Dr. Silverman wrote in an email.

A European research team had reported being unable to find any evidence of XMRV in blood from diagnosed CFS patients and their healthy peers and others have reported no evidence of the retrovirus in the blood of previously-found XMRV-positive patients.

[Ed. Note: For more details, view: : http://articles.chicagotribune.com/2011-03-17/news/ct-met-chronic-fatigue-xmrv-20110317_1_whittemore-peterson-institute-chronic-fatigue-syndrome-xmrv]

Fibromyalgia's economic impact

Hospital Munich, Germany - March 2011

The Department of Physical Medicine and Rehabilitation announced that Fibromyalgia affects a population mostly of a productivity age and is thus associated with significant lost productivity and disability, in addition to increased healthcare costs for medications and physician office visits. Other studies have examined FM costs in Europe but few have examined the cost of FM by severity level.

A total of 299 FM patients were recruited who were diagnosed by a rheumatologist from physician offices in France and Germany and completed questionnaires about pain level, health-related quality of life, treatment satisfaction, and FM-related out-of-pocket expenses. The results indicated that a total of 81% of subjects were receiving prescription medication for their FM while French subjects reported a lower use of anti-inflammatories but a higher use of other analgesics than its German counterparts. Those in full or part-time employment reported missing 6.0 days of work due to FM in France and 3.8 days in Germany over the last 4 weeks.

The study indicates that FM imposes a significant economic burden on society and is consistent with other studies. FM subjects were found to have substantial costs, over 75% of which were indirect costs due to lost productivity. These costs increased as FM severity increased resulting in a more than 200% difference in cost between mild and severe FM.

[Ed. Note: Ref. Winkelmann A, Perrot S, Schaefer C, Ryan K, Chandran !, Sakosky A, Zlateva G. - Appl. Health Econ Health Policy, 2011 Mar 1-9(2):125-35. Doi]

Canada - March 21, 2011

According to an Angus Reid National Study conducted for the Canadian Pain Society, one-third of all Canadians reported taking sick days, reducing productivity, losing income or their jobs due to pain they experienced in the last three months. The National Health Population Survey estimates direct health-care costs associated with pain have hit $6-Billion per year and is expected to hit $10 billion per year.

Young people were affected more than any other age group surveyed with 23% being between the ages of 18 and 34.

[For more details, view: http://www.canada.com/Pain+stings+Canadian+economy+Survey/4476452/story.html#ixzz1HF191pjx]

Virtual health library established in Canada

In conjuction with the Canadian Institutes of Health Research (CIHR), The Canadian Health Libraries Association, funded by CIHR, will provide all Canadian health professionals and administrators, policy and program planners, researchers and public health workers as well as clinicians, and nurses easy access to current, authoritative information and expert support from the network libraries contributing to its Canadian Virtual Health Library (CVHL).

Patrick Ellis, head of the W.K. Kellogg Library at Dalhouse University and the project's Principal Investigator stated that the "CVHL provides a groundbreaking opportunity to build on the strong foundations already in place in order to extend access to high-quality information resources and servies to all Canadian health practitioners, whether working in a remote northern nursing statement or in a large urgan hospital."

The CVHL will build a pan-Canadian virtual bilingual client-centric network linking local, regional and provincial health library services to maximize resources through coordinated resource sharing and licensing. The CVHL will be rolled out over a three-year period which began in 2010.

[Ed. Note: For more information, contact: Donna Livingstone, Director of Communications, Library & Cultural Resources: Tel. 403-220-3511 - Email: livingsd@ucalgary.ca]

CRD leads initiative to improve transparencies of systematic reviews

The Centre for Reviews and Dissemination (CRD), University of York, UK has launched a major global research initiative to register systematic review protocols.

PROSPERO is the first open access online web-based facility to prospectively register systematic reviews of the effects of interventions used in health and social care from around the world. It is completely free and open to all researchers planning to conduct a systematic review.

These reviews are widely accepted as providing the best quality evidence to support decision making in health and social care for policy and practice and is recognized and valued by decision makers as they provide the most reliable effects of health care interventions. Growing concerns and evidence of systematic reviews being selective about reporting and unintended duplication, Prospero was conceived to address these issues and increase transparencies, guarding against selective reporting and making it obvious if the research published differs from what was planned at the outset.

