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mefminfo@mefmaction.com

IACFS/ME Conference 2022

Introduction

The International Conference for ME took place from July 27 to 30, 2022. It was held virtually using two software packages. One is Zoom which many of us have become familiar with during the pandemic. Zoom allows people to come together for meetings on-line. The second software was Gather. It was new to me so let me take a minute to describe it.

Gather is built around a floor plan. In this case, there was a lobby area with seating, an information booth, a poster area, and two meeting halls for the first day. One hall was for the research workshop and the other was for the clinicians workshop. Each registrant signed onto Gather and was given a personal "avatar". Your avatar started in the lobby. You could walk your avatar into one meeting room or the other, sit down, and see the names of the people around you. You could then sign onto Zoom to

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Conférence de l'IACFS/ ME- 2022

Introduction

La Conférence internationale pour l'EM/SFC s'est tenue du 27 au 30 juillet 2022. Il s'agissait d'un événement virtuel faisant appel à deux applications logicielles. L'une d'entre elles était Zoom, devenue familière à beaucoup d'entre nous durant la pandémie. Zoom permet la participation à des rencontres en ligne. La seconde était Gather. Je ne la connaissais pas, et je prends donc un moment pour la décrire.

Gather fonctionne à partir du plan d'un lieu en deux dimensions. Dans notre cas, il y avait une salle principale avec des sièges, un kiosque d'information, un emplacement réservé aux affiches et deux salles de rencontre pour le premier jour. L'une des salles de rencontre accueillait l'atelier sur la recherche, l'autre, l'atelier sur la pratique clinique. Chaque personne enregistrée ouvrait une session sur Gather et recevait son

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hear the presentation. At any time, you could walk your avatar out of that room and into the other meeting room or go to the poster room or talk to people in the lobby or have private discussions in the seating area. This software gave the benefits of the presentations themselves along with opportunities to interact with other participants. Technology can be very creative!

Altogether, there were over 30 hours of oral presentations. In addition, there were 22 poster presentations. The quality of the presentations was very good.

The IACFS/ME, the organization running the conference, asked for volunteers to write and share reports on the meeting. I was going to write one anyway for the National ME/FM Action Network's quarterly newsletter Quest so I happily volunteered.

Other volunteers have written about bio-medical findings and clinical discussions so I won't repeat their work. You can find their reports on the website *www.iacfsme.org*. The National ME/FM Action Network is a Canadian patient-based charitable organization. My write-up has four focuses. The first is Canadian contributions to the conference. The second is issues around the recognition and diagnosis of ME. The third is the relationship between ME and long-Covid. The fourth is a question that patients are constantly asking - when are we going to see tangible changes to ME services.

Canadian Presenters

Dr Luis Nacul is the medical director of the Complex Chronic Diseases Program in British Columbia. He sits on the executive of the IACFS/ME and the Canadian research network ICanCME. He chaired presentations on the third day of the conference. In addition, he participated in a discussion on provocation techniques and gave a presentation on the BC long-Covid respirology cohort.

Dr Jane McKay has been with the Complex Chronic Diseases Program for several years. She was appointed as medical lead for the long-Covid program in BC where her ME background is very useful. She talked at the clinicans workshop about the long-Covid program. The program has clinics in Vancouver, Abbotsford, and Surrey and on Vancouver Island and has seen several thousand patients. It focuses on care, research and education. It adjusts its policies and procedures as new information arises. It has an informative website for clinicians and for the public. *http://www.phsa.ca/our-services/programs-services/post-covid-19-care-network*

The session on provocation techniques featured three speakers with Canadian connections. Provocation techniques are used to bring on ME symptoms, notably post-exertional malaise and orthostatic intolerance. This can be for the purpose of seeing whether the patient has ME, judging the degree of disability, or researching how ME operates. **Dr Alain Moreau** of the University of Montreal is head of the Canadian research network. He uses an inflated arm cuff to provoke symptoms. He has collected blood and urine samples before and after the provocation and has uncovered biochemical changes. **Dr Peter Rowe** of Johns Hopkins, who has roots in Canada, talked about two techniques. One was tilt table testing. For the other, patients reported that lying on their backs with legs raised was tiring. He thought that leg lifting might be a provocation technique and found that to be true. Dr Luis Nacul, medical director of the complex chronic diseases program in Vancouver, explained that using a hand gripper (like the kind used for exercise) can also be used to provoke symptoms.

Dr James Baraniuk of Georgetown University in Washington DC has roots in Canada. He described a metobolomic study using cerebro-spinal fluid to study the central nervous system.

Dr Rosemary Twomey of the University of Calgary gave two presentations. The first presentation described a project underway under the auspices of the Canadian Research Network to explore why ME patients are not receiving more services. The second presentation outlined an internet based program she and a respirologist had developed to support long-Covid patients in their home.

Cathy Kline (UBC) and **Gloria Gray** (president of the ME Association of Victoria BC) described a program they developed to bring the ME patient and caregiver perspectives to students in health related disciplines (see box).

Melody Tsai of the BC Women's Hospital research foundation had a poster discussing their investigation of a Canadian patient registry to see if it could be used to identify ME cases.

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« avatar » personnel. Votre avatar entrait d'abord dans la salle principale. Vous pouviez le déplacer pour vous rendre dans l'une ou l'autre des salles de rencontre, vous y asseoir et voir les noms des personnes assises près de vous. Vous pouviez alors ouvrir une session sur Zoom pour assister à la présentation. En tout temps, vous pouviez déplacer votre avatar vers l'autre atelier ou vers la salle des affiches, ou encore parler avec des gens, soit dans la salle principale, soit en privé dans la section assise. La plate-forme permettait d'assister aux présentations tout en ayant des interactions avec d'autres. La technologie peut être vraiment créative !

La conférence a compté plus de 30 heures d'exposés en personne ainsi que 22 affiches. Toutes les présentations étaient de grande qualité.

