MILLIONSMISSINGCANADA

Facts and Data about the Canadian

Myalgic Encephalomyelitis Crisis

Prepared by Millions Missing Canada, July 2017

Myalgic Encephalomyelitis (ME)

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Summary of ME data

- ME occurs in epidemics and Canadian ME rates, already the highest in the world, jumped by 37.6% in 2015 over the previous year to 560,000.
- Debunked research out of the UK has created a global institutional bias against ME:
  - Impeding ME research and funding
  - Promoting contraindicated treatments
  - Causing iatrogenic harm by ill-informed physicians
- Canadian Institute of Health Research funding for ME is the lowest of all chronic diseases:
  - e.g. HIV = $585 / patient vs ME = 11 cents / patient
- Canadians with ME have:
  - Lowest quality of life
  - Lowest income
  - Highest unmet health needs
  - Highest food insecurity
- No access to appropriate treatment: Ampligen is the only approved ME medication, but not in Canada.
- Some off-label cancer and HIV meds are used successfully to manage ME, but not in Canada.

Overview of ME in Canada

Myalgic encephalomyelitis is classified as a neurological disease by the World Health Organization and Health Canada. ME occurs in **sporadic and epidemic** forms and was first identified in the 1934 California outbreak. Initially called 'atypical poliomyelitis'.

Dysfunctional mitochondria **affects multiple systems**: immune, autonomic, endocrine, cognitive, neurological. A wide range of symptoms vary in frequency, duration, and intensity. Neither the cause nor the communicability of ME has been identified. Patient's anecdotal reports of ME onset include **sexual contact** and **blood transfusions**.

About 25% of people with ME are housebound or bedridden.

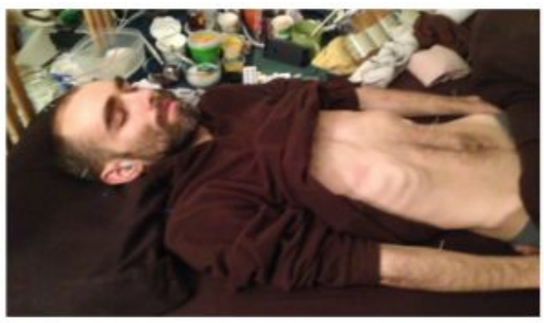
The hallmark symptom is **post exertional neuroimmune exhaustion**, also known as post exertional malaise (PEM), meaning even small amounts of activity (physical and/or cognitive) cause an increase in symptoms. For a person with moderate ME, walking up 2 flight of stairs may trigger disabling symptoms immediately or 24 – 48 hours

> *"there is **something being released in the serum** that is causing a lot of the effect"*
> - Professor Ron Davis

later and take 2 – 4 days to recover. For severe ME, showering may cause disabling symptoms. The Institute of Medicine in the US called ME 'systemic exertion intolerance disease' (SEID) to denote the key symptom.

Recent research: Norwegian researchers Fluge and Mella are using **cancer drugs** to treat ME patients. US researcher Naviaux found metabolic dysfunction in ME indicating **hypometabolism.** Davis at Stanford University found abnormalities **in the blood** of people with ME.

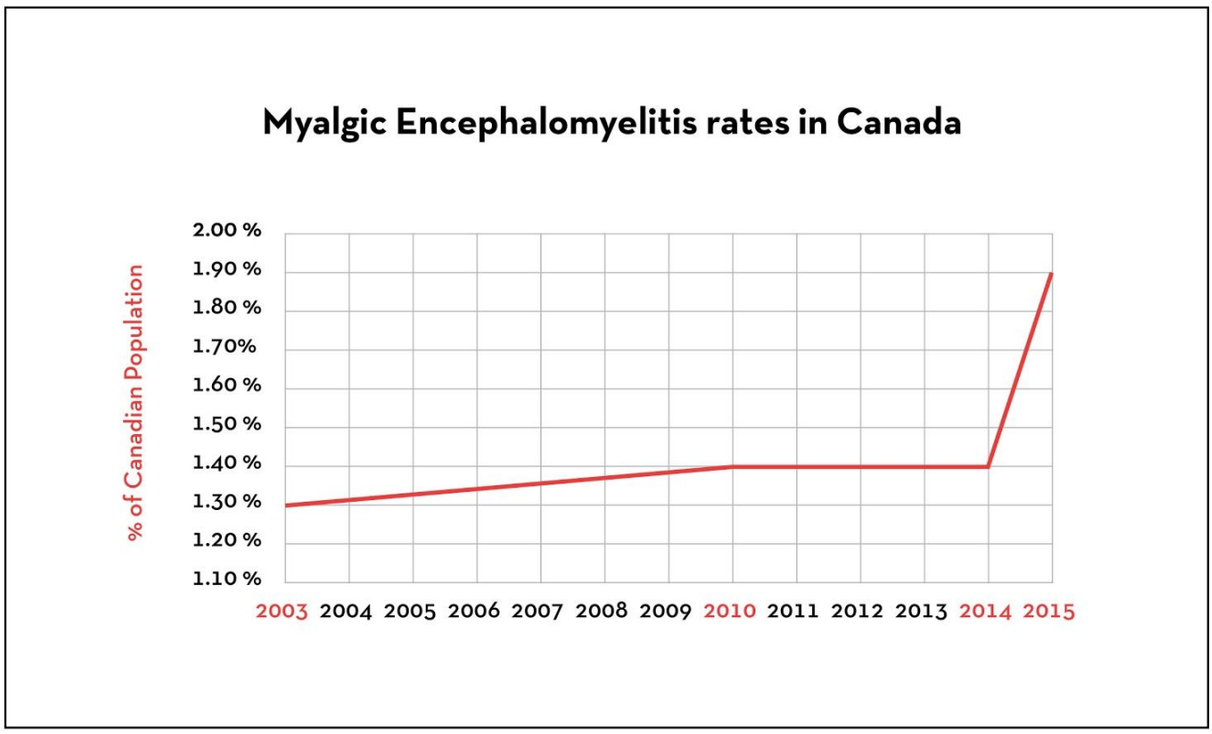
Professor Ronald Davis is a world-renowned scientific innovator, "*A substantial number of the major genetic advances of the past 20 years can be traced back to Davis in some way.*" Ron Davis's son, Whitney (pictured below), has very severe ME: bedbound, cannot walk or talk, need for dark room, no sound, no visitors, no speaking, and a feeding tube.



