



NATIONAL
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ACTION NETWORK

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It's Official!

The National ME/FM Action Network will be hosting the 10th International IACFS/ME Research & Clinical Conference

**Translating Evidence into Practice:
Chronic Fatigue Syndrome,
Fibromyalgia, and Related Illnesses.**

IACFS/ME Conference 2011

Dates and Location

The International Association for CFS/ME (IACFS/ME) Conference will be held at the Crowne Plaza Hotel in Ottawa, Canada from September 22nd to 25th, 2011.

This Conference will consist of a 4-day professional meeting and a one day (September 22nd, 2011) patient meeting which will coincide with the professional meeting. It is anticipated that this event will be accredited for continuing medical education.

Themes

The professional conference themes focus on fatigue, pain, sleep, pediatrics, cognition and brain function in ME/CFS/FM and related illnesses and will be addressed in scientific sessions on assessment and treatment and original research in the fields of immunology, virology and neuroendocrinology. There will also be workshops for clinicians and researchers.

The patient meeting will focus on matters that are of concern to them i.e. diagnosis, treatment, disability and legal issues, etc.

Please visit our website at <http://www.mefmaction.net> and find out how you can help us make this important conference a success. It is the first time that such a conference will be held in Canada.

To find out more about the IACFS/ME and its activities, please visit its site at <http://www.iacfsme.org>

Financial Help Needed

The National ME/FM Action Network needs your help for this major project . Why? Because it is an opportunity to have the best researchers in the world here in Ottawa, Canada, to meet with our Government officials, Public Health Agency of Canada, Canadian Institutes of Health Research to advocate for more research and service funding for ME/CFS and FMS.

For the first time, the IACFS/ME conference will be open to presentations on Fibromyalgia and other forms of chronic disabling fatigue. It is a huge undertaking. The estimated funds needed to host this event are \$150,000. If any of you have contact with a philanthropist or business that may be able to assist with

the fundraising and publicity required, please offer your assistance to the Network. If you think you might be able to make the trip, start saving now. There is always a full day program for patients and patient advocates the day before the scientific program starts (September 22nd, 2011) and patients are welcome at the scientific proceedings.

At the IACFS/ME you are truly not alone. Information will be posted on our Network's website and follow ups will be sent through email, snail mail and our QUEST newsletter. Another way you can help is to:

- Hold a collection at support group meetings;
- Support groups could hold a garage sale of items members bring;
- Gently-used clothing could be collected and sold;
- Ask relatives and friends to contribute;
- Ask in memoriam donations be made to the National ME/FM Action Network;
- Those who can work can ask their employer to make their charitable donation to the National ME/FM Action Network;
- If you make donations to other charities, consider the National ME/FM Action Network and ask relatives and friends to do the same;
- If you give to the United Way, specify you wish your donation to go to the National ME/FM Action Network;
- You can also donate through <http://www.CanadaHelps.org>;
- If you are not a member, please join us. Our membership includes our quarterly newsletter "QUEST"
- Let your imagination explore the ways you can donate.

Each one of you can make a difference and remember that all donators get a charitable receipt. No donation is too small and each one is important.

NATIONAL ME/FM ACTION NETWORK

Margaret Parlor, President

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

Letter from the IACFS/ME President

RE: Ottawa 2011 IACFS/ME Conference - Sept. 22-25th

I have been working closely with Lydia Neilson, CEO of the National ME/FM Action Network, in advance of the Ottawa Conference. Lydia has generously offered to help make this conference a success through fundraising efforts in Canada.

I think everyone who is interested in this meeting has a right to know how the ME/FM community will benefit from fundraising for this event.

First of all, as president of IACFS/ME since March, 2009, I am dedicated to increasing professional and public recognition of CFS/ME. Our first organized effort to this end began last spring where I presented testimony at the federal CFS Advisory Committee in Washington, DC. My statement advocated leadership change at the ineffective CFS program at the Centers for Disease Control (CDC). The committee adopted and published this recommendation.