L'IACFS/ME, un organisme international s'intéressant à l'encéphalomyélite myalgique / syndrome de fatigue chronique et responsable de l'organisation de la conférence, a demandé des volontaires pour rédiger et partager des rapports portant sur la rencontre. J'allais en écrire un de toute façon pour le bulletin trimestriel de notre réseau, le National ME/FM Action Network, je me suis donc portée volontaire avec plaisir.

D'autres volontaires ont traité des avancées biomédicales et des discussions cliniques, donc je ne reprendrai pas leur travail. Vous pouvez trouver leurs rapports sur le site *www.iacfsme.org*.

Notre réseau, le National ME/FM Action Network, est un organisme de bienfaisance canadien orienté vers les malades. Mon texte porte sur quatre grands points. Le premier : les contributions canadiennes à la conférence. Le second : les questions concernant la reconnaissance et le diagnostic de l'encéphalomyélite myalgique. Le troisième : la relation entre l'encéphalomyélite myalgique et la COVID-19 de longue durée, qu'on a coutume d'appeler la Covid longue. Le quatrième : la question que les malades posent toujours - quand verrons-nous des changements tangibles aux services dispensés pour la maladie.

Présentations canadiennes

Dr Luis Nacul est le directeur médical du programme des maladies chroniques complexes (ComplexChronicDiseases Program) en Colombie-Britannique. Il fait partie du comité de direction de l'IACFS/ME et du réseau canadien de recherche ICanCME. Il a assuré la direction des présentations du troisième jour de la conférence. Il a également participé à la discussion consacrée aux techniques de provocation et présenté un exposé sur une étude de cohorte en pneumologie relative à la COVID-19 de longue durée effectuée en Colombie-Britannique.

Dre Jane McKay travaille au même programme depuis plusieurs années. Elle a été nommée responsable médicale du programme de Colombie-Britannique consacré à la COVID-19 de longue durée, où son expérience en matière d'encéphalomyélite myalgique est fort utile. Elle est intervenue à ce sujet au cours de l'atelier sur la pratique clinique. Le programme comporte des cliniques à Vancouver, Abbotsford et Surrey, ainsi que sur l'île deVancouver ; on y a travaillé avec quelques milliers de malades. Il comprend trois volets, soit les soins, la recherche et l'éducation. Ses politiques et ses méthodes s'adaptent de façon continue aux nouvelles informations. Il offre un site Internet d'information ouvert à la pratique clinique et au grand public. *http://www.phsa.ca/our-services/programs-services/post-covid-19-care-network*

Trois personnes avec des liens avec le Canada ont participé à la session consacrée aux techniques de provocation. Ces techniques s'emploient pour susciter des symptômes de l'encéphalomyélite myalgique, en particulier le malaise après effort et l'intolérance orthostatique. L'opération de provocation peut avoir pour but de vérifier un diagnostic, d'évaluer un degré d'invalidité ou de faire des recherches sur le fonctionnement de la maladie. **Dr Alain Moreau**, de l'Université de Montréal, dirige le réseau de la recherche qui s'effectue au Canada. Il provoque des symptômes au moyen d'un brassard pneumatique. Il a recueilli des échantillons d'urine et de sang avant et après la provocation, et a ainsi mis au jour des changements biochimiques. **Dr Peter Rowe**, de Johns Hopkins, dont des racines sont canadiennes, a présenté deux techniques. La première était le test de la table basculante. La deuxième provient du fait que des malades signalaient que lever les jambes en position couchée entraînait de la fatigue. Il a supposé que l'élévation des jambes pourrait constituer une technique de provocation, et a vérifié l'hypothèse. Dr Luis Nacul, directeur du programme de Vancouver déjà mentionné, a montré comment l'on peut aussi se servir d'un crispateur (similaire à l'appareil d'exercice) pour provoquer des symptômes.

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Learning Objectives for the UBC Student Workshop on ME/FM/Lyme:

Following the workshop, students should be able to

- describe symptoms
- give examples of impact on daily living and quality of life
- explain effects of stigma on access to care and support
- identify resources and supports
- recognize patients as having expertise and as partners in care


Luis Nacul


James Baraniuk


Rosemary Twomey


Peter Rowe


Jane McKay


Gloria Gray


Alain Moreau


MelodyTsai


Cathy Kline

Dr James Baraniuk, de l'université de Georgetown à Washington (DC), a lui aussi des racines canadiennes. Il a décrit une étude métabolomique à partir du liquide cérébrospinal pour étudier le système nerveux central.

Dr Rosemary Twomey, de l'université de Calgary, a fait deux exposés. Le premier décrivait un travail en cours mené sous les auspices du réseau canadien de recherche et visant à explorer les raisons pour lesquelles les malades souffrant d'encéphalomyélite myalgique ne reçoivent pas plus de services. Le second présentait un programme Internet qu'elle a mis au point, en collaboration avec une consœur respirologiste, pour fournir du soutien à domicile aux malades souffrant de la COVID-19 de longue durée.

Cathy Kline (université de Colombie-Britannique) et **Gloria Gray** (présidente de l'association pour l'encéphalomyélite myalgique de Victoria, C.-B.) ont décrit un programme qu'elles ont mis au point pour sensibiliser les personnes qui étudient dans des disciplines reliées à la santé à la perspective des malades et des personnes qui les aident (voir encadré).

MelodyTsai, de la fondation de recherche du BC Women's Hospital (Hôpital de C.-B. pour les femmes) exposait une affiche discutant d'une recherche menée sur un registre canadien des malades pour voir s'il pourrait servir à trouver les cas d'encéphalomyélite myalgique.

