NATIONAL ME/FM ACTION NETWORK
SINCE 1993

# Quest Newsletter

www.mefmaction.com Quest 122, Spring 2020 mefminfo@mefmaction.com

## Raising Awareness From Home

*Last autumn, we received the most delightful letter.*

May's ME/CFS Awareness day inspired me to design this pamphlet because I wanted a simple way to inform people of my ME/CFS. I didn't include details like how to diagnose – as it requires a lot of space and it is well covered online. I figured if people wanted those details, I'd direct them to the back of the pamphlet where I have website links.

The idea was to give it to neighbours and those I met in shops (like at the hair salon or drug store – anywhere I had a conversation). I'd even hand it out to anyone who came to my house: plumber, friend, solicitor. "No one leaves without a pamphlet". And I'd encouraged them to pass it on when they were done with it saying that we needed more awareness to be built and there aren't enough well people to help our community.

I have been too sick to hand out many, but my parents have handed out 10 in their retirement community and sent about 5 to family members. Already there have been about 3 inquiries from people thinking that they know someone who might have the disease.

Anyone has my permission to make copies.

*J.J.*

*JJwantedtoshareherworkandwearehappytodoso.People receiving this newsletter by email can see the pamphlet at http://mefmaction.com/docs/ME-WhatYouShouldKnow.pdf People receiving the newsletter by snail mail will find two copies of the pamphlet enclosed. Feel free to make additional copies. Or feel free to create your own version.*

*Would someone would like to design a similar pamphlet for FM?*

## Disability Dynamics

*On International Disability Day in December 2019, a very important study by Statistics Canada and the department Economic and Social Development Canada was released. Here is their overview:*

The conventional view of disability is that it is a persistent and unchanging limitation. However, many persons with disabilities may not follow this relatively stable pattern. Instead, they may experience periods of good health interrupted by periods of their limitations (on-again/off-again episodes) or their limitations may change over time (worsening, improving, or fluctuating). Such changing disabilities can be characterized as dynamic, as opposed to continuous disabilities, which tend to be more stable over time. Thus, the collective experiences of persons with disability dynamics may look different than those of persons with continuous disabilities...

**Conclusion: Three in five persons with disabilities do not fit the conventional view of disability.**

*This study reinforces the importance of going back and reviewing ALL disability programs (provincial as well as federal) to ensure that they recognize that not all disabilities are traditional, stable and continuous.*

## Federal Government Priorities

Following the appointment of cabinet members, the Prime Minister issues each one a mandate letter outlining what he sees as their priorities. From the ME/FM perspective, there are very important provisions in two of the letters.

Minister of Health

As you will recall from the last newsletter, a new Minister of Health was appointed following the October 2019 election. We would like to thank former Minister Ginette

## Contents



Petitpas Taylor for her strong statement in support of ME (see Quest 120) and we look forward to working with current Minister Patty Hajdu.

Among the priorities in the mandate letter to the new Minister of Health are the following:

- *Work with the Canadian Institutes of Health Research to integrate sex- and gender-based analyses, as well as diversity analyses, to ensure research takes diversity factors into account to improve women's health care.*
- *Provide additional funding to the Canadian Institutes of Health Research so that it can create academic research grants for studies on race, diversity and gender.*
- *Create a National Institute for Women's Health Research, with the support of the Minister for Women and Gender Equality and Rural Economic Development, that will bring together experts in women's health from across the country to tackle persistent gaps in research and care using an intersectional approach.*

Statistics show that ME and FM affects many more women than men. The health system questions the credibility of female patients generally. This is a major factor in the lack of research and services for ME and FM patients. The provisions in the mandate letter show that the government has recognized the importance of looking at gender biases in health care and research. This could be extremely helpful to the ME/FM community.

The National ME/FM Action Network has contacted the office of the Minister of Health identifying the ME/FM community as an important stakeholder in women's health research and asking to be kept abreast of developments.

