"We also discussed

the need for equitable research funding,

public awareness,

training for physicians, and

the need to improve existing government programs and policies for ME patients.

They asked for action and not just words

and I'm listening,

and I could not agree more."

Canada's Minister of Health

August 22, 2019

CIHR funds ME Research Network

August 22 was a special day for ME in Canada. On that day, the federal Minister of Health and the Scientific Director of the Institute of Musculoskeletal Health and Arthritis at CIHR participated in a news conference announcing that a team of ME researchers, clinicians and patient/family representatives led by Dr Alain Moreau of Montreal has been successful in its application for a 5 year $1.4M grant. Announcing the grant, the Minister and CIHR used the term "Myalgic Encephalomyelitis", dropping the term "Chronic Fatigue Syndrome".

In this newsletter, we share the official news release and the National ME/FM Action Network's response for the media. For the media and public, we put a very positive spin on the event. To our community, we would like to add that there is much more to be done.

The official news release is on page 3-5, the National ME/FM Action Network response is on page 2, and three slides presented by Dr. Moreau are on page 5-6.

Contents

Response from the National ME/FM Action Network

On behalf of the National ME/FM Action Network, which has been working on behalf of Canadians with Myalgic Encephalomyelitis and/or Fibromyalgia for over 25 years, I would like to thank the Minister of Health for Canada for recognizing the impact of ME, Dr Moreau for assembling an outstanding research team, and CIHR for providing research funding.

ME is a disease that affects patients and families to such an extent that it has an impact on society and the economy. Dealing with ME issues is important to all Canadians. Research will lead to better understanding of the disease and to better diagnosis, treatment and support for those affected.

Today's announcement of funding for a research network provides the opportunity to work together to address ME issues.

Canada is joining an international push to recognize ME and to expand ME research. The US, Europe and Australia are among the jurisdictions that are developing ME research. Canadian researchers have already shown that they can contribute at the international level. Now they are being given more support to do so.

We believe that ME research will also provide insights into other related conditions including Fibromyalgia, meaning that ME research will have spin-off benefits beyond ME.

Today is a very special day.

Margaret Parlor
President
National ME/FM Action Network

News Release / Communiqué de presse

https://www.canada.ca/en/institutes-health-research/news/2019/08/government-of-canada-invests-14m-in-biomedical-research-to-improve-the-quality-of-life-of-people-living-with-myalgic-encephalomyelitis.html

Government of Canada invests $1.4M in biomedical research to improve the quality of life of people living with myalgic encephalomyelitis

From: Canadian Institutes of Health Research

News release

August 22, 2019 – Montréal, Québec – Canadian Institutes of Health Research

It is estimated that more than 580,000 Canadians live with myalgic encephalomyelitis (ME), formerly known as chronic fatigue syndrome, or ME/CFS.

This poorly understood, multi-system disease is debilitating and can strike individuals of all backgrounds and at any age.

Patients experience symptoms including unrelenting exhaustion following mild physical and cognitive activity that is not relieved by rest; muscle and joint pain; headaches; inability to remain standing due to sudden drops in blood pressure; and poor sleep quality. The cause is not fully understood, there are no diagnostic tests available, and there is currently no cure.

People living with ME, and their families and caregivers, can now look forward to a more promising future as a result of a $1.4M investment in a new national network that will create critically needed scientific knowledge about the causes of, and treatments for, myalgic encephalomyelitis.

The Honourable Ginette Petitpas Taylor, Minister of Health, made the announcement today while visiting the Sainte-Justine University Hospital Research Centre in Montreal, where the network will have its headquarters. This investment comes from the Government of Canada, through the Canadian Institutes of Health Research (CIHR).

Minister Petitpas Taylor made the announcement together with Dr. Alain Moreau, a professor at the University of Montreal. Working with a team of patient partners,

Le gouvernement du Canada investit 1,4 M$ dans la recherche biomédicale en vue d'améliorer la qualité de vie des personnes vivant avec l'encéphalomyélite myalgique

De : Instituts de recherche en santé du Canada

Communiqué de presse

Le 22 août 2019 – Montréal (Québec) – Instituts de recherche en santé du Canada

On estime que plus de 580 000 Canadiens et Canadiennes vivent avec l'encéphalomyélite myalgique (EM), auparavant connue sous le nom de syndrome de fatigue chronique (SFC).

Cette maladie multisystémique est invalidante et mal comprise; elle peut toucher n'importe qui, quels que soient son milieu ou son âge.

