May 12th Light Up The Night Challenge

What started as a friendly challenge between Canada and Northern Ireland is now growing to be international. The challenge is to get as many buildings as possible in your country to light up with one of the 3 colours used on May 12th - blue, purple or green. We want public buildings/places like City Halls, Niagara Falls and we want individual homes lit up too!

We'll all be winners but there will be bragging rights awarded to the country with the most photos in each of these categories:

1. # of Public Buildings/Places
2. # of Private Residences

The contest will be coordinated by May Twelfth and photos and final results posted on the May 12th International Awareness Day page *www.facebook.com/may12th.awareness*.

To enter, photos should be taken and sent to May Twelfth at info@may12th.org.

All pictures must be emailed by May 19th to be included. When sending the photo, include information about where the photo was taken (ie town, region, country) The May 12th team will count and post the photos as they come in and post the final results as soon as possible after the 19th.

We hope to get pictures from around the world!

If you are planning events for May 12th, we'd like to hear from you. Send us pictures of your event. We will publish them in the next newsletter.

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Share the Bounty Contest

Voting for the online Share the Bounty contest ended on April 8th, 2014. Although official results won't be available until April 16th we finished the contest in 2nd place with only a 188 vote lead over the third place entry.

We want to extend a huge thank you to all who participated. It was a long contest but we anticipate a $10,000.00 prize for finishing second.

Dr Alison Bested Scholarship Fund Recipients

The Dr Alison Bested Scholarship Fund was established to recognize the tremendous support and dedication that Dr Bested has given to Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Multiple Chemical Sensitivity(MCS) patients in Canada.

The purpose of the fund is to facilitate the training of medical students in ME/CFS, FM and MCS by reimbursing some or all of their expenses (such as accommodation, meals and transportation) while they receive training at a recognized ME/CFS, FM, MCS assessment or treating facility. Details of the fund can be found here: http://mefmaction.com/index.php?option=com_content&view=article&id=155&Itemid=233

We are pleased to provide funding for Randy Aung, who is in fourth year medical school at Dalhousie University. Mr Aung chose to spend two week at the Environmental Health Clinic in Toronto in November 2013. He chose to do a placement at the EHC because he wants to explore more about this disabling chronic condition which most of the physicians are unaware of. He found his experience very interesting, especially interacting with patients who have CFS and learning more about the symptoms, which has an enormous negative impact on their lives and careers. It is important for more people to be aware of environmental health conditions so that the patients can have more accommodations at their work.

Funding was also provided to Cathy Zhang of McGill University who sent us the following letter.

March 27, 2014

Dear kind donor of the Dr. Alison Bested Scholarship Fund,

I am a 3rd year medical student from McGill University and I am writing to express my deepest gratitude for your generous contribution in medical students' learning of chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivity. There is no way to fully express my gratitude, but it is my hope that this message will help communicate my infinite appreciation.

I feel extremely privileged to have been given this opportunity to work at the Environmental Health Clinic of University of Toronto's Women's Health College, alongside Dr. Riina Bray and Dr. Kathleen Kerr these last few weeks.

These passionate physicians have definitely opened my eyes to a whole new population of patients: they have shared their insight in managing some extremely deliberated patients, and whose care is too frequently overlooked in our medical community. Unfortunately, this neglect often stems from a lack of familiarity and understanding of this complex field, which themselves originate from the limited teaching of these conditions in medical school.

It is therefore essential to keep advocating for the recognition and acknowledgement of these conditions as medical entities themselves, on several different fronts in our society, as a substantial number of our patients have varying degrees of these illnesses, and each and every one of them deserves the best of care.

On this note, I would like to once again extend my most sincere thanks for your inspirational and continual support in the education of medical students on these prevalent, but often disregarded medical conditions, in the hopes that your persistent dedication and commitment will increase awareness, research and teaching of chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivity in medical school, clinical practice and beyond.

Yours sincerely,

Cathy Zhang

M.D.,C.M. Class of 2015,

McGill University

Many individual patients and supporters contributed to the scholarship fund when it was first established. Donations are always welcome. Simply make a donation to the National ME/FM Action Network and let us know that you want it designated to this scholarship fund.

IACFS/ME 2014 Conference in San Francisco

Anne Marie MacIsaac in San Francisco for the IACFS/ME 2014 Conference

The 11th Biennial IACFS/ME Conference was held in San Francisco from March 20-23. Two representative from the ME/FM Action Network attended, our president Margaret Parlor and Anne Marie MacIsaac. Margaret was also a presenter. She presented the "Results from the Canadian Community Health Survey (CCHS) 2005, 2010 and 2012" .

We spotted at least 20 other Canadians in attendance including patients, doctors, researchers and patient representatives. Also attending were two representatives from the Canadian Institutes of Health Research (CIHR), Dr Hani El-Gabalawy and Liz Sterling.

Speakers at the conference included virologist Ian Lipkin, best-selling author Abraham Verghese (professor of medicine at Stanford), and Noel Rose, pioneering immunologist from Johns Hopkins University. The conference was opened Dr Jose Montoya who also hosted a symposium at Stanford University the day before the conference.

A general feeling among attendees was that momentum is building buoyed by the level of research and the collaboration among multiple research centres.

A new positive Canadian development occurred at the conference when our president Margaret Parlor organized a luncheon meeting attended by herself, Dr. Hani El-Gabalawy, Scientific Director of CIHR-IMHA and Liz Stirling, Assistant Director, CIHR-IMHA and 4 Canadian doctors. At the meeting, CIHR committed to holding (and funding) a workshop to discuss research priorities before the end of this calendar year. We are very grateful to CIHR for attending and showing interest.

IACFS/ME Patient Day

The conference opened with a welcome message from Dr. Montoya of Stanford University. His enthusiasm and optimism are inspirational. His leadership on the Stanford multi-disciplinary research team brings a high degree of prominence to the research efforts.

Dr. Ian Lipkin, a leading expert in microbial research is committed to finding pathogens involved in ME/CFS. When he talks you get an understanding of the complexities of trying to find agents that may or may not trigger a complex array of symptoms and conditions. Yet he too is optimistic.

Dr. Anthony Komaroff reviewed evidence of underlying abnormalities in the brain, immune system, energy metabolism, oxidative and nitrositive stress as well as infectious triggers. Some studies in antiviral drugs have shown modest results. Some experiments are being done with drugs indicated for fibromyalgia.

Drs Fred Friedberg and Leonard Jason spoke on coping methods covering the topics of balancing activity and rest, reducing stress, positivity, support, relaxation techniques, better sleep, resolving anger, minimizing expectations of support and pacing. Dr Freidberg added some humour to his presentation and told of one jogger who said to another "I start slow and taper off from there". Dr Jason spoke on managing your energy envelope and stated that studies have shown improvements over time in fatigue severity, symptoms and physical functioning.

Denise King, Dr Kathleen Kerr, Dr John Molot

Dr Charles Lapp spoke on pharmacological and non pharmacological treatments of sleep and pain and symptom management.

Dr Montoya spoke on anti-virals. Some patients may be candidates for antiviral drugs after conducting tests for antibodies but it is difficult to determine who will respond to them. Some positive results have been shown when administered over a long period.

Dr Nancy Klimas talked about research on immunomodulators and her studies on exercise response.

Stacie Stevens stated that there is a biological basis for activity intolerance. Her presentation covered identifying activity coping style, determining anaerobic threshold, using a heart rate monitor and abdominal breathing.

Bruce Campbell also spoke on self management strategies and pacing and Lucinda Bateman covered the current status on treating and managing fibromyalgia. She stated that awareness of FM has skyrocketed since the FDA approval of 3 drugs for the treatment of fibromyalgia.

An encouraging presentation was given by Dr. Jarred Younger from the Stanford research team. There is increase scientific interest in fibromyalgia as evidenced by the increased number of research papers. He maintains that there is not one fibromyalgia but many types and treatment approaches will differ for different types. He is doing research on microglia activation (microglia induce a sickness response) and many drugs in early stages of testing. Dr Younger believes there is a strong overlap between fibromyalgia and ME/CFS and he believes there will be convergence in the research (though not all researchers concur).