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Minister of Employment, Workforce Development and Disability Inclusion

During the first four years of the Trudeau government, cabinet responsibility for disability issues jumped around, both among ministers and where it is placed. Previously, disability fell in the general area of welfare or social development. In 2015, Prime Minister Trudeau named Carla Qualtrough as Minister for sport and persons with disabilities. That portfolio was transferred to Kent Hehr and then to Kirsty Duncan. Later, the disability component was detached from sport and given back to Carla Qualtrough who was then Minister of Public

Works and Government Services. The title was changed from persons with disabilities to "accessibility" with the passage of the Accessible Canada Act as the focus. That Act passed shortly before the 2019 election.

Following the 2019 election, Carla Qualtrough was again given responsibility for disability issues, this time as "Minster of Employment, Workforce Development and Disability Inclusion". Her mandate letter from the Prime Minster has a number of priorities including the implementation of the Accessible Canada Act, development of an autism strategy and examination of disability employment issues. (The National ME/FM Action Network expects to be part of a project looking at disability employment.) But also included in the mandate letter is a very important clause which asks the Minister to look at disability overall:

*Conduct a comprehensive review to ensure a consistent approach to disability inclusion and supports across government that addresses the unfairness and inequities in government programs and services, and challenges the biases built into government processes. This includes a definition of disability consistent with the Accessible Canada Act*

Fortunately, the definition of disability in the Accessible Canada Act is broad and can include people with ME and/or FM who are struggling to participate in school, work, family, social and/or recreational activities:

***disability*** *means any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment — or a functional limitation — whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person's full and equal participation in society.*

This review of disability supports across government should open up very important discussions about how disability is described in federal programs like CPP-Disability, the Canadian Survey of Disability and the Disability Tax Credit.

## ME in the Education System

*[Media Release from DePaul University. The study shows how little awareness there is of pediatric ME overall and especially among visible minorities.]*

Most youth living with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) have not been diagnosed, according to a new prevalence study from researchers at DePaul University and Ann & Robert H. Lurie Children's Hospital of Chicago, published by the journal Child & Youth Care Forum. Leonard A. Jason, a professor of psychology at DePaul University, led the seven-year study to screen more than 10,000 children and teenagers in the Chicago area.

The researchers found that less than 5% of youth in the study who tested positive for ME/CFS had been previously diagnosed with the illness. Of the children assessed, African American and Latinx youth were twice as likely to be living with undiagnosed ME/ CFS. The study was funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, one of the National Institutes of Health. Jason has been studying ME/CFS for more than 30 years and says the illness can affect all aspects of a child's life, from physical functioning to attending school and participating in extracurricular activities.

"When you're talking about a condition that's as debilitating as this one, the health care response has not been good," said Jason. "There aren't that many physicians who are trained and skilled at diagnosing and treating this illness, and our health care system has not done a great job at trying to help people who are affected," said Jason, director of DePaul's Center for Community Research.

Working with Jason as co-principal investigator is Dr. Ben Z. Katz, a pediatric infectious disease specialist at the Ann & Robert H. Lurie Children's Hospital of Chicago. Katz is also a professor of pediatrics at Northwestern University Feinberg School of Medicine. He has collaborated with Jason and his group since the late 1990s. "Our finding that most youth with ME/CFS have not been previously diagnosed is comparable to findings in adults," said Katz. "We definitely need better

ways to identify people with this illness and to develop effective interventions for them. In particular, we need to reach African American and Hispanic youth, since in our study these groups had higher prevalence of ME/CFS. "

The prevalence of pediatric ME/CFS has been in dispute, so Jason and Katz set out to include a diverse sample of ethnic, socio-economic and demographic backgrounds. Other ME/CFS prevalence studies have drawn from tertiary care centers, which can exclude those without access to health care, explained Jason. The researchers tailored their approach by including a thorough medical and psychiatric examination, offering access to high-quality screening for those at-risk of having the illness.

