NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

www.mefmaction.com
Quest 126, Winter 2020
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Changing the Approach to ME and FM

Why change is needed now

Years ago, public policy decided that people with Myalgic Enchephalomyelitis had personal failings rather than genuine illness. The health care system provided advice that was unhelpful and was often harmful. The research system did not support research into ME and people with ME had difficulty accessing the disability supports they needed. There are almost half a million Canadians with a diagnosis of chronic fatigue syndrome and they show high rates of disability, disadvantage and unmet needs. It is now clear that ME has genuine biomedical dysfunctions, particularly post-exertional malaise or "exertion intolerance" and that the behavioural model of disability was flawed.

Years ago, the specialty of rheumatology took responsibility for Fibromyalgia, but then decided that FM did not belong and let it go. Despite there being over half a million Canadians diagnosed with FM and having high levels of disability, disadvantage and unmet needs, there is no specialty focused on FM, there is little research, and there is inadequate recognition in the disability support system.

Further, the relationship between ME and FM has not been clarified. The stated symptoms overlap (fatigue/reduced activity levels, pain, non-restorative sleep, memory and concentration problems...) Some people have both ME and FM or cycle between them. It is important that the relationship be clarified so that appropriate advice and treatment are provided.

There is extra urgency to address these issues. A new wave is coming. Many people who experience COVID-19 could go on to develop ME, FM or both.

Contents

Redesigning Health Care

The old ways of treating ME need to be dismantled and "unlearned" and the health care system needs to be redesigned to accept ME. The new ME guidelines from NICE in the UK (discussed on page 15) are important because they reject the old behavioural model. However, when it comes to specifying a new health care system, the guidelines are blah blah blah. Much more helpful is the European ME Network (Euromene) Expert Consensus on the Diagnosis, Service Provision and Care of Peoples with ME/CFS in Europe. https://www.preprints.org/manuscript/202009.0688/v1

What the Euromene report says

Euromene is a consortium of ME researchers and clinicians from across Europe. The purpose of this report is "to support the development of health services and standard clinical practices for people with ME across the continent". There are 22 countries in the network. People from 16 countries are listed as authors. Dr Luis Nacul, who divides his time between the UK and Canada, was one of the two lead authors.

There has been a lot of debate internationally around diagnostic guidelines for ME. The report concludes that "the relative simplicity" of the IOM criteria "makes it ideal for use in primary care". Then the report adds that "[t]he Canadian Consensus Criteria (CCC) is particularly suitable for diagnosis confirmation and case sub-grouping in secondary care, as well as research". The report notes that the 1994 CDC Fukuda definition "is still a preferred case definition by some in Europe" and therefore recognizes it as another option with the proviso that post-exertional malaise be mandatory. The report discusses pediatric diagnosis as well, pointing to the criteria in the IOM report, the Pediatric Primer and the CCC. The report applies the 3-month requirement for young people and the 6-month rule for adults, but encourages primary care physicians to consider diagnostic investigations, initial management and referrals if ME is suspected earlier.

The report spends time discussing the clinical evaluation, differential diagnoses, and possible co-morbidities. It also outlines treatment options. The report cautions health care providers to manage patient expectations by explaining "the current limits of treatment and understanding of the potential pathophysiology". This caution recognizes that current state of knowledge is frustrating for patients.

Having outlined diagnosis and treatment, the report goes on to discuss how the health system should be organized. The report says that "with good education of primary care physicians, diagnosis and monitoring of people with ME/CFS in primary care are possible and desirable, referral for specialist services may be indicated in some circumstances". They list:

- diagnosis confirmation
- young people
- severe cases or significant disability
- short duration of symptoms eg less than 1 or 2 years
- rapid deterioration in symptoms
- complex diseases
- inability to provide adequate care in the community

The report recommends 2 to 4 ME specialists per million population. The specialists would have "a supporting multi-disciplinary team" which could include "nurses, nurse practitioners, occupational therapists, psychologists, dieticians, social workers etc".

The report ends by noting that the following sectors need to be involved in discussion establishing and supporting ME health services:

- the health sector (to develop and evaluate services and to adopt guidelines)
- the public health sector (to raise awareness)
- the higher education sector (to provide training)
- the education sector (so they know how to accommodate students with ME)
- the employment sector (so they know how to accommodate employees with ME)
- funding agencies and the pharma industry

Observations on the Euromene report

The Euromene report shows that there is a strong international consensus around using the CCC and related products for diagnosis and management of ME. The National ME/FM Action Network takes pride in our role in the development of these guidelines. It was about twenty years ago that our organization convinced Health Canada of the need to appoint a panel of international experts to develop clinical guidelines for ME. The panel did such a good job of describing ME and its consequences that it has been used as the basis for the IACFS/ME primer (which updates treatment guidelines), the pediatric primer (which focuses on young people), the IOM criteria (which provide a method to screen for cases) and many other important documents.

We like the fact that the Euromene report went past diagnosis and treatment and into health system organization, describing roles for primary care physicians and specialists in the diagnosis and treatment of ME. Their estimate of the number of specialists required (75-150 for Canada) is at the low end of our estimate in Quest 104, 2015 (300 for Canada for ME and FM, so about 150 for ME). Discussion around the number of specialists should not delay implementation. The estimate can be adjusted while specialists are being trained.

There are still a few issues that need to be refined. We like the list of reasons to refer someone to a specialist, but we would add that everyone with ME should have the opportunity to see a specialist annually both for their own sake and so that the health system can learn more about disease course and impact over time. We like the list of sectors that need to be involved but we think that surveillance and research should have been specifically mentioned because they are so important to establishing and supporting ME services. We are also concerned that the report does not mention the social or disability sector. ME brings with it many social issues, and social programs are often not ME-sensitive.

One particular issues is whether the specialists should deal with ME narrowly defined or whether they should deal with related conditions as well. As will be seen, Ontario proposes to address ME, FM and Multiple Chemical Sensitivities together.

Ontario developments

The Government of Ontario has been doing important work in the area of ME, FM and MCS.

About five years ago, the then Minister of Health appointed a task force to look at services for Ontarians with ME, FM and MCS. The task force submitted its report to the new Minister in December 2018. In January 2020, the new Minister asked Public Health Ontario (PHO) to look at implementation. That work was interrupted by the pandemic.

In October 2020, the National ME/FM Action Network was invited to make a budget submission to Ontario's Minister of Finance. We put together a submission asking for four items.

- provide immediate funding for Public Health Ontario to complete the plan for implementation of the task force's report.
- invest in front line health care by providing immediate ongoing funding to the Environmental Health Clinic so that they can increase services, develop tools for other health professionals and assist in the development of the Centre of Excellence envisaged in the task force's report.
- provide immediate funding to the Ministry of Health for disease surveillance related to these illnesses, including post-Covid -19.
- anticipate ongoing funding for the Ministry of Health to support ongoing care.

