NATIONAL
ME/FM
ACTION NETWORK

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June 17, 2016

Bill Casey, MP
Chair, House of Commons Health Committee

Dear Sir

Thank you for meeting with the Anne Marie MacIsaac and me on Tuesday. We were representing the National ME/FM Action Network, a registered charity that has been working on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia since 1993.

We could have talked for days on the many issues and nuances around ME/CFS and FM. Instead, we focused on the letter you received from MP Robert Oliphant recommending that ME/CFS and FM be placed on the Health Committee agenda. The topic is important and we believe that the Health Committee could make an important contribution. I am attaching a review of our conversation. Please be aware that I have expanded on some of our discussions.

You agreed to ask the Health Committee members if they would add ME/FM to their priority list. There are already a number of issues on the list; therefore ME/FM would not come before the committee for discussion for some time. We understand, but also note that having ME/FM on the list would signal that this topic merits attention which by itself could open doors.

You also agreed to talk to the Minister of Health about issues that we raised.

Please also be aware that we plan to share this letter within our community. We truly appreciate your support and we know that others will too.

Yours truly

MParlor

Margaret Parlor
President

## Summary of Meeting – incorporating some additional thoughts/information:

Tuesday, June 14th, 10:30 am, Government House Lobby.
MP Bill Casey, Chair, House of Commons Health Committee,
Margaret Parlor, President, National ME/FM Action Network,
Anne Marie MacIsaac, Director, National ME/FM Action Network.

MP Robert Oliphant recommended that ME/CFS and FM be added to the Health Committee agenda. (Attachment 1) Before doing so, the Health Committee would undoubtedly ask two key questions.

- is the topic of ME/CFS and FM important enough to be put on the Health Committee agenda?
- is there valuable advice that the Health Committee could make to the government?

### Is the topic of ME/CFS and FM important enough to be put on the agenda?

You advised us that the Health Committee had already identified seventeen issues for their agenda, with priority being put on four of them (pharmacare, organ transplants, home care/palliative care and aboriginal health). We have no doubt that all seventeen topics are important, but we would argue that the topic of ME/FM is a major health issue as well.

ME/CFS and FM affect many Canadians. While most are women and most develop the conditions as adults, the illness affect people of different ages and genders. I described the case of a young man who "crashed" with ME/CFS and FM when he was 11 years old.

- After the crash, he could manage only about 40 minutes of school per day before his energy and concentration deserted him. This illustrates how debilitating ME/CFS and FM can be. (There are people with less serious and more serious cases.)
- The school was told that it was extremely important not to push him past his energy limit. They pushed him anyway which meant that it was unsafe for him to go to school. People with ME/CFS and FM are often mistreated.
- Problems in education policy around ME/CFS and FM were pointed out to the school board and the Ministry of Education. Years later, these problems still have not been corrected. This illustrates how little ME/FM voices are respected.
- Years later, this young man is still largely homebound. This illustrates that ME/CFS and FM can be a very long-term condition.

[In a British study, ME/FM was found to account for just over half the cases of long-term school absence among students, ahead of better known conditions like cancer, trauma or mental health. Pediatric ME/FM cases often go unrecognized since school absence is often attributed to motivational problems. Our organization has published a Sourcebook for Teachers, which is available free on line in both English and French.]

Statistics Canada's Canadian Community Health Survey estimates that there are over 800,000 Canadians who have a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia or both. The survey found that 20% of working age people who said they were permanently unable to work had one or both diagnoses. The statistics also show that people with ME/CFS or FM have high degrees of unmet health care needs despite frequent visits to health professionals.

The impact of the illness, the number of people involved, and the lack of services make ME/CFS and FM a very important health topic.