The keynote speaker, Dr Abraham Verghese, professor and best-selling author, encouraged a hands-on approach to medicine.

IACFS/ME Conference Day 2

The opening speaker was Dr. Noel Rose who gave a presentation on "How do we recognize an autoimmune disease?". Dr. Rose is the director of the Center for Autoimmune Research at Johns Hopkins School of Medicine. He is a very eloquent speaker and very knowledgeable in autoimmunity.

He did not talk about CFS but about autoimmunity and what it is. Three contributing elements in autoimmunity are genetic predisposition, environmental factors and endocrine effect. When asked why autoimmunity is more prevalent in women, he replied that hormones play a significant role. It is not clear whether or not ME/CFS is an autoimmune disease, but the message was that it might be.

Margaret Parlor and Marie Andree Normandin from AQEM

The next 2 session covered "The Latest Research in Immunology" and "Virology Research". While the details were scientific in nature the conclusions were that there were significant findings that warranted further research.

Nicole Baldwin presented a study on the treatment of orthostatic intolerance (OI) using midodrine in patients with CFS. Results showed small but significant improvements. This is a pilot study and future studies are required.

Other studies that showed measurable improvements in fatigue and functionality were Ba Duan Jin (a traditional Chinese qigong exercise), Isometric Yoga (sitting version) and home based self management.

The afternoon session was very interesting to observe. It was titled "Diagnosing CFS/ME; Difficult Clinical Cases". The panel consisted of Dr Nancy Klimas, Dr Charles Lapp, Dr Lucinda Bateman, Dr Rosamund Vallings and Dr Daniel Peterson. Each presented a difficult case from their practice and asked the doctors who were present to contribute their thoughts and suggestions. Some good discussions ensued.

IACFS/ME Conference Day 3

Dr Leonard Jason spoke on the importance of a good case definition and recommendations for an empirical definition.

Dr Ellie Stein and Dr Patricia Forbes

In the session on "Public Health Research", Margaret Parlor, president of the ME/FM Action Network presented the results from the Canadian Community Health Survey. Her presentation can be viewed at: *http://mefmaction.com/images/stories/conferences/Parlor-iacfsme-presentation.pdf*

Dr. Betsy Keller spoke on the advantages of 2 day testing over the single cardiopulmonary exercise test in indentifying functional impairment due to post exertional malaise.

The Saturday evening agenda included a banquet dinner and awards presentation. Dr Daniel Peterson was the keynote speaker at the dinner. He traced the history of the IACFS/ME. He started with film footage from 25 years ago that included interviews with Dr Cheney, Kamaroff, Klimas, Bell, Peterson and others. It is remarkable how long people like them have been involved. The conference is demonstrating that the issues are moving forward.

Awards were presented to:

Madison Sunnquist (Junior Investigator Award),

Peter Rowe (Research Excellence Award),

Pia and Richard Simpson (Special Services Award),

Katherine Rowe, (Clinician's Award)

Nancy Klimas, the Governor Rudy Perpich awardee for distinguished accomplishment in the field of CFS/ME.

IACFS/ME Conference Day 4

Sunday morning's sessions focused on pediatrics and neurology. On Sunday afternoon, the Primer was discussed. The conclusion of the conference was Dr Komaroff's summary of the biological findings.

There was considerable interest in pediatric issues among attendees of the conference. There was a report on what young patients found helpful, an observation that many young people experienced limited range of motion, another observation that about a quarter of young patients had delayed milk protein hypersensitivity, and a study which identified biochemical abnormalities in young people after mononucleosis that family doctors could monitor.

The Primer has now been updated, though the electronic version hasn't been posted yet. There have been changes in a number of sections, including the sections on prognosis and mortality, on the severely ill, on depression/anxiety, on activity/exercise, and on pediatrics. An index and a handout for patients were added. The main issue of discussion at the conference was around the difficult and sensitive section on mortality (page 26). There was some question whether the authors had found the right balance.

The primer is available online at *http://www.thebookpatch.com/BookStore.aspx*. Official printed versions will be available for $20, reductions for bulk purchases. There was discussion about how to make the document more widely known. The National ME/FM Action Network is making arrangements to have it translated into French.

Many of us observed that there is a new confidence in the community. One sign of this is the expansion of research programs. Dr Komaroff talked about the work in Florida and at Stanford, the inter-site Chronic Fatigue Initiative, NIH multicenter work, and the UK biobank. We in Canada can celebrate the commitment of Canadian clinicians and researchers that attended, and also the fact that CIHR has shown a willingness to get involved.

Dr Alison Bested and Dr Byron Hyde

Table: The proportion of Canadians with selected chronic conditions having additional diagnoses, CCHS, 2010

CHRONIC CONDITION	ADDITIONAL DIAGNOSIS												
	Bowel		Cancer	Circulatory			Diabetes	Musculoskeletal		Neurological	Respiratory		Urinary
	Ulcers (%)	Crohn's/Colitis/ IBS (%)	(%)	Effects of a Stroke (%)	Heart Disease (%)	High Blood Pressure (%)	(%)	Arthritis[1] (%)	Back Problems (%)	Migraine Headaches (%)	Asthma (%)	Bronchitis/Emphysema/ COPD[2] (%)	Incontinence[3] (%)
CFS	**16.9**	**24.5**	**7.4[E]**	**5.8[E]**	**16.1**	**32.7**	**13.1**	**50.6**	**49.3**	**33.8**	**19.6**	**18.0**	**21.4**
FM	**9.6[E]**	**20.3**	**3.8[E]**	**4.5[E]**	**11.1[E]**	**28.3**	**11.1[E]**	**56.1**	**54.5**	**26.9**	**23.2**	**12.0[E]**	**11.3[E]**
MCS	**10.1**	**13.6**	**3.7[E]**	**3.4[E]**	**10.0**	**27.7**	**9.3**	**39.3**	**42.7**	**24.5**	**22.7**	**12.8**	**10.4**
Cancer	6.0[E]	10.5	N/A	4.6[E]	18.6	37.6	17.0	40.2	33.6	12.3	11.0	10.0	13.2
Diabetes	4.8	5.3	5.1	4.3	18.9	56.4	N/A	35.3	28.3	8.2	9.4	7.1	9.6
Effects of a Stroke	11.0[E]	12.6[E]	8.2[E]	N/A	36.2	61.9	25.6	47.4	33.7	15.2[E]	13.4[E]	14.7[E]	19.4
Heart Disease	8.1	9.3	7.2	7.9	N/A	57.7	24.4	44.6	34.4	10.1	9.9	10.8	13.3
Total Population	2.8	4.3	1.9	1.1	5.0	17.1	6.4	16.1	18.9	10.0	8.5	4.3	4.0

Source: Statistics Canada, Candian Community Health Survey, 2010, public use microdata file

NOTES:

Row totals will be greater than 100% due to people having more than one type of additional diagnosis

[E] Use with caution (Coefficient of Variation between 16.6 and 33.3)

[1] ages 15+; [2] ages 35+; [3] ages 25+

Ulcers = Stomach or Intestinal Ulcers; IBS= Irritable Bowel Syndrome; Back Problems = Back Problems excluding Fibromyalgia and Arthritis; COPD = Chronic Obstructive Pulmonary Disease

Neurological conditions = Migraine Heachaches. Note there are several additional neurological conditions (e.g., Alzheimer's, Muliple Sclerosis, Parkinson's) available on the Statistics Canada master data file but not included in this analysis.

Table prepared by: E. Halapy; Commentary by: M. Parlor

Co-diagnoses

This analysis is based on the Statistics Canada Canadian Community Health Survey (CCHS) Public Use Microdata File, 2010. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network.

The CCHS has been described in previous editions of Quest. See for example Quest 88.

Respondents were asked if they have certain chronic health conditions. The interviewer says that s/he is only interested in long-term conditions that have been diagnosed by a health professional. A respondent can answer yes to any number of chronic health conditions.

The table on the ajdacent page looks at co-diagnosed conditions. For example, 16.9% of people reporting a diagnosis of CFS also reported a diagnosis of ulcers, whereas only 2.8% of the survey population reported ulcers. This means that people reporting CFS are about 6 times more likely to report ulcers than the general public.