Very shortly thereafter, there was action on the first request. PHO hired Bill Manson to develop an implementation plan. He is a recently retired senior health administrator with a long time interest in ME, FM and MCS and a track record of implementing change. No, we are not taking full credit for his appointment. Others including MEAO (ME Association of Ontario) have been working hard for action. Our budget presentation seems to have come at a very good time.

So what happens next? The Euromene report provides insight. Define the need, identify the important players, then invite them to the table to discuss how care should be delivered and how to make it happen.

What happens in Ontario will help Ontarians, but the Ontario experience will be watched closely by other jurisdictions in Canada and indeed around the world.

Growing Health Research

The Canadian Institutes of Health Research (CIHR) is responsible for allocating federal research dollars. They have already allocated $1.2 Billion for health research in the 2020-21 fiscal year.

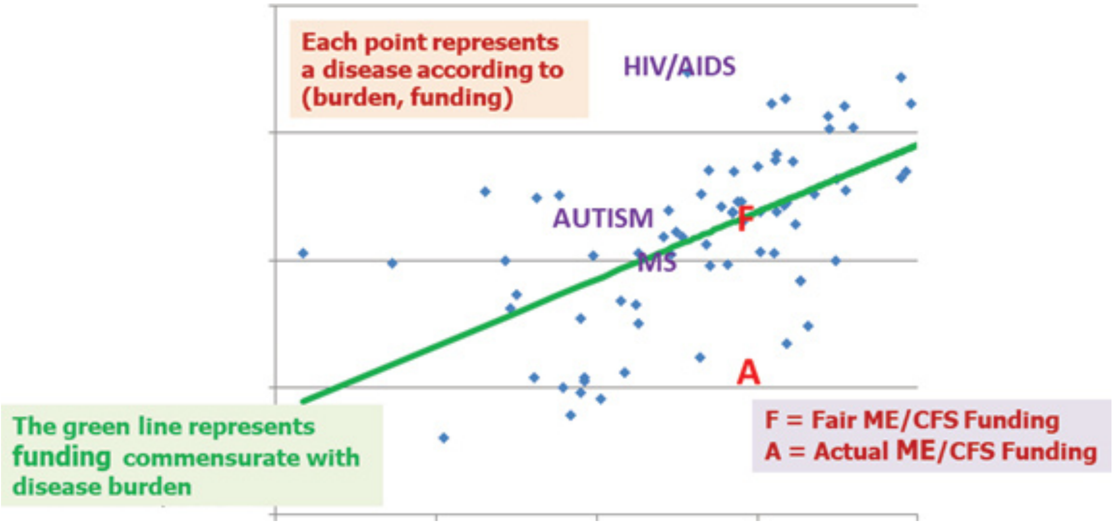
From the point of view of the Canadian ME/FM community, CIHR is not allocating anywhere near enough for ME and FM research. After all, CIHR is allocating public money which should be allocated in the public interest. Taking into account their prevalence and their seriousness, ME and FM have substantial public impact.

From the point of view of CIHR, ME and FM researchers have to go through the same application process as everyone else and the lack of funding indicates a lack of scientific competitiveness. After all, this is taxpayers money and it should be allocated based on scientific excellence. It shouldn't go to an immature scientific area.

With world-class researchers and Nobel Laureates interested in ME, one has to wonder why ME research is still considered immature.

The emergence of the COVID long-haulers, some of whom are undoubtedly developing ME, FM or both, has taken the health system by surprise. The system would have been ready, or at least more ready, if it had been listening and proactive.

Research under-funding is an issue in the US as well as in Canada. In Quest 110, we discussed a study which compared US NIH research funding to the burden of illness. This study was updated recently. The study found that ME was the most underfunded condition and that funding should be increased 14-fold. *https://content.iospress.com/download/work/wor203173?id=work%2Fwor203173*



In the past, we have produced a table showing CIHR funding of various medical conditions and the prevalence of the conditions. By dividing the funding by the prevalence, we arrive at the per-patient research funding.

We first produced this table in 2012. We had access to the 2010 Canadian Community Health Survey data. The survey included a special module on neurological conditions, so there were prevalence figures for a range of conditions that were compiled on a comparable basis We have hesitated to update the table because the number of conditions on the CCHS is much lower than it was in 2010 so it is harder to find data compiled on a comparable basis.

We went searching for more recent prevalence data. We found some on CCHS. We found some in a publication on neurological diseases. We asked the Public Health Agency for suggestions. They referred us to the Chronic Disease Surveillance System Data Tool *https://health-infobase.canada.ca/ccdss/data-tool/* and the Health Inequalities Data Tool *https://health-infobase.canada.ca/health-inequalities/data-tool/index* Unfortunately, we found them difficult to use because they were based on rates (not number of cases) and because they were based on different age ranges (1+, 10+, 16+, 20+. 35+. 40+.and 65+). We settled on using a combination of CCHS, the neurological study and organization website data. We picked the reference period of 2016 or 2015-16 because of data availability. It makes sense because that is the data that was available when funding decisions were made.

Our difficulty finding comparable prevalence figures suggests a major problem. How is it possible to manage a health system without having quick clear access to basic comparable data on disease prevalence?

Despite limitations in the prevalence data and in the funding data, the table makes it very clear that funding levels are very uneven and that people with ME, FM and MCS do have reasons to feel under-funded.

CIHR funding of research into chronic conditions
during the period April 2020 – March 2021
using keyword searches of the CIHR funded research database

Keyword	**Per Patient Funding 2020-21**	**Canadian Prevalance**	**Source of Prevalence Figure**	**CIHR Funding 2020-21**	**Studies Funded 2020-21**
Parkinson	$240.43	99,000	1	$23,802,190	163
Alzheimer	$119.90	395,000	1	$47,361,023	300
Multiple Sclerosis	$108.59	108,600	1	$11,792,572	91
Diabetes	$38.14	2,115,973	2	$80,698,203	529
Cerebral palsy	$37.31	79,800	1	$2,977,218	28
Epilepsy	$36.24	345,400	1	$12,515,944	94
Heart Disease	$33.40	1,398,892	2	$46,718,748	299
Dystonia	$15.77	50,000	3	$788,343	6
COPD	$5.91	833,148	2	$4,920,519	43
Asthma	$5.44	2,587,775	2	$14,077,516	99
Osteoporosis	$4.59	1,446,111	2	$6,630,775	48
Arthritis	$4.17	6,006,636	2	$25,035,575	169
Scoliosis	$1.36	1,028,049	2	$1,397,859	7
Chronic Fatigue Syndrome	**$0.54**	**572,440**	**2**	$309,204	1
Fibromyalgia	**$0.12**	**508,410**	**2**	$61,667	2
Multiple Chemical Sensitivities	$0.00	976,920	2	$0	0
All studies				**$1,254,366,327**	**7869**

Notes:

CIHR funding extracted from the funded decision database

https://webapps.cihr-irsc.gc.ca/funding/Search?p_language=E&p_version=CIHR

Extracted on Nov 26 , 2020.