The Canadian Institutes of Health Research (CIHR) and the Department of the University of York are part of the CRD.

[Ed. Note: For more information, please view www.crd.york.ac.uk/prospero/ and http://www.ottawacitizen.com/technology/Share+knowledge+health+researchers/4322259/story.html#ixzz1EguFEwCQ]

Headaches - a worldwide health problem

Ottawa Citizen - May 4, 2011

The World Health Organization (WHO) announced that almost half of all adults worldwide suffer from migraines and tension headaches which have huge economic and societal costs but are widely under-recognized, under-diagnosed and under-treated due to scant knowledge about them and the burden they impose.

WHO advised that they found 47% of all adults have a headache disorder and that in the European Union (EU) alone, 190 million days are lost from work every year because of migraine. Dr. Shekhar Saxena, WHO's director of mental health and substance abuse disorders, stated that too little attention is paid to its debilitating impact. During migraine attacks, 90% of people postponed household chores and almost three-quarters of them have limited ability to work and half of them miss work entirely. Migraine affects approximately one in six women and one in 12 men and is estimated to be the most expensive brain disorder to society.

Findings shed doubt on ME/cancer link

Science Magazine - March 8, 2011

New findings presented at a conference sheds doubt on the debate about the link between a novel mouse retrovirus, prostate cancer (PC) and ME/CFS. The data was presented at the 18th Conference on Retroviruses and Opportunistic Infections.

Two collaborating research teams researched over 20 years back stated they have evidence that XMRV resulted from chance recombination of pieces of two mouse viruses in lab experiments. Dr. Nathaniel Landau of New York University commented "That nails it. Everyone working on this thing has this virus contaminating their stuff. It's been a tremendous waste of time and money."

Dr. Vinay Pathak, a retrovirologist at the U.S. National Cencer Institute (NCI) in Frederick, Maryland explained he got intrigued by a 2009 study that showed how a human PC cell line was infected with XMRV. He acquired tumors grown in mice which were then "passaged" to other mice and established that the

See **FINDINGS** ***page 9***

In the Spotlight

On March 1, 2011 Dr. A. Martin Lerner of The Treatment Center for CFS in Beverly Hills, Michigan was presented with the Heart Award from Mothers Against Myalgic Encephalomyelitis (MAME), an international advocacy organization representing patients from all over the world with ME/CFS. The award was presented by an ME/CFS advocate, Ken Huddleston, a long-time patient who stated "Dr. Lerner saved my life."

This award comes on the heels of Dr. Lerner's third piece of ME/CFS research published in the last year entitled *A paradigm linking herpesvirus immediate early gene expression apoptosis and myalgic encephalomyelitis, chronic fatigue syndrome.*

Jean Harrison of MAME when asked why Dr. Lerner was selected for this Award responded "There is an innate need by Dr. Lerner to know and understand. But where Dr. Lerner stands apart is he then follows up that need to understand with the need to apply his research to improve the lives of his patients...He's devoted his life to this patient population. It takes courage. It takes heart."

Dr. A. Martin Lerner is pictured above receiving the Heart Award from Mothers Against Myalgic Encephalomyelitis (MAME). for his research and dedication to the ME/CFS community. A close-up of the award is pictured at right.

[Ed. Notes:
1. Dr. Lerner is on our Network's medical advisory and was on the panel for the ME/CFS Working Case Clinical Definition, Diagnostic & Treatment Protocols;
*2. **A PDF of Dr. Lerner's latest research article can be found at: http://www.treatmentcenterforcfs.com/links/documents/VAAT-15105-herpesvirus-immediate-early-gene-expression-induces-host-cel_022111.pdf]*

RADIO CANADA INTERNATIONAL conducted an interview with the Network's President, Margaret Parlor, on ME/CFS and FM after reading an article in a newspaper wherein Margaret was also interviewed.

To hear this interview, please visit www.rcinet.ca/english - The Link: Health & Wellness - Chronic Fatigue syndrome and Fibromyalgia.