Myalgic Encephalomyelitis in Canada

1. Are we experiencing another ME Epidemic?

- The 2015 data from the Canadian Community Health Survey found the number of Canadians living with Myalgic Encephalomyelitis jumped from about 410,000 in 2014, to over 560,000.
- An increase of 37.6% in one year.
- Although the cause of ME is not yet determined, researchers have found something, yet to be identified, in the blood of people with ME.



Data from Canadian Community Health Surveys 2003, 2010, 2014, 2015

Statistics Canada confirmation of data

While the 2015 Canadian Community Health Survey data for myalgic encephalomyelitis diagnosis is not available to the public, an **excerpt** from a **Statistics Canada email** (March 23, 2017) confirms the data:

"The numbers have been verified."

Total	561,500	1.9%
Males	195,100	1.3%
Females	366,400	2.4%

Previous ME epidemic in Canada: 1984

An account of the ME epidemic concentrated in Quebec and Ontario, but endemic throughout North America.

Excerpt from Dr Byron Hyde's book, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis.*

Epidemic 56

Montreal, Quebec-Ontario,Canada

Labour Day epidemic, Montreal, S O'Sullivan, in preparation

Over 500 cases of M.E./CFS documented in Ontario during the August-November 1984 period. Although these cases were recorded from all over Ontario, there seems to be a curious prevalence along the seaway valley from the area of Kingston to Cornwall, Ontario. This endemic was active in all parts of Canada during this period and appears have maintained its activity until the time of writing in 1991.

Review
Gray JA. Some long-term sequelae of Coxsackie B virus infection. J R Coll Gen Pract 1984; 24:3-5.

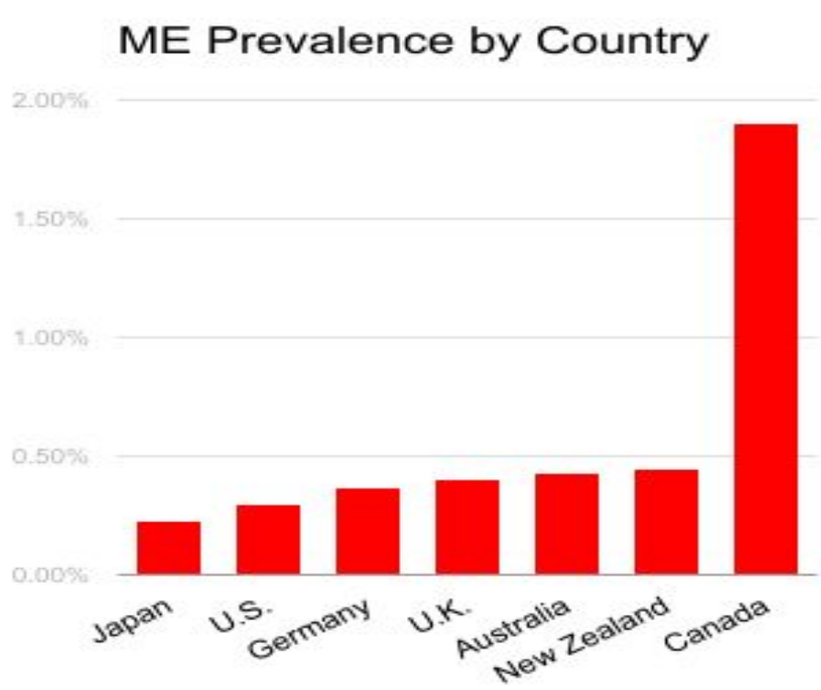
Nuclear MagneticResonance Study
Arnold DL, Bore PJ, Radda GK,Styles P, Taylor DJ. Excessive intracellular acidosis of skeletal muscle on exercise in a patient with a post-viral exhaustion/ fatigue syndrome. Lancet 1984; 1:1367-9.