The database includes a short description of each funded project. The inclusion of a keyword suggests but does not guarantee that this condition is a focus of the project. Projects often have multiple keywords (eg, diabetes and asthma).

Keywords include English variations and French equivalents

The Canadian Community Health Survey excludes

- Canadians under the age of 12
- Canadians living in institutions, on reserves, or in remote regions
- Full-time members of the Canadian Forces

Source of prevalence figures

1. Projected for 2016, Table 3-5
https://www.canada.ca/en/public-health/services/reports-publications/mapping-connections-understanding-neurological-conditions.html#toc
2. Canadian Community Health Survey, Public Use Microdata File, 2015-16
3 Dystonia Canada website

Ensuring Disability Supports

Disability is a poorly understood concept. We have observed a lack of understanding among:

- those who design and administer disability programs,
- health care professionals who are supposed to attest to disability, and
- people with disabilities themselves, especially those with less-recognized disabilities.

In particular, there is a wide-spread lack of recognition of how disabling ME and FM can be. The ME/FM community is frequently left out of disability discussions. The Supreme Court of Canada recognized that CFS, FM and chronic pain can be disabling in separate cases over a decade ago.

The International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Organization. We discussed it in Quest 106, our special issue on disability. Key parts of that article are shown on the next page.

The United Nations developed a Convention on the Rights of Persons with Disabilities (CRPD). Canada has ratified the Convention, meaning that it is law in Canada.

The CRPD recognizes:

that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others

One key concept is that disability is an evolving concept. Traditional thinking about disability may not be appropriate today. It is important that programs be reviewed regularly.

Another key concept is that the participation restriction must be due to impairment. If you can't participate because of your gender, your racial background, your income or the language you speak, that does not count as disability. If you don't participate because you are lazy or have a bad attitude, that does not count as disability. You can see the problem for people with ME or FM. Their difficulty participating can be attributed to being lazy or having a bad attitude. Being blind, deaf or wheelchair bound are thought of as impairments. Having a malfunctioning energy production system, autonomic nervous system or pain signalling system are impairments that are often overlooked.

A third key concept is that disability is based on difficulty participating in society. This can refer to difficulty participating in family life, the workplace, school, social events, recreational events etc. Disability is not limited to having particular impairments or having difficulty doing particular activities.

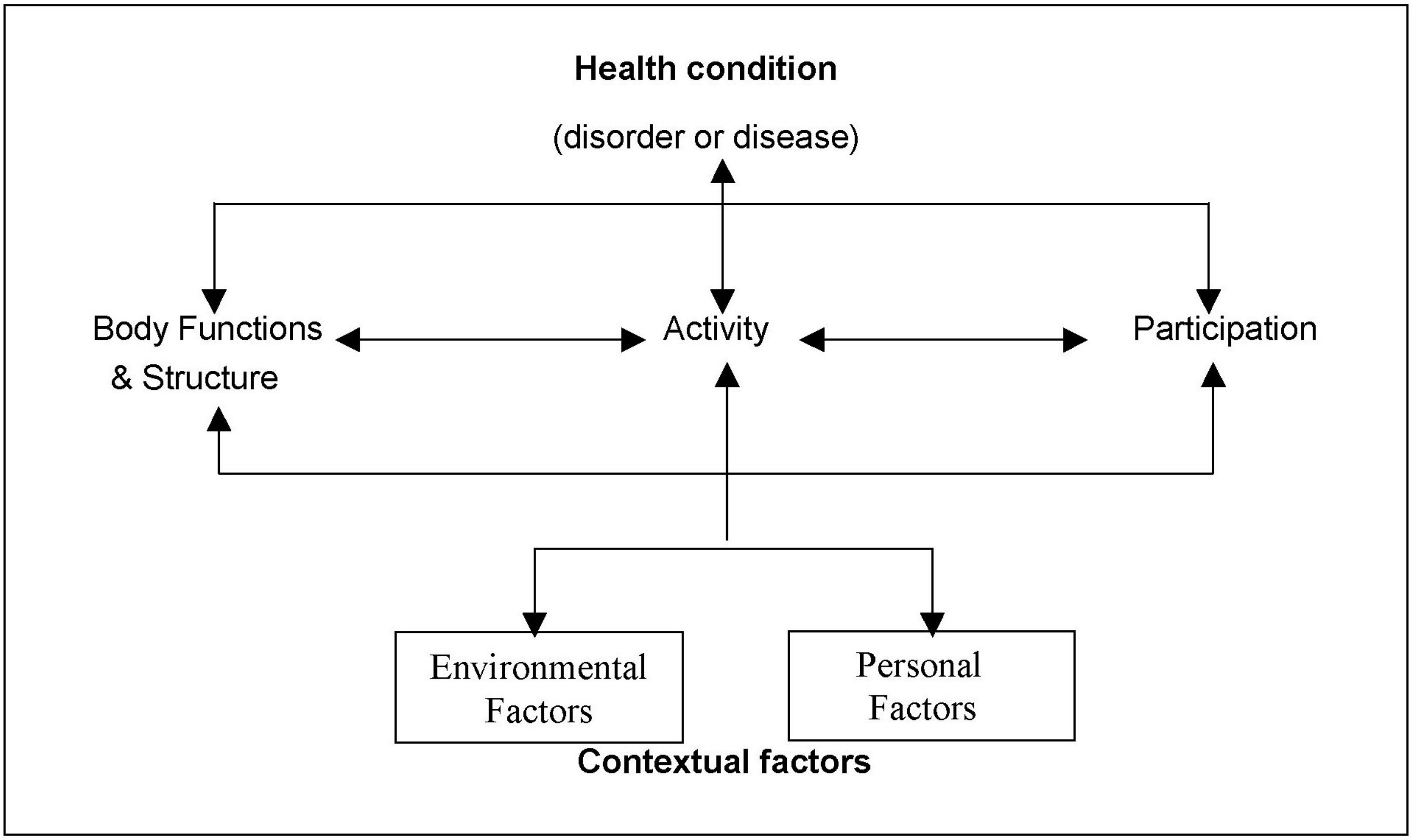
The Canada Pension Plan-Disability legislation is based on participation. The test for qualifying in the statute is the inability to pursue substantially gainful employment, which is restricted ability to participate in the workforce. The National ME/FM Action Network has recommended that the government look at CPP-D claims to see what causes people to stop participating in the workforce. Such a study would not cover young people or seniors, there are many people who were not sufficiently attached to the workforce to qualify for CPP-D, and it would not cover people who do not go through the application process. Nevertheless, we think that the study would provide important insights into what can lead to disability. And we think the reasons will be non-traditional in many cases.