Yet the recommendation was not acted upon or even acknowledged by the authorities at Health and Human Services. In fact, as late as Sept. 2009, the CDC told us that no leadership change would occur. Then, at the subsequent CFS Advisory Committee meeting in October, 2009, I arranged for 9 professionals (physicians and researchers) to speak at the meeting in support of the leadership change at CDC.

(Unfortunately, patient testimony has less impact.) The committee once again endorsed the recommendation and demanded a response from Health and Human Services.

Then in mid-January, 2010, the announcement was made by the CDC that Dr. Reeves would be leaving his CFS leadership position to be replaced by Dr. Elizabeth Unger. Although still a work in progress, this change is a big victory for the CFS/ME community. I'm sure other factors came into play (e.g., discovery of XMRV link to CFS) in promoting this change, but I believe that IACFS/ME played a critical role in this effort.

What we're working on now at IACFS/ME:

The organization has just received a \$10K grant to develop clinical guidelines for CFS/ME. This would be the first set of guidelines developed by an international CFS organization with input from a selected team of experts. More specifically, we will be putting together "modules" for a broad range of medical care that includes assessment, treatment and ongoing care for these domains: fatigue, pain, sleep, cognition, physical therapy, medications, exercise, and disability.

This project will be done in stages over the next 1-2 years and will be made available without charge to all health professionals who wish to use it.

Also, we are now publishing a quarterly scientific journal and a 3x a year Newsletter focused on CFS/ME. Our goals for the journal are (a) to team up with a professional publisher so that the journal will be listed in medical libraries; and (b) to apply for Medline indexing which in effect will increase its scientific credibility and mainstream the publication to the medical community. The Newsletter is our vehicle

to disseminate the latest information on CFS/ME to our membership.

With these efforts, I believe that CFS/ME will begin to receive the recognition that it truly deserves. This will benefit everyone.

The Conference itself is an important venue for the exchange of ideas and the development of collaborations to further the science and practice related to CFS/ME and related illnesses. We also plan to have dedicated presentation panels for XMRV, the Canadian Case Definition, and the latest information on diagnosis and treatment.

All of these initiatives require funding to succeed. Right now IACFS/ME operates on a shoestring with our dedicated voluntary board of 9 scientists and clinicians running the organization.

That's why I'm asking for your support of the Ottawa conference.

Thank you,

Best regards,

Fred Friedberg, PhD
President
IACFS/ME www.iacfsme.org

Information for Presenters

To select speakers and presenters for the conference, IACFS/ME will issue a call for abstracts in January 2011.

A review committee will evaluate all submissions for (a) scientific merit and/or (b) clinical relevance/expertise.

I want to encourage everyone who wants to present to submit abstracts. Abstracts will be considered for oral presentations or poster presentations. Specific submission information will be

available when the call is issued.

Thank you for your interest.

Fred Friedberg, PhD, President
IACFS/ME

Facts about IACFS/ME

- Founded in 1990, it is the only international professional organization (500 members) dedicated to scientific advocacy and improved patient care in the area of ME/CFS and FMS.
- It has held biennial international conferences since 1994
- It publishes an online peer review professional journal (quarterly; *Bulletin of IACFS/ME*) and an online newsletter (3x a year) with timely and important information for researchers and clinicians interested in ME/CFS.
<http://www.iacfsme.org>
- It has been developing a track record to increase recognition of ME/CFS worldwide.
- In 2007, it presented a 2-day conference (1 day for professionals; 1 day for patients) in Oslo, Norway that resulted in increased government recognition and funding of ME/CFS programs.

Leadership Transition at the CDC

January 27, 2010

Dr. Steve Monroe, Director, Division of Viral & Rickettsial Diseases at the Centers of Disease Control & Prevention, Atlanta, Ga. Announces that **Dr. William Reeves** has accepted an assignment as Senior Advisor for Mental Health Surveillance in the Public Health Surveillance Program Office with the Office of Surveillance, Epidemiology, and Laboratory Services effective February 14, 2010.

Dr. Elizabeth Unger, effective February 14, 2010 has accepted to serve as Acting Chief, Chronic Viral Disease Branch and is taking on new leadership responsibilities within the Branch.