Correspondence: Muscle acidosis in post-viral fatigue. Lancet 1984; 2:293 Fulop M, Arnold DL (Bore PJ, Radda GK, Styles P, Taylor DJ), Gow PJ

Review
Murdoch JC. Myalgic encephalomyelitis and the general practitioner. N Z Family Physician 1984; 11:127-8.

2. Canada has highest ME rates globally

- 1.9% of the Canadian population have been diagnosed with ME.
- More than 4X the rate of other countries.



3. Enteroviruses: The Poliomyelitis – Myalgic Encephalomyelitis connection

- A number of researchers believe ME is caused by enteroviruses.
- Polio and ME are from the same enterovirus family and often occurred in tandem in epidemics until the use of the Polio vaccine in 1955.

> *"...both polio and Myalgic Encephalomyelitis occurred **in the same epidemics at the same time and the same place** up to 1955, specifically in Los Angeles County Hospital, Akureyri Iceland and Royal Free Hospital."*
>
> - Dr Byron Hyde, Nightingale Research Foundation

- As Dr Hyde observed:

> *"This is **the virus family we recovered in Canada during the 1984 North American pan-epidemic** that struck Lake Tahoe, North Carolina, **Montreal, and across Ontario** and in all subsequent M.E. patients where a viral cause was found."*

- Dr Hyde contends the major difference between polio and ME is the site of infection of the central nervous system (CNS): polio affects the lower CNS causing paralysis, while ME affects the upper CNS causing brain dysfunction affecting cognitive, sensory and motor systems.

> *"I so strongly believe this, that it is a wonder someone hasn't referred to **M.E. as The Forgotten Polio**."*

4. Policy influenced by debunked research: PACE-gate

- A group of well-connected UK psychiatrists have built their careers and reputations on researching their hypothesis that people with ME are not physically ill, but have a 'false illness belief', a psychological condition.
- The UK psych researcher's treatment involves graded exercise therapy, they tested it in their 5 million pound PACE trial, and declared it a success, and set up government funded treatment centers.
- Undisclosed to patients, some of the researchers were on the Board of an Insurance company. Insurance companies are less likely to cover illnesses that are labeled psychological and can be treated with exercise.
- People living with ME were suspicious of the results – being in direct opposition to their lived experience with exertion - and patients requested the PACE data.

> ***"a deceptive and morally bankrupt piece of research"***
>
> - Professor David Tuller, Columbia University

- After repeated refusals, the UK researchers were ordered by a tribunal to share the data.

> "*The PACE-Trial stands out as a showcase example of why data transparency is needed in contemporary science… especially if this evidence is* ***used to direct health policy*** *or promote certain treatments...*"
> Dr. Keith Geraghty, University of Manchester (UK)

Professor of Journalism at Columbia University, David Tuller, has been pivotal in exposing the long list of problems with PACE, has questioned if it is scientific fraud, and has spearheaded the call for its retraction from prestigious medical journals, including *The Lancet*. As Tuller noted:

> "*Yet PACE suffered from major flaws that have raised serious concerns about the validity, reliability and integrity of the findings…* ***greatly impacted treatment, research, and public attitudes towards ME.***"

5. Systemic institutional bias against ME from policy to physician

- Before it was refuted, the debunked research had done its damage:
- Disease denial with the health care system
- Impeded research funding and research
- Impeded accurate education about ME for physicians
- Impeded appropriate treatments
- Derisively called 'chronic fatigue syndrome'

> "*The term* ***'chronic fatigue syndrome' feels like an accusation, not a diagnosis.***"
> Person with ME

6. ME patients are being harmed physically and psychologically

- There is evidence emerging of harm caused by 'graded exercise therapy' and 'cognitive behavioural therapy' for ME patients - yet physicians are still prescribing these contraindicated treatments.

> "***Forced activity*** *in our experience has resulted in* ***death & in permanent house bound invalids.***"
> Dr Byron Hyde, Nightingale Research Foundation

> "***They came to the doctor with [ME]. They left with PTSD.***"
>
> Dr Nancy Klimas, Nova Southeastern University

- Patients suffer PTSD from interaction with ill-informed physicians and the health care system.
- Repeated iatrogenic harm undermines physician credibility and trustworthiness.