The CRPD calls on governments ("states parties") to ensure certain rights of persons with disabilities. A list of rights, such as rights to education, adequate income, and housing is provided. The CRPD is asking governments to ensure that they are doing what they can to make it possible for persons with disabilities to participate in society. The CRPD is telling governments to look at their services, systems and policies (or lack thereof). These are "environmental factors" in the ICF.

Different impairment groups have different priorities from the CRPD list. There are two basic reasons. Firstly, different impairments lead to different problems. People with vision problems want Braille books and screen readers, people with hearing loss want closed captioning, and people with mobility issues want wheelchair ramps. Secondly, the more established disabilities have had more time to integrate themselves into disability systems. For example, the school system has experience with special education programming for students with vision and hearing impairments, but not necessarily for students with pain or energy impairments.

The Canadian Human Rights Commission has been given responsibly for the monitoring of the implementation of the CRPD. The CHRC is now consulting the disability community on how they should proceed. We suggested that a very important aspect of monitoring is to have statistics. We suggested that they try aligning CRPD

International Classification of Functioning, Disability and Health (ICF)



Functioning refers to all body functions, activities and participation.

Body functions and structures can have **impairments**.

Activities are tasks or actions executed by the individual. Examples are watching, listening, speaking, grasping, lifting, walking, driving, cooking, cleaning, and dressing. Activities can be **limited**.

Participation is involvement in a life situation such as going to school, working, being part of a family or being part of a social group. Participation can be **restricted**.

Disability is an umbrella term for body function impairments, activity limitations and participation restrictions.

Environmental factors and **personal factors** can be facilitators or barriers.

Environmental Factors:

- Products and technology (drugs, assistive devices, building design...)
- Natural environment and human-made changes to the environment (climate, air quality, light, sound...)
- Support and relationships (family, friends, acquaintances, professionals, pets...)
- Attitudes
  - family,
  - friends,
  - care providers,
  - health professionals,
  - societal attitudes,
  - social norms, practices and ideologies
- Services, systems and policies

issues with data being collected. The main data source is the Canadian Survey of Disability. The CSD is conducted every 5 years with the next cycle in 2022.

Canada has to report to the UN every few years on its implementation. Canada is now preparing for its second review. The disability community will be asked to contribute to this.

In 2019, Canada passed the Accessible Canada Act (ACA). The ACA used the CRPD definition of disability with a few extra descriptors:

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.

We participated in the consultations around the design of the act. We asked that the new legislation amend the provisions of the Disability Tax Credit to make it more inclusive. That was not included in the Act. The ACA is mainly about developing disability standards for organizations in federally regulated sectors. One project arising out of the ACA is a project on employment in the financial sector. We are participating in this project.

With the emergence of the COVID long-haulers, we expect a wave of applications to income support programs like CPP-D or long-term disability plans. This could put an unexpected strain on the program budgets. If their budgets are under strain, the programs are more likely to deny this type of claim or, indeed, any claim that is deniable. This is a situation that needs to be monitored.

All in all, there are a lot of issues to be resolved under disability. It would be nice to see a coordinated and collaborative approach. Otherwise, we will be tackling issues one-by-one.

Income Security

Canada's income security system is extremely fragmented. The rules are different if you are a child, an adult or a senior. Income assistance or tax reductions for adults with disabilities can come from Canada Pension Plan Disability, Employment Insurance-Sickness. Veterans plans, private plans, workers compensation, the registered disability savings plan, the Disability Tax Credit, provincial income assistance programs, the working income tax benefit-disability or disability auto insurance. Canada's income security system is also not very generous, with many people living well below poverty lines.

In the 2020 speech from the throne, the federal government announced that it would work toward a new Canadian Disability Benefit modelled after the Guaranteed Income Supplement for seniors. It will be interesting to see what, if anything, will come of this considering how difficult it is to bring in new programs. A number of academics have studied the idea of a basic income and we expect them to be actively involved in discussions.

There are several issues to watch for. Watch how eligibility will be determined. Watch the negotiations between the federal government, the provinces and the private sector since this proposal will result in redistributing responsibilities. Watch for the amount of the payments, but also watch to see what programs are cancelled. It is possible that payments will increase, but supports like drug plans will be removed negating some of the advantages.

PACING AND MANAGEMENT GUIDE FOR ME/CFS

#ME ACTION

What is **PEM**?

The cardinal symptom of ME/CFS is **post-exertional malaise (PEM).** PEM is a flare of symptoms and/or the appearance of new symptoms after exertion, often presenting 24 hours after the triggering event. Physical activity, cognitive overexertion and sensory overload can all trigger PEM.

Post-exertional malaise is a unique symptom, incongruent with experiences of fatigue after overexertion in healthy individuals. It is not the same as being more tired than normal after activity.

What is **pacing**?

Pacing is a **self-management** strategy for activity. Patients who pace well are active when able, and rest when tired. They may plan extra rest ahead of strenuous activities.

Graded exercise is a gradual increase in activity over time as directed by a clinician, until the patient returns to a healthy activity level. While graded exercise may be useful in patients who are deconditioned after surgery or a severe illness, graded exercise does not address the metabolic changes and atypical reactions to activity that lead to symptoms in people with ME.

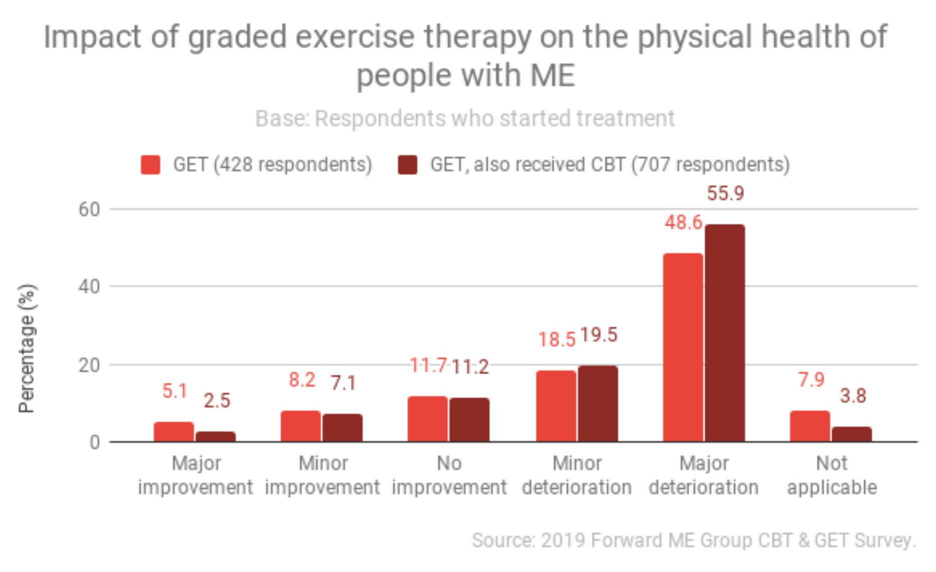
Because post-exertional malaise is the hallmark symptom of ME, programs that gradually increase exercise may do more harm than good. A recent, large-scale survey found that ~80% of people with ME found no benefit or significantly worsened on graded exercise regimens.