Objectifs d'apprentissage pour l'atelier sur l'encéphalomyélite myalgique et la maladie de Lyme à l'université de Colombie-Britannique

(Au terme de l'atelier, vous serez en mesure de :)

- décrire les symptômes de ces maladies
- donner des exemples de leur impact sur la vie quotidienne et la qualité de vie
- expliquer les effets de la stigmatisation sur l'accès aux soins de santé et aux services de soutien
- connaître les ressources et les organismes de soutien
- reconnaître que les malades ont une expertise et sont des partenaires de leurs propres soins

Diagnostic et prévalence de l'encéphalomyélite myalgique

Une affiche préparée à l'Institut Karolinska (Suède) s'est penchée sur les dossiers médicaux pour voir quels diagnostics avaient d'abord été posés avant celui d'encéphalomyélite myalgique.Dans la plupart des dossiers examinés, plusieurs diagnostics avaient d'abord été posés, ce qui pourrait s'expliquer soit par le fait que les examens avaient porté sur divers symptômes pris séparément, avant de considérer la globalité de l'encéphalomyélite myalgique, soit encore à cause des co-morbidités de la maladie. On aurait aussi pu considérer d'autres diagnostics possibles sur lesquels investiguer.

Geoffrey Hallmann est un avocat australien atteint d'encéphalomyélite myalgique qui participe souvent aux conférences de l'IACFS/ME. Dans un exposé oral, il a soulevé des problèmes de langage et de vocabulaire. Il a souligné que le vocabulaire de la maladie est imprécis, ce qui suscite beaucoup d'incompréhension face aux termes de la famille « fatigue ». Il a également fait remarquer que les malades cherchent souvent leurs mots. La conjugaison de ces deux phénomènes leur nuit, notamment à l'étape du diagnostic.

WebMD est un site Internet accessible au grand public qui recherche des informations médicales. Un sondage demandé par le CDC des États-Unis (Centers for Disease Control and Prevention (CDC) - Centre pour le contrôle et la prévention des maladies) a porté sur le degré de familiarité des internautes avec l'encéphalomyélite myalgique. Selon une affiche sur ce sondage, la moitié des personnes qui avaient répondu n'en avaient jamais entendu parler et la plus grande partie de l'autre moitié n'en avait que des notions très limitées. On voit à quel point la maladie est généralement peu comprise, ce qui fait que des discussions individuelles ou collectives sont difficiles.

Un exposé oral a présenté un contrat également accordé par le CDC à l'association américaine des infirmier.ère.s scolaires (US National Association of School Nurses), pour étudier la faisabilité de déceler les élèves souffrant d'encéphalomyélite myalgique. En plusieurs endroits, des infirmier.ère.s ont reçu une formation de base sur la maladie. Dans le cadre de leurs fonctions courantes, on leur a demandé d'étudier le cas des élèves avec des problèmes d'assiduité. S'il leur semblait possible que l'encéphalomyélite myalgique soit en cause, il leur fallait suggérer une consultation en médecine familiale.

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Diagnosis and Prevalence of ME

A poster from the Karolinska Institute in Sweden looked at medical records to see what diagnoses people had received prior to the ME diagnosis. Those records showed that people often received multiple diagnoses before being diagnosed with ME. This could be because various symptoms were identified and investigated separately before the big picture of ME was put together. It could also be that people with ME have co-morbidities. There could also have been alternate diagnoses that were considered and investigated prior to the ME diagnosis.

Geoffrey Hallmann is an Australian lawyer with ME who is a frequent contributor to IACFS/ME conferences. In an oral presentation he raised issues around language and vocabulary. He pointed out that the vocabulary around ME is not precise so that words like fatigue and tired are often misunderstood. He also pointed out that word-finding difficulties are common with ME patients. Together, these issues put ME patients at a disadvantage, including at the diagnostic stage.

WebMD is a website for the general public looking for medical information. A survey commissioned by the US CDC asked visitors to this website about their familiarity with ME/CFS. There was a poster showing that over half the visitors had not heard of ME/CFS. Of those who had, most knew very little about it. This shows how little common understanding there is of ME. This makes it difficult to have individual or collective discussions.

An oral presentation talked about a US CDC contract with the US National Association of School Nurses to study the feasibility of identifying students with ME. At several locations, school nurses were trained on the basics of ME. As part of their regular duties, they checked on students with attendance difficulties. When they suspected ME, they were to suggest that the family consult the family doctor. Nurses met with several thousand students with attendance issues. Not one case of ME was officially identified by family doctors. Not finding a single case in a cohort that size is technically possible but highly unlikely. We can speculate on why no diagnoses were forthcoming. Perhaps family doctors did not recognize ME. Perhaps doctors were seeing components of ME and had not put the big picture together. Perhaps doctors recognized ME but did not want to make an official diagnosis to protect the doctor's own reputation or because the doctor did not believe it would be useful to the student. Note that in the last case the doctor might or might not have unofficially informed the student and family of the possibility of ME.

A poster described a study in Australia which used primary care records to come up with an estimate of the prevalence of ME in Australia. The calculated rates were low. Ms Tsai's Canadian poster, looking at a Canadian patient registry, found that some people on that registry claimed to have CFS but did not meet ME criteria when a symptom questionnaire was analysed. When discussing a long-Covid study she is running, Dr Nancy Klimas said that they are having a hard time finding patients because many people don't know they have long-Covid (the same way that many people don't know they have ME). The Australian study suggests that medical records likely underestimate ME. The Canadian study suggests that self-report surveys pick up some false diagnoses. Dr Klimas' remarks suggest that some people with ME wouldn't know they have ME and therefore wouldn't self report. It would be nice to have better prevalence figures on ME. For now, it is indisputable that there are too many people with ME who are not receiving appropriate services. The lack of refined data should not be used as an excuse for inaction.