The easy message from the table is that people reporting one chronic condition often report other chronic conditions. The difficult questions are why. Do the diagnoses overlap? (e.g. Perhaps health professionals use the terms fibromyalgia and arthritis for the same symptoms.) Are the various conditions biologically related? (e.g. Perhaps CFS, colitis and migraines occur as a package.) Are there other factors that influence co-occurences? (For example, cancer and stroke are more prevalent in seniors, so we might expect to see them appear together.) Is there cause and effect? (For example, does CFS lead to cancer or does cancer lead to a diagnosis of CFS?) These are questions that need to be explored.

Coping with CFS and FM

A very helpful article was published in February 2014 in the journal "Anxiety, Stress, Coping". It is entitled "Living with the unexplained: Coping, distress and depression among women with chronic fatigue syndrome (CFS) and/or fibromyalgia compared to an autoimmune disorder". The authors are Opal A. McInnis, Kimberly Matheson and Hymie Anisman. They are with Carleton University's departments of neuroscience and psychology.

I have included the official abstract which was written for psychologists and neuroscientists. I am also including my interpretation of the article written for the ME/FM community.

Margaret Parlor

Abstract

Chronic fatigue syndrome (CFS) and fibromyalgia are disabling conditions without objective diagnostic tests, clear-cut treatments, or established etiologies. Those with the disorders are viewed suspiciously, and claims of malingering are common, thus promoting further distress. It was hypothesized in the current study that levels of unsupportive social interactions and the coping styles used among those with CFS/fibromyalgia would be associated with perceived distress and depressive symptoms. Women with CFS/fibromyalgia (n = 39), in fact, reported higher depression scores, greater perceived distress and more frequent unsupportive relationships than healthy women (n = 55), whereas those with a chronic, but medically accepted illness comprising an autoimmune disorder (lupus erythematosus, multiple sclerosis, rheumatoid arthritis; n = 28), displayed intermediate scores. High problem-focused coping was associated with low levels of depression and perceived distress in those with an autoimmune condition. In contrast, although CFS/fibromyalgia was also accompanied by higher depression scores and higher perceived distress, this occurred irrespective of problem-focused coping. It is suggested that because the veracity of ambiguous illnesses is often questioned, this might represent a potent stressor in women with such illnesses, and even coping methods typically thought to be useful in other conditions, are not associated with diminished distress among those with CFS/fibromyalgia.

Now my interpretation:

According to the model used in this study, there are three ways of handling problems:

- Avoiding them (cognitive distraction, passive resignation, emotional containment and self-blame).
- Becoming emotional (rumination, emotional expression, blaming others and wishful thinking)
- Confronting them (problem solving, cognitive restructuring, active distraction, and social support).

One would think that avoiding problem and becoming emotional are bad ways of handling problems, while confronting problems is a good way of handling them.

In this study, the researchers looked at three groups of women:

- Women with CFS (Fukuda definition) and/or FM.
- Healthy women with no current medical or psychiatric diagnosis.
- Women with autoimmune illnesses (rheumatoid arthritis, multiple sclerosis and lupus erythematosus). This group was picked as having some but not all of the problems associated with CFS and FM. These autoimmune illnesses are still chronic illnesses but they are more recognized and accepted.

The study asked whether people who avoided problems or used emotional strategies had higher rates of depression and perceived stress than people who didn't use these strategies. The study found this to be true for all three groups. This supports the view that avoidance and becoming emotional are bad ways of handling problems.

The study asked whether people who confronted problems had lower rates of depression and perceived stress than people who didn't confront problems. This was found to be true for two of the groups. However, and this is key, it was not true for the CFS/FM group. In this group, the women who confronted problems had the same rate of depression and perceived stress as the women who didn't confront problems. Confronting problems did not help the CFS/FM group.

Why didn't confronting problems help people with CFS/FM? One possibility is that the sample of women with CFS/FM was not representative. Another possibility is that the women with CFS/FM who confront problems encounter negativity and this counteracts the benefits of confronting problems.

The study identified four types of negativity, which the study refers to as "unsupportive social interactions":

- distancing (not wanting to hear about the problem)
- bumbling (not knowing what to say about the problem)
- minimizing (suggesting the problem isn't all that bad)
- blaming (suggesting that the problem is the patient's fault)

The study found that women with CFS/FM encountered all of these unsupportive attitudes significantly more often than healthy women did.

Women with CFS/FM encountered distancing and minimizing significantly more often than women with the autoimmune illnesses, but there was not a statistically significant difference between the two CFS/FM and the autoimmune groups for bumbling and blaming. This suggests to me that, as the public learns more about CFS and FM and becomes more accepting of them, patients would experience decreases in minimizing and distancing more than they would experience decreases in bumbling and blaming.

The study concludes that the standard approach of confronting the illness does not work as expected for women with CFS/FM, likely because the women encounter unsupportive attitudes and lack of information when they reach out for help. It points out the importance of increased awareness among health care providers and the public so that women with CFS/FM receive supportive social interactions when they seek out help. The study also notes that research validation of CFS and FM would change the dynamics between patients and the public which would make it easier for patients to cope.

We owe a big vote of thanks to the authors for bringing these issues into the light.

Comments on the Order Paper

Questions about ME/CFS were placed on the House of Commons Order Paper in 2009, 2012 and 2014 by Members of Parliament Rob Oliphant, Carolyn Bennett and Hedy Fry. The government's response to the 2014 questions was tabled in the House of Commons on March 24, 2014.

Thank you to Dr Fry (and to Dr Bennett and Mr Oliphant) for putting the questions on the order paper. The replies are very helpful in understanding what government is thinking and in opening doors to future discussions.

Thank you to the six Ministers who responded for your honest, respectful answers.

To the Minster responsible for Employment and Social Development Canada (ESDC), thank you for the open invitation to meet with your staff. The ME/FM community would like to talk about the concept of disability. Many people and programs think of disability in a narrow sense that does not include the type of disability that people with ME/CFS and FM experience or that underestimates the impact. There are also practical access issues in applying for disability benefits. We need further discussions with staff at the Office for Disability Issues and the CPP-Disability program. Because of your comment that the National ME/FM Action Network did not participate in a particular ESDC consultation process, we have posted the correspondence on our website. The National ME/FM Action Network does not have resources to spend on activities that will have little benefit to the ME/FM community.

To the Minister of Health, thank you for the steps forward that have occurred. Canada has an amazing health care system; nevertheless, aggressive action is required to meet the health care needs of the ME/FM community in Canada. Statistics show that Canadians with these illnesses make multiple visits to health professionals and yet they still have unmet healthcare needs. The health system is not working well for ME/CFS or FM patients, their family and friends, employers, health professionals, or taxpayers. Concerted, coordinated federal leadership would help in the areas of knowledge transfer, healthcare delivery, surveillance and health research. The sentence in your response about XMRV suggests that the advice you are receiving on ME/CFS is behind the times. Research on ME/FM will be of value to an understanding of many diseases and disorders. Support for research on ME/FM directly or indirectly benefits research on, for example, cancer, sleep disturbances, chronic pain, fatigue, neurological disorders, autoimmune diseases, and infectious diseases. We appreciate very much that two representatives from CIHR were at the IACFS/ME biennial conference. They held a meeting with research, clinical and patient representatives, and they agreed to host a research workshop in 2014. We have high hopes for this workshop.

To the Minster responsible for Statistics Canada, we very much appreciate the support we have received from the organization and are very appreciative that the questions on ME/CFS, FM and MCS are slated for inclusion on the Canadian Community Health Survey in four of the next eight years. The CCHS statistics have been extremely useful in describing the scope of the issues. We are interested in the Survey on Disability and hope to have input into it.

To the Minister responsible for the Canada Revenue Agency, thank you for considering the issues facing Canadians with ME/CFS. We would question whether the ME/FM community has equitable access to the Disability Tax Credit and the various programs that are based on it.

To the President of the Treasury Board, please consider how well federal employees who become disabled through ME/CFS or FM are accommodated or supported.