Researchers screened a random sample of 10,119 youth ages 5-17 from 5,622 households. The first stage was a phone interview with parents and caretakers about the health and behavior of their children and teens. Missing school because of fatigue was one of the common symptoms among youth who showed a higher risk of having ME/CFS, and was a red flag for parents, said Jason.

Of those who screened positive over the phone, 165 youth went on to medical and psychiatric examinations. Following evaluations, a team of physicians made final diagnoses. Youth were given a diagnosis of ME/CFS if they met criteria for case definitions. Of the 42 youth diagnosed with ME/CFS, only 2 (4.8%) had been previously diagnosed with the illness.

Prevalence of pediatric ME/CFS was 0.75%, which is a bit less than 1%, with a higher prevalence among African American and Latinx youth compared to their Caucasian peers. "Clearly people of color do get this illness, and there are some myths that you have to be white middle class to have ME/CFS," said Jason.

A lack of access to health care, and therefore less opportunity for an earlier diagnosis, could explain this racial disparity, according to Jason. "There are barriers to researchers gaining access to underserved populations. They may not trust institutions as easily, and they may not also have time to bring their children into appointments," said Jason.

And, there is still stigma and misunderstanding about ME/CFS among health care providers. "They may not believe this is a condition, or might attribute it to fatigue," said Jason.

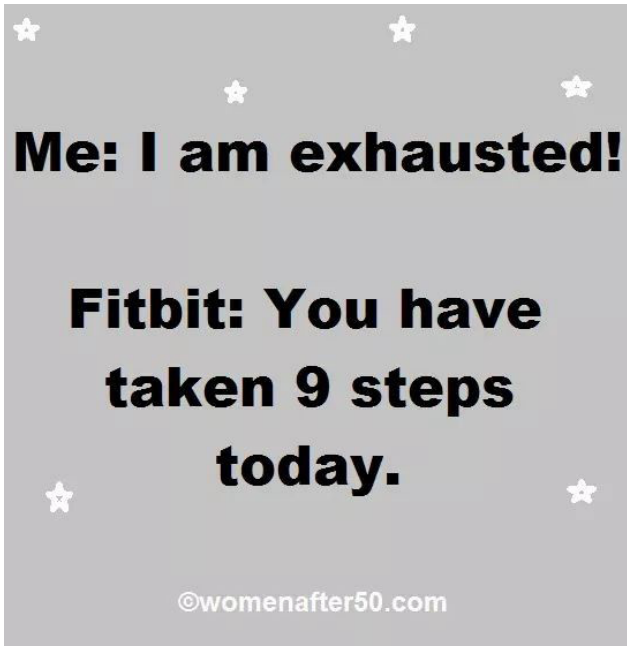
The findings point to the need for better ways to identify and diagnose youth with this illness, said Jason, who has secured more than $46 million in research grant support during his 45-year professional career at DePaul. Co-authors of the study are DePaul University graduate students Madison Sunnquist, Chelsea Torres, Joseph Cotler and Shaun Bhatia.

"We're trying to help people who have this illness have information that could be used to argue for more resources for diagnosis and treatment," said Jason.

**Journal Reference**:

Leonard A. Jason, Ben Z. Katz, Madison Sunnquist, Chelsea Torres, Joseph Cotler, Shaun Bhatia. **The Prevalence of Pediatric Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome in a Community-Based Sample**. Child & Youth Care Forum, 2020; DOI: 10.1007/ s10566-019-09543-3

*Note: the prevalence of ME averages out to 0.75% across the age 5-17 age group, but it is more prevalent among older youth. The rate for students youth aged 15-17 was in the range of 1.0% to 1.5%.*



## CPP-D Guide 2020 Edition

The National ME/FM Action Network publishes a Guide for applying for CPP-Disability. The guide was last updated in 2016. A lot has changed since then. There is a new application form, a new "toolkit" (instructional material about how the process works) and much better documentation around the procedures at the Social Security Tribunal. This has led to changes in many sections, notably chapter 4 (disability) and Appendix A, chapter 5 (the application form) and chapter 6 (appeals). And there are rewrites in other places (eg changing ME/CFS to ME, FMS to FM, MQP to coverage period and disability benefits to disability payments or supports).