7. ME has <u>near zero research</u> funding

- $88 millions missing annually from research funding (560,000 ME patients x $158.58 → average funding of Parkinson's, Epilepsy, Multiple Sclerosis, Alzheimer's)
- Disease denial: The only application for the only ME research funds for the CIHR [Catalyst Grant was denied] based on bias, as the reviewer stated that there is no evidence that ME "*is a disease*".

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

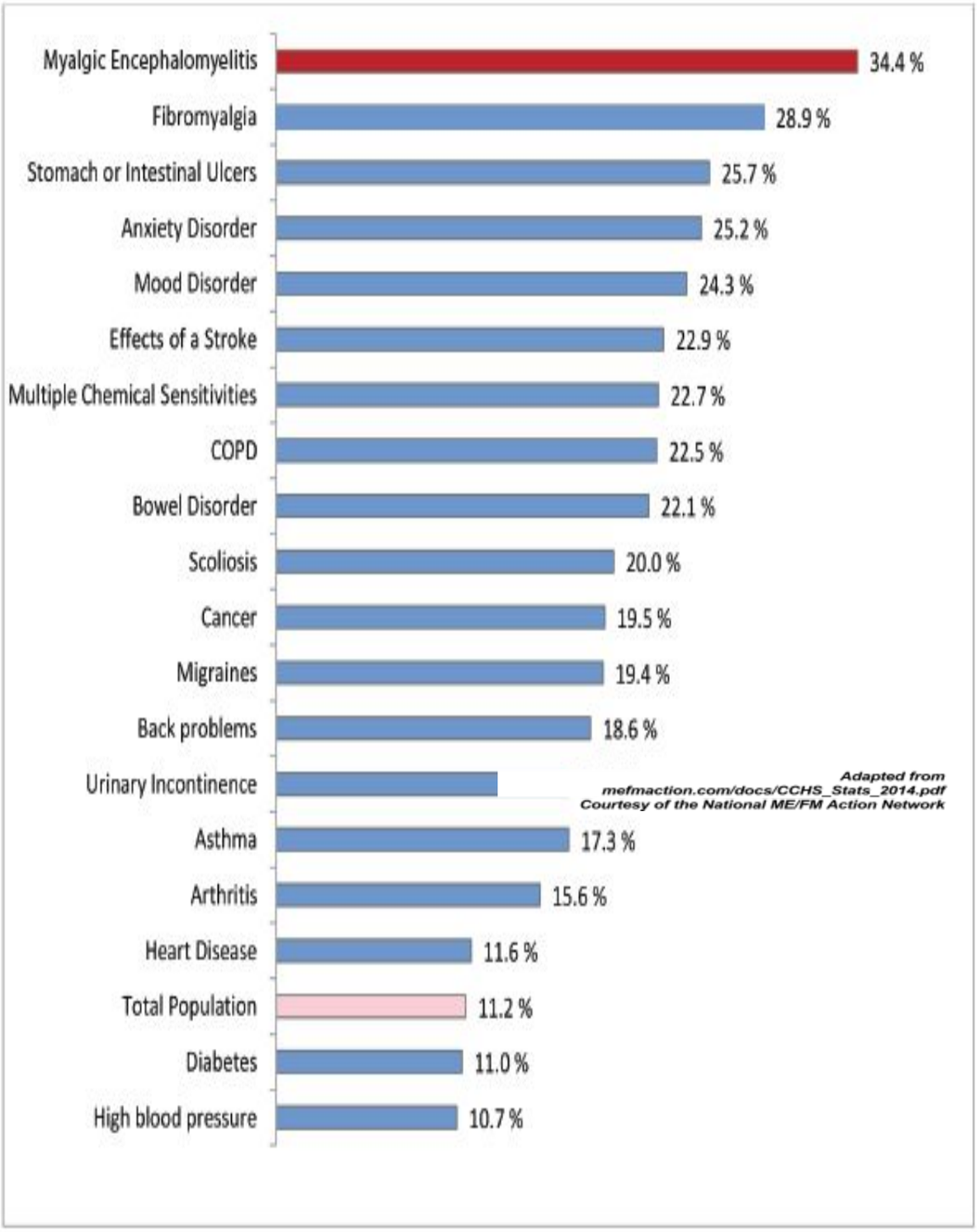
Adapted from mefmaction.com/docs.CCHS_Stats_2014.pdf
Courtesy of the National ME/FM Action Network

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
Myalgic Encephalomyelitis*	$0.11	411,500	$45,000	1

8. ME patients have <u>highest unmet health care needs</u>

UNMET HEALTH CARE NEEDS

Canadians Aged 12 and Older Reporting Unmet Health Care Needs According to their Chronic Health Condition, 2014