Additions to Medical Advisers

The **National ME/FM Action Network** is pleased to announce the addition of two more medical consultants to our organization:

DR. ALISON CHRISTINE BESTED, MD., B.Sc. (Hons.), F.R.C.P.C. and

DR. LEONARD A. JASON, Ph.D.

We are grateful for their commitment to the ME/CFS and FMS community.

XMRV and the Canadian Blood Supply

By Dana V. Devine, Ph.D., Vice President, Medical, Scientific & Research Affairs, Canadian Blood Services.

Canadian Blood Services takes the safety of the blood supply very seriously. We remain focused on the identification of potential threats to the blood supply whether they are blood borne pathogens or issues that may jeopardize the sufficiency of the supply of blood and blood products needed by patients.

Last fall, a report was published in the medical literature which suggested that there was an association between chronic fatigue syndrome and the presence of a virus called xenotropic murine leukemia virus-related virus (XMRV). Lombardi and co-workers found that there was not only evidence of the genetic material of this virus in blood samples from American CFS patients, it was much more common than in samples from healthy individuals, 67% in CFS patients versus 4% in healthy people. Furthermore, these researchers could show that the virus from

patient blood samples was able to infect cultured cell lines in the laboratory. What remained unknown was whether this virus was actually the cause of CFS.

It was also unclear from this study whether there was actually live virus in healthy people as these researchers were only able to demonstrate a piece of the XMRV genome called 'gag' but not other parts of the virus that one would expect to find if the virus was intact and capable of being infectious. So, important questions remained unanswered, particularly with respect to risk to the blood system. Nevertheless, the information was sufficiently important that Canadian Blood Services along with its sister organizations in the United States began to determine what should be done about protecting the blood supply while other researchers work to confirm whether the Lombardi findings can be reproduced.

There are no fewer than four different groups of people representing a wide variety of researchers from both the transfusion medicine community and from the public health community working together to understand the significance of XMRV to the blood supply. One of the first steps was the recognition that we lack a proper test to look for XMRV because the virus is quite new and there has not yet been any clinical demand to test for it outside of highly specialized research laboratories.

In order to have confidence in a blood screening test, we must know that it has a high level of sensitivity, that is, it is good at finding a particular virus, while at the same time it needs to have a high level of specificity, meaning that if it is positive, the particular virus is present. So, the development of XMRV tests that allow us to confidently identify the virus is a critical first step. The second step will be to test enough of the North American blood donor base to be able to understand whether XMRV actually is carried by healthy blood donors.

It is an integral part of the scientific discovery process that new findings must be confirmed by other researchers working independently from those who reported the initial observation. Although science is never completely free of bias, this process has evolved as an effective way for scientists to determine whether or not a new discovery is 'true'. The publication of discoveries in the medical literature uses a somewhat proscribed format to describe what the study design was, how it was conducted, what the results were, any problems or pitfalls with the research and what the research might mean.

In early January, 2010, a second report looking for XMRV in CFS patients appeared in the medical literature. This study, conducted in the United Kingdom, used samples from an even larger group of CFS patients with strong symptoms. Although the study appears to have been conducted with appropriate scientific rigor, these investigators were unable to confirm the findings of the American study. They found only a single CFS patient with evidence of XMRV in their large cohort. So, we are left with a common scientific conundrum – uncertainty over whether research findings are correct or not. Is XMRV a virus that is more common in North America than on other continents? If these CFS patients in the UK do not have XMRV, does that rule out XMRV as a cause of CFS, or not? More studies will be required before we know how this issue will play out.

So what will Canadian Blood Services do in the meantime? At the present time, we have accepted blood donations from donors who report a history of CFS but are now well. Donors who are not well may not donate blood. Given the lack of clarity around XMRV, we are changing the way we manage donors such that any donor who has a medical history of CFS will be indefinitely deferred from donating blood. Once we understand more about the possible role of XMRV in the etiology of CFS, we will revisit this decision to determine whether the indefinite deferral is still warranted.