From* FINDINGS *page 8

original human tumor could not have harbored XMRV. Dr. John Coffin, who works at both NCI and Tufts University, and his team made a similar discovery with different samples. When the teams compared notes, they saw that the two sequences perfectly overlapped to form XMRV. Dr. Pathak emphasized in his talk that the DNA sequences are nearly identical to the XMRV sequences reported found in humans but suspected to be a lab contaminent.

1. [Ed. Notes: For further information, please view: http://news.sciencemag.org/sciencenow/2011/03/fresh-doubts-about-connection-be.html

2. "As long as selective ME/CFS research definitions are used, the results will produce selective science" Ed.]

The layout design, writing and editorial services for this publication are provided on a volunteer basis by:

James Deagle
Newsletter Publishing Services

Writing, Editing, Proofreading, Research, Layout and Formatting, Graphic Design

mefm.jamesdeagle@yahoo.com

NIH State of the Knowledge Workshop

April 7-8, 2011
Bethesda Campus, USA

The National Institutes of Health (NIH) brought together 32 investigators from a variety of scientific disciplines with the goal of assessing what is currently known about ME/CFS, look for gaps in knowledge needing more research and to identify outstanding opportunities in science and technology that could advance biomedical research. Subjects covered were infectious diseases, systems biology, immunology, neurology, exercise physiology/energy metabolism, diagnosis, and treatments.

[Ed: The entire workshop webcast is available on the NIH VideoCast Past Events page at: http:_//videocast_.nih.gov/PastEvents.asp]

Paliative care site launched

Ottawa - April 21, 2011

CommunityiCare Access Centre (CCAC) has launched Alavida Palliative Care Info Site, which provides information on Palliative Care services in the Champlain region including how and when to access them.

Rather than providing clinical information, this site is intended to help patients, families and heath care partners to find the right services and when. The services are of benefit to any patient with a progressive incurable illness of advanced stages of heart, lung, neurological and kidney diseases amongst others and is not only for the terminally ill.

[Ed. Note: For more information, please view www.alavidapalliativehelp.ca or call 1-877-430-1394 between 9 am to 5 pm Monday to Friday]

The Journey
Life & Living with ME/CFS and FMS
Issue # 2 Published by the National ME/FM Action Network Spring 2011

Acupuncture for pain and fatigue

Study results bolster claims by practitioners of Chinese Medicine

By James Deagle
The Journey

Scarbborough ME-FM-MCS Support Group photo

Brenda O'Flaherty (left) and Tina Zappulla (right) of the Scarborough ME-FM-MCS Support Group are shown here with Dr. Allison Bested (centre), medical advisor to the National ME/FM Action Network, at a craft sale on April 16 at St. Dunstan Church to raise money and awareness for May 12 activities. Also 'on hand' was Fibro Duck.

Is acupuncture an effective way to combat the symptoms of chronic illnesses?

Steven Ryu, a Licensed Accupunturist and certified herbalist, outlined the case for the eastern approach to treating CFS in an article featured in the May 2011 issue of *TONE*, an alternative health and spirituality magazine based in Ottawa. Ryu.

“Fatigue in Chinese Medicine includes both CFS and short-term or ongoing fatigue,” writes Ryu, further outlining various potential fatigue sources, including “hereditary weak constitution”, which “can manifest in any of the five 'vital' organis, or yin organs as Chinese Medicine calls them, because they are said to store the body's essence.”

Ryu also cites more obvious causes of fatigue, including lifestyle and improper diet.

As for CFS, he says that in western medicine it is “a difficult-to-understand syndrome with uncertain causes,” but that “in Chinese Medicine chronic fatigue has well-understood causes, which explains why it may develop in some people and not others.

“When the cause is clear, treatment is straightforward and effective.” This, he says, makes acupuncture an effective treatment option.

Practitioners of Chinese Medicine aren't the only ones who see the value of acupuncture for treating chronic illness.

The results of a study published late last year showed that acupuncture not only changes the perception and processing of pain, but also can relieve it for patients with Fibromyalgia.

The study, presented at the 2010 meeting of the Radiological Society of North America (RSNA), used functional magnetic resonance imaging (fRMI) to take pictures of patients being exposed to a painful stimulus, both with and without acupuncture.

For the study, 18 volunteers each had a pain stimulus attached to one ankle while undergoing fMRI. They were first given doses of pain without the presence of acupuncture needles and then with.