Another question around diagnosis is how ME overlaps with other chronic conditions such as FM, MCS, MCAS, dysautonomia, Ehlers-Danlos Syndrome, IBS, chronic Lyme and long-Covid. The Swedish group referred me to a paper they published in 2020 which found high rates of hypermobility, intracranial hypertension and craniocervical obstructions in ME patients. Another group (not at the conference) are building a model around the concept of Post Active Phase of Infection Syndromes, thinking that there are commonalities in the long term damage done by infections. The health system will want information about overlapping diagnoses in order to design services most efficiently, but again lack of definitive answers should not be an excuse for inaction.

https://www.frontiersin.org/articles/10.3389/fneur.2020.00828/full

https://www.mdpi.com/1648-9144/57/3/200

What is the Relation Between ME and Long-Covid?

On the surface, conference participants were saying that it is too early to say what the relationship between ME and long-Covid is. Below the surface, the feeling is that

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L'enquête a porté sur plusieurs milliers d'élèves avec des problèmes d'assiduité. Aucun de ces cas n'a résulté en un diagnostic d'encéphalomyélite myalgique. Qu'on n'ait trouvé aucun cas dans une cohorte de cette envergure est techniquement possible mais fort peu probable. On peut donc se demander pourquoi il n'y a eu aucun diagnostic. Peut-être que les médecins de famille n'ont pas reconnu la maladie, ou bien en ont vu des éléments sans la voir dans sa globalité, ou bien encore l'ont reconnue mais n'ont pas voulu poser un diagnostic officiel, soit pour protéger leur propre réputation, soit en croyant que le diagnostic ne serait pas utile pour l'élève. À noter que, dans ce dernier cas, il est possible que l'élève et/ou la famille ait reçu un diagnostic non officiel.

Une affiche présentait une étude australienne menée sur des dossiers en soins primaires et destinée à évaluer la prévalence de l'encéphalomyélite myalgique en Australie. Le taux de prévalence ainsi calculé était faible. Selon une affiche canadienne de Mme Tsai, qui a étudié un registre canadien de dossiers médicaux, certaines personnes affirment souffrir de SFC mais ne répondent pas aux critères de l'encéphalomyélite myalgique quand on analyse un questionnaire sur leurs symptômes. Au cours d'une discussion traitant de son étude sur la COVID-19 de longue durée, D^re^ Nancy Klimas a fait état de sa difficulté à recruter des malades parce que beaucoup de gens ignorent en souffrir (tout comme beaucoup de gens ignorent souffrir d'encéphalomyélite myalgique). L'étude australienne semble indiquer une sous-évaluation de la maladie dans les dossiers médicaux tandis que l'étude canadienne semble indiquer que les enquêtes à partir des diagnostics rapportés dans les questionnaires incluent parfois de faux diagnostics. Les remarques de D^re^Klimas suggèrent que des malades souffrant d'encéphalomyélite myalgique pourraient ne pas le savoir et ne pas le rapporter. Il serait bon d'avoir des chiffres plus sûrs sur la prévalence de la maladie. À l'heure actuelle, incontestablement, beaucoup tropde malades ne reçoivent pas les services appropriés à leur état. Le manque de données fines ne devrait pas servir d'excuse à l'inaction.

Un autre problème concernant le diagnostic, c'est la façon dont l'encéphalomyélite myalgique rejoint d'autres conditions chroniques, par exemple la fibromyalgie, l'hypersensibilité chimique multiple, l'activation mastocytaire, la dysautonomie, le syndrome d'Ehlers-Danlos, le syndrome de l'intestin ou du côlon irritable (SII), la maladie de Lyme chronique et la COVID-19 de longue durée. Le groupe suédois m'a renvoyée à leur article scientifique publié en 2020, relevant des taux élevés d'hypermobilité, d'hypertension intracrânienne et d'obstructions craniocervicales chez les malades souffrant d'encéphalomyélite myalgique. Un autre groupe (non à la conférence) travaille à l'élaboration d'un modèle basé sur le concept des syndromes d'infection en phase post-active, selon lequel les dommages à long terme causés par des infections présenteraient des points communs. Le système de santé aura besoin d'information sur les diagnostics qui se chevauchent pour concevoir des services de façon plus efficace, mais là encore, le manque de réponses précises ne saurait servir d'excuse à l'inaction.

https://www.frontiersin.org/articles/10.3389/fneur.2020.00828/full

https://www.mdpi.com/1648-9144/57/3/200

Quelle est la relation entre l'encéphalomyélite myalgique et la COVID-19 de longue durée ?

Au premier abord, selon les participations à la conférence, il est trop tôt pour définir cette relation. Mais en creusant plus loin, l'impression générale est que la COVID-19 de longue durée changera la donne, pour l'encéphalomyélite myalgique et pour d'autres maladies.

Commençons par les statistiques recueillies et publiées par le CDC en juin 2022. Selon cette enquête, plus de 40 % des adultes aux États-Unis ont rapporté avoir déjà souffert de COVID-19 dont 19 %, soit près d'une personne sur 5, rapportaient présenter encore des symptômes de « COVID-19 longue ». Ce qui signifie que 7,5 % des adultes des États-Unis devaient composer avec la COVID-19 de longue durée en juin. L'enquête relevait que la maladie affectait davantage les jeunes adultes.

Les cas de COVID-19 de longue durée ne sont pas tous des cas d'encéphalomyélite myalgique. On trouve plusieurs définitions de la COVID-19 de longue durée. Dans l'enquête de juin, il s'agissait de symptômes perdurant au moins trois mois après la phase active de la COVID. On y regroupait les cas avec des symptômes peu nombreux ou légers, les cas avec des dommages à certains organes en particulier (cœur, poumons, etc.) résultant de la COVID, et les cas avec des infections pouvant avoir été contractées durant l'hospitalisation. On parlerait alors de COVID-19 de longue durée, et non pas d'encéphalomyélite myalgique.

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long-Covid will be a game-changer for ME and related diseases.

Let’s start with statistics collected and published by the US CDC in June 2022. The survey found that more than 40% of adults in the United States reported having COVID-19 in the past, and nearly one in five of those (19%) were still having symptoms of “long COVID.” This means that about 7.5% of US adults were dealing with long-Covid in June. The survey noted that younger adults were more affected than seniors.