XMRV represents a single agent that raises concerns about blood safety, but it is not alone on the list of potential risks to blood safety. Canadian Blood Services monitors the current state of the science as well as the movement around the globe of a series of pathogenic agents that are known to be transmissible in blood. These include well known agents such as the dengue fever virus, and relative newcomers such as the Chikungunya virus. There are literally dozens of agents which present some level of risk, however, as long as the risk is actively managed, harm to patients can be avoided. At the present time, we either ask risk-based questions to defer donors or we implement blood screening tests where it makes sense to do so. However, going forward, Canadian Blood Services is working toward the implementation of a relatively new technology called pathogen inactivation which is a broad-spectrum treatment to kill all kinds of pathogens in fresh blood products.

At the present time, systems are in the marketplace that can be used to treat platelet products and plasma products and researchers are actively working to develop processes that can be used for red blood cells. This technology will allow Canadian Blood Services to proactively protect the blood system from pathogenic agents. While systems are not yet here that can be used to treat the full blood supply, even partial treatment will afford an increased level of protection from known as well as emerging pathogens.

<p>XMRV Virus and What it Means – Dr David S. Bell to Speak in Toronto</p>

The Myalgic Encephalomyelitis Association of Ontario and the Environmental Health Clinic, Women's College Hospital, will present their special guest lecturer, **Dr David S. Bell**.

Topic: "Current Findings and Research into ME/CFS: XMRV Virus and What It Means"

Date: Saturday, March 6, 2010, 1-4 p.m.

Location: Women's College Hospital Auditorium, 76 Grenville Street, Toronto
Suggested donation at the Door: \$10

Everyone Welcome. Wheelchairs accessible. Fragrance free/Scent free only and, please, do not use alcohol or other sanitizers right before entering the event.

For further information, call 416.222.8820 or 1.877.632.6682 or visit www.meao-cfs.on.ca

David S. Bell, MD, FAAP, is a Harvard graduate, with an MD degree from Boston University School of Medicine, 1971. In 1978, he began work at the University of Rochester but soon began a private practice in the town of Lyndonville, New York. In 1985 nearly 220 persons became ill with an illness subsequently called chronic fatigue syndrome in the communities surrounding Lyndonville, New York. This illness cluster began a study of the illness which continues today. Dr. Bell is the author or co-author of numerous scientific papers and books on CFS. He has also lectured on the ways ME/CFS affects the neurological and immune systems and the possible explanations for this illness, right down to the body's ability to handle oxygen at the cellular level. He has been rigorously following the research into the XMRV virus and will be speaking about this research.

CIHR Identifies FMS and CFS Research Projects

By Margaret Parlor, President

The Canadian Institutes of Health Research (CIHR) is the Government of Canada's agency responsible for funding health research in Canada. CIHR was created

in 2000 under the authority of the CIHR Act and reports to Parliament through the Minister of Health. CIHR's budget for 2008-09 was \$928.6 million.

CIHR was asked how much funding it had provided for projects researching Fibromyalgia and Chronic Fatigue Syndrome. CIHR identified projects using a modified keyword search methodology. Multiple key words were used to produce a pool from which projects were selected. CIHR listed its validated projects in a spreadsheet dated April 14, 2009 and covering the period from 2001-2 to 2013-14. The amount of the allocations past 2008-9 are not shown because they are subject to change.

To give you an idea of the types of projects on the list, we have focused on projects that were funded in the year 2008-9 (including multi-year projects which were approved in earlier years and received funding in 2008-9). According to CIHR, \$715k was spent on Fibromyalgia research and \$216k was spent on CFS research in that year. One study costing \$35k in 2008-9 was included under both Fibromyalgia and Chronic Fatigue Syndrome.

You can review the complete CIHR spreadsheet on the National ME/ FM Action Network website or you can contact the Network directly for a copy. You can get additional information on each of these projects at http://webapps.cihr-irsc.gc.ca/funding/search_e.