When the fMRI pictures of each case were compared, the results were telling.

"Activation of brain areas involved in pain perception was significantly reduced or modulated under acupuncture," said lead researcher Nina Theysohn, M.D.,

See **ACUPUNCTURE** *page 3*

Today's youth are charting their own course

By James Deagle
Editor-In-Chief

In this issue we are proud to feature a personal account written by Katie Martin, a young woman from La Mesa, California, who is living with Fibromyalgia, and who in March 2011 was crowned Miss La Mesa.

I believe a story like Katie's is very important on a few levels. For starters, she demonstrates that one can still pursue dreams and ambitions despite adversity due to illness. (While Fibromyalgia can certainly weigh a person down, it doesn't have to stop them. Life goes on, however heavy the load may be at times.)

The greater value here is that by being open about her struggles, she subverts whatever two-dimensional assumptions the general public may have about those with chronic illnesses and, for good measure, those who win beauty pageants. (As a rule, subverting two-dimensional assumptions should always be valued as a public service.)

The two-pronged message to take from her story seems to be that Fibromyalgia patients (and others with chronic illnesses) are hiding in plain sight, or even in the public eye, and also that those who take part in beauty pageants are people with intelligence and wit as well as fears and anxieties like anyone else.

By having the courage to go public with her struggles, she demonstrates that meaningful success, on the pageant stage or in life itself, is about a whole lot more than mere perfection.

In a similar vein, two other important stories in this issue have to do with how today's youth are using technology. One concerns a new social networking site (www.healKick.com) that grew out of a Facebook group. The site is geared towards young adults with neuro-immune illnesses such as Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, Chronic Lyme Disease, Fibromyalgia, Rheumatoid Arthritis, Lupus, Sarcoidosis, Reflex Sympathetic Dystrophy, Multiple Scelerosis, Multiple Chemical Sensitivity, and mold-related Illness.

The site is a place where members can share information and resources as well as connect on a social level.

Another story is that of Treya McEvoy, a young Irish woman who has used her blog both as a way to tell her own story of living with multiple chronic illnesses as well as discover more about herself and the health conditions that so affect her life. (As she noted in her interview with *The Journey*, if not for connections she made through her blog she wouldn't have taken the steps that led her to be diagnosed with Lyme Disease and Rickettsial Disease, in addition to her previously-diagnosed Chronic Fatigue Syndrome.)

As many of you are probably all-too-aware, it has been an uphill battle to get Fibromyalgia and Myalgic Encephalomyelitis to be taken seriuously by society-at-large, a major component of which includes the media. While it seems some momentum is building, it wasn't that long ago that ME was being written off as the 'yuppie flu'.

And now today, as the traditional media feverishly tries to keep on top of social networking and other technological phenomenon, the kharmic wheel has come full circle. The youth of today are saying to the traditional media: “We don't need you. We have each other.”

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

mefm.jamesdeagle@yahoo.com

Former MP advises support group on disability benefits

Provides insight into application process, urges groups to engage in and

© House of Commons

Former Kitchener Centre MP Karen Redman

Former Kitchener Centre MP Karen Redman met with the Kitchener-Waterloo Fibromyalgia Support Group on March 15 to talk about disability benefits.

Redman said that to qualify for Canada Pension Plan (CPP) disability benefits, a person needs to prove “severe and prolonged” illness. The “episodic” nature of Fibromyalgia, she added, makes it difficult to fit into this requirment. (She defined “prolonged” as meaning unable to work in the next 12 months.)

Redman added that one must ensure that the doctor's forms are complete and correct, and that the doctor must clearly describe the condition and indicate inability to work.

As for getting assistance under the Ontario Disability Support Program (ODSP), Redman said that to qualify, a person must show needs based on income, assets and medical assessment, and that a person can apply through Ontario Works or self apply. (Ontario Works, she noted, can help with application completion.)

Redman advised the audience to ask their MP or MPP for assistance with the application process. She warned that in order to qualify for disability tax credit the doctor must complete a form, but that although one may already have qualified for CPP disability benefits and/or ODSP, tax credit eligibility has a higher threshold of disability.