ME/CFS

*Myalgic encephalomyelitis/ chronic fatigue syndrome (**ME/CFS**) is a neurological disease triggered by an infection in the majority of patients.*

It is a complex chronic disease with symptoms in multiple body systems, including neurological, immunological, endocrine, and metabolic.

One out of four people with ME are housebound or bedbound, with ~13% able to work full-time.



From a 2019 survey from Forward ME, a coalition of ME organizations in the US and UK

The core symptoms of ME are not due to deconditioning. Patients with minor presentation may have activity levels similar to that of healthy people, but still experience all the symptoms of ME, including post-exertional malaise (PEM) when they overexert.

EXERTION ≠ EXERCISE

Exertion is defined here as anything that **stresses or strains the system**. Some stressors are within the patient's control and some are not. Identifying triggers for post-exertional malaise is vital to a person with ME's physical and psychological well-being. Potential triggers include:

- **Physical** (exercise)
- **Orthostatic** (standing for long periods of time)
- **Cognitive** (long conversations, scholarly reading/writing)
- **Sensory** (loud, repetitive noises, bright or flashing lights)
- **Emotional** (challenging interactions, tragic events)
- **Environmental** (proximity to allergens, changes in weather, seasonal changes)

No trigger can be controlled all of the time. The goal of pacing is to **minimize** post-exertional malaise, rather than eliminate it. Keeping an **activity and symptom diary** each day can help identify triggering events.

Post-exertional malaise may be delayed by approximately 24 hours. Anecdotally, these delays are more common in long-standing disease and may increase on a circadian cycle with greater and greater distance between the triggering event and PEM. This is an important consideration when connecting PEM to a triggering event.

Beyond pacing: activity management

Radical rest

Some people with ME have found that being **inactive** before planned exertions, such as attending a wedding or giving a talk can help mitigate the effects of post-exertional malaise. This strategy is called **radical rest.**

Knowing that exertion is coming can help the patient plan for worsened illness before it occurs. Pre-making meals, asking friends or family for additional help, making sure water and crash-friendly snacks are nearby, making sure any medication is in reach, and planning on soothing, low-energy activities like shows to catch up on can mitigate the fallout after necessary exertions.

Cut activity in half

Decreasing activity by half to start with can help the person with ME find a baseline -- with the understanding that the baseline can become better or worse over time. While some people with ME have a progressive disease course, many may increase their baseline by avoiding PEM.

Monitor objective values like heart rate

People with ME can use a **wearable device** to monitor their heart rates and stop their activity if their heart rate rises above a level they know may trigger PEM. Use this formula to calculate a heart rate that may be less likely to induce PEM, or your **anaerobic threshold** heart rate:

Men: (220 -- age in years)* 0.6 =
Women: (220 – (age * .88)) * 0.6 =

If you develop PEM even though you keep your heart rate below this value, you may have to lower your target heart rate until it reaches a level that does not induce PEM. Likewise, you may be able to increase your target heart rate if you do not experience PEM at those values. You can find more information about monitoring your heart rate to help reduce PEM here.

Break necessary activities into manageable tasks

Avoid ‘performing healthy’ -- sit down wherever you like, stop whenever you like, and speak up when you are with others. It's rare that an activity must be performed all at once.

- Fold a few laundry items at a time
- Do prep-work for meals, like chopping or measuring, the day before cooking
- If you are able to take a walk, sit frequently and wait for your heart rate to return totally to normal before resuming your activity

Prioritize activities you value & perform them differently

When faced with a challenging activity, consider its:

→ **Importance**:
How necessary is it to complete this activity? What would happen if it were left undone?
→ **Difficulty**:
How challenging would it be for you to do this activity on your own?
→ **Specificity**:
Could others do this for you, or are you the only one who can?

After considering each, you may choose to:

- Drop this activity if it isn’t necessary or isn't helpful
- Ask someone else to do this activity, either temporarily or for good
- Hire someone to do this activity, if that is within your means
- Do this activity, but less often than before, or only when absolutely necessary
- Do this activity, but adapt/change *how* you do it to support your current well-being

Example: meeting your friends at a coffeehouse

1. **Importance** Your well-being is important! It’s important to have healthy social interaction when you can. If it's stressful rather than a positive social experience, it's may be time to drop the activity.
2. **Difficulty** Socializing in person may be challenging, but not impossible. Perhaps the café is noisy and sometimes you can’t find a parking spot.
3. **Specificity** You're the only one who can carry out social activities for yourself.

Adapting this activity

1. Ask a friend to pick you up so that parking and walking isn’t as much of an issue; they could drop you at the door.
2. Tell your friends beforehand that, as much as you love their company, you have a ‘hard stop’ after a certain amount of socializing time.
3. Stay in bed and still participate by asking a friend to call you when they arrive at your coffee meet-up and teleconference.
4. Wear earplugs or headphones if you have increased sensory sensitivity.

Post-Covid study funded

https://news.nova.edu/news-releases/nsu-researchers-receive-4-million-from-cdc-for-covid-long-haulers-study/

NSU Only Institution to Receive $4 Million From CDC for 'COVID Long Haulers' Study

Posted on October 28, 2020

– Many COVID-19 Patients Suffering Long-Lasting Effects After Recovery –

NSU Only Institution to Receive This Grant to Begin New Study

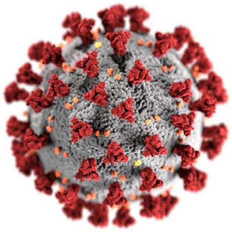
FORT LAUDERDALE/DAVIE, Fla. – As the COVID-19 pandemic continues to evolve, health care providers are finding more and more patients are experiencing lingering symptoms after recovering from the virus. These symptoms can vary from being bone-tired, utterly exhausted, or drained of energy , but in most cases they continue to negatively impact the patient's overall well-being and ability to return to normal activities. While the medical community is still working hard to address the virus itself and racing toward a vaccine, there is very little known or being done to address these residual health issues being experienced by those now called "COVID long haulers."