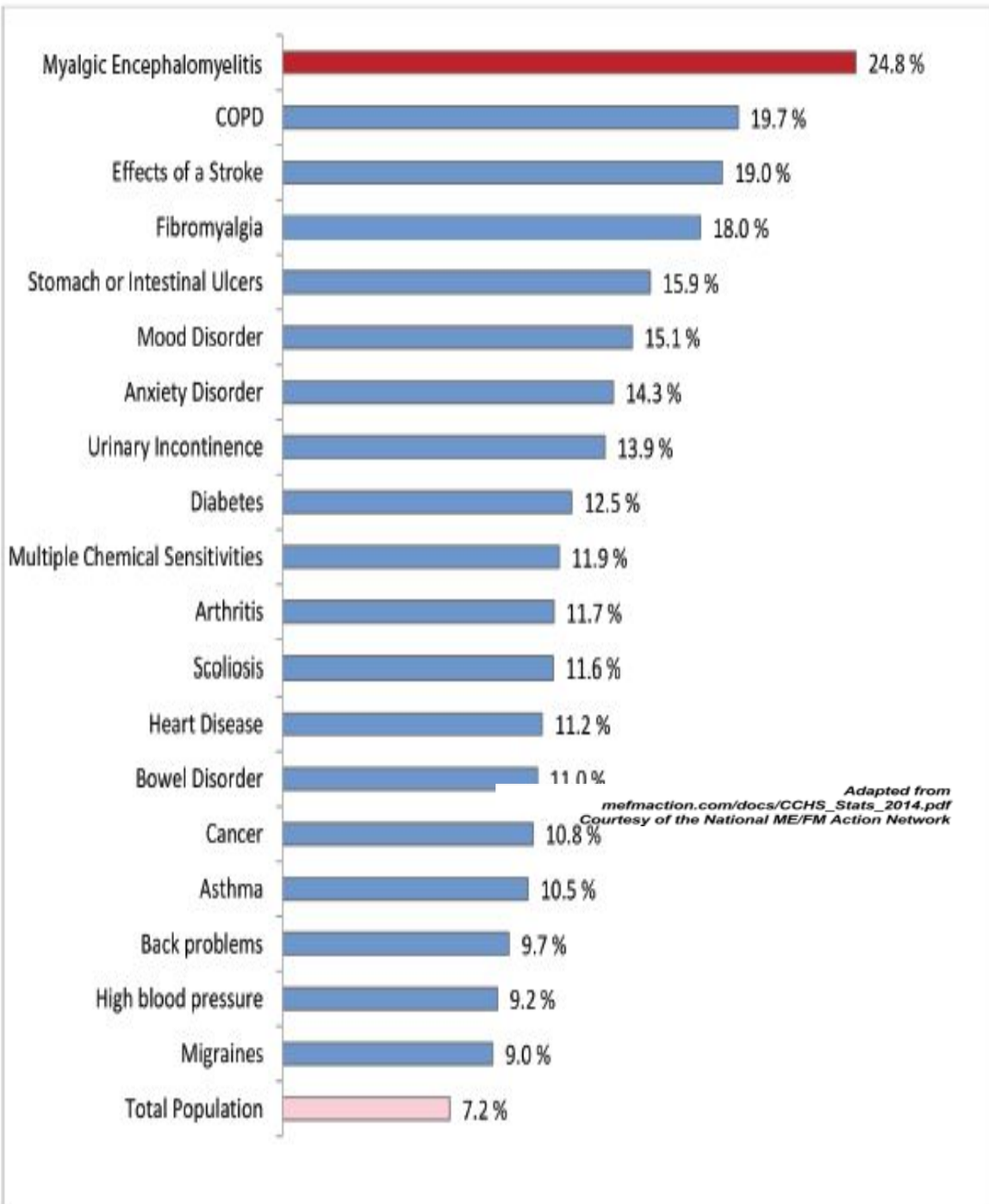


Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
Arthritis = ages 15+ , COPD = ages 35+; Urinary Incontinence = ages 25+

9. Poverty – People living with ME have the <u>lowest income</u> according to chronic health condition

HOUSEHOLD INCOME

Canadians Aged 12 and Older Reporting Household Income Less Than $20,000 Per Year According to their Chronic Health Condition, 2014