To the Minister of Justice, your response was a surprise. We were expecting you to refer us to the group responsible for human rights, but instead you referred us to the group responsible for ethics, conflict resolution and wellness. We are interested in learning more about this group. We are also looking forward to be invited to participate in future consultations at the Department of Justice.

Overall, the responses show that ME/CFS is starting to gain traction, but that there is a lot of work to be done. Very importantly, the response opens doors for dialogue.

A special mention goes to the individual who worked with Dr Fry to have the questions placed on the order paper. People ask why FM wasn't included. Remember that this was a private initiative. FM patients have the opportunity to ask a Member of Parliament to submit questions about FM.

Special mention also goes to the people who contacted their Members of Parliament to say that they were interested in receiving the government response. This would have encouraged the government to put extra effort into their answers.

Please feel free to talk to your Member of Parliament about your reaction to the order paper questions and response and about what you wish to see happen at the federal level.

Margaret Parlor, President

House of Commons Order Paper

Questions:

Q-2442 - January 28, 2014 - Ms. Fry (Vancouver Centre) - With regard to Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS):

(a) how much money has the Canadian Institute for Health Research (CIHR) invested or allocated into researching ME/CFS in 2012-2013 and 2013-2014, specifically into: (i) the etiology, (ii) diagnostic markers, (iii) pathophysiology, (iv) treatment of ME/CFS;

(b) how much research has CIHR funded into treating ME/CFS with (i) Rituximab, (ii) other autoimmune medications, (iii) anti-viral medications, (iv) other medications;

(c) what strategies has CIHR designed and implemented to ensure that ME/CFS research is fairly funded;

(d) what strategies has CIHR designed and implemented to (i) develop a ME/CFS scientific research community in Canada, (ii) ensure that the ME/CFS research community is multidisciplinary bringing together immunologists, neurologists, cardiologists, endocrinologists, system biologists, geneticists, etc.;

(e) has CIHR considered creating a new institute to focus on this emerging area;

(f) has CIHR outlined areas of ME/CFS research as priorities for funding, and designating a specific amount of money for ME/CFS research and, if so, how much;

(g) will CIHR amend the grant application process to remove the barriers for new and stigmatized conditions to ensure that ME/CFS as an emerging area of research has a fair chance of being funded;

(h) how has the government, including (i) Health Canada (HC), (ii) CIHR, (iii) Public Health Agency of Canada (PHAC), (iv) Employment and Social Development Canada (ESDC), (v) Statistics Canada (StatCan), (vi) Department of Justice Canada (JUS), (vii) Treasury Board of Canada Secretariat (TBS) and (viii) Canada Revenue Agency (CRA) educated itself on ME/CFS;

(i) did representatives from (i) HC, (ii) CIHR, (iii) PHAC attend or will they be attending (1) the Invest in ME International Conferences, (2) the Biennial International Association for CFS/ME Conference in Ottawa in 2011, (3) 2014 Stanford University ME/CFS Symposium on March 19, 2014, (4) the Biennial International Association for CFS/ME Conference co-hosted by Stanford University from March 20-23, 2014;

Q-2442 - 28 janvier 2014- Mme Fry (Vancouver-Centre)- En ce qui concerne les Canadiens atteints de l'encephalomyélite myalgique ou syndrome de fatigue chronique (EM/SFC) :

a) combien d'argent les Instituts de recherche en santé du Canada (IRSC) ont-ils affecté aux recherches sur l'EM/SFC en 2012-2013 et 2013-2014, notamment sur (i) l'étiologie, (ii) les marqueurs diagnostiques, (iii) la pathophysiologie, (iv) le traitement;

b) quelle est l'ampleur des recherches subventionnées par les IRSC sur le traitement de l'EM/SFC par (i) le rituximab, (ii) d'autres médicaments auto-immuns, (iii) des médicaments antiviraux, (iv) d'autres médicaments;

c) quelles stratégies les IRSC ont-ils mises au point et en oeuvre pour subventionner de façon équitable les recherches sur l'EM/SFC;

d) quelles stratégies les IRSC ont-ils mises au point et en oeuvre pour (i) constituer au Canada une collectivité de la recherche sur l'EM/SFC, (ii) faire en sorte que cette collectivité compte à la fois des immunologues, des neurologues, des cardiologues, des endocrinologues, des biologistes des systèmes, des généticiens, etc.;

e) les IRSC envisagent-ils de créer un institut de recherche sur cette maladie;

f) les IRSC ont-ils fait de certains domaines de la recherche sur l'EM/SFC des priorités de financement et, si oui, quel budget leur affectent-ils;

g) les IRSC modifieront-ils le processus de demande de subvention de manière à supprimer les obstacles à la recherche sur les maladies nouvelles et stigmatisées et à garantir que la recherche sur l'EM/SFC pourra obtenir sa juste part des subventions;

h) comment le gouvernement, y compris (i) Santé Canada (SC), (ii) les IRSC, (iii) l'Agence de la santé publique du Canada (ASPC), (iv) Emploi et Développement Social Canada (EDSC), (v) Statistique Canada, (vi) le ministère de la Justice Canada (MJC), (vii) le Secrétariat du Conseil du Trésor du Canada (SCT), (viii) l'Agence du revenu du Canada (ARC), se sensibilisent-ils à l'EM/SFC;

i) des représentants (i) de SC, (ii) des IRSC, (iii) de l'ASPC ont-ils assisté ou vont-ils assister (1) aux conférences internationales sur l'investissement dans la recherche sur l'EM, (2) à la conférence biennale de l'Association internationale de l'EM/SFC à Ottawa en 2011, (3) au colloque de l'Université Stanford sur l'EM/SFC le19 mars 2014, (4) à la conférence biennale de l'Association internationale de l'EM/SFC organisée conjointement avec l'Université Stanford du 20 au 23 mars 2014;

(j) to what extent has the government, including (i) HC, (ii) CIHR, (iii) PHAC, (iv) ESDC, (v) StatCan, (vi) JUS, (vii) TBS, (viii) CRA, fulfilled its obligation under the UN Convention on Rights of Persons with Disabilities (article 4.3) to closely consult with and actively involve people with ME/CFS through their representative organizations, notably the National ME/FM Action Network;

j) dans quelle mesure le gouvernement, y compris (i) SC, (ii) les IRSC, (iii) l'ASPC, (iv) EDSC, (v) Statistique Canada, (vi) le MJC, (vii) le SCT et (viii) l'ARC, s'acquitte-t-il de l'obligation que lui fait l'article 4.3 de la Convention sur les droits des personnes handicapées de consulter étroitement et de faire activement participer les personnes atteintes de l'EM/SFC par l'intermédiaire des organisations qui les représentent, notamment le Réseau national d'action EM/FM;

(k) when will (i) the Minister of Health, (ii) Health Canada (iii) CIHR, (iv) PHAC, (v) ESDC, (vi) StatCan, (vii) JUS, (viii) TBS, (ix) CRA next meet with the National ME/FM Action Network;

k) quand (i) le ministre de la Santé, (ii) Santé Canada (iii) les IRSC, (iv) l'ASPC, (v) EDSC, (vi) Statistique Canada, (vii) le MJC, (viii) le SCT, (ix) l'ARC se réuniront-ils à nouveau avec le Réseau national d'action EM/FM;

(l) when will foundational documents, notably (i) CFS/ME: A Primer for Clinical Practitioners, (ii) Profile and Impact of 23 Chronic Conditions in the 2005 Canadian Community Health Survey, be posted on government information websites in English and French;

l)quand le gouvernement affichera-t- il sur ses sites web en anglais et en français les documents de base comme (i) CFS/ME: A Primer for Clinical Practitioners et (ii) Profile and Impact of 23 Chronic Conditions de l'Enquête sur la santé dans les collectivités canadiennes de 2005;

(m) how is the government working with the provinces, territories, professional organizations, educational institutions and other stakeholders to meet the needs of Canadians with ME/CFS;

m) comment le gouvernement collabore-t-il avec les provinces, les territoires, les organismes professionnels, les établissements d'enseignement et les autres intervenants pour répondre aux besoins des Canadiens atteints d'EM/SFC;

