

Federal Funding for Health Research into Fibromyalgia and Chronic Fatigue Syndrome

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Introduction:

Fibromyalgia and Chronic Fatigue Syndrome are serious illnesses. Statistics Canada data show that over 300,000 Canadians have been diagnosed with each illness and that patients with these illnesses experience very high levels of disability, disadvantage and unmet needs.

This was documented in our special issue of Quest at <http://www.mefmaction.net/Portals/0/docs//Quest%2080.pdf>.

There is a great need for health research into these illnesses. The Canadian Institutes of Health Research (CIHR) is the federal agency that is the primary source for health research funding in Canada. How much has CIHR invested in research into Fibromyalgia and Chronic Fatigue Syndrome?

Both the US National Institutes of Health and the Australian National Health and Medical Research Council publish spreadsheets showing how spending is distributed among health topics. CIHR does not publish such a spreadsheet. However, CIHR maintains two databases that describe the studies that have been approved for funding and it provides a keyword search function. A knowledgeable user can generate such a spreadsheet.

Findings:

Since December 2007, CIHR has approved 6,240 studies worth over \$1.5 billion. Only 6 studies worth \$1.3 million refer to Fibromyalgia. No studies whatsoever refer to Chronic Fatigue Syndrome.

Since 1999, CIHR has approved 30,854 studies worth over \$8.2 billion. Only 20 studies worth \$5.6 million refer to Fibromyalgia. Only 4 studies worth \$800 thousand refer to Chronic Fatigue Syndrome.

Conclusion:

To increase transparency and accountability, CIHR should publish a spreadsheet showing how it distributes funding among health topics so that this information is available for public discussion.

Health research funding is not equitably distributed. Fibromyalgia and Chronic Fatigue Syndrome receive very little funding especially considering their prevalence and the burden of illness. CIHR's mandate includes "building research capacity in under-developed areas". Research into CFS and FM are truly under-developed. There is a need for proactive efforts to build research capacity for these illnesses.

Table 1: CIHR Funding for Research into 15 Chronic Illnesses

Keyword	# of studies approved since Dec 2007	Amount approved since Dec 2007	# of studies approved since 1999	Amount approved since 1999	# Canadians affected column (6)	Source for column (6)
Diabetes	416	\$116,971,959	1956	\$613,618,828	1,324,874	CCHS 2005
HIV or HIV/AIDS	364	\$83,923,549	1240	\$342,111,092	63,000	Canadian AIDS Society
Arthritis	152	\$34,497,505	865	\$296,821,906	4,441,851	CCHS 2005
Heart Disease	226	\$80,488,960	715	\$250,311,171	1,288,009	CCHS 2005
Alzheimer	191	\$57,149,257	903	\$237,695,175	500,000	Alzheimer's Society of Canada
Asthma	114	\$33,947,703	587	\$166,635,228	2,249,228	CCHS 2005
Parkinson	94	\$29,569,916	453	\$142,355,849	Over 100,000	Parkinson's Society of Canada
Schizophrenia	91	\$32,289,696	495	\$139,488,250	1% of population	Schizophrenia Society of Canada
Epilepsy	51	\$19,643,345	337	\$ 105,326,721	159,759	CCHS 2005
Multiple Sclerosis	57	\$16,506,577	221	\$ 77,172,438	55,000-75,000	Multiple Sclerosis Society of Canada
Autism	69	\$13,786,410	210	\$ 51,093,716	200,000	Autism Society of Canada
Yu Glaucoma	17	\$ 5,292,728	95	\$ 28,362,051	407,390	CCHS 2005
Fibromyalgia	6	\$ 1,257,783	20	\$ 5,648,998	389,782	CCHS 2005
Chronic Fatigue Syndrome	0	\$ 0	4	\$ 804,854	333,816	CCHS 2005
Multiple Chemical Sensitivities	0	\$ 0	1	\$ 17,500	598,585	CCHS 2005
{all projects}	6,240	\$1.548B	30,854	\$8.217B		

Data for columns 2-5 were compiled on September 26, 2010.

* A study will appear more than once in this table if its description includes more than one of the keywords.

Table notes:

The CIHR databases can be found at:

http://webapps.cihr-irsc.gc.ca/cfdd/db_search?p_language=E, (studies approved since Dec 2007), and http://webapps.cihr-irsc.gc.ca/funding/Search?p_language=E&p_version=CIHR. (studies approved since 1999) The website states that these databases are updated weekly. This table was compiled on September 26, 2010.

The keyword search function will display the studies that include the keyword in the description of the project, along with cumulative spending up to the end of the current fiscal year.

Example: A study on proteins that cleave RNA was approved in mid-2007, with funding running to 2012. Because it was approved before December 2007, it appears on the second database but not on the first. The funding (\$406,028) reflects the amount approved up to the end of the 2010-11 fiscal year. In 2011-12, the study will receive additional funding and will show a larger amount. The study description mentions that RNA cleavage issues arise in illnesses such as Chronic Fatigue Syndrome, diabetes and Alzheimer's. Thus, searches using the keywords "chronic fatigue syndrome", "diabetes" and "Alzheimer" will find this study. This study will count as one study worth \$406,028 in columns 4 and 5 for each of these three illnesses.

A few studies are described in French and hence are not identified using English keywords. No studies for Chronic Fatigue Syndrome or Fibromyalgia were missed because they were in French.

The US and Australian spreadsheets showing health research grants by health topic can be found at

United States : <http://report.nih.gov/rcdc/categories/>

Australia : <http://www.nhmrc.gov.au/grants/dataset/lay/index.htm>

Column 6 shows the number of Canadians affected by each of the chronic conditions. Where possible, the information was taken from Statistics Canada's Canadian Community Health Survey (CCHS) 2005 to tie in with the statistics published in Quest 80. Otherwise, the information was taken from the website of the organization representing Canadians with the condition. (Website search done in October 2009).