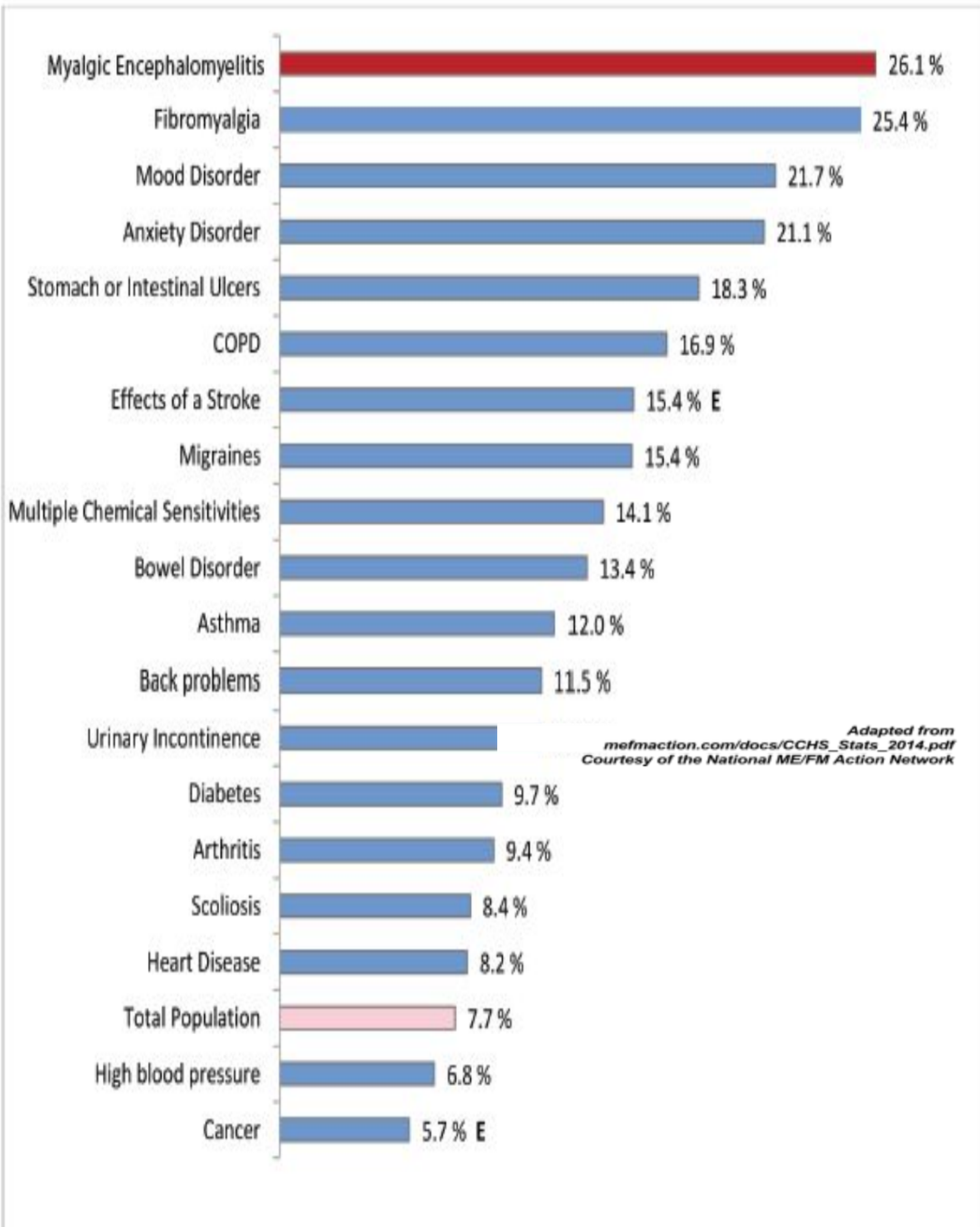


Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
COPD – Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
Arthritis – ages 15+, COPD – ages 35+, Urinary Incontinence – ages 25+

10. Food insecurity - People living with ME have the <u>highest rate of food insecurity</u> according to chronic health condition

FOOD INSECURITY

Canadians Aged 12 and Older Reporting Moderate or Severe Household Food Insecurity According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
COPD - Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
Arthritis - ages 15+, COPD - ages 35+, Urinary Incontinence - ages 25+
[E] Use with caution (Coefficient of Variation between 16.6 and 33.3)
Respondents from Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island

11. People with ME have the <u>lowest quality of life</u> on every measure: physical functioning, role – physical and emotional, vitality, social functioning, general health, bodily pain.

Nacul *et al. BMC Public Health* 2011, **11**:402
http://www.biomedcentral.com/1471-2458/11/402