(n) what steps has the government taken to ensure that ME/CFS patients in its jurisdiction have access to appropriate medical care;

n) quelles mesures le gouvernement a-t-il prises pour que les personnes atteintes d'EM/SFC relevant de sa compétence aient accès aux soins voulus;

(o) how many medical professionals in Canada including (i) doctors, (ii) nurses currently specialize in ME/CFS and how is the Health Human Resources Strategy ensuring that there will be an adequate supply of health providers specializing in ME/CFS in Canada in the future;

o) au Canada, combien de professionnels de la santé, notamment (i) de médecins, (ii) d'infirmières, se spécialisent dans le traitement de l'EM/SFC et que prévoit la Stratégie pancanadienne relative aux ressources humaines en santé pour assurer un nombre suffisant de professionnels de la santé spécialisés dans le traitement de l'EM/SFC;

(p) how is the Health Care Policy Contribution Program being used to improve health care for ME/CFS patients;

p) comment le Programme de contributions pour les politiques en matière de soins de santé sert-il à améliorer les soins prodigués aux personnes atteintes d'EM/SFC;

(q) how is the government working with stakeholders to deal with other needs of Canadians with ME/CFS shown by the 2005 and 2010 Canadian Community Health Survey (CCHS) including (i) reducing the levels of unmet home care needs, (ii) reducing the levels of food insecurity, (iii) increasing the sense of community belonging experienced by Canadians with this condition;

q) comment le gouvernement collabore-t-il avec les intervenants pour répondre aux autres besoins des Canadiens atteints de l'EM/SFC tels que définis dans l'Enquête sur la santé dans les collectivités canadiennes de 2005 et de 2010, y compris (i) réduire le niveau de besoins non satisfaits en soins à domicile, (ii) réduire l'insécurité alimentaire, (iii) accroître le sens d'appartenance à la collectivité des Canadiens atteints de cette maladie;

(r) why has the CCHS decided to monitor the extent and impact of ME/CFS, only every four years;

r) pourquoi l'Enquête sur la santé dans les collectivités canadiennes a-t-elle décidé d'évaluer tous les quatre ans seulement· l'ampleur et l'impact de l'EM/SFC;

(s) will the government review disability programs and services to ensure that they cover the full spectrum of disabilities so that people with ME/CFS have fair and equitable access and will the government review the information and documents it disseminates to ensure that ME/CFS issues are presented adequately and fairly;

s) le gouvernement examinera-t-il les programmes et les services offerts en cas d'invalidité pour s'assurer que les personnes atteintes d'EM/SFC y ont accès de façon juste et équitable et examinera-t-il l'information et les documents qu'il diffuse pour s'assurer que l'EM/SFC y est présentée de façon juste et équitable;

(t) when will the Canada Pension Plan-Disability Adjudication Tool that guides adjudicators in their assessment of ME/CFS, Fibromyalgia, Multiple Chemical Sensitivities and Chronic Pain cases be reviewed in conjunction with the stakeholder communities to ensure that people with the conditions have fair and equal access to Canada Pension Plan-Disability; and

(u) when will the Canada Pension Plan-Disability Adjudication Tool that guides adjudicators in their assessment of ME/CFS, Fibromyalgia, Multiple Chemical Sensitivities and Chronic Pain cases be posted on government websites?

t) quand le Cadre d'évaluation de l'invalidité du Régime de pensions du Canada en ce qui concerne l'EM/SFC, la fibromyalgie, la polysensibilité aux produits chimiques et la douleur chronique sera-t-il examiné conjointement avec les collectivités d'intervenants pour faire en sorte que les personnes atteintes de ces affections aient un accès juste et équitable au Programme de prestations d'invalidité du Régime de pensions du Canada;

u) quand le gouvernement publiera-t-il sur ses sites web le Cadre d'évaluation de l'invalidité du Régime de pensions du Canada en ce qui concerne l'EM/SFC, la fibromyalgie, la polysensibilité aux produits chimiques et la douleur chronique?

Answers to Order Paper Questions from Ministries:

Note: The government's response was provided on scanned hardcopy, and converted to electronic form by an optical character reader. Small typographic errors may have been introduced in the process.

Minister of National Revenue (CRA) - Honourable Kerry-Lynn Findlay

With respect to the above-noted question, what follows is the response from the Canada Revenue Agency (CRA). The CRA has been asked to answer to Parts (h)(viii), (})(viii) and (k)(ix).

Part (h)(viii): The CRA administers the Disability Tax Credit (DTC) based on the criteria set in the Income Tax Act (ITA). The DTC is a non-refundable credit that may reduce the amount of income tax that either a person with a disability or their supporting person has to pay. To qualify, an individual must have a severe and prolonged impairment in physical or mental functions, as defined in the ITA and as certified by a qualified practitioner. The ITA is very clear in that the medical condition itself is not a considering factor in determining an individual's eligibility for the DTC, but rather the effects that the impairment has on the person's ability ta perform one of the basic activities of daily living (e.g., walking, dressing, speaking, etc.).

Individuals diagnosed with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) may be eligible for the DTC if they are markedly restricted in performing at least one of their basic activities of daily living, all or substantially all of the time.

Part (/)(viii): Though the UN Convention on Rights of Persons with Disabilities does not specifically require the CRA to consult with ME/CFS, the CRA will continue to consult and communicate with persons with disabilities, the general public,

Ministre Du Revenu National - l'honorable Kerry-Lynn Findlay

En ce qui concerne la question ci-dessus, vous trouverez ci-après la réponse de l'Agence du revenu du Canada (ARC). On a demandé à l'ARC de répondre aux parties h)(viii), j)(viii) et k)(ix).

Partie h)(viii) : L'ARC administre le crédit d'impôt pour personnes handicapées (CIPH) selon les critères établis dans la Loi de l'impôt sur le revenu (LIR). Le CIPH est un crédit non remboursable pouvant réduire le montant d'impôt sur le revenu à verser par une personne handicapée ou par une personne ayant une personne handicapée à sa charge. Pour être admissible, un particulier doit avoir une déficience grave et prolongée des fonctions physiques ou mentales, conformément à la LIR, telle qu'attestée par un praticien qualifié. La LIR précise clairement que la condition médicale en soi n'est pas un facteur décisif lors de la détermination de l'admissibilité d'une personne au CIPH, mais que ce sont plutôt les effets que la déficience a sur la capacité de la personne à accomplir une des activités courantes de la vie quotidienne (p. ex. marcher, s'habiller et parler).

Les personnes qui ont reçu un diagnostic d'encéphalomyélite myalgique ou syndrome de fatigue chronique (EM/SFC) pourraient être admissibles au CIPH si elles sont considérées comme étant limitées de façon marquée ·dans leur capacité à effectuer au moins une des activités courantes de la vie quotidienne, toujours ou presque toujours.

Partie j)(viii) : Même si la Convention sur les droits des personnes handicapées des Nations Unies n'exige pas spécifiquement que l'ARC consulte les personnes atteintes de l'EM/SFC, l'ARC continuera de consulter les personnes handicapées, le grand

other government departments, qualified practitioners, disability associations, and medical associations concerning the eligibility criteria for the DTC, how to apply for the credit and ways to improve the processing of applications.

Part (k)(ix): With respect to when the CRA will next meet the National ME/FM Action Network, the CRA does not have any plans to meet with the National ME/FM Action Network at this time.

Minister of Employment and Social Development Canada-Honourable Jason Kenney

(h) how has the government, including (iv) Employment and Social Development Canada (ESDC), educated itself on ME/CFS.

- Representatives of the National Myalgic Encephalomyelitis and Fibromyalgia (ME/FM) Action Network met with officials of Employment and Social Development Canada's (ESDC) Office for Disability Issues (ODI}. During the meeting, both organizations exchanged information on their mandate and program objectives. The Network also expressed an interest to work more closely with government officials to improve the lives of people suffering from ME/FM.
- ODI invited the National ME/FM Action Network to participate in a consultative process, as part of its efforts to consult with stakeholders on the eligibility requirements for the creation of a national funding stream. The National ME/FM Action Network declined to participate in this process.