Table 1: Research Projects Identified by CIHR as being related to Fibromyalgia: 2008-9

Researcher/ Institution	Amount	Research Project Title
Frank S Prato/ London Health Sciences Centre Res. Inc	\$186,035	Mechanisms by which low frequency magnetic fields interact with biological systems
Peter A Smith U Alberta	\$113,494	Cellular electrophysiology of neuropathic pain
Denise Adams / U Alberta	\$ 35,000	Investigating the effectiveness of acupuncture versus conventional care for fatigue related to infectious mononucleosis
Serge Marchand /U Sherbrooke	\$106,618	The role of sex hormones in pain perception during the development in healthy subjects and patients suffering of chronic pain
Pierre Rainville / Institut universitaire de gériatrie de Montréal	\$129,375	Electrophysiology and brain imaging of normal and abnormal pain modulatory systems
Michael Knauer / U Western Ontario	\$ 10,208	The Role of Skeletal Muscle Transporters in Statin-Induced Myopathy
Joanna L Bennett / UBC	\$ 10,208	Inhibition and Flexibility in Adolescents with Juvenile Primary Fibromyalgia Syndrome
Michel Fortier / U Laval	\$ 24,383	Genes and proteins of the prostaglandin synthesis and signalling cascades associated with menstrual disorders
Linda E Levesque / Queen's	\$100,000	Cardiovascular Outcomes of Drug Treatment for Neuropathic Pain and Fibromyalgia: A Population-based Cohort Study.
TOTAL	\$715,321	

Table 2: Research Projects Identified by CIHR as being related to Chronic Fatigue Syndrome: 2008-9

Researcher/ Institution	Amount	Research Project Title
Geoffrey L Hammond / UBC	\$131,766	Corticosteroid-binding globulin: Programmed regulator of glucocorticoid action during development and disease
Denise Adams / U Alberta	\$ 35,000	Investigating the effectiveness of acupuncture versus conventional care for fatigue related to infectious mononucleosis
Brett D Thombs / McGill U	\$ 45,000	Development of Assessment Tools for Fatigue Related to Systemic Sclerosis: Research, Diagnostic, and Screening Applications
Elana C Taub / U Calgary	\$ 4,375	Exercise tolerance in patients diagnosed with myalgic encephalomyelitis/chronic fatigue syndrome.
TOTAL	\$216,141	

CIHR Underfunds FMS and ME/CFS Research

By Margaret Parlor, President

On the Canadian Institutes of Health Research (CIHR) website there are two databases which list studies that have been approved for funding. A database showing funding decisions over the past year can be found at http://webapps.cihr-irsc.gc.ca/cfdd/db_search?p_language=E, A database showing decisions made since 1999 can be found at http://webapps.cihr-irsc.gc.ca/funding/Search?p_language=E&p_version=CIHR. At the time of writing, these databases had been updated to October, 2009.

Keywords can be used to search the databases. If you type in keywords like “fibromyalgia” or “chronic fatigue syndrome”, the database will show all funded studies that include the keyword in the description of the project. I searched the databases using keywords referring to 15 chronic conditions. Table 1 shows the keywords I used and what I found. I have added a column showing the number of Canadians affected by each of the chronic conditions. Where possible, I took the information from Statistics Canada's Canadian Community Health Survey (CCHS) 2005 to tie in with the statistics published in Quest 80. Otherwise, I found the information on the website of the organization representing Canadians with the condition.

Caution is needed in interpreting the data. It is not known whether the CIHR databases are complete and accurate. When it comes to dollar values, the databases include future commitments which are subject to change. The keyword search results depend on what keywords are used and how the study is described. If the description mentions fibromyalgia, the study will be picked up even if fibromyalgia is not particularly

relevant. If the description doesn't mention fibromyalgia, the study won't be picked up even if the study is very relevant to people with fibromyalgia. If the description uses just the term “chronic fatigue”, the study won't be picked up in a search for the keyword string “chronic fatigue syndrome”. And there is a chance that a keyword like HIV could be picked up as part of another word like shiver or chivalry.

Despite these limitations, the resulting data provide an interesting and useful portrait of research funding in Canada today. Note that both the US National Institutes of Health and the Australian National Health and Medical Research Council publish detailed tables showing funding for a variety of conditions so that their citizens can see how research dollars are spent.

These results show that only one FMS or CFS related project worth \$100,000 was approved last year out of a total of almost 4,000 approved projects and over \$1billion in research funding. Since 1999, only 19 FMS or CFS related projects have been approved out of a total of almost 30,000 projects. Only \$5.3Million in research funding has been approved for FMS or CFS projects out of total spending of over \$7Billion.