The more we worked on the Guide, the more we became convinced that it is very difficult for people with ME and FM to apply for CPP-D. When they fall ill, they may not recognize that this is a long term problem. They may have difficulty finding medical support. There are tests to run and treatments to try, though the treatments generally have limited value. They may be having problems with their employers and LTD company (if they even have LTD). Their family may not be on-side. If they figure out to apply for CPP-D, they may have nobody to help them apply. They have to figure out the concepts of coverage period, date of onset, disability, substantially gainful occupation, severe, and prolonged. They have to sort out why they can't work and they have to figure out how to tell this story on an application form which does not ask all the questions that should be asked. Also, their full story can be nuanced - eg good days and bad days. They need to have support from a health care professional. They may have to help the health care professional put together the disability story. They have to hope that the health care professional answers appropriately, and they have to hope that they don't get tripped up by something on their medical file. Meanwhile, it is not clear what definitions the adjudicators are using (back in 2006 it was a modified Fukuda for ME and 1990 ACR for FM) or what the adjudicators are assuming in terms of treatment and prognosis. The system should not be so difficult to navigate!

It is possible to qualify for CPP-D with ME and FM. The purpose of the Guide is to make it as easy as possible for people to complete the application form and weave through the process.

The 2020 Guide is now available in English on our website. The French version will be available as soon as possible.

### SST Decisions

While preparing the CPP-D Guide, we took a quick look at Social Security Tribunal decisions to see what type of ME and FM cases are being appealed and how they are being decided. The cases confirmed that we are addressing important issues in our CPP-D Guide.

Recall that if an application is turned down, the applicant can ask for reconsideration. If that is turned down, the applicant can ask for a hearing at the Social Security Tribunal General Division Income Security. If that appeal is turned down, the applicant can seek leave (permission) to appeal again. If leave is granted, the case is heard in the Social Security Tribunal Appeals Division. When you look at the links below, you can see which have been heard by the General Division Income Security (gdis), which are asking for leave to appeal (sstad) and which are being heard at the Appeals Division (sstadis).

Text in italics are direct quotes from SST decisions.

*https://www1.canada.ca/en/sst/ad/gdis-2019-sst-1227.html*

The rule of thumb is that you should be earning less than around $16,000 per year to qualify as being unable to pursue substantially gainful employment. The applicant earned almost $20,000 in 2018 and on that basis her appeal was rejected.

*https://www1.canada.ca/en/sst/ad/gdis-2019-sst-1250.html*

The appellant could not show that the date of onset of the disability was within the coverage period.

*https://www1.canada.ca/en/sst/ad/gdis-2019-sst-1252.html*

The coverage period ended in 2012. The appellant was able to provide evidence of severe disability from that time forward.

*His family doctor at the time discouraged him from talking about his mental health and fibromyalgia. He felt ashamed that he had emotional symptoms and did not push his doctor for help since it seemed his doctor thought a diagnosis of a mental health condition or of fibromyalgia would make people think less of the Claimant. The Claimant now has access to health care for all of his conditions. Letters from his current family physician combined with testimony from the Claimant and his wife satisfy me the Claimant likely had at least some disabling conditions before 2012 that he tried to manage on his own to avoid shame and embarrassment.*

*https://www1.canada.ca/en/sst/ad/sst-2017-sstadis-618.html*

*Given that the Appellant claimed that fibromyalgia and chronic pain syndrome were her primary disabling conditions, it was incumbent upon the General Division to have conducted at least a rudimentary analysis of these two conditions. It was insufficient to merely indicate that the Appellant had been diagnosed with fibromyalgia and chronic pain syndrome without determining how they impacted her, examining what treatment she might have had, knowing her response to any treatment and finding out the anticipated long-term prognosis. The General Division's analysis fell short and amounted to a failure to consider the totality of the evidence.*

*https://www1.canada.ca/en/sst/ad/sst-2017-sstadis-757.html*

The Appeals Division sent the case back for a new hearing. The previous hearing had assumed she would respond to treatment, had found her non-compliant when she could not afford certain treatments, and had found she could work because she had a small part-time job.