## Is there valuable advice that the Health Committee could make to the government?

ME/CFS and FM are multi-system illnesses that are very challenging for the health and social systems. Rather than seeking to understand the problems, the health system internationally has relied for years on a fantasy - that patients would get better with more exercise and better attitudes. Since the illnesses were viewed so simplistically, there was little need for research. Since the patient could control their illness, there was no need for clinical support – indeed clinical support might encourage illness behaviour. Since the patient could control their illness, they did not really deserve disability benefits.

The community has fought back, building the case that these illnesses are real, pointing out strategies that do help, and pointing out avenues for research. The community's line of thinking has been endorsed in several recent US documents, including one by the prestigious US Institute of Medicine.

Canada's health and social policy is firmly rooted in the old approach. Canada is having real difficulty admitting that the old approach does not work and needs to be dismantled and replaced. This inertia is leaving patients extremely frustrated.

We gave you a list of action patients would like to see happen (Attachment 2). To some extent, this list is asking the Health Committee to pick sides, something we would strongly recommend but something the committee might not be ready to do.  At this stage, the Health Committee could be asking questions such as:

- Why is research funding so low considering the prevalence and impact of these illnesses and the significant research findings internationally? (For comparative research statistics for last fiscal year and this fiscal year, see attachment 3)
- How is Canada's health system planning to serve people with these conditions in the years to come?
- What strategies is the public health system implementing to protect people with exertion intolerance from being pushed beyond their limits?
- What messages about ME/CFS and FM are being conveyed on Government of Canada websites?
- How many public servants are looking at ME/CFS and FM issues?
- How is the government working with the ME/FM community?

## Other comments

We provided statistics on CIHR research funding for selected conditions (attachment 3). Cancer was not included. At your request, we have just done a search for 2016-17 funding. Cancer funding was $112M which works out to about $200/patient using the CCHS 2010 figure for Cancer. HIV/AIDS funding (also not in the table) was around $20M, which works out to about $270 per HIV/AIDS patient in Canada.

[These numbers are not strictly comparable because they would include research approved since attachment 3 was compiled in April. However, approved funding has increased only 2% overall since then so this should not be a big issue.  Please also consider the methodological notes with the tables.]

We know that there can be very good reasons why different conditions do not receive the same per capita funding. Nevertheless, we see no acceptable reason why ME/CFS and FM funding is as low as it is. CIHR's response is that the current funding is a result of the process they follow. We conclude that their process has systemic biases.

Incidentally, you could be asking CIHR to publish comparative funding figures. They are important public information and figures like these are published by the government funding agencies in other countries.

ME/CFS and FM overlap with each other and overlap with chronic Lyme disease. The relationship between these illnesses needs to be sorted out.

You asked us to identify Member of Parliament who were interested in this issue and who might perhaps champion our cause. It is unlikely that any MP's are directly affected – they would not be able to keep up with the work required. We have not been made aware of any spouses, partners or family members affected. We do know that both Dr Fry and Dr Bennett had ME/FM patients when they were in private practice and we know that Mr Oliphant had people with these illnesses in his congregation. There are conversations going on with individual Members of Parliament. We are building support, but it is a slow process. Complicating this is that fact that many members of our community have difficulty with conversations or meetings.

We are in close touch with the international community. Events are moving rapidly. Canada is highly regarded on the international scene for developing the “CCC”, the Canadian Clinical Criteria for ME/CFS. However, any advantage Canada had is being frittered away by inaction.

We were pleased to provide you with several documents:

- the Canada Pension Plan Disability Guide Application and Appeals Guide now available on our website in French as well as English. Dr Fry will be notifying MP's about this resource.
- Statistics from the 2005 Canadian Community Health Survey (Quest 80, 2009 under resources on our website)
- Overviews of the ME/CFS and FM Canadian Consensus documents (available in English, French and other languages on our website)

**ATTACHMENT 1**

HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

March 23, 2016

Bill Casey, M.P.
Chair of the House of Commons Standing Committee on Health
House of Commons
Ottawa, ON K1A 0A6

Dear Mr. Casey:

I am writing to you in your capacity as Chair of the House of Commons Standing Committee on Health regarding the crucial issue of myalgic encephalomyelitis/chronic fatigue syndrome and fibromyalgia, or ME/CFS and FM. Some 756,000 Canadians have been diagnosed with one of these chronic neuroimmune diseases that severely impair their well-being, enjoyment of life and ability to engage fully in the economy. I personally have a number of friends, colleagues and former parishioners who have lived with it. Unfortunately, there are no Health Canada approved treatments for ME/CFS and only a few modest ones for FM.