The former MP ended her presentation by exhorting the audience members to attend candidates meetings (for the Federal Election, which was then in-progress) and ask questions about disability issues, such as:

“Why are CPP disability benefits taxable?”

“What will you do about this issue to help us if elected?”

“What will you do to ensure more research into the cause and cure of Fibromyalgia if elected?”

Redman advised those in attendance to join the Canadian Pain Coalition to give a stronger voice to non-profit organizations who lobby governments on their behalf.

Karen Redman was the MP for Kitchener Center from 1997 to 2008, and served as the Chief Government Whip in the 2004-05 Parliament, and then as the Chief Official Opposition Whip in the 2006-08 Parliament.

With notes from Barb Elve

From **ACUPUNCTURE** *page 3*

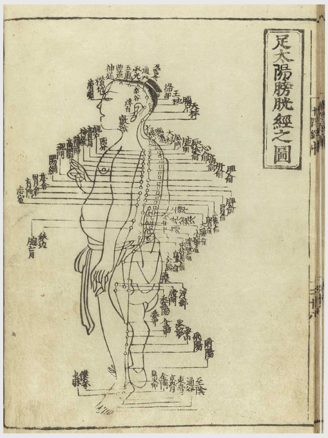
from the Department of Diagnostic and Interventional Radiology and Neuroradiology at University Hospital in Essen, Germany, in a press release from the RSNA.

According to Dr. Theysohn, “acupuncture is supposed to act through at least two mechanisms—nonspecific expectancy-based effects and specific modulation of the incoming pain signal.”

Dr. Theysohn praised fMRI for its diagnostic value. "Functional MRI gives us the opportunity to directly observe areas of the brain that are activated during pain perception. and see the variances that occur with acupuncture."

Acupuncture is the practice of inserting filiform needles into the body at various points on the body for pain relief or other therapeutic purposes.

In Ontario, acupuncture is relulated at the provincial level by the "Traditional Chinese Medicine Act, 2006".



Acupuncture chart from the Hua Shou (Ming Dynasty).

Photo: Ken Stone / La Mesa Patch

Breaking the Silence:

Pageant winner opens up about life with Fibromyalgia

The following is a letter from Katie Martin, who was crowned Miss La Mesa in March of 2011, which was published on May 12 by www.lamesa.patch.com.

To the editor:

As I sit in bed typing this, I can't help but shift from the discomfort of simply having to sit up. My hips ache from the pressure of my body weight. My fingers begin to lose the dexterity necessary to type. My leg muscles slowly contract into a painful state of tetany, and my mental clarity starts to fade into a haze lacking its usual acuity.

I go through my to-do list for tomorrow with a sense of apprehension—the prospect of having to go to the DMV in the morning fills me with a sense of dread. It is not the monotony of the task that bothers me, but

See **SILENCE** *page 5*

ME self-help support group issues urgent appeal due to shortage of volunteers

MESH Ottawa has been unable to provide programs to those living with Chronic Fatigue Syndrome or Fibromyalgia due to a critical shortage of volunteers, and is therefore searching for entrepreneurial people who are willing to roll up their sleeves to help us get back on track.

We need administration, newsletter and program volunteers along with board members to keep going. Our plea to you is please help us help those in need.

If you wish to volunteer, please send an email to **president@meshottawa.org** with your resume and a short description of what you would like to do for MESH as a volunteer.

Any and all assistance is greatly appreciated. This is an URGENT plea for volunteers.

Submitted by MESH Ottawa

From **SILENCE** *page 4*

knowledge that I will not be able to physically stand in line for more than about 10 minutes.

I think about lying down to go to bed, but I know that the second my focus is averted from whatever menial task I am working on, all of my concentration will be consumed by fully recognizing every ache and pain that occupies my body because of the task that has become simply living.

All of this would be understandable if I was, say, in my late 60s. But in reality, I am a 21-year-old student who struggles to simply get out of bed everyday because of a condition called Fibromyalgia.

I was diagnosed with Fibromyalgia shortly after my high school graduation when I was 18 years old. I had spent the previous two years in and out of the hospital, on multiple muscle relaxants and heavy-duty painkillers, occasionally confined to a wheelchair, and generally feeling like I had been hit by a bus on a regular basis.

