

MILLIONS MISSING CANADA

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Key Questions for Health Petipas Taylor

Emergency Response:

- Why has the Public Health Agency of Canada not initiated an emergency response to the alarming increase in ME numbers, as with HIV/AIDS, SARS, H1N1, and Zika?
- How long has Health Canada known about the 2015 Canadian Community Health Survey results about the increase in ME diagnosis?
- What actions has Health Canada taken since that time?
- What steps has the Canadian Medical Association taken to apprise physicians?
- What public awareness plans about ME are in effect?
- What physician awareness plans about ME are in effect?

Research:

- What ME surveillance processes are in place?
- What ME epidemiological studies are being conducted?
- What research about ME is currently being conducted?
- Why is there virtually no ME research funding?
- Why are ill-informed physicians very often prescribing contraindicated treatments, causing harm to patients?
- When will equitable research funding approaching \$88 million annually be available?

Testing and Treatment:

- Why are virtually no Canadian physician's aware of the Canadian Consensus Criteria for diagnosing and treating ME?
- What biological testing is being done on Canadians with ME symptoms?
- Why is there no enteroviral testing?
- What symptom treatment options are provided for ME patients?
- What actions are increasing access to appropriate treatment, such as Ampligen and other antivirals?
- Ampligen is most effective in those sick less than 8 years - how quickly can Ampligen be fast tracked?

FAQs

Myalgic Encephalomyelitis

What is ME?

- Classified as a neurological disease by the World Health Organization.
- ME can occur in sporadic and epidemic forms.
- ME affects many bodily systems like immune, endocrine, neurological, cognitive, and autonomic,
- The experience of symptoms can vary in intensity and duration, from patient to patient, and moment to moment.

What causes ME?

- Not enough research (funding) yet to unequivocally determine, but some researchers believe ME is caused by the same enteroviruses that cause polio.
- Dr Byron Hyde says myalgic encephalomyelitis is an "analog to poliomyelitis".
- Recent research indicates a state of "hypometabolism" in ME patients.
- Other research has found "*something being released in the serum*".

What is different about ME?

- The hallmark symptom occurs from mild physical and/or cognitive activity and causes an exacerbation of symptoms immediately or up to 48 hours later, and can be disabling for days or weeks.
- Because of this unique and defining symptom, the Institute of Medicine in the US called ME '*systemic exertion intolerance disease*'.

What is life like with ME?

- Folks with mild ME may be able to walk up one flight of stairs but not two in a row; may be able to work part time at non-physical job.

- Folks with severe ME may have symptoms exacerbated by brushing their teeth, and will require a lot of horizontal time to minimize 'exertion' and symptoms.
- Folks with very severe ME cannot stand, sit up or speak, require a dark room, no sound, no visitors, and a feeding tube.

How come my doctor doesn't know about ME or says that it's not a real disease?

- Stigma against ME has resulted in very few medical schools including ME in their curricula.
- Results in generations of doctors graduating either ill-equipped to help patients, or, worse, armed with a bias against ME patients, believing them to be attention seekers.

How did it happen that hardly anybody knows about ME? 560,000 is a lot of sick and disabled Canadians.

- There are more Canadians living with ME than with multiple sclerosis, epilepsy, Parkinson's, Alzheimer's, and HIV/AIDS combined.
- There are a couple contributing factors, see Sustaining Factors below.
- One reason you don't see folks with ME marching in protest is because we're too sick and marching makes us sicker!

How come Canadians with ME have the lowest quality of life and highest unmet health care needs? But also the lowest research funding? That doesn't make sense.

- We know, right? See Sustaining Factors below.
- Approximately \$88 million is missing annually from ME research
 - Average research funding per patient for Alzheimer's, Parkinson's, epilepsy and multiple sclerosis is \$158.58 / patient.
 - ME research funding per patient is 11 cents.

How could physicians not know ME is a biological disease, like polio and AIDS, and be prescribing contraindicated treatment?

- It's a pattern in the medical establishment. Multiple sclerosis, diabetes, ulcers and many other disease were first erroneously attributed to psychological causes and patients were often accused of faking or imagining their symptoms until research proved otherwise.
- Even then, it takes strong leadership to quickly change the deep institutional bias against ME and Canadians living with ME that emerges from misinformation.

How come Health Minister Philpott has not taken steps to stop the harm, fund the research, and start the treatments?

- That is an excellent question. We'd like to know too.