Research into ME/CFS and FM is underfunded in Canada. Although our government has taken some laudable actions, including some notable investments through the Canada Institutes for Health Research, the severity of these conditions requires a broader strategy as well as funding more proportional to their prevalence. I think the Standing Committee on Health could offer important advice to the government through a study of this issue.

I have enclosed a fact sheet from the National ME/FM Action Network, which I found to be very helpful in explaining the situation in Canada. I encourage the committee to investigate this critical health issue.

Yours truly,

Rob Oliphant

Robert Oliphant, M.P.
Don Valley West

C.C. Hon. Jane Philpott, Minister of Health
Hon. Bill Morneau, Minister of Finance
Hon. Carla Qualtrough, Minister of Sport and Persons with Disabilities
Maureen MacQuarrie ✓

Enclosure

Robert Oliphant, M.P.
Don Valley West
House of Commons
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## ATTACHMENT 2

If ME/FM were to be discussed by the Health Committee, what recommendations might be made?

- Respect for patients. Respect for biological basis for illness. Meaningful inclusion in decision-making. Public servants familiar with ME/FM. Review government websites for their portrayal of ME/FM.

- larger investment in ME/FM research and knowledge translation
  - ballpark $20M per year
  - make it known that researchers can plan careers around ME/FM

- more comprehensive ME/FM surveillance
  - ME and FM on CCHS every year
  - data analysed immediately, results used as performance measures
  - special studies (eg food security, housing)

- vision a health system that meets ME/FM patient needs
  - at least 300 full time doctors supported by physiotherapists, occupational therapists, nurses, naturopaths, social workers etc
  - recognition of pediatric and homebound patients and patients in remote areas
  - define roles/competencies

- work with medical associations, provinces/territories to implement the vision

- health promotion – deal with implications of exertion intolerance
  - nuance exercise recommendations
  - replace FM guidelines

- ensure people with ME/FM have fair access to disability benefits – CPP-D, DTC, homecare, workplace accommodation, etc.

- increase public awareness of ME/FM, remove stigma.

# ATTACHMENT 3

CIHR funding of research into chronic conditions
during the period April 2015 – March 2016
using keyword searches of the CIHR funded research database
(sorted by average per-patient funding)

| **Keyword** | Average per patient funding 2015-2016 | Canadians affected CCHS 2010 | CIHR funding 2015-2016 | Number of studies funded 2015-2016 |
|---|---|---|---|---|
| Parkinson | $416.03 | 39,000 | $16,225,287 | 143 |
| Alzheimer | $216.67 | 111,500 | $24,158,331 | 236 |
| Muscular dystrophy | $194.81 | 26,000 | $5,065,044 | 50 |
| Cerebral palsy | $81.20 | 36,000 | $2,923,331 | 25 |
| Epilepsy | $77.60 | 134,500 | $10,436,836 | 83 |
| Multiple Sclerosis | $60.66 | 108,500 | $6,581,893 | 57 |
| Dystonia | $43.05 | 15,500 | $667,337 | 7 |
| Diabetes | $31.66 | 1,841,500 | $58,304,526 | 555 |
| Tourette | $25.22 | 18,000 | $453,969 | 3 |
| Crohn | $23.89 | 102,500 | $2,448,420 | 35 |
| Heart Disease | $19.12 | 1,431,500 | $27,370,705 | 256 |
| Spina Bifida | $13.47 | 35,000 | $471,508 | 4 |
| Bronchitis, Emphysema, COPD | $5.97 | 805,000 | $4,806,653 | 46 |
| Asthma | $4.82 | 2,246,500 | $10,830,842 | 100 |
| Arthritis | $4.24 | 4,454,000 | $18,866,022 | 177 |
| **Fibromyalgia** | **$0.34** | **439,000** | **$150,609** | **2** |
| **Chronic Fatigue Syndrome** | **$0.25** | **411,500** | **$101,241** | **2** |
| Multiple Chemical Sensitivities | $0.00 | 800,500 | $0 | 0 |
| | | | | |
| **All projects** | | | $681,485,629 | 6,259 |