But all of that is about to change, thanks to research scientists at Nova Southeastern University (NSU.)

"With our long-standing research into ME/Chronic Fatigue Syndrome, we've been selected by the Centers for Disease Control and Prevention to begin researching these symptoms in COVID-19 patients," said **Nancy Klimas, M.D**. "Because the symptoms are so similar – joint and muscle pain, severe fatigue and memory and cognitive issues – to Chronic Fatigue Syndrome, NSU is uniquely positioned to study this emerging development in the pandemic."

With more than 30 years of professional experience, Dr. Klimas has achieved international recognition for her research and clinical efforts in multi-symptom disorders, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Gulf War illness (GWI), fibromyalgia and other neuro-immune disorders. Because of her expertise and the work she is involved with at the university, the CDC has awarded NSU a **federal contract of more than $4 million** to study these residual symptoms in COVID-19 patients.

NSU is the only institution to receive this federal contract.



Dr. Klimas, who is also the Director of NSU's **Institute for Neuro-Immune Medicine**, said that similar symptoms were identified in patients after other viral infections, such as the severe acute respiratory syndrome (SARS) outbreak in 2003. Over the years, patients suffering from these symptoms were given a variety of treatments, including respiratory, cardiovascular and physical therapy. Unfortunately, it's not a one-size-fits-all situation, and in some cases, existing therapies can actually make the patient worse.

That's why this research is so important – with COVID-19 so widespread, there are going to be thousands upon thousands of long-haulers who are going to need help.

For this research study, NSU will work with the Florida Department of Health to identify potential participants. NSU researchers then will contact individuals to describe the study and to ask their interest and permission to participate in the study. As you can imagine, this list is quite extensive – more than 40,000 patients and counting. In addition, NSU is working with partner health care providers, such as **Community Health of South Florida, Inc.** in Miami, to identify other patients. So between both pools of participants, NSU researchers want to have 2,200 individuals agree and opt in for the study.

"One of the things we want to ensure is that our group of participants is truly a diverse sample of people who are affected by this new syndrome," said **Nicole Cook, Ph.D., MPA**, and associate professor, Public Health at NSU. "We hope to engage members of underserved communities, including minorities, who have been disproportionately impacted by COVID-19 and therefore will likely have a higher number of 'long haulers'."

Cook said that the group will participate in various ongoing online surveys to collect data, with a smaller subgroup (approximately 200) participating in clinic-based assessments. Regardless of which aspect of the study they are involved with, this research will not impact or impede any ongoing health care they may be receiving to treat their symptoms.

Along with Drs. Klimas and Cook, others on the NSU research team include Drs. Irma Rey and **Alison Bested** and nurse practitioners Drs. Violeta Renesca and Irina Rozenfeld.

"We need to understand and describe this new disease and we're still in the early stages of learning about it," said Klimas. "This study will provide the chance to see patients early on in their conditions, and that's vital for development treatments."

Chronic Pain and Opioids

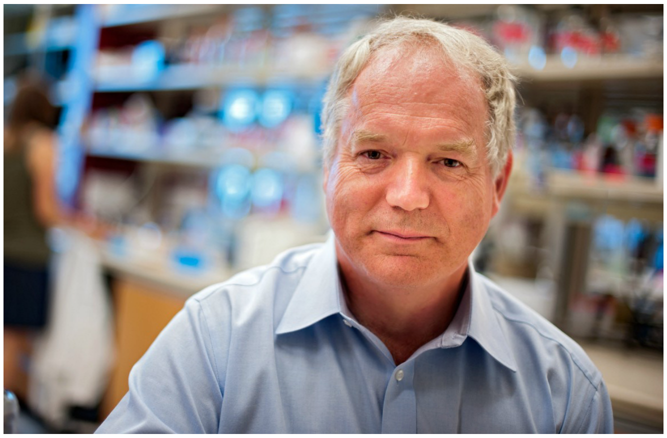
The federal government's chronic pain task force has finished the second year of their three year mandate. They just released a fact-finding report with no recommendations for action. The Chronic Pain Association of Canada argues that Health Canada's 2018 response to the opioid crisis has had negative consequences for people with chronic pain and for their health care providers. They wanted the Task Force to recommend that health professionals be given back a greater degree of discretion to prescribe opioids in the interests of people with chronic pain. Here is an excerpt from CPAC's response to the report. We think that they make a very good point!

... The main reason that chronic pain patients could not get the help needed was Health Canada's foolish decision to attack addiction and overdose deaths by cutting medication to pain patients. They incorrectly believed that addiction caused by MD's prescribing opioids to their patients and getting them "hooked". Despite countless studies and reports that disprove this, Health Canada continues to make that assertion. It has simply driven many qualified physicians out of the field creating the huge shortages of physicians that now exist.

If they still believe their 2018 edict, the fact that addiction and overdose deaths continue to soar should convince them they have taken the wrong path. But it hasn't. Now they have pain patients deprived of their medications, with reduced quality of life, increased pain, patients committing suicide, as they are no longer able to cope, with some seeking street drug dealers to see if they can find some relief... Nothing illustrates the folly of government policies better that the rising number of pain sufferers who turn to street heroin because they can no longer get legal medication...

The solution is simple. Let doctors be doctors and treat people with what each individual needs... [W]e call on Health Canada and the Canadian government to cease their war on pain patients and immediately rescind their misinformed Opioid Guideline and allow doctors to be doctors.

Dr Houghton wins Nobel Prize



Congratulations to virologist Dr Michael Houghton who was awarded the Nobel prize for medicine based on his work on Hepatitis C in the 1980's. Since 2010, Dr Houghton has been working at the University of Alberta.

Dr Houghton is a friend to the ME/CFS community. Dr Houghton has participated in efforts to test the involvement of XMRV in ME/CFS and in studies to discover a potential diagnostic profile of cytokines/chemokines in ME/CFS patient blood. From 2010 to 2014, he was a member of the CFS Advisory Committee to the US Secretary of Health and Human Services.

Proposed British guidelines reject useless chronic fatigue syndrome treatments

https://www.statnews.com/2020/11/17/proposed-british-guidelines-reject-useless-chronic-fatigue-syndrome-treatments/

By DAVID TULLER and STEVEN LUBET
NOVEMBER 17, 2020

For years, the prevailing "wisdom" about people diagnosed with chronic fatigue syndrome was they were just terribly out of shape and harbored irrational fears they had an organic illness. The favored treatments were graded exercise therapy, designed to counter the deconditioning with a program of progressively increasing activity, a form of cognitive behavior therapy specifically designed to address the unfounded illness beliefs, or a combination of the two.