Not all long-Covid is ME. There are many definitions of long-Covid. In the June survey, it meant having symptoms at least three months after the active phase of Covid. Some people could have few symptoms or mild symptoms, some people could have specific organ damage (heart, lungs, etc) as a result of Covid and some people could have picked up a separate infection in hospital. These would qualify as long-Covid but not as ME.

Overall, the impact of long-Covid is not yet well understood, but it is clear that there is a problem and that the problem affects the workforce and economy. It is also clear that there is some relationship between long-Covid, ME and several other related conditions. We see the US organization Solve ME working with the US long-Covid community and lobbying the US government to take this seriously. We see research underway on long-Covid and drawing inspiration from previous work on ME. We see long-Covid researchers speaking at the IACFS/ME conference. We see ME and long-Covid researchers and clinicians learning from each other.

In summary, while the present is murky, attention is being paid to long-Covid which will likely lead to increased understanding and service improvements for long-Covid and related diseases.

When will ME Patients see Tangible Improvements in Service?

The good news is that there is a strong dedicated team working on ME. More and more of the issues around patient services have been worked through. For instance, one of the presentations was on how physiotherapists and occupational therapists can support people with ME, another was on how patients can be involved in sensitizing health sciences students, and a third was on how school nurses can support students with ME.

The bad news is that there has been little change in services and any change that has occurred has been hard-fought. What is the hold-up?

One presenter put the blame on the lack of research on the official record. That is true in one sense but there are barriers to doing research and getting research on the official record. The problems go deeper than that.

What we know is that decision makers in charge of the research, health care, and social systems are still not taking the needs of the ME community seriously. A comparison illustrates the situation.

The international conference for AIDS took place from July 29 to August 2, 2022 (with a pre-conference from July 26-28). The conference was hosted in Montreal, Canada. People could attend in person or virtually. Three Canadian cabinet ministers attended and spoke, along with the chief public health officer for Canada. Two other cabinet ministers made statements of support. Special funding of $18M for testing and $15M for international efforts were announced, which is in addition to existing funding. *https://www.aids2022.org/about/conference-theme-and-objectives/*

In contrast, nobody from the Canadian government came to the international Fibromyalgia conference in May or, to my knowledge, the IACFS/ME conference in July. There were no statements or funding announcements at either the ME or FM conference.

Yes, tangible improvements in service will happen. They will happen when decision makers decide to get involved. The existing ME research and clinical community is doing what it can to prepare for that time.

AIDS 2022, the 24th International AIDS Conference, will call on the world to come together to re-engage and follow the science. It will define future research agendas, shift latest evidence to action, and chart a new consensus on overcoming the HIV epidemic as a threat to public health and individual well-being.

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De façon générale, on ne connaît pas encore vraiment l’impact de la COVID-19 de longue durée mais il est clair qu’il y a un problème et que ce problème affecte la main-d’œuvre et l’économie. Il est clair aussi qu’il existe un rapport entre la COVID-19 de longue durée, l’encéphalomyélite myalgique et diverses autres conditions apparentées. On observe que l’organisme américain Solve ME travaille avec d’autres groupes américains reliés à la COVID-19 de longue durée et fait des pressions sur le gouvernement afin de faire reconnaître la gravité du problème. On observe que des recherches en cours sur la COVID-19 de longue durée s’inspirent de travaux antérieurs sur l’encéphalomyélite myalgique. On observe que des spécialistes de la recherche sur la COVID-19 de longue durée participent à la conférence de l’IACFS/ME. On observe que les gens qui travaillent en recherche ou en pratique clinique sur la COVID-19 de longue durée ou sur l’encéphalomyélite myalgique s’inspirent mutuellement.

En résumé, même si la situation actuelle est trouble, la COVID-19 de longue durée reçoit une attention qui débouchera probablement sur une meilleure compréhension et sur une amélioration des services offerts pour cette maladie et pour d’autres qui lui sont apparentées.

Quand verra-t-on des changements tangibles dans les services dispensés aux malades souffrant d’encéphalomyélite myalgique ?

La bonne nouvelle, c’est qu’une équipe forte s’y consacre actuellement. De plus en plus de problèmes reliés aux services aux malades ont été résolus. Par exemple, l’une des présentations portait sur le soutien que les physiothérapeutes et les ergothérapeutes peuvent apporter aux malades, une autre, sur la façon dont les malades peuvent sensibiliser les gens qui étudient en sciences de la santé, et une troisième sur le soutien que le personnel infirmier en milieu scolaire peut apporter aux élèves.

La mauvaise nouvelle, c’est que les services n’évoluent guère, et que chaque changement s’obtient de haute lutte. Pourquoi n’avance-t-on pas davantage ?

Selon une présentation, le manque de recherche officielle serait en cause, ce qui n’est pas faux, en un sens, mais ne tient pas compte des barrières à la recherche et à son officialisation. Les problèmes sont plus profonds.

Ce que l’on sait, c’est que les décisionnaires responsables de la recherche, des soins de santé et des systèmes sociaux continuent à ne pas prendre au sérieux les besoins de la communauté reliée à l’encéphalomyélite myalgique. Une comparaison illustre bien la situation.

La conférence internationale sur le SIDA s’est tenue du 29 juillet au 2 août de cette année (avec une pré-conférence du 26 au 28 juillet). La ville hôtesse était Montréal, au Canada. Il était possible d’y participer en personne ou virtuellement. Trois ministres du cabinet fédéral ont fait acte de présence et y ont pris la parole, ainsi que l’administratrice en chef de la santé publique du Canada. Deux autres ministres ont envoyé des messages de soutien. On a annoncé un financement spécial de près de 18 millions de dollars pour le dépistage et de 15 millions pour la participation à la lutte mondiale contre la maladie ; il s’agit là d’un supplément aux dépenses actuelles. *https://www.aids2022.org/about/conference-theme-and-objectives/*

Par contraste, le gouvernement canadien n’a délégué personne pour participer à la conférence internationale sur la fibromyalgie en mai, ni (à ma connaissance) à la conférence de l’IACFS/ME en juillet. Il n’y a eu aucune déclaration officielle, aucune annonce de financement ni à l’une ni à l’autre des conférences.

