NATIONAL ME/FM ACTION NETWORK

● Phone 613-829-6667 ● Fax 613-829-8518
● 512-33 Banner Road
●Ottawa, ON K2H 8V7 Canada
●mefminfo@mefmaction.com
● (BN) 89183 3642 RR0001

June 30, 2016

To: Advisory Panel for the Review of Federal Support for Fundamental Science

Re: Barriers to Science Funding

The National ME/FM Action Network welcomes the appointment of an Advisory Panel to review federal support for fundamental science. We are a registered charity supporting Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia since 1993. A Statistics Canada survey showed that these illnesses affect over 750,000 Canadians and bring with them high degrees of disability and disadvantage.

The ME/CFS and FM communities around the world have been calling for funding of fundamental science into the causes and treatments of ME/CFS and FM. Some top scientists have become interested in this research topic. A US researcher has three Nobel laureates on his advisory committee.

Our organization has generated tables for Canada showing consistently low CIHR funding for ME/CFS and FM over the years. The attached table shows the results for this fiscal year. A competition for a three year catalyst grant for ME/CFS is underway; this could increase the figure for ME/CFS by fifty cents per patient this year.

Our experience suggests that ME/CFS and FM are encountering at least three substantial barriers.

1. ME/CFS and FM have not broken into the research funding system. It helps to have resources, experience, and the validation that comes from being previously funded.
2. ME/CFS and FM are multi-system illnesses that do not align with the existing institute structure or with the existing medical specialty structure. We do not have automatic allies.
3. The science behind ME/CFS and FM is not well understood, and funding agencies seem to be uncomfortable providing funding to projects that do not fit into a well-established agreed-upon theoretical framework.

We would like the opportunity to meet with you to discuss our story and the experiences of our colleagues in other countries.

MParlor

Margaret Parlor
President

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
- 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.