Les personnes atteintes ressentent notamment une fatigue intense et persistante à la suite d'une activité physique ou cognitive légère que le repos ne parvient pas à atténuer, de la douleur musculaire et articulaire, des maux de tête, l'incapacité de rester debout en raison d'une chute soudaine de la tension artérielle et une mauvaise qualité du sommeil. Les causes ne sont pas bien comprises, et il n'existe aucun test diagnostique ni aucun remède.

Les personnes atteintes d'EM, leur famille et leurs soignants peuvent maintenant espérer un avenir meilleur puisque 1,4 M$ seront investis dans un nouveau réseau national qui créera des connaissances scientifiques essentielles sur les causes et les traitements de l'encéphalomyélite myalgique.

L'honorable Ginette Petitpas Taylor, ministre de la Santé, en a fait l'annonce aujourd'hui lors de sa visite au Centre hospitalier universitaire Sainte-Justine, à Montréal, où le réseau sera basé. L'investissement provient du gouvernement du Canada, par l'entremise des Instituts de recherche en santé du Canada (IRSC).

La ministre Petitpas Taylor a fait l'annonce, accompagnée du Alain Moreau, professeur à l'Université de Montréal. Ce dernier dirigera, avec la collaboration d'une équipe

clinicians, and more than 20 researchers, Dr. Moreau will lead the network that will fill gaps in biomedical ME research and build capacity for research into the disease here in Canada.

Quotes

"Our government is proud to support the work of researchers pursuing improved quality of life for people living with myalgic encephalomyelitis, their families and caregivers. With this investment, we will advance research into ME, work towards developing testing and treatment options, better medical education and, ultimately, better help for patients."

The Honourable Ginette Petitpas Taylor, Minister of Health

"It is absolutely necessary to keep promoting research at the Sainte-Justine Hospital, and I am proud that our researchers in Outremont are once again enjoying the confidence of the Government by being granted significant funding to advance patients' quality of life."

Rachel Bendayan, Member of Parliament for Outremont

"CIHR aims to improve the health of Canadians, and this community of Canadians is one that has tremendous need. People living with myalgic encephalomyelitis were at the forefront of this successful high-quality research application. This network will produce important clinical results—treatments for patients with ME—as well as improving health professional education and connecting Canada with international leaders in this field."

Dr. Karim Khan, Scientific Director of CIHR's Institute of Musculoskeletal Health and Arthritis

"Cutting-edge research at the Centre hospitalier universitaire Sainte-Justine is at the forefront of scientists' efforts to unravel the mystery of debilitating diseases that weigh heavily on patients and their families. I am very proud to see our institution and our scientists at the heart of this initiative that brings hope to so many people."

Ms. Caroline Barbir, President and CEO, Sainte-Justine University Hospital Centre

de patients partenaires, de cliniciens et de plus de 20 chercheurs, ce réseau qui promet de combler les lacunes dans la recherche biomédicale sur l'EM et de développer les capacités de recherche sur cette maladie, ici au Canada.

Citations

« Notre gouvernement est fier de soutenir les chercheurs qui travaillent à améliorer la qualité de vie de ceux et celles qui vivent avec l'encéphalomyélite myalgique. Grâce à cet investissement, nous pourrons faire avancer la recherche sur l'EM, faire un pas vers des tests diagnostiques, des traitements, améliorer la formation médicale, et ce, au bénéfice des patients, de leurs familles et leurs proches. »

L'honorable Ginette Petitpas Taylor, ministre de la Santé

« Il est absolument nécessaire de continuer à faire avancer la recherche à l'hôpital Sainte-Justine, et je suis fière que nos chercheurs d'Outremont bénéficient une fois de plus de la confiance du gouvernement en se voyant octroyé un financement important afin de progresser dans l'amélioration de la qualité de vie des patients. »

Rachel Bendayan, députée d'Outremont

« Les IRSC tentent d'améliorer la santé des Canadiens et Canadiennes, dont ceux de cette communauté aux besoins criants. Les personnes qui vivent avec l'encéphalomyélite myalgique sont au premier plan de ce projet de recherche de qualité. Le réseau produira d'importants résultats cliniques – des traitements pour les patients atteints d'EM – en plus de perfectionner les connaissances des professionnels de la santé et d'établir des liens entre le Canada et des chefs de file du domaine ailleurs dans le monde. »

Dr Karim Khan, directeur scientifique de l'Institut de l'appareil locomoteur et de l'arthrite des IRSC

« La recherche de pointe réalisée au Centre hospitalier universitaire Sainte-Justine est à l'avant-garde des efforts des scientifiques en vue de percer le mystère des maladies débilitantes qui pèsent lourd sur les patients et leur famille. Je suis très fière que notre établissement et nos scientifiques soient au cœur de cette initiative porteuse d'espoir pour nombre de gens. »

Mme Caroline Barbir, présidente-directrice générale du CHU Sainte-Justine

"ME is possibly the last medical enigma of the 21st century. The complexity of unresolved questions around its etiology and pathophysiology requires the coordinated efforts of an interdisciplinary collaborative research network to benefit the health of all Canadians living with ME."