Oui, on verra se produire des améliorations tangibles dans les services. Quand les décisionnaires décideront de s’en mêler. Les milieux actuels de la recherche et de la pratique clinique sur l’encéphalomyélite myalgique font de leur mieux pour s’y préparer.

AIDS 2022, la 24e conférence internationale sur le SIDA, invitera les participants à se rassembler pour se réengager et suivre la science. Il définira les futurs programmes de recherche, transformera les dernières données en actions et établira un nouveau consensus pour vaincre l’épidémie de VIH en tant que menace pour la santé publique et le bien-être individuel.

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Housing Issues of the ME/FM Community

Housing – a national priority

Housing has become a national priority. The National ME/FM Action Network asked members about their housing issues. Our question was very open-ended. The responses showed some important themes.

Myalgic Encephalomyelitis and Fibromyalgia are debilitating chronic illnesses that are poorly served. Nearly one million Canadians have been diagnosed with ME (or chronic fatigue syndrome, a former name), FM or both.

People with ME/FM face income issues

One person with ME/FM said that she was barely able to keep her house when her work disability was cut off for three years. Another said that winning her medical disability pension case allowed her to afford housing. Another said that an inheritance when her parents died allowed her to buy a condo. This shows how important timely income support is.

One person said that the biggest issue is property taxes which had risen 200% in the last 10 years. That amount creates an undue hardship.

With reduced capacity to earn income, some people are forced onto provincial support programs. People pointed out how small disability shelter allowances are. People said that they had to cut back on other expenses to afford shelter.

One person on provincial disability support pointed to a vicious circle. She said that she could only afford a one-bedroom unit, which meant that she did not have enough space for self employment to earn supplemental income.

Subsidized housing is hard to find. One person has been on a list for 16 years. Several people mentioned that Ontario offers someone only one choice of subsidized units and if they don't take it they go back to the bottom of the list.

People with ME/FM have special housing needs

One person noted that she had not seen a single listing that offered insulation from noise (because she needed an exceptional amount of rest and sleep, including during the day), or safety from off-gassing and fumes from other units (such as tobacco, marijuana and vaping).

One person listed several accommodations that would help her – a countertop dishwasher to reduce the work involved in washing dishes, grab bars in the washroom, and a generator for emergency situations. There were barriers to having these installed.

People with ME/FM have periods where symptoms flare. One person noted that a one-bedroom unit does not allow any room for guests to come and stay when disability leaves you in a state of increased need for assistance. Another referred to being able to live relatively independently when well, but needing help with tasks like meal prep, cleaning, laundry and grocery shopping during flares. These services may be available to seniors but less so to disabled younger people.

People with ME/FM have reduced capacity to take on challenges

Someone with ME/FM outlined how much effort she was expending in her attempts to find a new place because she is about to run out of money. She noted that this effort was interfering with her capacity to earn money to support herself.

"Those with MCS can't go stay with a friend or share lodging with strangers... and usually don't have the money any more to get our own clean lodging."

"I can't even imaging packing up my belongings to move as it would require a strain infinitely beyond what I am able to do."

These issues make people with ME/FM vulnerable

A person with ME/FM commented that landlords use tactics like bullying or coercion to try to force tenants out. She said that she took the landlord to the Landlord Tenant Board. It took her health weeks to recover from the effort and stress. It also meant that she could not even try to earn income during this period. On top of everything, there was nobody to help her with the case.

People with ME/FM who "are not in safe housing conditions (mould, abuse, etc.) are often trapped in those really bad situations."

"If I were to end up homeless, I know I would not survive as a ME/FM patient."

"If I don't find a cheaper apartment within a few months I won't be able to pay this rent so my options are very bleak. I could end up in a crisis shelter or worse."

One person with FM reported fleeing violence and landing in a homeless shelter.

People with ME/FM deserve autonomy and dignity

A person who lived in subsidized housing hated it because it was dark, institutional-like and depressing. She called it “the cave”.

“I am just trying to survive and maintain my dignity.”

“Where there are rent geared to income units, the units are so small and without outdoor space, such as a patio or balcony, that they leave the tenant feeling as though they are seen as less than human and expected to simply survive out of the way of the rest of the world, rather than thrive among the rest of the world.”

One of our people provided an excellent synopsis

“Our health care system must redefine illness, disability, and health such that those who live with symptoms of ME and other “unseen” complex physical illnesses can be served with expertise, dignity and respect.

Housing should be designed with our needs in mind. In my experience, a home should be the primary tool to my well being, where I spend a great majority of time. How can that be achieved without knowledge about ME?

To me this includes factors such as spaciousness, plenty of accessible storage, temperature control for severe weather, good lighting, safe community, accessible services, privacy, and ergonomic factors. The location should acknowledge the needs of the individual and provide comfort so that personal passions, interests, abilities can be maintained as desired. Living with ME is a form of life, not a death sentence. Housing should not foster invisibility and force idleness. It should provide ease of life so that people can maintain their unique contribution and endeavors as their fluctuating abilities permit.”

Pain and Opioids

In January we wrote to the Honourable Carolyn Bennett, Minister. One of the issues we raised was access to opioids for the treatment of pain. We received a reply on September 6 from the Executive Director of the Opioid Response Team at Health Canada. The government directory indicates that about 50 people work on the Opioid Response Team. Here is what the Executive Director wrote. We have highlighted some key statements. We would be very interested in your thoughts on this reply.