*https://www1.canada.ca/en/sst/ad/sst-2015-sstad-1011.html*

Leave to appeal was denied because the application for leave to appeal was not well organized.

*https://www1.canada.ca/en/sst/ad/sst-2017-sstadis-246.html*

The General Division found that the applicant had not attended a pain management or fibromyalgia support program and therefore did not mitigate her damages. The applicant argued that the General Division did not consider her reasons for not doing so or the impact that this would have. The case was sent back for a new hearing.

*https://www1.canada.ca/en/sst/ad/sst-2017-sstadis-762.html*

The applicant was granted leave to appeal because the previous hearing focused on her key diagnoses and not on the cumulative effect of all her diagnoses.

*https://www1.canada.ca/en/sst/ad/sst-2017-sstadis-558.html*

T*he Appellant has convinced me that the General Division erred in law by effectively ignoring her testimony about the subjective severity of her pain and its effect on her capacity to work.*

*https://www1.canada.ca/en/sst/ad/sst-2017-sstadis-407.html*

This appeal was dismissed because the appellant did not convince the person hearing the case that she was severely disabled. The medical records did not show strong evidence and the fact that the appellant did not try a number of treatments worked against her.

## Closing the Health Care Gender Gap – ME and FM

To: Women's College Hospital Foundation foundation@wchospital.ca

The National ME/FM Action Network agrees with you that closing the gender gap in health care is critical for the well-being of women. This was the title of your sponsored page in the March 7 edition of the Globe and Mail.

We have been working on behalf of Canadians with Myalgic Encephalomyelitis (often referred to as chronic fatigue syndrome) and/or Fibromyalgia since 1993. These illnesses are estimated to affect nearly a million Canadians, mostly women. The ME/FM community reports high levels of unmet health care needs despite multiple contacts with the health care system. This situation cries for attention but has received little. A key reason for the lack of attention is gender – women's voices have not been respected.

Attitudes toward ME and FM are improving. For instance, the leading medical organization in the US validated ME, the previous federal Minister of Health made a strong supportive statement, CIHR is now funding a ME research network and the Ontario government has received a task force report on ME, FM and Multiple Chemical Sensitivities.

Closing the gender gap has to include looking at ME and FM. We hope that the research that you fund will put high priority on this neglected female-predominant area of medicine.

## Doctor to Doctor

*This was a guest column in the College of Physicians & Surgeons of Alberta website: Nov 14, 2019. The author implores his colleagues to be more open to patients with ME and related diseases. Thank you to Linda MacDonald for drawing it to our attention.*

Colleagues:

At age 80 and as a newly retired internist, I welcome the opportunity to share a concern about our profession that has been growing over the last few decades. I call it the "orphan patient" problem.

I define an "orphan patient" as a patient who either cannot find a family physician (FP) who will accept them, not because the FP has a full practice, but because of the patient's medical conditions, or patients have an FP who is unable to find an appropriate specialist to help the patient manage specific healthcare needs.

This practice of "cherry picking" patients has become all too common in all specialties, but especially among FPs. In my own practice as an internist, I found this problem is most common for patients with a diagnosis of chronic fatigue syndrome (ME/CFS) and related disorders; however, the orphaning of patients is by no means limited to these conditions and is a problem across all specialties.

I recognize that every physician has not only the right but also the duty, to refuse to accept cases for which they are not competent. However, that does not mean FPs have the right to exclude patients from their practice because they have a condition they do not wish to treat or care for.