Notes:

Extracted from the CIHR funded research data base at http://webapps.cihr-irsc.gc.ca/funding/Search?p_language=E&p_version=CIHR

Extracted on April 6, 2016.

The database includes a short description of each funded project. The inclusion of a keyword suggests but does not guarantee that this condition is a focus of the project. Projects often have multiple keywords (e.g., diabetes and heart disease).

Keywords include English variations and French equivalents

The Canadian Community Health Survey excludes

- Canadians under the age of 12
- Canadians living in institutions, on reserves, or in remote regions
- Full-time members of the Canadian Forces

Thus, the prevalence in all categories would be understated. Some conditions would be more understated than others.

CIHR funding of research into chronic conditions
during the period April 2016 – March 2017
using keyword searches of the CIHR funded research database

| **Keyword** | Average per patient funding 2016-2017 | Canadians affected CCHS 2010 | CIHR funding 2016-2017 | Number of studies funded 2016-2017 |
|---|---:|---:|---:|---:|
| Parkinson | $346.30 | 39,000 | $13,505,519 | 110 |
| Alzheimer | $172.46 | 111,500 | $19,229,819 | 159 |
| Muscular dystrophy | $156.88 | 26,000 | $4,078,910 | 35 |
| Cerebral palsy | $63.37 | 36,000 | $2,281,482 | 16 |
| Epilepsy | $61.46 | 134,500 | $8,265,917 | 62 |
| Multiple Sclerosis | $54.11 | 108,500 | $5,870,426 | 44 |
| Dystonia | $44.22 | 15,500 | $685,358 | 6 |
| Diabetes | $24.97 | 1,841,500 | $45,990,697 | 344 |
| Tourette | $12.42 | 18,000 | $223,549 | 2 |
| Crohn | $20.57 | 102,500 | $2,108,908 | 24 |
| Heart Disease | $13.51 | 1,431,500 | $19,338,016 | 166 |
| Spina Bifida | $9.50 | 35,000 | $332,370 | 3 |
| Bronchitis, Emphysema, COPD | $4.87 | 805,000 | $3,919,791 | 29 |
| Asthma | $3.86 | 2,246,500 | $8,671,007 | 69 |
| Arthritis | $3.14 | 4,454,000 | $13,980,148 | 107 |
| **Fibromyalgia** | **$0.35** | **439,000** | $151,887 | 2 |
| **Chronic Fatigue Syndrome** | **$0.11** | **411,500** | **$45,000** | **1** |
| Multiple Chemical Sensitivities | $0.00 | 800,500 | $0 | 0 |
| | | | | |
| **All projects** | | | $545,842,675 | 4112 |

Notes:

Extracted from the CIHR funded research data base at http://webapps.cihr-irsc.gc.ca/funding/Search?p_language=E&p_version=CIHR

Extracted on April 8, 2016.

The database includes a short description of each funded project. The inclusion of a keyword suggests but does not guarantee that this condition is a focus of the project. Projects often have multiple keywords (e.g., diabetes and heart disease).

Keywords include English variations and French equivalents

The Canadian Community Health Survey excludes

- Canadians under the age of 12
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Thus, the prevalence in all categories would be understated. Some conditions would be more understated than others.