The Government of Canada recognizes the profound impacts and challenges faced by Canadians who live with chronic pain and conditions that may have chronic pain as a symptom, such as those living with Myalgic Encephalomyelitis or Fibromyalgia (ME/FM). In 2019, Health Canada established the Canadian Pain Task Force (CPTF) to better understand chronic pain as well as identify potential actions to prevent and manage it, including the benefits and risks of opioid use.

The relationship between pain, opioids, and opioid-related harms in Canada is complex and actions taken to mitigate opioid-related harms have had negative unintended consequences for some people who live with pain. We are aware that some people in Canada have been unable to access opioid medications, and others who previously relied on opioids to manage their pain have been unable to continue their medications, or have had significant adjustments to lower their prescriptions, sometimes against their will. Increased stigma, anxiety, and fear surrounding opioid use for pain management has compounded these challenges and created additional barriers for people living with pain.

In May 2021, the Task Force released its third and final report – *An Action Plan for Pain in Canada.* The report provided over 150 recommendations for priority actions, so that **people with pain are recognized and supported and that pain is understood, prevented, and effectively treated across Canada.** Some of the key recommendations to be addressed by Health Canada relate to **public education on chronic pain, in order to help reduce stigma and increase available knowledge about resources and tools for both the public and healthcare providers**. The report also highlighted the importance for **improved awareness about the risks associated with rapid opioid discontinuation and tapering, and the dangers of opioid de-prescribing in the absence of shared decision-making with patients.** We are looking forward to continue working with pain stakeholders to implement some of the Task Force recommendations.

https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2021.html

Health Canada firmly believes the medical needs of patients, including which prescription medications they should be taking, are best determined through shared decision-making between the patient and their health provider based on the unique needs of the individual. We will continue to work with stakeholders and partners to promote patient-centered interventions for the treatment and management of chronic pain as well as the complex relationship between physical and mental health.

News Items

Federal Dental Care Plan

In an agreement with the New Democratic Party dated March 22, 2022 , the minority Liberal government made a number of commitments including the following:

Launching a new dental care program for low-income Canadians. Would start with under 12-year-olds in 2022, then expand to under 18-year-olds, seniors and persons living with a disability in 2023, then full implementation by 2025. Program would be restricted to families with an income of less than $90,000 annually, with no co-pays for anyone under $70,000 annually in income.

On July 25, 2022, the Canadian Minister of Health sent out the following announcement:

Having access to quality dental care is an integral part of overall health and wellbeing. Canadians shouldn't have to choose between dental care and basic needs like food or housing.

In Budget 2022, the Government of Canada committed $5.3 billion over five years to provide dental care for the estimated 7 to 9 million Canadians who are unable to access proper dental care because of the cost.

Seeing a dentist is important for our health, but can be expensive. We know that a third of Canadians do not have dental insurance. This must change. The goal of the national dental care program is to help Canadians with the costs of dental care, starting with under 12-year-olds in 2022, and then expanding to those under 18-year-olds, seniors, and persons living with a disability in 2023, with full implementation by 2025. The program will be designed for families with an income of less than $90,000 annually.

As part of the affordability plan announced on September 13, 2022, the Prime Minister announced that the government would:

Provide a Canada Dental Benefit to children under 12 who do not have access to dental insurance, starting this year. Direct payments totalling up to $1,300 per child over the next two years (up to $650 per year) would be provided for dental care services. This is the first stage of the government's plan to deliver dental coverage for families with income under $90,000, and will allow children under 12 to get the dental care they need while we develop a comprehensive national dental care program.

We invited our on-line members to comment on the July proposal. We would like to thank those that provided input. Based on the replies, the National ME/FM Action Network has written the Minister of Health asking for clarification of several points concerning year 2. The affordability announcement indicates that there will not be 100% coverage in the early years, but we have asked anyway.

The following is the email to the Minister of Health:

The National ME/FM Action Network is very interested in the proposed expansion of the dental care plan in 2023 to include seniors and persons living with a disability.

Based on preliminary feedback we have received from our members, we would like to pose the following questions:

- How will "persons living with a disability" be defined? For instance, if disability will be based on DTC eligibility, it will leave out a lot of people who would benefit from this coverage.
- Will having existing dental coverage disqualify a person from this plan? Some people who would benefit from this plan may have some dental coverage as part of a provincial disability program or provincial seniors program. We heard from someone on long term disability who pays for extended medical benefits which covers some dental care. We would not like to see these people excluded.
- What dental services will be covered and will they be covered 100%?
- Will there be quality control? We heard of some less-than-satisfactory dental experiences.
- What training will there be to make dental care sensitive to different forms of disability, including the disabling symptoms associated with ME and FM?

We would like to thank you in advance for responding to these questions.

Disability Tax Credit changes

On June 23, 2022, the CRA announced changes to the eligibility requirements for the Disability Tax Credit (DTC). The changes include:

- More criteria added under the category of mental functions,
- More activities recognized in determining time spent on life-sustaining therapies,
- Required frequency of life sustaining therapy decreased (now required a minimum of two times per week from three),
- People with Type 1 diabetes now deemed to receive life-sustaining therapy.

These changes are retroactive to the 2021 taxation year.

The good news is that the DTC can be changed. The bad news is that these changes did not address some of our core issues. The National ME/FM Action Network will be pushing for more changes.

Canada Pension Plan-Disability Letter

CPP-D sent a letter to recipients in May. The topic was when CPP-D recipients need to notify Service Canada. One situation is when earnings pass a certain amount (currently $6,400 for the year). Another situation is when the recipient's medical condition improves enough to consider returning to work. A new situation was added in this letter – when school and/or volunteering amounts to 15 hours or more per week for 4 months.

Service Canada saw this letter as supporting recipients in possible return-to-work situations. Many recipients, however, saw this letter as undermining their dignity. Service Canada has been made aware of the negative reaction.