My diagnosis came with great relief, validating the difficulties I had faced over the previous years, and assuring me that I was not alone in this fight. I learned that Fibromyalgia is a musculoskeletal disorder with neurological complications that results in an almost constant state of elevated pain despite the absence of painful stimuli.

There is no known cure for FM, and a variety of inhibiting symptoms often occur alongside the pain. Despite the lack of scientific understanding of this disorder however, I was hopeful that the future would bring great breakthroughs that could drastically improve my quality of life and the quality of life of others diagnosed with FM.

'My life has been turned upside-down because of Fibromyalgia, and my story is not unique. So why is there a virtual silence about this issue?'

Naturally, when I was crowned Miss La Mesa in early March of this year, I instantly knew that I wanted to participate in some kind of awareness activity for National Fibromyalgia Day to help bring attention to the silent warriors who fight a battle with Fibromyalgia everyday of their lives.

According to the American College of Rheumatology, between 3 million and 6 million Americans have FM and it’s the second most common musculoskeletal disorder. Because of this, I didn’t stop to consider that there would be no event to participate in. There’s a walk or demonstration for just about everything, right? Southern California is a big region, and if I Googled it long enough, surely something would come up.

You can imagine my frustration and confusion then when my extensive search efforts turned up fruitless. With the exception of a Facebook Event calling for virtual recognition of May 12, National Fibromyalgia Awareness Day, there was nothing.

It was not even a blip on the radar. My mind flashed back to my Junior Prom, where I sat on the side of the dance floor in excruciating pain as my friends danced all night. Then to the Emergency Room, as a doctor refused to treat me for an unrelated issue because he didn’t believe in the legitimacy of Fibromyalgia despite clear physiological evidence.

I then imagine myself in the audience of a Los Angeles dance competition in 2006, watching myself collapse onstage midroutine and being carried offstage by my teammates. My life has been turned upside-down because of Fibromyalgia, and my story is not unique. So why is there a virtual silence about this issue?

I can’t answer this question, but I can attempt to address it in what little ways I can. This May 12, I challenge you to break the silence.

While Fibromyalgia may have been nicknamed the “invisible disease,” its effects are not invisible in my life, nor in the lives of the millions of others who are affected by the disorder. I refuse to stay silent about the difficulties I face on a day-to-day basis, and I humbly ask you to do the same.

Whether you are simply learning more about FM through independent research, starting a conversation about its effects with a friend or loved one, or committing to helping to find a cure, please help me to break the silence.

I am confident that someday the great scientists of our day will be able to map the complexities of this illness and chart a course towards a cure. But until then, we need all the help we can get. We must never accept the silence, and instead chug along steadily, step by step, day by day.

Katie Martin, La Mesa

Reprinted with permission

Young ME/FM patients connect with social networking

Site allows users to socialize, share information and experience

By James Deagle
The Journey

After being diagnosed with ME at 22 shortly after graduating from UC Berkeley, Joey Tuan began to feel disconnected from his friends, like he was in a "no-man's land" that many sufferers of chronic illnesses would find familiar.

Craving social connection with others in his situation, he formed a Facebook group last year to fulfill his own needs and, in turn, created an online solution for others that has now evolved into a full-fledged social networking site in its own right, www.healkick.com. The site features several forums in which members can connect, plan social outings and share information and experiences.

"During the 5 years I've been sick, I've always wanted to meet other patients around my age," said Tuan, now 27 and living in Las Vegas, in an interview with *The Journey*. "Despite living in large metro areas such as San Francisco, Los Angeles, Columbus, and Las Vegas, I never succeeded in finding one in any forum, whether online or local support groups, but instead always stumbled upon one by chance."

He further explained that young adult patients "already deal with an inhuman amount of suffering and isolation due to neuro immune diseases, so it really is hard to fathom that there is no dedicated online group for us to find other patients near our age. This lack of support for young adults, often fresh out of the most socially-embedded times of their lives, is what I'm trying to change with this group."

Although the project hasn't been around that long, it already seems to be quite successful. According to Tuan, "members so far seem to be enjoying this platform far more than the anonymous and stale formats of the Google group and the traditional forums we've have before. It's far more face-to-face with full-fledged profiles and albums, and instantaneously interactive with activity feeds and embedded chat. I sincerely think many patients will benefit on a social level from this tool."