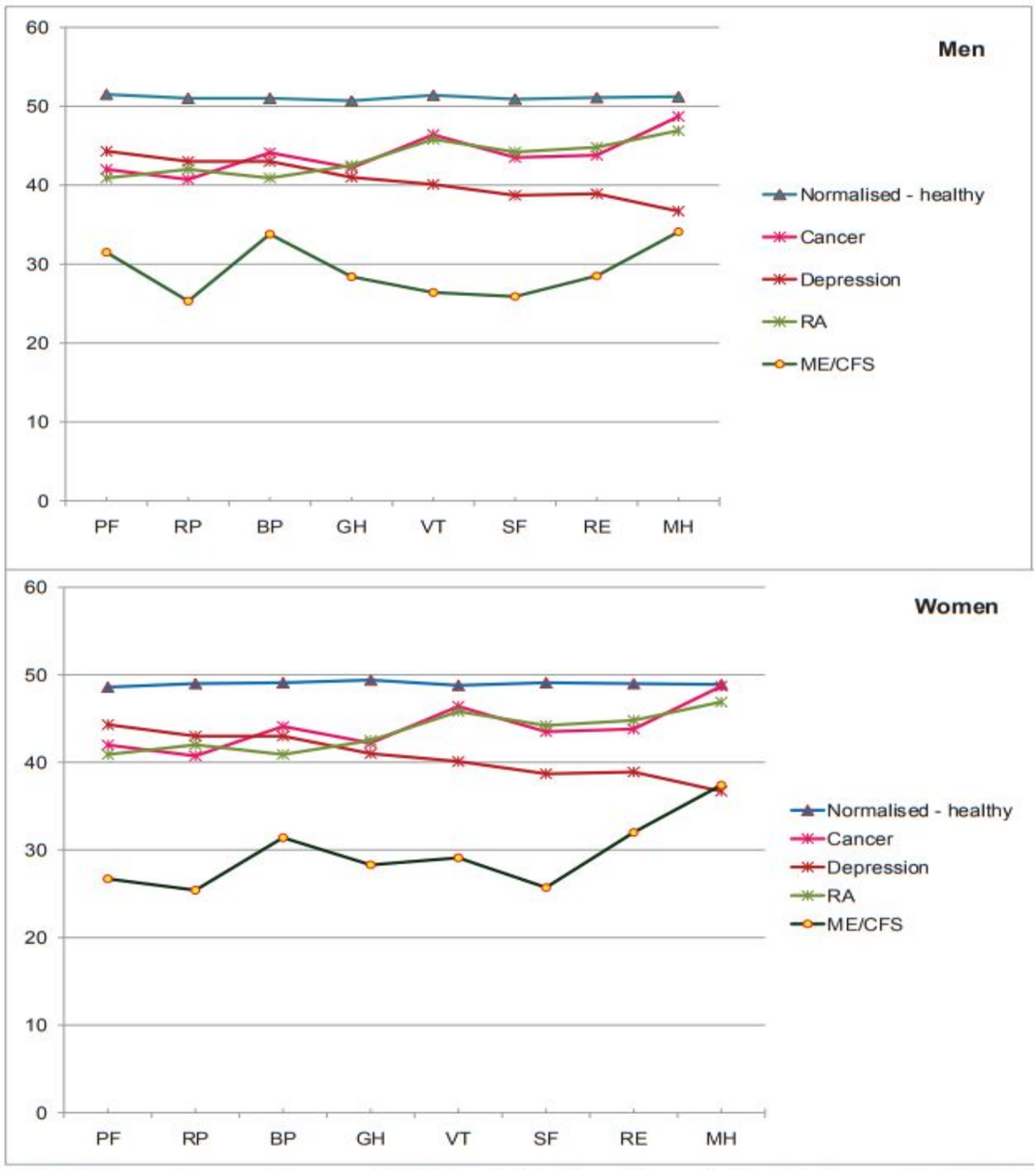


Figure 1 SF-36v2™ scores in men and women with ME/CFS, other health conditions or healthy. RA - Rheumatoid arthritis; PF - Physical Functioning, RP - Role-Physical, BP - Bodily pain, GH - General Health, VT - Vitality, SF - Social Functioning, RE - Role-Emotional, MH - Mental health.

12. <u>No treatment access</u> appropriate for ME

- Ampligen is approved for ME under the Special Access Programme for 20 years, but ME patients cannot access it
- Valcyte and Valtrex antivirals have improved and cured many people with ME in other countries
- Critical lack of ME education in Canadian medical schools and critical lack of ME physicians

- Very little awareness and use by physicians of the Health Canada's diagnostic and treatment tool, the Canadian Consensus Criteria for ME
- Result: Under diagnosing and misdiagnosing, lack of testing & treatment, denial of disability coverage

> 44% of Canadians living with ME report that their GP is "not at all" familiar with ME.

Off-label treatment success

The following medications have successfully been used off-label, either individually or in a small research studies, to treat and manage ME:

- HIV / AIDS medications
- Cancer medications (Rituximab, Cyclosphosphamide)
- Staphyloccocus vaccine
- Anti organ rejection medication (Sirolumus)