Dr. Alain Moreau, Professor, University of Montreal
Scientific Director, Viscogliosi Laboratory in Molecular Genetics of Musculoskeletal Diseases, CHU Sainte-Justine Research Centre
Scientific Lead and Director of the Interdisciplinary Canadian Collaborative ME Research Network

« L'EM est peut-être la dernière énigme médicale du 21e siècle. La complexité des questions d'étiologie et de physiopathologie qu'elle soulève nécessite les efforts coordonnés d'un réseau de recherche concertée et interdisciplinaire pour améliorer la santé de toutes les personnes vivant avec l'EM au Canada. »

Prof. Alain Moreau, professeur à l'Université de Montréal et directeur scientifique du Réseau canadien de recherche concertée interdisciplinaire sur l'EM

"Myalgic encephalomyelitis is a long-term disabling disease that greatly affects individuals who live with it. This CIHR grant is a huge opportunity for Canadian researchers and clinicians to work together with patient partners towards finding answers and developing effective treatment options to improve the quality of life for those living with ME."

Dr. Luis Nacul, Medical Director and Research Director, Complex Chronic Diseases Program, BC Women's Hospital + Health Centre

« L'encéphalomyélite myalgique est une maladie à long terme très invalidante. La subvention des IRSC se veut une occasion inouïe pour les chercheurs et les médecins canadiens de collaborer avec des patients partenaires dans l'espoir de trouver des réponses et de concevoir des options de traitement efficaces qui permettront d'améliorer la qualité de vie des personnes qui vivent avec l'EM. »

Dr Luis Nacul, directeur médical et scientifique du programme sur les maladies chroniques complexes, Hôpital et centre de santé des femmes de la Colombie-Britannique

"ME has devastated my personal and professional life, as it has that of so many individuals living with this disease. Today, we applaud the Government for recognizing the debilitating life-changing effects of ME and for funding urgently needed research. As we embark in a new partnership with researchers, clinicians and government, we hope that this financial support will be a stepping stone to further funding and research required to understand this complex disease and develop diagnostic tools and effective treatments."

Christiane Garcia, Interdisciplinary Canadian Collaborative ME Research Network Patient Partner, Board Member - Action CIND and AQEM (Association Québécoise de l'Encéphalomyélite Myalgique)

« L'EM a détruit ma vie personnelle et professionnelle, et c'est le cas de nombreuses autres personnes atteintes de cette maladie. Aujourd'hui, nous félicitons le gouvernement de reconnaître les effets invalidants de cette maladie qui bouleversent la vie des personnes atteintes et nous le remercions de financer la recherche dont nous avons tant besoin. Alors que nous entamons un nouveau partenariat avec les chercheurs, les cliniciens et le gouvernement, nous espérons que cet appui financier constituera un tremplin vers du financement supplémentaire et d'autres recherches pour comprendre cette maladie complexe et mettre au point des outils diagnostiques et des traitements efficaces. »

Christiane Garcia, patiente partenaire du Réseau canadien de recherche concertée interdisciplinaire sur l'EM, membre des conseils d'administration d'Action CIND et de l'AQEM (Association québécoise de l'encéphalomyélite myalgique)

Quick facts

This $1.4M, five-year investment aims to improve the quality of life of people living with ME through:

- investigating the causes of ME, including possible links to viruses and genes;
- linking cohorts of patients and researchers in Canada and the US, enabling investigators to share research samples, clinical data, and analysis methods;
- supporting graduate students working on ME to build Canadian capacity to research this condition; and
- benefiting from the wisdom of people with ME who are active research partners.