In the U.S., this psychological and behavioral theory of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), as the illness is now often called, has steadily lost ground in favor of a biomedical one. In 2015, a landmark report from the Institute of Medicine (now the National Academy of Medicine) described ME/CFS as a "serious, chronic, complex, systemic disease that often can profoundly affect the lives of patients." Three years ago, the Centers for Disease Control and Prevention dropped its recommendations for graded exercise therapy and cognitive behavior therapy (CBT) as treatments for ME/CFS treatments - an implicit acknowledgement that the findings from research purporting to prove their effectiveness could not be trusted.

However, graded exercise therapy and cognitive behavior therapy have remained the dominant and deeply entrenched interventions for ME/CFS in the U.K., where this approach first emerged three decades ago. The two interventions have been nearly unquestioned as the official standard of care and routinely promoted at specialized clinics around the country. The most powerful voices in the medical and academic establishments have doggedly upheld and defended them. Until now.

In a draft of new ME/CFS clinical guidelines released last week, a key British agency has not only explicitly rejected graded exercise therapy and cognitive behavior therapy as treatments for this condition but also the rationales behind them. The draft from the National Institute for Health and Care Excellence (NICE) acknowledges that there is "no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS" - just what patients have argued for years. Moreover, notes the draft, "CBT is not a cure for ME/CFS and should not be offered as such," although the therapy may help patients "manage their symptoms." The new guidelines will replace a 2007 version that promoted the two interventions.

The draft represents a welcome repudiation of a deeply flawed body of research that had been conducted by a prominent group of British psychiatrists and other mental health experts. Members of this group first developed the psychological and behavioral treatment approach for ME/CFS in the late 1980s. They have single-mindedly insisted on it ever since, disparaging critics who raised legitimate concerns about their research as "anti-science" zealots. In developing its draft, NICE reviewed the science and assessed the evidence from studies promoting graded exercise therapy and cognitive behavioral therapy to be of "low" or "very low" quality.

The NICE draft will undergo a six-week public comment period and further review, with a final version to be published in April. While revisions are possible, the draft itself has already been hailed as a major advance by ME/CFS patients and advocates in the U.K. and across the U.S. Since history shows that old habits die hard in primary care medicine, every new report based on an accurate evaluation of the science represents an important step toward educating well-meaning but poorly informed physicians.

Up to 2.5 million Americans live with chronic fatigue syndrome, many of them undiagnosed. The illness is often triggered by an acute viral infection, like mononucleosis or the flu, and leaves some people homebound, and even bedbound. Although studies have documented a range of neurological, metabolic, and other dysfunctions, no causes of the condition or biomarkers for it have been identified so far. No medications have been approved to treat the underlying illness, although a few can relieve some symptoms.

In addition to overwhelming fatigue and cognitive problems, a cardinal symptom of ME/CFS is a prolonged relapse after minimal physical or mental exertion, called post-exertional malaise or, in the NICE draft, post-exertional symptom exacerbation. People with ME/CFS routinely report significant worsening of symptoms if they push themselves beyond their capacities. Surveys have repeatedly found that people with ME/CFS are far more likely to report harms than benefits from interventions that encourage them to increase their activity levels.

In the U.S., as in the U.K., many primary care providers have remained skeptical of ME/CFS despite the 2015 Institute of Medicine report and the subsequent change in the CDC's recommendations. Dismissing the possibility that it is an organic disorder, these clinicians continue to refer patients for psychotherapy and exercise programs, at least in part because of the absence of recognized alternatives.

For their part, patients and advocates in the U.S. have spent years pressing the National Institutes of Health to increase funding for research into biomedical causes and pharmacological treatments. While these efforts have achieved some success, funding still lags far behind the amounts allocated for research into many conditions that are less debilitating and affect fewer people.

Ironically, it has taken a pandemic to shine a brighter spotlight on ME/CFS.

A significant number of people diagnosed with Covid-19 report disabling symptoms that persist for months after they have cleared the virus that causes it. As Anthony Fauci, the director of the National Institute for Allergy and Infectious Diseases, has observed, symptoms experienced by post-Covid-19 patients are "highly suggestive" of those associated with ME/CFS. And like ME/CFS patients before them, many of these Covid-19 "long-haulers" report that health care providers have been similarly dismissive, automatically attributing their symptoms to stress, depression, and deconditioning, and recommending psychotherapy and exercise.

Medicine can be both wondrously innovative and stubbornly resistant to change. In 1847, the Hungarian physician Ignaz Semmelweis could not convince his fellow doctors in Vienna to wash their hands before delivering babies as a way to prevent often fatal cases of puerperal fever in new mothers. It would be another 30 years before Joseph Lister gained widespread acceptance for his approach to sterilization and aseptic surgery.

Things are better these days, with an average time lag of only 17 years before research evidence reaches clinical practice. The British psychiatrists and others still pushing graded exercise therapy and cognitive behavioral therapy for ME/CFS have done their part to keep the median delay as high as it is.

Clinical guidelines developed by NICE are influential in medical practice around the world, including in the U.S. Its new draft on ME/CFS is a long-overdue and much-needed corrective to years of misguided and potentially harmful recommendations.

David Tuller is a senior fellow in public health and journalism at the Center for Global Public Health at the University of California, Berkeley. Members of the ME/CFS patient and advocacy community have donated to crowdfunding campaigns in support of Tuller's position at Berkeley. Steven Lubet is a professor of law at Northwestern University's Pritzker School of Law. He has been living with chronic fatigue syndrome since 2006.

You Don't Have to Do It All This 2020 Holiday Season

Many look to the holidays as a salve for our stress, but it is all too easy to set such high expectations that we run ourselves ragged in trying to achieve an unobtainable form of holiday magic.

So, as you are figuring out how you are going to navigate the 2020 holiday season, remember: You don't have to do it all. You don't have to add in more this year to compensate for the changes. You can, instead, pare down to the simple joys of the season and save yourself from added stress in an already exceptionally stressful year.

It took years for me to finally realize that we did not have to keep up with all the demands and expectations of the season.

To recognize that we did not even need to keep maintaining the traditions we had always had.

If it no longer brought us joy, we could let it go.

We could create new traditions or, better yet, we could leave some

sweet empty space

to simply sit and be and soak in the holidays without any agenda.