We invite you to contact your Member of Parliament and the Minister of Health to ask for fair funding for research into FMS and ME/CFS.

(Note: The information in this table differs from the information in the previous article. Firstly, CIHR used modified keyword searches whereas this study used unmodified keyword searches. Secondly, this table shows projects that were approved during the last year whereas the previous article includes multi-year studies where funding occurred during 2008-9.)

Table 1: CIHR funding for research into 15 chronic illnesses

Keyword	# of studies approved last year	Amount approved last year	# of studies approved since 1999	Amount approved since 1999	# Canadians affected	Source for column (6)
Diabetes	213	\$55,897,148	1783	\$537,737,694	1,324,874	CCHS 2005
HIV or HIV/AIDS	196	\$49,797,288	1104	\$296,764,813	63,000	Canadian AIDS Society
Alzheimer	89	\$25,950,878	817	\$213,141,376	500,000	Alzheimer's Society of Canada
Arthritis	81	\$12,784,108	797	\$265,663,049	4,441,851	CCHS 2005
Heart Disease	113	\$45,341,422	620	\$207,152,438	1,288,009	CCHS 2005
Asthma	63	\$15,373,389	539	\$150,634,751	2,249,228	CCHS 2005
Parkinson	58	\$23,579,165	424	\$124,990,572	Over 100,000	Parkinson's Society of Canada
Schizophrenia	51	\$19,136,229	460	\$121,728,145	1% of population	Schizophrenia Society of Canada
Epilepsy	28	12,692,633	319	\$ 93,718,506	159,759	CCHS 2005
Multiple Sclerosis	28	\$11,415,720	204	\$ 71,644,899	55,000-75,000	Multiple Sclerosis Society of Canada
Autism	38	\$6,842,232	183	\$ 42,094,438	200,000	Autism Society of Canada
Glaucoma	12	\$1,866,057	90	\$ 26,830,190	407,390	CCHS 2005
Fibromyalgia	1	\$ 100,000	15	\$ 4,659,102	389,782	CCHS 2005
Chronic Fatigue Syndrome	0	\$ 0	4	\$ 694,080	333,816	CCHS 2005
Multiple Chemical Sensitivities	0	\$ 0	1	\$ 17,500	598,585	CCHS 2005
{all projects}	3,964	\$1.086B	28,738	\$7.345B		

Data for this table was compiled by the National ME/FM Action Network.

[Ed. Note: Margaret Parlor was a statistician with the Federal Gov. for 25 yrs.]

National CFIDS Foundation

The **National CFIDS Foundation** adds to its Innovative Research Grant Funding for 2009

The **National CFIDS Foundation** (NCF) of Needham, MA has announced its latest research grant recipient to add to its growing list of funded projects which total **\$451,160** for 2009.

Vitaly Citovsky, Ph.D., Professor in the Department of Biochemistry and Cell Biology at SUNY Stony Brook, is the latest recipient of a research grant for \$ 105,000 from the NCF. Citovsky's grant is titled "Potential synergism between cyanobacteria and Agrobacterium and its molecular basis."

According to **Alan Cocchetto**, NCF's Medical Director, "This research is aimed at determining if there is a synergistic relationship between two very unique bacteria. It may be possible for agrobacterium to develop a symbiotic relationship with cyanobacteria within the human microbiome, ultimately enhancing the cyanobacteria's pathogenicity and to aggravate the medical condition of the host. This is important since agrobacterium is known to genetically transform human cells. Furthermore, this research will complement the toxicology work currently underway by Harry Davis, Ph.D. and his team at the University of Hawaii on ciguatera and cyanobacteria and how they relate to CFIDS/ME."

Gail Kansky, NCF's President stated "2009 has been a terrific year for the Foundation. Through the hard work of dedicated volunteers along with generous donations from patients and benefactors, we have been able to provide directed funding to some truly outstanding researchers worldwide in an effort to conquer this disease. 2009 represents our largest funding year ever since the Foundation first began

its formal research grant program in 2002. We have made tremendous strides in our knowledge of this disease. These grants reflect our efforts to build upon our previous research in a step-by-step fashion to connect all the scientific and medical dots relating to CFIDS/ME. The NCF represents what a true charity should be as there are no paid employees and our donations go to fund innovative research projects. We look forward to 2010 because the results of this research should provide much hope to millions of patients around the globe."