Faits en bref

Cet investissement de 1,4 M$ sur cinq ans vise à améliorer la qualité de vie des personnes vivant avec l'EM :

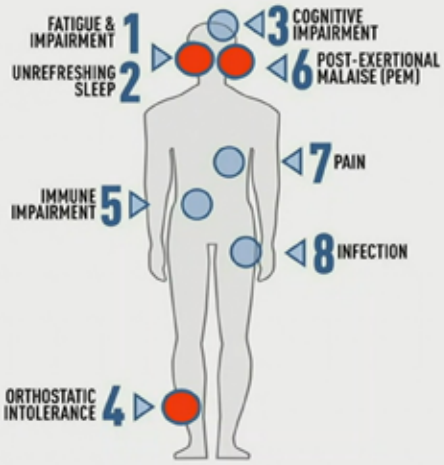
- par l'étude des causes de l'EM, y compris des liens possibles avec des virus et des gènes;
- par l'établissement de liens entre des cohortes de patients et des chercheurs du Canada et des États-Unis, permettant aux chercheurs de partager leurs échantillons de recherche et leurs données cliniques, et d'échanger sur les méthodes d'analyse;
- par l'appui d'étudiants des cycles supérieurs travaillant sur l'EM pour développer les capacités de recherche du Canada sur cette affection;
- par l'utilisation des connaissances des personnes qui vivent avec l'EM et qui prennent une part active à la recherche.

Research Nerwork Summary Slides

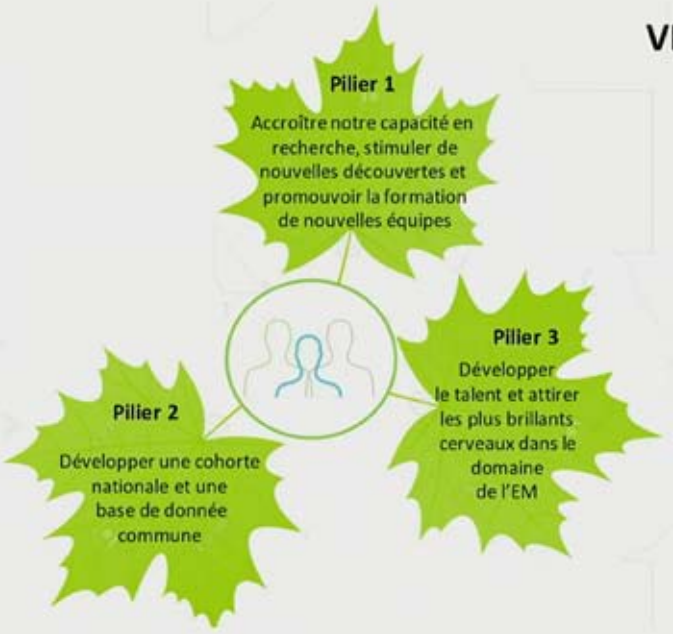
L'encéphalomyélite myalgique:

La dernière énigme médicale du 21e siècle

- Maladie chronique complexe et multi-systémique dont l'étiologie reste mal comprise.
- Elle est causée par des perturbations du métabolisme énergétique, du système immunitaire et des anomalies au niveau de la réponse physiologique à l'effort.
- Incidence au **Canada** en 2016: 582,000 cas
- Prévalence : Les femmes entre 30 et 50 ans (60% des cas)



Interdisciplinary Canadian Collaborative
Myalgic Encephalomyelitis Research Network
Réseau Canadien de Recherche Concertée
Interdisciplinaire sur l'Encéphalomyélite Myalgique



VISION ET MISSION DU RÉSEAU

- Être un pôle d'innovation, promoteur d'excellence en recherche sur l'EM et centré sur le patient et ses besoins.
- Devenir la principale ressource pour initier, soutenir et maintenir une recherche novatrice et concertée au Canada.
- Contribuer à améliorer la santé de tous les Canadiens vivant avec l'EM.

Interdisciplinary Canadian Collaborative
Myalgic Encephalomyelitis Research Network
Réseau Canadien de Recherche Concertée
Interdisciplinaire sur l'Encéphalomyélite Myalgique

US Research Funding

An article by Cort Johnson emphasizes that the US National Institutes of Health does not look at health research funding in the same way as the ME community does.

A book by Maya Dusenbery looks at health services and health research from a feminist viewpoint, She talks about two interlocking problems that affect the quality of care received by women and by men with female-predominant diseases - a knowledge gap since doctors don't know as much about women's bodies and the health problems that affect them, and a trust gap since women's accounts of their symptoms are too often not believed. Included in the book are descriptions of how the medical system has viewed hypochondria, chronic pain and myalgic encephalomyelitis over time.