– Elizabeth Joyce –

Innovative clinical diagnostic test to diagnose myalgic encephalomyelitis (ME)

https://recherche.chusj.org/en/Communications/Nouvelles/2020/Un-test-diagnostique-clinique-innovant-pour-diagno

MONTREAL, November 12, 2020

Myalgic encephalomyelitis (MS), better known as chronic fatigue syndrome, is a complex chronic disease with little known etiology, although it affects approximately 600,000 Canadians and up to 2.5 million people in the United States. To date, there have been no validated blood diagnostic biomarkers or tests to diagnose the disease. However, a team from the Sainte-Justine University Hospital and the University of Montreal led by Alain Moreau, a full professor at the Faculty of Dentistry and the Faculty of Medicine at the University of Montreal, has developed an innovative diagnostic test that allows for the first time to test people with severe ME who do not participate in clinical studies because of the severity of their condition. The result of this work has just been published in the journal Scientific Reports.

Why

The development of this test represents the first molecular diagnostic tool for ME long awaited by many clinicians and patients. It also opens up the possibility of stratifying patients into subgroups to better understand the molecular mechanisms involved in certain symptoms and to better select patients who could benefit from certain therapeutic approaches by repositioning certain existing drugs.

How

The application of mechanical stimulation applied to the arm by an inflatable cuff induces post-stress discomfort that represents the cardinal symptom of ME and allows us to obtain a precise molecular signature allowing us to differentiate subjects with ME from normal subjects or suffering from related conditions, for example fibromyalgia. Among the eleven microRNAs measured in the test, the elevation or reduction of some of them can predict the therapeutic response to certain drugs which increases the chances of finding the right therapy by customizing the treatment.

Un test diagnostique clinique innovant pour diagnostiquer l’encéphalomyélite myalgique (EM)

https://recherche.chusj.org/en/Communications/Nouvelles/2020/Un-test-diagnostique-clinique-innovant-pour-diagno

MONTRÉAL, 12 novembre 2020

L’encéphalomyélite myalgique (EM), mieux connue sous le nom de syndrome de fatigue chronique, est une maladie chronique complexe dont l’étiologie reste mal connue, bien qu’elle touche environ 600 000 Canadiens et jusqu’à 2,5 millions de personnes aux États-Unis. Il n’existait jusqu’à ce jour aucun biomarqueur diagnostique sanguin validé ni de test pour diagnostiquer la maladie. Or une équipe du CHU Sainte-Justine et de l’Université de Montréal dirigée par Alain Moreau, professeur titulaire à la Faculté de médecine dentaire et à la Faculté de médecine de l’Université de Montréal, a mis au point un test diagnostique innovant qui permet pour la première fois de tester les personnes sévèrement atteintes de l’EM et qui ne participent pas aux études cliniques à cause de la sévérité de leur état. Le résultat de ces travaux vient d’être publié dans la revue Scientific Reports.

Le pourquoi

Le développement de ce test représente le premier outil de diagnostic moléculaire pour l’EM longuement attendu par de nombreux cliniciens et les patients. Il ouvre aussi la possibilité de stratifier les patients en sous-groupes permettant de mieux comprendre les mécanismes moléculaires impliqués dans certains symptômes et de mieux sélectionner les patients qui pourraient bénéficier de certaines approches thérapeutiques en repositionnant certains médicaments existants.

Le comment

L’application d’une stimulation mécanique appliquée sur le bras par un brassard gonflable induit un malaise après-effort qui représente le symptôme cardinal de l’EM et permet d’obtenir une signature moléculaire précise nous permettant de différencier les sujets atteints d’EM des sujets normaux ou souffrant de conditions apparentées, par exemple la fibromyalgie. Parmi les onze microRNAs mesurés dans le test, l’élévation ou la réduction de certains d’entre eux permet de prédire la réponse thérapeutique envers certains médicaments ce qui augmente les chances de trouver la bonne thérapie en personnalisant le traitement.

Hopes

The research team is continuing the project to see validation of this test in other populations to determine whether the biomarkers used here are still as sensitive to detecting ME and equally relevant to launching new clinical trials. Finally, with the COVID-19 wave, we believe that this test will allow early detection of ME in people with persistent post-COVID-19 symptoms that are very similar to ME in order to intervene early to prevent ME.

Thanks to the partners of this research

This breakthrough has been achieved thanks in part to the help of patients and numerous patient associations in Canada, including the Quebec Association of Myalgic Encephalomyelitis (AQEM).

ABOUT SAINTE-JUSTINE UNIVERSITY HOSPITAL RESEARCH CENTRE

The Sainte-Justine University Hospital Research Centre is a leading mother-child research institution affiliated with the University of Montreal. Focused on the discovery of innovative prevention methods, less intrusive and faster treatments and promising avenues of personalized medicine, it brings together more than 210 researchers, including more than 110 clinical researchers, as well as 450 graduate and postdoctoral students. The centre is an integral part of Sainte-Justine University Hospital, the largest mother-child centre in Canada and the second largest pediatric centre in North America. Details in recherche.chusj.org

Les espoirs

L’équipe de recherche poursuit le projet de voir la validation de ce test dans d’autres populations afin de déterminer si les biomarqueurs utilisés ici sont toujours aussi sensibles pour détecter l’EM et tout aussi pertinents pour lancer de nouveaux essais cliniques. Finalement, avec la vague de COVID-19, nous croyons que ce test pourra permettre le dépistage précoce de l’EM chez les personnes présentant des symptômes post-COVID-19 persistants et qui sont très similaires à l’EM afin d’intervenir précocement pour prévenir l’EM.

Merci aux partenaires de cette recherche

Cette avancée a pu être réalisée entre autres grâce au concours de patients et de nombreuses associations de patients au Canada dont l’Association Québécoise de l’Encéphalomyélite Myalgique (AQEM).

À PROPOS DU CENTRE DE RECHERCHE DU CHU SAINTE-JUSTINE

Le Centre de recherche du CHU Sainte-Justine est un établissement phare en recherche mère-enfant affilié à l’Université de Montréal. Axé sur la découverte de moyens de prévention innovants, de traitements moins intrusifs et plus rapides et d’avenues prometteuses de médecine personnalisée, il réunit plus de 210 chercheurs, dont plus de 110 chercheurs cliniciens, ainsi que 450 étudiants de cycles supérieurs et postdoctorants. Le centre est partie intégrante du Centre hospitalier universitaire Sainte-Justine, le plus grand centre mère-enfant au Canada et le deuxième centre pédiatrique en importance en Amérique du Nord. Détails au recherche.chusj.org

Workshop on Post-Acute Sequelae of COVID-19

NIAID (National Institute of Allergy and Infectious Diseases) is hosting a virtual Workshop on Post-Acute Sequelae of COVID-19 on December 3-4, 2020 to summarize existing knowledge on post-acute manifestations of COVID-19 and to identify key knowledge gaps.

December 3, 2020 - December 4, 2020
10:00 AM-5:00 PM

For more info go to:

https://www.niaid.nih.gov/news-events/workshop-post-acute-sequelae-covid-19 http://mefmaction.com

http://www.facebook.com/MEFMActionNetwork

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