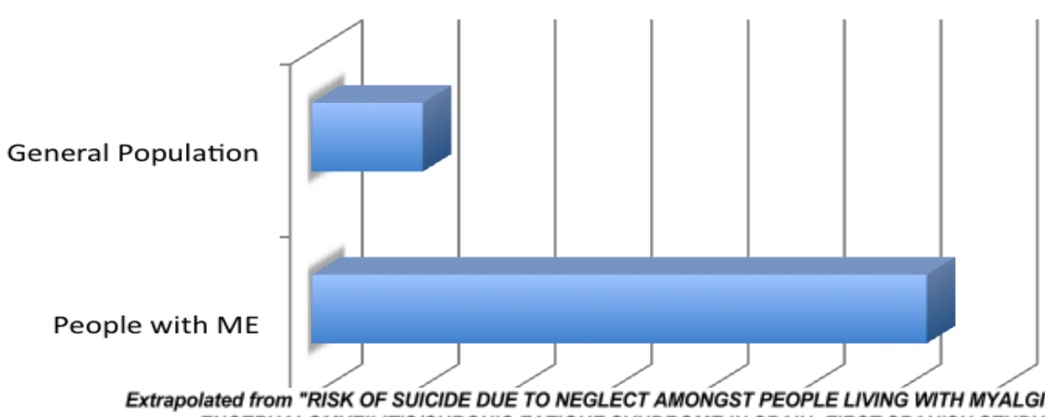
> "***If you are a Canadian with ME, your only hope for treatment, is to hope for cancer.***"
> - Canadian living with ME

13. Risk of suicide among persons with ME are up to 5 times the national average

The severity of the illness, in combination with the neglect and mistreatment patients experience from the health care system and society, leaves ME patients with a very high level of hopelessness, depression, pain and suffering. [source]

> "*The high level of risk of suicide, depression and hopelessness in these patients is much higher ...* ***due to, mostly, the lack of relevant health care services.***"
> Juan Jimenez-Ortiz

RISK OF SUICIDE AS A PERCENTAGE OF THE GENERAL POPULATION



Extrapolated from "RISK OF SUICIDE DUE TO NEGLECT AMONGST PEOPLE LIVING WITH MYALGIC ENCEPHALOMYEILITIS/CHRONIC FATIGUE SYNDROME IN SPAIN: FIRST SPANISH STUDY", Juan Jimenez-Ortiz, LigaSFC May 12, 2016

14. Stigma continues under Liberal Government

In spite of the overwhelming government data that clearly and unequivocally show Canadians living with ME to be vastly underserved, and most often dis-serviced, by the health care system, **the situation for Canadians living with ME has gotten worse since the Liberals took office.** Here is the record under Minister Jane Philpott's leadership:

- April 2016: The Minister fails to stop the iatrogenic harm of contraindicated treatment in spite of meeting with her policy advisor and providing two Patient Perspective submissions outlining the iatrogenic harm and need for a public inquiry into the institutional stigma condoning contraindicated treatment and impeding research, funding and treatment access.
- August 2016: the Minister fails to deny or correct the CIHR Reviewer's rejection of a research application because it took a biological approach to ME. The Reviewer explicitly stated there was no evidence ME "*is a disease*". As a result, the only application for the only ME research funding was rejected.
- January 2017: the Minister refuses to state publicly that ME is a biological condition. As a result, Canadians with ME continue to be harmed by the health care system. (CTV coverage)
- March 2017: the Minister permits the inclusion of misleading psychological term 'medically unexplained symptoms' to encompass ME. It's a useless label as all symptoms are medically unexplained until research is done. The fact that ME is specifically included indicates the institutional bias. As a result, it further embeds in institutions and in the minds of policy-makers, researchers, physicians, and the public, the incorrect notion that ME is psychological.
- April 2017: the Minister fails to acknowledge the ME epidemic. There is a 37.6% increase in ME diagnosis in one year, and if the Health Minister thought ME was as real a disease as polio or AIDS, an emergency response would have been initiated so Canadians could access care and treatment.

15. Hope for 560,000 Canadians with ME

We look forward to working with the new Minister of Health, **Hon. Petitpas Taylor,** to eradicate the stigma against patients with ME, to drastically raise research funding to fight this real and terrible disease, and to provide supports and services to patients who have been too long ignored and left suffering in the shadows.

"If there is one thing you should take away from the disease myalgic encephalomyelitis, it is fear.

You should be deeply afraid that it will come for you, or someone you love. It can strike anyone at any time with no rhyme or reason.

It is spreading around the country like wildfire with denial from the political world."

- Family member of person with ME

Resources:

Professor David Tuller exposing the fraudulent research:
http://www.virology.ws/2017/07/10/trial-by-error-the-cdc-drops-cbtget/

The Journal of Health Psychology - Special Issue: The PACE Trial

Summary of recent significant ME research.

'Chronic Fatigue Syndrome' is a misnomer, burdened with a negative psychological connotation, often conflated with Myalgic Encephalomyelitis. ME patient: "*Chronic fatigue syndrome sounds like an accusation, not a diagnosis*."

Millions Missing Canada is advocating for equitable research funding and treatment access for Canadians living with myalgic encephalomyelitis.

STOP the Harm
FUND the Research
START the Treatment