Founded in 1997, the goals of the NCF are to help fund medical research to find a cause, expedite treatments and eventually a cure for CFIDS/ME. The NCF is funded solely by individual contributions. Additional information can be found on our website at www.ncf-net.org and in The National Forum quarterly newsletter. The NCF can be reached by phone at **781-449-3535**.

Press Release - December 11, 2009 Co-Cure.

National ME/FM Action Network's Request to PHAC

The National ME/FM Action Network continues its communication with the Federal Government.

Date: Tue, 08 Dec 2009

Ms Lisa Underhill
Senior Chronic Disease Management Analyst
Public Health Agency of Canada
CHRONIC DISEASE MANAGEMENT DIV.
785 Carling Avenue
Ottawa, Ontario K1A 0K9 Canada

The October 8th announcement dealing with XMRV and CFS raises 3 very significant issues:

1) The announcement showed that a high percent of people with ME/CFS had evidence of the XMRV retrovirus. This raises the distinct possibility that XMRV is a cause of the illness, and this could lead to new diagnostic and treatment possibilities. The retrovirus concept is resonating within the ME/CFS community because it seems to reconcile with what is already known about the illness. There is a great need for follow-up research. In addition, the announcement had the effect of seriously undermining the credibility of the CDC with regards to ME/CFS. The CDC is known to have quashed retrovirus research in 1991, used research funding in unproductive ways, developed definitions that hamper rather than help our understand the illness, and generally given the illness little respect.

2) The announcement suggested that 4% of the general population carries this retrovirus. This raises the possibility that other chronic illnesses may be related to XMRV. Very preliminary testing found XMRV in people with FMS. The announcement also raises the possibility that people with XMRV who are currently healthy may develop chronic illnesses just as people with the retrovirus HIV may develop AIDS. There is a great need for follow-up research.

3) The announcement suggests that the retrovirus is transmissible through the blood donation system and perhaps through other channels. There is a great need for follow-up research.

To get some perspective on this announcement, look at some statistics. Up to the end of 2005, approximately 20,000 Canadians had been diagnosed with AIDS (<http://www.avert.org/canada-aids.htm>). The Canadian Community Health Survey for 2005 showed 334,000 Canadians diagnosed with CFS, which is FIFTEEN TIMES as many. While CFS is not normally fatal, CFS patients are said to be at least as debilitated as AIDS patients.

Since this announcement

1) CIHR has advised us that research funding will not be available until October 2010 and only through the normal funding process. That is a year away and the current funding process has been far from generous to ME/CFS research.

2) PHAC has not identified a person responsible for monitoring developments around XMRV or for liaising with our organization on this matter.

3) HC has advised us it is monitoring issues around XMRV in the blood supply though it has made no public announcement.

4) Several Canadian researchers have advised us that they would like to investigate this area but that funding is an issue.

We believe that immediate concerted action is called for.

We ask that CIHR, PHAC and HC make it a priority to develop Canadian research into the link between XMRV and ME/CFS, the scope of XMRV (notably whether XMRV is linked to FMS), and the transmissibility of XMRV. This work should begin as soon as possible - within days rather than months or years. The research strategy should take advantage of work being done in other countries, but Canada should not opt out of research by assuming that it will be done elsewhere. It should be recognized that the Canadian research infrastructure around ME/CFS and FMS is seriously lacking and that "incubation" of research into these illnesses is a necessity.

We also ask that CIHR, PHAC and HC recognize that new health care delivery models (with much greater capacity) are urgently required for ME/CFS and FMS and that planning for the new models be started right away. The objectives of the exercise would include reducing the current unacceptable level of unmet needs (seen in

CCHS), ensuring that health care delivery is based on factual rather than discredited information, and ensuring that research developments can be translated into improved patient care quickly and appropriately.