(j) to what extent has the government, including (iv) ESDC, fulfilled its obligation under the UN Convention on Rights of Persons with Disabilities (article 4.3) to closely consult with and actively involve people with ME/CFS through their representative organizations, notably the National ME/FMAction Network.

• ESDC. has fulfilled its obligation with respect to Article 4.3 of the UN Convention on Rights of Persons with Disabilities.

(k) when will (v) ESDC, next meet with the National ME/FM Action Network.

• ESDC has informed the National ME/FM Action Network that they would like to keep an ongoing dialogue and are available to meet whenever the ME/FM Action Network is available.

Minister Of Health - Honorable Rona Ambrose

The Government of Canada is committed to a publicly funded, universally accessible healthcare system that provides

public, d'autres ministères ou organismes gouvernementaux, les praticiens qualifiés, les associations pour personnes handicapées et les associations médicales, et de communiquer avec eux, concernant les critères d'admissibilité au CIPH, la façon de demander le crédit et les moyens d'améliorer le traitement des demandes,.

Partie k)(ix) : En ce qui concerne le fait de savoir quand l'ARC se réunira à nouveau avec le Réseau · national d'action EM/FM, pour le moment, l'ARC ne prévoit pas rencontrer le Réseau national d'action EM/FM.

Ministre De L'emploi Et Du Développement Social - l'honorable Jason Kenney

h) Comment le gouvernement, y compris (iv) Emploi et Développement social Canada (EDSC), se sensibilisent-ils à l'EM/SFC?

- Des représentants du Réseau national d'action encéphalomyélite myalgique et fibromyalgie (EM/FM) ont rencontré des agents du Bureau de la condition des personnes handicapées (BCPH) d'Emploi et Développement social Canada (EDSC). Pendant cette rencontre, les deux organisations ont échangé de l'information relativement à leur mandat et à leurs objectifs de programmes. Les représentants du Réseau ont par ailleurs manifesté leur intérêt à travailler plus étroitement avec les agents du gouvernement afin d'améliorer la vie des personnes atteintes d'EM/FM.
- Le BCPH a invité le Réseau national d'action EM/FM à participer au processus de consultation des parties intéressées relativement aux critères d'admissibilité en vue de la création d'un volet de financement national. Le Réseau national d'action EM/FM a refusé de prendre part à ce processus.

j) Dans quelle mesure le gouvernement, y compris (iv) EDSC, s'acquitte-t-il de l'obligation que lui fait l'article 4.3 de la Convention sur les droits des personnes handicapées de consulter étroitement et de faire activement participer les personnes atteintes de l'EM/SFC par l'intermédiaire des organisations qui les représentent, notamment le Réseau national d'action EM/FM?

• EDSC s'est acquitté de ses obligations que lui fait l'article 4.3 de la Convention sur les droits des personnes handicapées.

k) Quand (v) EDSC se réuniront-ils à nouveau avec le Réseau national d'action EM/FM?

• EDSC a informé le Réseau national d'action EM/FM qu'il aimerait garder un dialogue permanent et ils sont disponibles pour des rencontres à la convenance du Réseau d'Action ME/ME.

La Ministre De La Santé – l'honorable Rona Ambrose

Le gouvernement du Canada est déterminé à offrir un système de soins de santé public et universel qui garantit l'accès aux

healthcare for all Canadians, according to the criteria and conditions of the Canada Health Act. While the provinces and territories have primary responsibility for the design, delivery and management of healthcare in their jurisdictions, federal actions and investments make an important contribution. Federal funding through the Canada Health Transfer will reach a record high of $30.3 billion this year and continue to grow to more than $40 billion by the end of the decade. These investments will help ensure that Canada's healthcare system continues to be sustainable over the long-run, and provides the provinces and territories with both the certainty they need to plan a head and the flexibility to invest where they see fit.

The management and treatment of Myalgie Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) is not unique to a specific medical or nursing specialty in Canada. As such, reliable data on the number of healthcare professionals practicing in this field is presently unavailable. While provincial and territorial governments plan for and manage their health workforces, the federal government acts within its jurisdiction to help them and health system stakeholders create and maintain a health workforce that meets the needs of all Canadians. Health Canada's Health Care Policy Contribution Program (HCPCP), which includes the Health Human Resources Strategy, is a national program designed to promote policy research and analysis, evidence-based projects and evaluations on current and emerging healthcare system priorities. The HCPCP has not provided funding specific to the healthcare needs of patients with ME/CFS, however, it has made investments to support key areas such as: health human resources, the integration of internationally educated ·health professionals, access and wait times, primary healthcare, chronic disease management, home and continuing care, quality care, patient safety, and palliative and end-of-life care.

Federal investments to support the health human resources needs of Canadians include: $39.5 million, over six years, to support the training of up to 100 family physicians in rural and remote communities across Canada; $9 million per year in Canada Student Loan relief for new family physicians, medical residents, nurse practitioners and nurses who choose to practice in rural and underserved communities; $18 million per year to support the integration of internationally trained health professionals and advancement of the Pan-Canadian Framework for the Assessment and Recognition of Foreign Qualifications; $6.5 million for a research project at McMaster University to evaluate team-based approaches to healthcare delivery; and, nearly $4 million in support of a multi-stakeholder project on the Future of Medical Education in Canada, including the implementation of recommendations that will help align medical education with population health needs.

Consistent with its public health surveillance mandate,

soins de santé pour tous les Canadiens, conformément aux dispositions de la Loi canadienne sur la santé. Bien que les provinces et les territoires soient principalement responsables de la conception, de la prestation et de la gestion des soins de santé sur leur territoire, les mesures et les investissements du fédéral y apportent une contribution importante. Dans le cadre du Transfert canadien en matière de santé (TCS), le financement fédéral atteindra un sommet record de 30,3 M$ cette année et continuera d'augmenter pour atteindre plus de 40 M$ d'ici la fin de la décennie. Cette approche permettra d'assurer la pérennité du système de soins de santé canadien et donnera aux provinces et aux territoires la certitude nécessaire pour planifier et la flexibilité d'investir là où bon leur semble.

La prise en charge et le traitement de l'encéphalomyélite myalgique ou syndrome de fatigue chronique (EM/SFC) ne sont pas uniques à une spécialité médicale ou infirmière au Canada. Ainsi, aucune donnée fiable sur le nombre de professionnels de la santé exerçant dans ce domaine n'est actuellement disponible. Bien que les provinces et les territoires s'occupent de la planification et de la gestion de leurs effectifs de santé, le gouvernement fédéral agit dans les limites de ses compétences pour les aider et aider les intervenants du système de santé à créer et à maintenir un effectif de santé qui répond aux besoins de tous les Canadiens. Le Programme de contributions pour les politiques en matière de soins de santé (PCPSS) de Santé Canada, qui comprend la Stratégie relative aux ressources humaines en santé, est un programme national conçu afin de promouvoir la recherche et l'analyse des politiques, les projets et les évaluations fondés sur l'expérience relatifs aux priorités actuelles et émergentes du système de soins de santé. Le PCPSS ne prévoit pas le financement particulier des soins de santé des patients atteints d'EM ou du SFC; il comprend toutefois des investissements dans des secteurs clés comme les ressources humaines en santé, l'intégration des professionnels de la santé formés à l'étranger, l'accès aux soins et les temps d'attente, les soins primaires, la prise en charge des maladies chroniques, les soins à domicile et les soins continus, la qualité des soins, la sécurité des patients, les soins palliatifs et les soins de fin de vie.

Les investissements du gouvernement fédéral pour répondre aux besoins de la population en ressources humaines en santé comprennent: 39,5 M$ sur six ans pour soutenir la formation de près d'une centaine de médecins de famille en région rurale et éloignée au Canada; 9 M$ par an pour alléger les prêts étudiants canadiens des nouveaux médecins de famille, des médecins résidents, du personnel infirmier praticien et du personnel qui choisissent de travailler dans des collectivités rurales et mal desservies; 18 M$ par an pour soutenir l'intégration des professionnels de la santé formés· à l'étranger et l'avancement du Cadre pancanadien d'évaluation et de reconnaissance des qualifications professionnelles acquises à l'étranger; 6,5 M$ pour un projet de recherche de l'Université McMaster sur l'évaluation d'approches de soins en équipe; et près de 4 M$ pour soutenir

the Public Health Agency of Canada (PHAC) monitors the prevalence of ME/CFS using data from Statistics Canada's Canadian Community Health Survey (CCHS), a national health survey that asks Canadians about their health and well-being, the factors that affect their health, and their use of health care services. Data from the 2010 CCHS are available online at www.infobase.phac-aspc.gc.ca.