A book by Rachel Kahn Best looks at how individual diseases have been marketed by organizations and viewed by the US public over time. The book traces disease campaigns over the last hundred years, going back to tuberculosis and polio campaigns. It focuses on the positive - how these campaigns brought disease issues to public attention and how well the public responded to some of the campaigns. It provides relatively little advice to stigmatized diseases like ME and FM, except to caution us not to tear down the diseases that are doing well since a rising tide lifts all boats. The question which is not answered is whether the fact that the public supports diseases unevenly can justify government agencies supporting diseases unevenly.

US Research Funding - Cort Johnson

As we celebrate the announcement of CIHR funding for ME, we also sense how little the funding is. How does one reconcile the two reactions?

Cort Johnson looked at this issue in an article interviewing and profiling Carol Head who recently resigned as CEO of Solve CFS/ME, an organization that has been working to build ME research in the US for decades.

Sections of that article are shown here, with permission of Cort Johnson.

https://www.healthrising.org/blog/2019/07/27/straight-talk-carol-head-solve-me/

**

Carol Head

She told me she recognized early on that if we were going to get the dollars needed to solve this disease, the NIH needed to vastly increase its support for ME/CFS. She quipped, "Just as when the gangster Willie Sutton was asked why he robbed banks, he said 'because that's where the money is' – so the big basket of money at the NIH required she learn "how they operate, how they think, and what their perceptions are".

She realized that the NIH uses a slow, methodical process that relies on a highly structured, time-tested manner of distributing funds to disease research. That approach has benefited millions but to people with ME/CFS, that slow methodical pace seems like dishonest stonewalling. To the NIH, it seems like prudent, caring stewardship of taxpayer dollars. Both the below statements, Carol said, are true in her experience:

- The NIH is unconscionably, immorally slow in supporting ME.
- The NIH is working unusually quickly to support work in ME.

To us the pace is maddeningly slow: to them – adding three research centers, an intramural study and a two-day ME conference – it was moving very quickly in such a small field.

Carol's statement made sense to me. For over a decade, I've been hammering the NIH for their unconscionable neglect. I'd concluded that the NIH was an evil, morally bankrupt institution. Given their neglect of so many ill people over the decades – including myself, at the end of

my fourth decade with ME/CFS – I didn't see how else to view them.

After more thought, though, I concluded that the NIH is morally bankrupt – but not because it's evil – but because morality gets no say at the NIH. Unmet needs mean NOTHING to the NIH. Suffering doesn't compute either, and don't even think about bringing fairness into the equation: you might as well be speaking Latin for all the agency cares about fairness.

The NIH is also not, surprisingly enough, dedicated to answering the health needs of the nation. The NIH has NO regulatory system designed to ferret out and fix research funding inequities or to assess health needs. Nothing in the grant review process gives diseases with more needs a leg up. There's no year-end review of funding priorities which identifies neglected disease areas which should get a funding boost.

The NIH's main focus is simply to support medical research – or more accurately – medical researchers. In doing so, it's embraced a laissez-faire, free-market Adam Smith-like notion that the invisible hand of the medical research field will take care of all. The NIH is simply there to institute rigor into the funding process.

Several problems with this exist. For one, medical researchers don't exactly have the health needs of the nation in mind. Their most immediate priorities include having a successful career, being intellectually stimulated, gaining their peers' and their mentors' approval, etc.

Plus, just like the monopolies of the past or the big businesses of the present – any disease that gets "in" automatically has an edge. It has more allies, more laboratories, better equipment, can offer researchers more cutting-edge opportunities, etc. than diseases on the fringes. Its grant applications will be reviewed by a panel more amenable to pushing them through. Since the NIH largely works by peer review, it is susceptible to being captured by buddy-buddy networks.

Diseases like ME/CFS, fibromyalgia and migraine – diseases which affect millions and millions of people, cause enormous amounts of suffering and cause huge economic losses, but haven't built that kind of infrastructure – get shut out.

If this analysis is correct, this kind of lassez-faire approach to medical research means that even people like Francis Collins, the head of the NIH, don't, by themselves, have the kind of impact we might think they would have.

Because the NIH doesn't operate via fiat (e.g. Francis Collins does not wave a magic wand) – and hasn't in almost 130 years created any mechanisms to address funding inequities – in order to succeed, we need to establish allies up and down the chain of command; from the individual researchers submitting grants; to the grant review committees; to the institutional leaders making the final decisions.

At the same time Carol Head refused to cast the NIH as an evil monster, she recognized that something more than simply yelling at the NIH from the bleachers had to be done.