Request for Assistance Updating the CPP disability Guide

The National ME/FM Action Network is updating and revising its Guide on applying for Canada Pension Plan Disability benefits. Applying for CPP-D can be a difficult and stressful experience and we want to help as much as possible. Many people have complimented us on our current guide, saying that it was very useful. We think we can make it even better, and we want your assistance.

Please share with us your experiences in applying for CPP-D. We are looking for personal anecdotes that we could incorporate into the document. We are looking for words of advice that we could quote. We are also looking for documents (completed application forms, requests for reconsideration, statements to a tribunal etc.) that could be used as models by others. Any material used in the new guide will be anonymous, of course. All identifying names and details will be removed.

Please submit you material to the National ME/FM Action Network by mail, fax, phone or email. We are hoping to have the new guide available this spring, so please do not delay.

Books/Newsletters/Links, etc.

The Environmental Illness Resource – U.K.

Website content relating to ME/CFS, FM, MCS and others <http://www.ei-resource.org>

Jason, L.A., Jessen, T., Porter, N., Boulton, A., Njoku, M.G., & Friedberg, F. (2009). Examining types of fatigue among individuals with ME/CFS. *Disability Studies Quarterly*, 29, available at <http://www.dsqsds.org/article/view/938/1113>

<http://www.AfraidtoAsk.com>

Answers questions on many health topics.

http://www.afraidtoask.com/?page_id=13

Answers questions on Lyme Disease which includes pictures

National Fibromyalgia Association of Anaheim, Ga, U.S.A.

Its award-winning newsletter *Fibromyalgia Aware* is now available free on line at <http://www.fibromyalgiaaware.org>

Radio Program on Disability Issues

Mr. Geoff Langhorne has a weekly radio show on disability, disadvantage, learning about them and overcoming them and is available weekly on **CFMU radio** without any special audio software if you tune in to **cfmu.mcmaster.ca** at **12 noon Thursdays**.

Geoff Langhorne is producer, often host and writer for *disRespect Radio*, which probes challenges to dignity for those with disability and disadvantage, archived for streaming or download at www.radio4all.net. Play it with WinAmp (winamp.com, nullsoft.com). Broadcast for the past ten years at **93.3 CFMU Thursdays at noon**.

RESOURCES

Complete Original Consensus Documents

-FMS Consensus Document - US\$24.95

"The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners".

Haworth Press, 2004. (soft cover book)

ISBN: 0-7890-2574-4

Phone: 800-429-6784 **Fax:** 607-771-0012

Email: orders@haworthpressinc.com

Online: [http://www.haworthpress.com/
store/product.asp?sku=5342](http://www.haworthpress.com/store/product.asp?sku=5342)

-ME/CFS Consensus Document US\$14.95

"Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols".

Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004

ISBN: 0-7890-2207 9

Phone: 800-429-6784 **Fax:** 607-771-0012

Email: orders@haworthpressinc.com

Online: [http://www.haworthpress.com/
store/product.asp?sku=4958](http://www.haworthpress.com/store/product.asp?sku=4958) CFS46

Overviews of the Consensus Documents

Fibromyalgia Syndrome, 24 pp, 2006

Chronic Fatigue Syndrome, 20 pp, 2006

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

**Version française : Abrégé du Consensus sur le SFC: \$5.00,
payable par chèque seulement, à AQEM**

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

Network Resources

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

Quest Collections

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

Quest Collection I: presently out of print

Quest Collection II (1999 – 2003): \$38.00

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

NEW

TEACH-ME: A Sourcebook for Teachers (Second Edition): \$22.00 *Discount on bulk orders With Dr. D. S. Bell, Dr. B. M. Carruthers and the TEACH-ME Task Force (teachers with ME/CFS and/or FMS)*

This educational resource book will enhance teachers' and parents' understanding of ME/CFS and FMS in young people, and assist educators in developing educational modifications and programs.

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

LEGAL PRECEDENTS: \$60.00

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

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

**MEMBERSHIP: \$25.00 per year, which includes quarterly newsletters
Payment can be made by CHEQUE, VISA or MASTERCARD.
Do not email credit card information.**

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