**Order Paper Questions submitted January 28, 2014**

**Q-244**[2] — 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; (*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; (*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; (*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; (*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; (*n*) what steps has the government taken to ensure that ME/CFS patients in its jurisdiction have access to appropriate medical care; (*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; (*p*) how is the Health Care Policy Contribution Program being used to improve health care for ME/CFS patients; (*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; (*r*) why has the CCHS decided to monitor the extent and impact of ME/CFS, only every four years; (*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; (*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?

**Answers from Ministries:**

**Minister responsible for Canada Revenue Agency**

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, 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**

(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**

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

**MINISTER OF INDUSTRY**

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.

(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**

(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**

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