The NIH had to be gotten at in other ways. They included: 1) funding more seed grants with the Solve ME Ramsay programs; 2) pushing for non-researcher projects (e.g. the national ME conference); and 3) going to the one institution which could make the NIH change its ways: Congress.

If NIH is structured to ignore medical research inequities, Congress is tasked with ensuring that the government meets the needs of the people. Since Congress holds the purse strings and the NIH was clearly not fulfilling our needs – and was not going to anytime soon – Congress was the place to go. Congress is the only place that could force the NIH to quickly change its ways.

That required, though, not just reviving Solve ME's moribund advocacy program but boosting it to levels never seen before. When Carol became President in 2013, Solve ME was purely a research organization. Recognizing that ME/CFS research was never going to progress at the NIH on any kind of satisfactory timeline, she pivoted.

She brought Emily Taylor, and her five-year plan to force change at the NIH, before Solve ME's Board of Directors. Solve ME would put a significant portion of its meager resources into advocacy again, but this time it would go for the gusto: a long-term project to create legislation to force the NIH (and also the Department of Defense) to devote more dollars to ME/CFS.

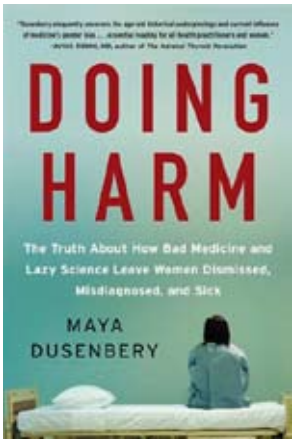
Carol said she has watched virtually every new Solve ME board member go through a humbling experience. The Solve ME board, she said, is composed of highly capable, successful, professional individuals who tend to have friends with resources; people who could contribute really significant amounts to this disease – but it just doesn't happen. The Board members go to their friends

with high expectations – they pour their hearts out – and they expect a response which just doesn't come – not yet.

From what Carol said, it was clear we have some issues to deal with – some ideas about ME/CFS that have to change. The flip side of that is that changing those ideas will unleash vastly more support.

Carol believes there's too much energy, too much passion, too many good ideas for this field not to succeed.

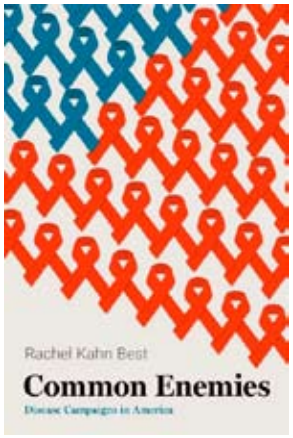
US Research Funding - Maya Dusenbery



Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick

[From the front flap] An eye-opening read for patients and health care providers alike, Doing Harm shows how women suffer because the medical community knows relatively less about their diseases and bodies and too often doesn't trust their reports of their symptoms. The research community has neglected conditions that disproportionately affect women and paid little attention to biological differences between the sexes in everything from drug metabolism to the disease factors—even the symptoms of a heart attack. Meanwhile, a long history of viewing women as especially prone to "hysteria" reverberates to the present day, leaving women battling against a stereotype that they're hypochondriacs whose ailments are likely to be "all in their heads".

US Research Funding - Rachel Kahn Best



Common Enemies: Disease Campaigns in America

For over a hundred years, millions of Americans have joined together to fight a common enemy by campaigning against diseases. In Common Enemies, Rachel Kahn Best asks why disease campaigns have dominated a century of American philanthropy and health policy and how the fixation on diseases shapes efforts to improve lives. Combining quantitative and qualitative analyses in an unprecedented history of disease politics, Best shows that to achieve consensus, disease campaigns tend to neglect stigmatized diseases and avoid controversial goals. But despite their limitations, disease campaigns do not crowd out efforts to solve other problems. Instead, they teach Americans to give and volunteer and build up public health infrastructure, bringing us together to solve problems and improve our lives.

Chronic Pain in Canada

A decade ago, there were three areas with an interest in Fibromyalgia, the arthritis-rheumatology area, the ME/FM area, and the chronic pain area.

The arthritis-rheumatology area has more or less lost interest in FM.

The chronic pain area is gaining prominence and resources. The International Association for the Study of Pain has over 7,000 members from over 100 countries. Chronic pain has become a recognized subspecialty of the Royal College of Physicians and Surgeons of Canada. The Canadian government established a task force to study chronic pain.

The Canadian government task force on chronic pain has been operating for only a few months but has already released an initial report. We are including a summary of the report prepared by Pain BC as well as the table of contents of the report.