PHAC develops and provides surveillance information to ME/CFS stakeholders, including the National ME/FM Action Network. PHAC has worked with the National ME/FM Action Network for several years in analyzing surveillance findings on ME/CFS for the development and publication of scientific papers. PHAC officials meet with the National ME/FM Action Network as necessary pertaining to the analysis of surveillance data. Meetings were held in June 2012 and January 2013 to discuss the needs and

challenges of ME/CFS patients, developments in surveillance, collaborate on scientific papers, and facilitate the Network's access to federal data.

PHAC currently provides document links for CFS/ME: A Primer for Clinical Practitioners on its website (www.phac-aspc.gc.ca/dpg-eng.php#cfs). PHAC ·officials also attended the Biennial International Association for ME/CFS Conference in Ottawa in 2011.

Since 2006/07, the Government of Canada, through the Canadian Institutes of Health Research (CIHR), has invested over $231K in research related to Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), including more than $198K in 2012/13 alone. The 2012/13 projects included an operating grant entitled "Structure function analysis of the dual protein kinase-RNase signalling proteins and the eIF2a protein kinases", which is aimed at determining the structure function of protein kinases; including RNaseL, whose function has been found to be perturbed in patients with chronic-fatigue syndrome (CFS). Another CIHR-funded new investigator award, "Characterization of a glycoprotein entry complex from a novel human retrovirus", aims to understand the viral life cycle of, and how xenotropic murine leukemia virus-related virus (XMRV) enters the human host. XMRV was recently detected in a large proportion of CFS patients and understanding its function may help provide a template for novel entry inhibitors and therapeutics.

CIHR's Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA)is deeply engaged in understanding the research agenda for ME/CFS through attendance at scientific meetings. Also, CIHR-IMHA aims to raise awareness about ME/CFS and other health issues through, newsletters to its research community. This past May, CIHR-IMHA highlighted that May 12 is Fibromyalgia and Chronic Fatigue Syndrome National Awareness Day.

CIHR-IMHA is also focused on fostering international

un projet multilatéral sur l'avenir de l'éducation médicale au Canada, y compris la mise en oeuvre de recommandations qui contribueront à adapter l'enseignement médical aux besoins de la population en matière de santé.

Conformément à son mandat de surveillance de la santé publique, l'Agence de la santé publique du Canada (ASPC) surveille la prévalence d'EM/SFC au moyen des données de l'Enquête sur la santé dans les collectivités canadiennes (ESCC) de Statistique Canada, une enquête nationale qui pose aux Canadiens des questions sur leur santé et leur bien-être, les facteurs qui affectent leur santé, ainsi que leur utilisation des services de soins de santé. Les données de l'ESCC de 2010 sont accessibles en ligne à www.infobase.phac-aspc.gc.ca.

L'ASPC produit et fournit des données de surveillance aux intervenants d'EM/SFC, y compris le Réseau national d'action EM/FM. Depuis plusieurs années, l'ASPC collabore avec le Réseau national d'action EM/FM à l'analyse des données de surveillance sur l'EM et le SFC en vue de l'élaboration et de la publication d'articles scientifiques. Des agents de l'ASPC rencontrent des responsables du Réseau national d'action EM/FM au besoin en ce qui concerne l'analyse des données de surveillance. Des réunions ont eu lieu en juin 2012 et en janvier 2013 afin de discuter des besoins et des défis des patients atteints d'EM/SFC, des développements en matière de surveillance, collaboré sur des articles scientifiques, et pour faciliter l'accès des membres du Réseau aux données fédérales.

En outre, l'ASPC offre sur son site Web un lien vers le document CFS/ME: Petit guide pour la médicine clinique (http://www.phac-aspc.gc.ca/dpg-fra.php#sfc). Des agents de l'ASPC ont aussi participé à la conférence biennale de l'Association internationale de l'EM/SFC à Ottawa en 2011.

Depuis 2006-2007, le gouvernement du Canada, par l'entremise des Instituts de recherche en santé du Canada (IRSC), a investi plus de 231 000$ dans la recherche sur l'encéphalomyélite myalgique ou syndrome de fatigue chronique (EM/SFC), dont plus de 198 000 $ en 2012-2013 seulement. Une subvention de fonctionnement a entre autres été accordée en 2012-2013 au projet « Analyse structure-fonctionnelle des protéines de signalisation à double fonction protéine kinase et RNase et des protéines kinases eIF2a » qui a pour but de déterminer la structure-fonction de protéines kinases, notamment RNaseL, dont la fonction perturbée a été observée chez les personnes atteintes du syndrome de fatigue chronique (SFC). Une autre bourse de nouveau chercheur financée par les IRSC, « Caractérisation d'un complexe d'entrée glycoprotéique d'un nouveau rétrovirus humain », vise à comprendre le cycle de vie du virus apparenté au virus de la leucémie murine xénotrope (XMRV) et la façon dont il envahit l'hôte humain. XMRV a récemment été isolé chez une importante proportion de personnes atteintes du SFC, et comprendre sa fonction pourra aider à fournir un gabarit pour de nouveaux inhibiteurs d'entrée et produits thérapeutiques.

discussion and understanding of MEICFS. As such, it will be sending two representatives, Dr. Hani El-Gabalawy, Scientific Director of IMHA and Liz Stirling, Assistant Director of IMHA, to the Biennial International Association for CFS/ME Conference co-hosted by Stanford University from March 20-23, 2014.

CIHR has good ties with the research community in this field and many of our staff have an understanding of the impact, complexities and challenges the conditions pose on so many Canadians. Our team is always open to discussing opportunities and concerns with our research community and relevant stakeholders. Additionally, since ME/CFS falls under the mandate of numerous CIHR Institutes, the research community is encouraged to contact the Assistant Directors of the Institutes as well as to monitor CIHR's ongoing funding opportunities.

L'Institut de l'appareil locomoteur et de l'arthrite des IRSC (IALA des IRSC) s'investit à fond pour comprendre le programme de recherche sur l'EM/SFC en assistant à des rencontrés scientifiques. Il accroît également la sensibilisation à l' EM/SF C et à d'autres questions de santé par des bulletins d'information destinés à sa communauté de recherche. Le 12 mai dernier, l'IALA des IRSC a souligné la Journée nationale de sensibilisation à la fibromyalgie et au syndrome de fatigue chronique.

L'IALA des IRSC s'efforce aussi de favoriser la discussion et la compréhension de l'EM/SFC au niveau international. Le Dr Hani EI-Gabalawy, directeur scientifique de l'IALA, et Liz Stirling, directrice adjointe de l'IALA, assisteront à la conférence biennale de l'Association internationale pour l'EM/SFC dont l'Université Stanford sera un des hôtes du 20 au 23 mars 2014.

Les IRSC entretiennent de bons liens avec le milieu de la recherche dans le domaine, et plusieurs membres de notre personnel comprennent l'impact, la complexité et les défis que les affections en question représentent pour tant de Canadiens. Notre équipe est toujours prête à discuter des possibilités qui se présentent et des préoccupations qui existent avec le milieu de la recherche et les intervenants concernés. En outre, puisque l'EM/SFC relève du mandat de plusieurs instituts des IRSC, les chercheurs sont encouragés à s'adresser aux directeurs adjoints des instituts ainsi qu'à surveiller les possibilités de financement courantes des IRSC.

Minister Of Industry - Honourable James Moore

With regard to Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS):

(h) Statistics Canada (STC) consults extensively with its federal, provincial and territorial stakeholders on the need to collect information on chronic conditions and diseases and relies on their expertise in this area to guide the content determination process of its surveys.