The name of the site is a play on words. As Tuan told blogger Mindy Kitei in a January 29 post on www.csfcentral.com, "the kick is meant to imply liveliness and socializing. Healing from a disease doesn't have to be a bore and isolating, but instead can be fun and social with the right format to make this possible. It is meant to imply liveliness and socializing."

Blog profile:

Living with Chronic Fatigue, Lyme Disease & Rickettsial Disease

By James Deagle
The Journey

Although social networking is getting a lot of media attention these days, many young (and not-so-young) people with chronic illnesses are getting the word out via blogging.

For the unitiated, a blog (a contraction of web log) is a website that allows a person to post messages on any topic as often as they like. These messages can be quick updates on their daily lives or lengthy thought pieces of a more serious nature. Blogs generally provide a forum for readers to comment on each post. Popular blog sites include www.blogger.com and www.wordpress.com. (Both of these sites allow users to create blogs free of charge.)

For those with Myalgic Encephalomyelitis or Fibromyalgia, this form of social media is allowing many to share their struggles with the world as well as each other.

One such blogger is Treya McEvoy, a 31-year-old woman from Ireland who has been diagnosed with ME as well as Lyme Disease and Rickettsial Disease. Her blog (*Living with Chronic Fatigue, Lyme Disease & Rickettsial Disease*, at http://jen-mecfs.blogspot.com) chronicles her life and struggles as she comes to terms with her multiple illnesses.

According to her online bio, "I started this blog when I was 29 years old. At the time I had just had a bad relapse after getting well enough to go back to work. I have been sick five years now. It all started when I was living in the Himalayan foothills in India and things have never been the same since. I was first diagnosed with ME/CFS, and lived with that diagnoses until very recently. This blog follows my journey hopefully back to good health. I have recently been diagnosed and started treatment for Lyme Disease and Rickettsial Disease."

McEvoy told *The Journey* that writing the blog has helped her in many ways. "Most importantly," she said, "it has helped my confidence to know that I am still achieving something while being unwell. Having

See **BLOG PROFILE** *page 7*

U.S. survey results portray lives reshaped by Fibromyalgia

Ninety-two percent of respondents report significant on major life decisions, intimacy, career and family life

The results of a recent survey underscores the drastic toll fibromyalgia can take on one's life.

Conducted by the Amercian-based National Fibromyalgia Association (NFA) and the American Pain Foundation (APF), the survey was completed online by 3,018 people living with diagnosed or undiagnosed Fibromyalgia (or other chronic pain conditions). The results portray lives dramatically reshaped.

According to a joint announcement by the NFA and APF on May 12, the survey revealed that:

“Almost 9 in 10 respondents (approximately 87 percent) feel they are no longer the person they were before they started living with chronic pain.

“Nearly all respondents (92 percent) report their condition has had a significant impact on major life decisions, including whether to initiate or remain in a relationship, change jobs and/or have children.

“Of the more than 650 respondents who have children currently under the age of 18, 95 percent report their pain condition affects at least one of their parenting duties, such as taking care of daily household and childcare needs, enjoying their children's milestones or managing their children's activities/scheduling.

“Approximately 7 in 10 survey respondents (68 percent) agree that pain limits their ability to care for their family.

“Nearly all respondents (approximately 98

See **STUDY** *page 8*

From **BLOG PROFILE** *page 6*

to leave work so shortly after entering the (graphic design) industry was a very difficult pill to swallow. It's nice to know I'm still accomplishing something, however small that is.”

She added that before she got sick, she had always liked to help others who were less fortunate than herself. “It's nice to be able to continue this in some way with my blog, hopefully helping some people out there.”

The process of writing the blog has also helped her sort through “the many emotions that one gets bombarded with living with a chronic illness,” emotions that she says constantly set limitations. “It has helped me a lot being able to write about things that I just don't feel comfortable talking about to those around me. I guess it's a form of therapy in one way.”

McEvoy noted that one of the most suprising things about starting her blog was the sheer number of people it put her in contact with who share her illness. “There is a little blogging community of us out there. I really believe I would be in a very lonely place emotionally had I not started (it) and met all these people. The Internet is a godsend to people like me who don't get to go out and socialize much.”