Chronic pain is a very broad topic. Broad issues lead to generalized explanations and treatments. The report refers to three types of pain (nociceptive, neuropathic and nociplastic).

The report discusses having to address physical, psychological and social issues that surround chronic pain. The report distinguished primary chronic pain where "the symptoms are not better accounted for by another diagnosis" from chronic secondary pain where the "pain originally emerges as a symptom of another underlying health condition" like cancer or surgery. Hence the difference between primary and secondary chronic pain is whether science has figured out the trigger or mechanism.

Over half a million Canadians are dealing with FM but that is a small proportion (something like one-tenth) of those dealing with chronic pain. FM is mentioned a few times in the report but receives no specific attention. FM is classified as primary chronic pain meaning that it is considered unexplained. ME is not mentioned at all in the report even though chronic pain can be a very significant for people with ME.

Understanding of FM is likely going to come as part of ME research. There is so much overlap between ME and FM that ME research findings will likely provide insights into the mechanisms of FM. Of course, there is a need for FM-focused research as well.

It is also highly likely that diagnosis and treatment for FM are going to be provided by ME/FM/MCS clinics as is already the case in BC, Ontario and Nova Scotia, and as was recommended by the Ontario Task Force on Environmental Health. The ME/FM/MCS clinics could then refer patients to chronic pain clinics for support with pain symptoms, something that is already happening.

The Canadian chronic pain task force is expected to hold public consultations this fall and winter. This will be an opportunity to say that FM needs research, public awareness, education of health professionals and reviews of programs and policies, just as ME does. This will be an opportunity to say that FM does share some issues with the broad chronic pain community, but that burying the large category of FM into the much larger category of chronic pain does not serve the FM community well at all.

Two new reports on the state of chronic pain in Canada

Reprinted by permission from the Pain BC newsletter of July, 2019

https://www.painbc.ca/

What's the current state of pain care, education and research in Canada? Two new reports shed light on the significant problem of unrecognized and untreated pain.

The Angus Reid Institute (ARI) , in partnership with the Mindset Social Innovation Foundation and Pain BC, looked at the issue of chronic pain in Canada. In a national poll, we sought to understand the experience of Canadians living with pain and to gain insight into the perceptions of the Canadian public on pain-related issues. What jumped off the page? The broad impacts of pain, Canadians' experiences with cannabis and opioids, and overwhelming support for policy change:

- From sleep to mental health to day-to-day functioning, 1 in 5 Canadians shared that pain is limiting their quality of life and ability to function.
- The pendulum swing around opioid prescribing is impacting Canadians in pain - 37% of those surveyed said that they can no longer access pain medications when needed.
- Financial barriers are a big impediment to Canadians with pain having better quality of life - 64% said if they could afford the treatments they need, they would be living with less pain and better quality of life today.

- Cannabis was reported as being effective by 74% of those who tried it for pain relief; this was the highest number of all treatments surveyed.
- Canadians are near-unanimous in their support for more access to publicly funded pain treatments.

The ARI report highlights the need for federal and provincial policy change to improve access to care in Canada. To learn more, read the whole report .

Pain BC is grateful to the Mindset Foundation and the Angus Reid Institute for their generous support of this project.

The ARI report echoes what is outlined in the first report of the Canadian Pain Task Force (CPTF). The CPTF was launched in March by the federal government and is mandated to examine the current state of pain in Canada, to outline an improved approach to treatment, education and research, and to support uptake of this approach across the country. The main messages in the CPTF's report are that:

- There is a global consensus that chronic pain is a significant chronic disease in its own right and as such, needs concerted attention. This is not reflected in the current state in Canada.
- Care for chronic pain is largely dependent on where people live and what type of insurance coverage they have.
- People living with chronic pain need better access to a range of treatment services beyond medication, including psychological support, physical therapies, integrated health care services, and others.
- There is a clear deficit in education of health professionals in the causes, types, underlying mechanisms, and effects of pain, as well as how best to treat it.
- Efforts to reduce the number of opioid-related overdose deaths in Canada have had significant consequences on chronic pain patients, including increased stigma and reduced access to treatment. For some patients, it has also resulted in inappropriate prescribing practices such as abrupt stoppage of opioids or tapering without consideration of the risks associated with withdrawal or the medical needs of patients.
- Data and evidence need to be improved to make more informed decisions on individual treatment, health system change, and policy.