Nearly all patients, regardless of any chronic issues, need a family physician to gain access to secondary or tertiary medical resources. When FPs select patients based on certain conditions they may have, some patients are inevitably not only left as orphans, but are also unable to access any further medical care or assessment.

My concerns are twofold. First, I have been repeatedly dismayed to hear that patients who were referred to me for assessment of fatigue had been told to find another doctor because their current physician "does not see chronic fatigue patients." Additionally, I've had numerous patients referred to me, seemingly for consultation and diagnosis, only to find that their FP had the expectation I would become the patient's primary care physician—because, in the words of one referring physician, "I do not know anything about CFS." I find this concerning.

My second concern is about specialists (mainly, but not exclusively, general internists) who refuse to see CFS patients. Though FPs can easily (and possibly best) manage the patient's ongoing care, complications and diagnostic puzzles that come with CFS should be managed by internists. When I was closing my practice, I found it nearly impossible to find internists willing to be "back up" specialists for FPs caring for CFS patients. I find this equally concerning.

Both of these situations are not a matter of physicians declining to see patients who have conditions for which the physician lacks competence in treating. These patients, regardless of how complex their medical needs, still have the same basic care requirements as any other patient and deserve an ongoing advocate who will seek appropriate secondary and tertiary consultations for them when needed—no one else in the healthcare system can do this better than FPs. Moreover, when secondary or tertiary care is required, patients and their FPs deserve to have specialists who are willing to provide support in ensuring good patient care.

In the case of treating CFS, an internist's diagnostic assessment may well be indicated, but the ongoing management of CFS can be easily and possibly best done by any FP. FPs have all the skills and tools needed to be the primary care physician for patients with CFS and any general internist is able (or should be able) to diagnose CFS and provide guidance on management.

I have used CFS as the model for my discussion because I know it so well from my own practice; however, the principle remains the same for any other conditions any FP or specialist may not like to see. For the patient, the problem is most severe when it is the FP who refuses to care for them because, in essence, the FP is both the gatekeeper and advocate for all further secondary and tertiary health care. Without an FP, the patient is truly an orphan, but all specialists have an equal duty not to ''orphan" the FPs who need their expertise.

The question that remains is how, in good conscience, can a physician refuse to care for a patient on the basis on not wanting to treat a certain condition? If any physicians discriminated in a similar way against patients of various religions, sexual orientations and identities, ethnicities, or any other identifiable groups, they would face discipline very quickly. Why do we allow this kind of diagnostic discrimination?

I believe that addressing this orphan patient problem together as a profession will not only benefit many patients enormously, but also enhance our image greatly amongst Albertans.

Yours sincerely,

A. Voth, MD, LMCC, FRCP, (Can) Fellow ACP

## Consultation on Chronic Pain

We are writing to let you know that the Canadian Pain Task Force online consultation is now open *https://www.canada.ca/en/health-canada/programs/consultation-understand-prevent-manage-pain*

We would like your help to identify ways to improve how we address pain in Canada. The online consultation will be available from February 27, 2020 to April 17, 2020.

Your input will help shape our report to Health Canada, which we will submit to the department in June 2020. At that time, we will identify best and leading practices, potential areas for improvement, and elements of an improved approach to understand, prevent, and manage pain in Canada.

The consultation invites all Canadians to share their ideas and experiences including:

- People personally impacted by pain
- Family members and friends of people living with pain
- Health care professionals, service providers, support workers and caregivers
- Civil society and community groups working in areas related to pain, or social determinants of pain
- Pain researchers and academics
- Private industry and insurers

We encourage you to share the link to the online consultation with others. Please include your family, friends, colleagues and anyone else you may know who would like to help improve the lives of Canadians impacted by pain.

It will take approximately 15 to 30 minutes to complete the consultation 'questionnaire', depending on how much input you would like to provide. You may also use the 'share your experience' tool to share your experience and comments with all viewers. You can save your work at any point by registering to the Letstalkhealth platform and submit your response at any time before the closing date.