(j) STC has worked very closely with the Persons with Disabilities Technical Advisory Committee (TAG) in the development of the Canadian Survey on Disability. Regular consultations occur through face-to- face meetings, teleconference calls and emails between disability experts and members from the disability community.

In addition, the Canadian Community Health Survey (CCHS) team at STC has ongoing contact with the President of the ME/ FM Action Network and has built a relationship around open dialogue. The President has contacted the CCHS team with questions and has also provided answers to questions from STC on the ME/CFS.

(k) STC routinely consults the President of the ME/FM Action Network as needed during content consultation and development processes for the CCHS.

Ministre De L'industrie – l'honorable James Moore

En ce qui concerne les Canadiens atteints de l'encéphalomyélite myalgique ou syndrome de fatigue chronique {EM/SFC) :

(h)Statistique Canada (SC) tient des consultations exhaustives avec les intervenants fédéraux, provinciaux et territoriaux concernant la nécessité de recueillir des données sur les problèmes de santé chroniques et les maladies et il se fie à leur expertise dans ce domaine pour guider le processus de détermination du contenu de ses enquêtes.

(j) SC a collaboré très étroitement avec le Groupe consultatif technique (GCT) sur les personnes handicapées pour l'élaboration de l'Enquête canadienne sur l'incapacité. Des consultations régulières se poursuivent au moyen de réunions en personne, de conférences téléphoniques et courriels entre experts et représentants des personnes handicapées.

En outre, l'équipe de l'Enquête sur la santé dans les collectivités canadiennes (ESCC) à SC a des contacts permanents avec la présidente du Réseau national d'action EM/FM et a établi une relation basée sur un dialogue franc. Le Président a communiqué avec l'équipe de l'ESCC pour lui poser des questions et a aussi répondu aux questions de SC concernant ce problème de santé.

(k) SC consulte régulièrement la présidente du Réseau national d'action EM/FM au besoin pendant les processus de consultation sur le contenu et d'élaboration du contenu de l'ESCC. Il n'y a

(r) According to the CCHS content plan for 2015-2022 that was approved by the Canadian Population Health Survey Program (CPHSP), questions about ME/CFS will be included in CCHS for 2015, 2016, 2019 and 2020. To ensure an acceptable leve! of response burden for the CCHS, modules must be rotated in and out of the survey on a regular basis to manage the competing demands for increased information across a number of health dimensions. This process strikes a balance between the information needs of people interested in ME/CFS versus those interested in other health related topics such as functions health and food security.

Minister Of Justice And Attorney General Of Canada - Honourable Peter MacKay

(h) (vi) The Centre for Ethics, Conflict Management and Wellness of the Department of Justice does not offer services and tools specific to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Activities by the Centre focus on preventative measures that can be implemented to maximize overall personal well-being.

(j) (vi) Article 4.3 of the UN Convention on Rights of Persons with Disabilities (Convention) requires states to closely consult with and actively involve persons with disabilities in developing and implementing legislation and policies to implement the Convention. This obligation allows for a broad range of ways in which the government can engage persons with disabilities and their representative organizations. Pursuant to Article 4.3 of the Convention, the Department of Justice consults with persons with disabilities and their intermediary organizations in the development, design and evaluation of public policies, programs, legislation and services. This includes informal discussions and exchanges between officials from the Department of Justice and persons with disabilities. As a recent example, in-person and public consultations were held in the summer and fall of 2013 with disability organizations, professionals, and individuals with disabilities in developing the proposed Canadian Victims Bill of Rights.

(k) (vii) There are no current plans to meet with the National ME/FM Action Network.

President Of The Treasury Board - Honourable Tony Clement

The Treasury Board of Canada Secretariat is responsible for responding to parts (h){vii), O)(vii) and (k)(viii).

pas de plans confirmés pour le moment en vue de consulter le Réseau national d'action EM/FM, mais SC a les coordonnées du réseau et communiquera avec lui au besoin.

(r) Selon le plan de contenu de l'ESCC pour les années 2015 à 2022 qui a été approuvé par le Comité directeur du Programme des statistiques sur la santé de la population canadienne (PSSPC) le 13 décembre 2013, des questions concernant l'EM/SFC seront incluses dans l'ESCC pour 2015, 2016, 2019 et 2020. Pour assurer un fardeau de réponses acceptable à l'ESCC, les modules doivent être inclus de façon régulière sur une base rotative, afin de gérer le nombre croissant de demandes concurrentes de données en relation avec un certain nombre d'aspects de la santé. Ce processus établit un équilibre entre les besoins d'information des personnes intéressées par l'EM /SFC contre ceux qui s'intéressent à d'autres sujets liés à la santé tels que les fonctions de la santé et de la sécurité alimentaire.

Ministre De La Justice Et Procureur Général Du Canada – l'honorable Peter MacKay

h) (vi) Le Centre pour l'éthique, la gestion des conflits et le mieux-être du ministère de la Justice n'offre pas de services ou des outils qui sont spécifiques à l'encéphalomyélite myalgique ou syndrome de fatigue chronique (EM/SFC). Les activités offertes se concentrent plutôt sur des mesures préventives qui cherchent à maximiser le mieux-être personnel général.

j) (vi) L'article 4:3 de la Convention de l'ONU relative aux droits des personnes handicapées (Convention) oblige les états à consulter étroitement et faire activement participer les personnes atteint d'un handicape dans l'élaboration et la mise en oeuvre des lois et des politiques adoptées aux fins de l'application de la présente Convention. Cette obligation permet une vaste gamme de façons dont le gouvernement peut faire participer les personnes handicapées et leurs organisations.

Conformément à l'article 4.3 de la Convention, le ministère de la Justice consulte les personnes handicapées et les organisations qui leur servent d'intermédiaires à l'élaboration, à la conception et à l'évaluation des politiques, des programmes et des services. Ceci comprend des discussions et échanges informelles entre les fonctionnaires du ministère de la Justice et les personnes handicapées.

À titre d'exemple récent, des consultations publiques auprès d'organisations de personnes handicapées, de professionnels et de personnes handicapées ont été tenues au courant de l'été et de l'automne 2013 pour l'élaboration de la proposée Déclaration canadienne des droits des victimes.

k) (vii) Il n'y a pas de plans actuels pour rencontrer le Réseau national d'action EM/FM.

Président Du Conseil Du Trésor – l'honorable Tony Clement

Le Secrétariat du Conseil du Trésor du Canada est responsable de répondre aux parties h)(vii), j)(vii) et k)(viii).

(h) how has the government, including (vii) Treasury Board of Canada Secretariat (TBS), educated itself on ME/CFS; ... (j) to what extent has the government, including (vii) TBS, fulfilled its obligation under the UN Convention on Rights of Persons with Disabilities (article 4.3) to closely consult with and actively involve people with ME/CFS through their representative organizations, notably the National ME/FM Action Network; ... {k) when will {vii) TBS next meet with the National ME/FM Action Network.

With regard to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, the activities noted in the question are not part of the mandate of the Treasury Board of Canada Secretariat.

h) comment le gouvernement, y compris (vii) le Secrétariat du Conseil du Trésor du Canada {SCT) se sensibilisent-ils à l'EM/SFC;...l) dans quelle mesure le gouvernement, y compris (vii) le Secrétariat du Conseil du Trésor du Canada (SCT) s'acquitte-t-il de l'obligation que lui fait l'article 4.3 de la Convention sur les droits des personnes handicapées de consulter étroitement et de faire activement participer les personnes atteintes de l'EM/SFC par l'intermédiaire des organisations qui les représentent, notamment le Réseau national d'action EM/FM;...k) quand (viii) le SCT se réuniront-ils à nouveau avec le Réseau national d'action EM/FM;

En ce qui concerne l'encéphalomyélite myalgique ou syndrome de fatigue chronique, les activités qui sont énumérées dans la question ne font pas partie du mandat du Secrétariat du Conseil du Trésor du Canada.

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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] and The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4}] can be viewed on our website at www.mefmaction.net and is also available at Amazon.com or at Chapters.ca

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ME/CFS and FM Overviews - $7.00 each

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

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

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