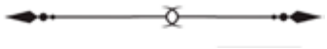
While neither report yields big surprises to people living with pain, they serve as a wake-up call for the general public and for federal and provincial policy makers. Through the efforts of Pain BC, our allies and supporters, and the work of the CPTF, I'm hopeful that increasing awareness will result in concrete change

Read the Angus Read Report here:

http://angusreid.org/chronic-pain-in-canada/

Read the CPTF report here:

https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2019.html



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Disability Advisory Committee Report

As promised in the last newsletter, we are including a review of the Disability Advisory Committee year-1 report.

In November 2017, when issues around the Disability Tax Credit (DTC) were receiving a lot of media attention, the Minister of National Revenue appointed a Disability Advisory Committee (DAC). Consisting of ten people with disability/tax expertise, the committee was given the mandate to advise the federal government on disability/tax issues.

The Disability Advisory Committee had an amazingly active first year. They met several times. They asked for feedback from disabled individuals, disability organizations, disability experts, tax preparers and health care professionals showing great openness. They had one tangible success: the federal budget contained a provision that people who qualified for the DTC, opened a Registered Disability Savings Plan (RDSP) and then failed to qualify at a later date no longer had to close the plan. The DAC submitted a year-1 report which addressed a wide range of issues. Hopefully the DAC will continue in the future because there are issues still to be addressed.

Being declared eligible for the DTC gives individuals two obvious advantages.

- It allows them to reduce their taxes payable by up to $1,235.25 (2018 figure). If people owe less than that amount in taxes, they do not get the full benefit of the reduction. If they do not owe any taxes, they get no benefit from the reduction.
- It makes them eligible for programs that are tied to

the DTC, two notable programs being the registered disability savings plan and the disabled child benefit.

Being declared eligible for the DTC has another advantage that is not addressed in the Disability Advisory Committee's first annual report. It is a formal declaration by government that the individual is disabled in a way that is deserving of public sympathy and support.

The eligibility criteria have evolved over the years as new categories of disability received government recognition and were added to the list. Currently, these are the eligibility provisions as quoted from page 6 of the report:

The person must meet one of the following criteria:

- Is blind
- Is markedly restricted in at least one of the basic activities of daily living; [note: the "activities" listed in the legislation are walking, dressing, feeding, mental functions, eliminating, hearing and speaking.]
- Is significantly restricted in two or more of the basic activities of daily living (can include vision impairment); or
- Needs life sustaining therapy.

In addition, the person's impairment must meet both of the following:

- Is prolonged
- Is present all or substantially all the time.

As can be seen, there are multiple paths to qualify for the DTC - (vision problems, seven other types of problems, numerous combinations of these problems, and life sustaining therapy). The government has to determine how people qualify on each of these paths. They also should be ensuring that there are paths for everyone and that there is equity between paths.

The committee found that there were problems with the current provisions around many of the paths. They recommended changes in some, notably the mental functions category where they recommended multiple new paths.

The committee noted that some categories are based on impairments of bodily functions (eg problems seeing or hearing) while other categories are based on activity limitations (problems with doing things such as dressing oneself). Functional impairments and activity limitations are conceptually different: see Quest 106, page 6-7. http://mefmaction.com/images/stories/quest_newsletters/Quest106.pdf The committee recommended that the existing list be recast as functional impairments. This puts the criteria on a conceptually consistent basis (except for the life-sustaining therapy).

But this also brings to the surface a very important issue. The World Health Organization has developed a list of bodily functions. Many categories on the WHO list are not reflected in the DTC criteria. For instance, problems in the creation of energy, management of pain, or circulation of blood are impairments of bodily functions which can be very debilitating but are not on the DTC list. In essence, the DTC program is saying that people with some types of bodily impairments are deserving of sympathy and support, but people with other types of bodily impairments are not. This is extremely arbitrary.

It is important to remember that government, not the Disability Advisory Committee, is responsible for ensuring fairness in government programs. At a certain point, government officials will recognize that they have to go back to basic principles and ask what the program is trying to accomplish and how it can be designed to be fully inclusive and fair. They will need to think about the implications of Canadian human rights legislation such as the UN Convention on the Rights of Persons with Disabilities. Only when this is done will the DTC program join the 21st century.

Upcoming Federal Election

With a federal election coming soon, we would like to remind you that

- there are many ways to vote, including voting from home. For information, call the Elections Canada office for your riding asap. You can get the riding office number by calling 1-800-463-6868.
- the election period is a good time to raise important issues with candidates like the need for equitable research funding, public awareness, training of health professionals, and review of government programs and services.


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