## Consultation sur la douleur

Nous voulons vous informer que vous pouvez maintenant participer à la consultation en ligne du Groupe de travail canadien sur la douleur *https://www.canada.ca/fr/sante-canada/programmes/consultation-comprehension-facon-prevenons-gerons-douleur*

Nous aimerions que vous nous aidiez à trouver des moyens pour améliorer notre façon de lutter contre la douleur au Canada. La consultation en ligne se déroulera du 27 février au 17 avril 2020.

Vos commentaires nous aideront à élaborer le rapport que nous soumettrons à Santé Canada en juin 2020. Notre but est de cerner les pratiques exemplaires et de pointe, les aspects pouvant être améliorés et les éléments qui devront faire partie d'une approche améliorée pour comprendre, prévenir et gérer la douleur au Canada.

Tous les Canadiens sont invités à partager leurs idées et leurs expériences durant la consultation, notamment :

- Personnes touchées personnellement par la douleur
- Membres de la famille et amis de personnes souffrant de douleur
- Professionnels du domaine de la santé, fournisseurs de services, travailleurs de soutien et soignants
- Société civile et groupes communautaires qui travaillent dans des domaines liés à la douleur ou aux déterminants sociaux de la douleur
- Chercheurs et universitaires spécialisés dans la douleur
- Secteur privé et assureurs

Nous vous encourageons à fournir le lien vers la consultation en ligne à d'autres personnes. Veuillez la transmettre aux membres de votre famille, à vos amis et à vos collègues et à toute autre personne que vous connaissez qui aimerait aider à améliorer la vie des Canadiens touchés par la douleur.

Il vous faudra environ 15 à 30 minutes pour répondre au sondage, selon le nombre de commentaires que vous souhaitez donner. Vous pouvez partager votre expérience et vos commentaires avec toutes les personnes qui visitent le site en utilisant l'outil « Partagez votre expérience ». Vous pouvez sauvegarder vos commentaires à n'importe quel moment en créant un compte sur la plateforme Parlons santé, et soumettre votre réponse n'importe

For more information about the Canadian Pain Task Force and our mandate, please visit our website at the following link: *https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force.html*

Sincerely,

Maria Hudspith and Fiona Campbell, Co-Chairs

On behalf of the Canadian Pain Task Force

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Here are the Questions:

What challenges and barriers to understanding, preventing, or managing pain exist in your community and in Canada?

What needs to be done to respond to these challenges and barriers?

What is working to address pain in your community and in Canada? Please provide specific examples of practices and/or activities.

What is it about these practices/activities that makes them successful?

What should be the 3 top priorities for research in pain from your point of view?

What would help to better integrate research and new knowledge into education and training, policy, clinical practice, and everyday life?

What other strategies would help us to better understand, prevent, and/or manage pain in Canada?

If you have any additional comments or ideas on addressing pain in Canada, please include them here:

quand avant la date de clôture de la consultation.

Pour en savoir plus sur le Groupe de travail canadien sur la douleur et son mandat, visitez notre site Web à l'adresse suivante: *https://www.canada.ca/fr/sante-canada/organisation/a-propos-sante-canada/mobilisation-publique/organismes-consultatifs-externes/groupe-travail-douleur-chronique.html*

Cordialement,

Maria Hudspith et Fiona Campbell, coprésidentes

Au nom du Groupe de travail canadien sur la douleur

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Questions du sondage:

Quels sont les défis et les obstacles à la compréhension, la prévention ou la gestion de la douleur dans votre communauté et au Canada?

Que faut-il faire pour relever ces défis et surmonter ces obstacles?

De votre point de vue, qu'est-ce qui fonctionne pour aborder le sujet de la gestion de la douleur dans votre communauté et au Canada? Veuillez donner des exemples précis de pratiques ou d'activités.

Qu'est-ce qui fait de ces pratiques ou ces activités une réussite?

Selon vous, quelles devraient être les 3 principales priorités en matière de recherche sur la douleur?