Another unexpected boon was that by following other people's blogs, she learned more about Lyme Disease, and is certain that if she hadn't started her blog and become connected to her online community, “I would never have known to send my blood to the US (for testing and diagnosis).” Similarly, she also found out about Rickettsia.

“Who knows where I would be at with my illness now. I think I found out just in time, as I was seriously starting to deteriorate.”

Lastly, this project has also shown her where she wants to go with her life. “It has shown me how much I love writing. I am hoping to become a writer.”

For all that her activity has helped her cope with the illness, the illness itself stands in the way at times.

“I would like to be writing posts more often. I try to achieve writing a post once a week. It drives me insane when I can't keep this up.” She specified the issues that impede her writing, including “brain issues (concentration, short-term memory), weak arms, depression, and toxic overload.”

As for life before she became sick, she said living in India was “such an amazing life experience, yet truly a life-changing one.” In the midst of working towards a degree in Graphic Design in Wales, she decided to go to India in the summer before her final school year, and do volunteer work as an English and art teacher for children.

“The village I lived in was scattered around the hills. The clouds used to actually be at level with my classroom. I am a keen photographer, so I had a great time documenting my experience in photographs. My plan was to go back and spend six months around the rest of India on a photography project five years later.

“Ah, well. Such is life.”

National ME/FM Action Network seeking 'unheard voices'

~

Submissions open to patients, caregivers

Dear Friends:

This project was started about six months ago and is about you. We would like to know your story. It can be a specific incident or experience or it can be on anything relevant to ME/CFS and/or FM. Children, young adults and people of any age in any country can participate as although the location may be different, the experiences and knowledge can be of great assistance to others as well as to yourself. To know you're not alone can make a difference to those who are isolated and having no support net.

Caregivers who find themselves in the unique situation of having an ill person in their family or a friend becomes ill will be faced with challenges and difficulties. They too have a story to tell. No one is left untouched when someone is ill.

Please send your story by email at mefmaction@ncf.ca, or via fax at 613.829.8518 or by regular mail to the National ME/FM Action Network, 512 – 33 Banner Road, Nepean, Ontario K2H 8V7 Canada.

From* STUDY *page 7

percent) report that they have implemented some type of adaptation to their daily routine in order to conduct activities and tasks – three-quarters of respondents have made three or more daily adjustments."

Micke Brown, BSN, RN and Director of Communications for the AFP, noted that the survey results are consistent with what she has seen from working closely with the illness. "Through my clinical experience and advocacy work, I have seen the significant impact that Fibromyalgia and other persistent pain conditions have on everyday activities that others take for granted, such as holding your child, walking your dog or cooking a familiy meal."

The survey is one part of an overall educational initiative, "The Faces of Fibromyalgia", that was launched on May 12 through the NFA, APF and Pfizer Inc.

DISCLAIMER:
All information in the National ME/FM Action Network newsletters in both *QUEST* and *The Journey* sections on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and/or Fibromyalgia (ME/CFS and or FM) and related illnesses is intended for your general knowledge only and is not a substitute for medical advice or treatment. The National ME/FM Action Network does not advocate or recommend adopting any treatment modality based solely on any of the information provided. You should seek prompt medical advice and care for any possible medical issues and consult your physician before starting any new treatments. The information is intended to provide broad personal understanding and knowledge and should not be considered complete. This information should not be used in place of a visit, call, consultation or advice from your physician or other health care provider. The National ME/FM Action Network does not recommend using only self-management of ME/CFS, FM or related illnesses without the expert advice from a physician or health care provider and strongly urge decisions are based on scientific back-up information for any treatments undertaken.

The layout and formatting of this publication was done with:

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The Final Word:

Nature loves courage. You make the commitment and nature will respond to that commitment by removing impossible obstacles. Dream the impossible dream and the world will not grind you under, it will lift you up. This is the trick. This is what all these teachers and philosophers who really counted, who really touched the alchemical gold, this is what they understood. This is the shamanic dance in the waterfall. This is how magic is done. By hurling yourself into the abyss and discovering it's a feather bed.

-Terence McKenna (1946-2000)
Philospher, ethnobotanist