News from the ME/FM Society of BC

The BC Select Standing Committee on Finance and Government Services held consultations this spring/summer and provided recommendations to the BC government on what should be in the 2023 budget. The ME/FM Society of BC took an active part in these consultations.

The committee recommended that the government "prioritize and fund the development of myalgic encephalomyelitis-specific billing codes for BC clinicians and the development of continuing medical education credits, modules or incentives for BC physicians, medical students, and other medical professionals to attend training about myalgic encephalomyelitis".

This recommendation now moves forward to the BC Cabinet for consideration of inclusion in the 2023 budget. The ME/FM Society of BC will be encouraging the implementation of this recommendation.

News from MEAO

MEAO is pleased to announce that the name CareNow Ontario has been approved. The former The Myalgic Encephalomyelitis Association of Ontario (MEAO) is now CareNow Ontario.

Care Now was the title of the final report of the Task Force on Environmental Health.

Webinar on EDS

A webinar on Ehlers-Danlos Syndrome and related conditions will be held on Saturday November 5, 2022. Dr Alain Moreau will be one of the speakers. Registration is free for patients and caregivers. For more information and to register, go to *https://www.theilcfoundation.org/annual-conference/scientific-information/*

I'm a Doctor. Here Are 5 Lessons I Only Learned About Fibromyalgia Once I Developed it Myself.

By: Ginebra Liptan

The mysterious fatigue and muscle pain started during my second year of medical school. Finally it was diagnosed as fibromyalgia, which started me on a crash course towards learning what it was like to have an invisible illness, one that remains poorly misunderstood and marred by stigma.

My first lesson came one day during teaching rounds, when my senior physician authoritatively announced, "Fibromyalgia does not exist." I quickly learned that many doctors, even my closest friends in medical school, didn't believe the illness was real and dismissed sufferers as hypochondriacs or "hysterical women".

Prior to fibromyalgia I thought I was an empathetic and compassionate person; after all, I went to medical school because I wanted to help other people. But my experience with this disease made me acutely aware that beyond the physical symptoms of this disease lay so many additional levels of suffering created by the disbelief and judgment of others. Here are the five biggest lessons that being both patient and doctor has taught me about fibromyalgia:

Lesson 1: I believe sexism is why we don't have a cure for fibromyalgia.

I am sorry to say it, but sexism is alive and well in medicine, and I believe it is the primary reason why fibromyalgia science is at least 30 years behind where it should be. Fibromyalgia research has lagged far behind other diseases, bogged down by controversy and a century of arguments about whether it was a "real" illness. People who have fibromyalgia are mostly female and the illness has suffered from a gender bias that has hampered it being taken seriously by medicine. If this illness primarily affected males, I think we would have a cure by now, or at the very least a well-funded governmental institute dedicated to finding a cure!

Lesson 2: Having an invisible illness is a double-whammy.

Sufferers show no outward signs of the disease and standard blood testing is normal. Having an invisible illness – one in which you look fine – is a double-whammy, because not only do you have to try to manage your symptoms and grieve the loss of your health, you also have to fight against doctors, employers and even family members that may not believe you or understand your struggle.

Sometimes fibromyalgia feels like carrying a 200-pound invisible backpack. If others could see the backpack of fatigue and pain we carry, they would better understand our limitations. And your employer may be more forgiving when you need accommodations: "Wow, of course you need an ergonomic chair, you have a 200-lb backpack weighing you down!" But truthfully, employers, family and doctors don't always understand or see the burden, which just makes the burden heavier.

Lesson 3: Pain is a subjective experience that cannot be truly understood by another.

Everyone experiences physical pain, and doctors as humans have usually experienced the typical pain that is described to them by their patients. Bad sunburn pain, check. Ankle sprain, been there. Sore throat, yep, had one last month myself. Doctors have a personal vocabulary to understand those types of pain.

But come into the office trying to describe a deep, aching, burning muscle pain that is migrating throughout your body, and you will get blank stares. I still remember the *you-are-a-crazy-person* look my doctor gave me in medical school when I tried to explain that it felt like my neck was tired of holding up my head.

These days I feel like my role is to help in the translation of the fibromyalgia experience so other doctors can gain more understanding. In part I do this by using the medical lingo they are used to, but I also try to harness the universal human response to the power of art. That is why I always show them the best visual depiction of fibromyalgia pain I have seen: "**The Broken Column**," a self-portrait by the Mexican painter and fibromyalgia sufferer Frida Kahlo, in which her body is pierced by multiple nails.

Lesson 4: Most doctors still don't know much about fibromyalgia – but it's not entirely their fault.

In the years since my diagnosis, our understanding and ability to treat fibromyalgia has made huge progress. Yet most of this information has not filtered down to the actual doctors providing care. The majority of care falls to busy and overwhelmed primary care providers who don't have time to go searching for new treatment ideas among the sea of medical publications. And the medical journals they are most likely to read tend to neglect fibromyalgia. In fact, since 1987, only one fibromyalgia study has been published in the *New England Journal of Medicine*, the most widely read medical publication in the world.

Lesson 5: Fibromyalgia is *not* caused by depression, but it most certainly can cause depression.

Several of the doctors I saw when my symptoms first started in medical school suggested my symptoms were caused by depression. But they were wrong. I was indeed depressed, but only because my life was falling apart around me, my doctors could offer me no help and I was exhausted and hurt all over. Anyone dealing with that would be depressed.

We also know that pain can actually cause changes to the brain that activate the areas associated with depression. So while depression does not cause fibromyalgia, fibromyalgia most certainly can cause depression.

Getting my own depression treated was vital in my ability to forge forward while carrying that 200-pound invisible backpack in order to find treatments on my own that helped me to feel better.

Ginevra Liptan, M.D. is the author of "The FibroManual: A Complete Fibromyalgia Treatment Guide for You and Your Doctor" and a graduate of Tufts University School of Medicine. This article appeared at: https://themighty.com/topic/fibromyalgia/doctor-lessons-about-fibromyalgia

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