Qu'est-ce qui aiderait à mieux intégrer la recherche et les nouvelles connaissances dans l'éducation et la formation, les politiques, la pratique clinique et la vie quotidienne?

Quelles autres stratégies nous aideraient à mieux comprendre, prévenir ou gérer la douleur au Canada?

Si vous avez des commentaires ou des idées supplémentaires sur la façon de lutter contre la douleur au Canada, veuillez les inclure ici :

## Update from ICanCME Research Network: Let's stop ME together

Since its inception in September 2019, thanks to a catalyst network grant funded by the CIHR Institute of Musculoskeletal Health and Arthritis (IMHA), the Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis (ICanCME) Research Network has stretched its wings. Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), is a complex chronic multi-systemic disease whose etiology remains poorly understood. ME is life-altering and in its more severe forms can be life-threatening. An estimated 600,000 Canadians currently have ME.

Among the first ICanCME Research Network goals is the launch of our website by the end of March, 2020. Equally important, we are organizing several Town Hall meetings across Canada. We will be reaching out to Canadians living with ME, as well as researchers and clinicians to collaborate to address this 21st century medical enigma.

The ICanCME Research Network is an excellent example of patient engagement given their key role in network governance. In March, we will also launch our ME Stars of Tomorrow competition to support new talent in the field of ME/CFS by offering bursaries for graduate students and postgraduate fellowships across Canada. In April, we plan to launch the New Frontiers ME Discovery Grants competition to sustain the formation of interdisciplinary research teams. Both competitions are part of our strategy to attract researchers and clinicians from other fields as well as to develop the next-generation of scientists interested in ME. We look forward to hearing from you, and hope to count of all of you as new members soon!

## Mise à jour de la part du Réseau canadien de recherche concertée interdisciplinaire sur l'EM : « Arrête-MOI si tu peux »

Depuis sa création en septembre 2019, grâce à une subvention du réseau catalyseur financée par l'Institut de l'appareil locomoteur et de l'arthrite (IALA) des IRSC, le Réseau canadien de recherche concertée interdisciplinaire sur l'encéphalomyélite myalgique (EM) a été mis à contribution. L'EM, également connue sous le nom de syndrome de fatigue chronique (SFC), est une maladie chronique multisystémique complexe dont l'étiologie reste mal comprise. L'EM altère la vie et, dans ses formes les plus graves, peut mettre la vie en danger. On estime que 600 000 Canadiens sont actuellement atteints d'EM.

L'un des premiers objectifs du Réseau de recherche est le lancement d'un site Web d'ici la fin mars 2020. Tout aussi important, nous organisons plusieurs rencontres publiques partout au Canada. Nous ferons appel aux Canadiens qui vivent avec l'EM, ainsi qu'aux chercheurs et aux cliniciens pour qu'ils collaborent afin de résoudre cette énigme médicale du 21e siècle.

Le Réseau canadien de recherche concertée interdisciplinaire sur l'EM est un excellent exemple de participation des patients, compte tenu de leur rôle clé dans la gouvernance du réseau. En mars, nous lancerons notre concours Étoiles de demain de l'EM afin de soutenir les nouveaux talents dans le domaine de l'EM-SFC en offrant des bourses d'études aux étudiants de deuxième et troisième cycles partout au Canada. En avril, nous comptons lancer le concours de subventions à la découverte Nouvelles frontières EM pour appuyer la formation d'équipes de recherche interdisciplinaires. Ces deux concours s'inscrivent dans notre stratégie visant à attirer des chercheurs et des cliniciens d'autres domaines ainsi qu'à former la prochaine génération de scientifiques

Prof. Alain Moreau PhD

Director, Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis Research Network

s'intéressant à l'EM. Nous avons hâte de vous entendre et espérons vous compter bientôt parmi nos nouveaux membres!

Prof. Alain Moreau, Ph.D.

Directeur, Réseau canadien de recherche concertée interdisciplinaire sur l'encéphalomyélite myalgique




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