What medications are available for ME?

- Health Canada has not approved any medications for ME.
- Two cancer drugs (Rituximab and Cyclophosphamide) are used off-label in studies.
- Antivirals - valacyclovir (Valtrex), valganciclovir (Valcyte) - and HIV medications.
- Ampligen is accessible and/or approved for ME in other countries.
- Ampligen has high safety profile: > 93,000 doses administered to > 1,200 patients.
- Appropriate testing, which is required for any of these treatments, is not being done.

If Ampligen is used in other countries for ME, how can Health Minister Petitpas Taylor help bring it to Canadians with ME?

- Minister Petitpas Taylor could fast track access, like was done with HIV/AIDS medications
- Provide funding for Ampligen and other antiviral treatments.
- Minister Petitpas Taylor could invoke a 'right to try' medication not yet approved by Health Canada.
- Ampligen is most effective for people sick less than 8 years, so immediate action is necessary to prevent thousands of Canadians from losing hope each year.
- Millions Missing Canada, Dr Ian Hyams in BC, and the makers of Ampligen, Hemispherx Biopharma, are collaborating and look forward to working with the Health Minister to facilitate and expedite access to Ampligen.

Sustaining Factors

The medical system has a **long history of mistakenly attributing biological diseases to psychological causes** until research confirms the biological cause. A short list includes multiple sclerosis, diabetes, ulcers, Parkinson's. Can you imagine a physician in this day and age telling a person with multiple sclerosis that they were imagining their symptoms and not really sick? Welcome to the world of Canadians with ME.

Contributing significantly to sustaining the bias against ME and ME patients is the term **'chronic fatigue syndrome'** - a misnomer, burdened with a negative psychological connotation, and often conflated with the

original and World Health Organization term myalgic encephalomyelitis. As has been said, “*chronic fatigue syndrome*’ sounds like an accusation, not a diagnosis.”

As a result of this ongoing systemic error in the health care system:

- **an institutional bias**, from policy development to research funding to physicians’ offices, has developed **against ME and ME patients**
 - *“I wish they would stop calling us patients. It implies we receive health care.”* - Canadian with ME
- **contraindicated treatment** is often prescribed
 - *“for most patients, graded exercise therapy leads to worsening of symptoms”*
- many ME patients experience **iatrogenic harm**
 - *“Ask any ME patient about their experience with the health care system, and you will hear a story of trauma.”* - Canadian with ME

It cannot be understated how damaging it is to people living with ME, from repeated experiences of stigma and disbelief in the health care system. As ME physician Dr Nancy Klimas noted:

“They came to the doctor with [ME]. They left with PTSD.”

Disease Denial

If there was not a deep bias against ME in the health care system, than ME would not score the lowest of all chronic diseases on every metric: quality of life, research funding, health care access, poverty, food security. And Canadians with ME are often hamed physically and/or psychologically by the health care system.

In spite of the overwhelming evidence of institutional bias, successive Health Ministers have failed to stop the harm, and in their neglect have only sustained and strengthened the bias against ME and Canadians living with ME.

As a physician, former Health Minister Dr Jane Philpott was especially not immune to this institutional bias and there is evidence it may have influenced her (non)actions with ME:

- During this [CTV news](#) clip, Minister Philpott refused to publicly state that ME is a biological disease.
- When the only ME research application for the [only ME research funds was rejected](#) because the reviewer stated that ME in “not a real disease”, Minister Philpott did not contradict the statement.

- The federal government has labeled ME with the useless, biased and misleading psychological term '[medically unexplained symptoms](#)' (all symptoms are unexplained until research discovers the cause.)
- The ME community has [repeatedly brought these issues to Minister Philpott's](#) attention, but the situation for Canadians with ME has actually deteriorated and the numbers sick and disabled has increased.
- With a 37.6% increase in ME diagnosis in one year affecting more than half a million Canadians, with 25% so ill they are house or bed bound, the Health Ministry's silence speaks volumes.

Collectively, the lack of meaningful action indicates the Health Ministry does not consider myalgic encephalomyelitis to be a real disease like polio or AIDS, nor the 560,000 Canadians living with ME in need of research and treatment.

Research on Myalgic Encephalomyelitis

More information about the relationship between poliomyelitis and myalgic encephalomyelitis can be found in [Dr Byron Hyde's May 2017](#) publication.

For a summary of **latest ME research**, check out [this resource](#).

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