



# Quest

## Newsletter



[www.mefmaction.com](http://www.mefmaction.com)

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## Press Release from Fibro Winnipeg

### Winnipeg & Montréal — January 2026

The **Fibromyalgia Support Group of Winnipeg** is proud to announce a \$40,000 investment over one year to support a new fibromyalgia research project led by **Dr. Alain Moreau**, Professor at the Université de Montréal (Faculty of Dentistry and Faculty of Medicine) and Researcher at the Azrieli Research Center, CHU Sainte-Justine.

This funding supports a focused research effort to better understand *why people living with fibromyalgia experience severe pain, fatigue, and symptom crashes after even mild physical or emotional effort*—one of the most disabling and least understood aspects of the condition.

### Why This Research Matters to Patients

Many people with fibromyalgia feel as if their body reacts too strongly to everyday activities. Simple tasks like walking, concentrating, or dealing with stress can trigger days of increased pain, exhaustion, and brain fog. Yet routine medical tests often show nothing abnormal, leaving patients without clear answers.

This research aims to identify a **measurable biological process in the blood** that may act like a **pain amplifier**, turning small stresses into major symptom flares. By understanding this mechanism, the study could:

- Help **validate fibromyalgia as a real, biological illness**
- Lead to **objective blood tests** that explain post-exertional symptom worsening
- Open the door to **new treatment options**, including medications that already exist but have never been tested for fibromyalgia

For patients, this means replacing doubt with understanding - and symptoms with explanations.

### Patients as True Partners

Members of the Fibromyalgia Support Group of Winnipeg will be actively involved in the project, participating in regular progress meetings and helping guide communication of results. This partnership ensures the research stays aligned with the real needs and priorities of people living with fibromyalgia.

### A Strong Commitment to Progress

By investing \$40,000 over one year, the Fibromyalgia Support Group of Winnipeg is making a clear statement: fibromyalgia deserves serious science, meaningful funding, and solutions grounded in biology. This project represents an important step toward better recognition, better care, and renewed hope for patients and families.

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*Please Note: Our mailing address has changed  
The new address is:*

200 - 38 Auriga Drive  
Ottawa, ON K2E 8A5  
Canada

## Young people with ME - A Research Study

Young people with ME are often overlooked. Therefore we were thrilled this fall to be contacted by Brian Abernethy, a PhD student at Trent University who had picked this as his thesis topic. Here is the information we received from him.

February 2, 2026

Hello!

My name is Brian Abernethy and I am a PhD student in the Environmental and Life Sciences Department at Trent University in Canada. I am working on a research project under the supervision of Dr. Sarah West.

I am inviting you to participate in a research project that aims to understand the effect Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) symptoms may have on the quality of life and school participation of young people living in Canada.

If you have already signed up for this study but did not receive an email containing a link to the questionnaire, we are sorry. If this has happened to you, we ask that you sign up for the study again or contact Brian at [brianabernethy@trentu.ca](mailto:brianabernethy@trentu.ca).

This study is open to Canadian residents, aged 14 – 29, who meet one of the following conditions:

1. Are enrolled in high school or post-secondary school and self-report an **ME/CFS diagnosis** or experience **unexplained fatigue**.
2. Are enrolled in high school or post-secondary school and are **without health conditions** (control group).
3. Have **had to withdraw** from high school or post-secondary school **due to ME/CFS** or **unexplained fatigue**.

If you choose to participate, you will be asked to complete two online surveys approximately three months apart. Each survey is approximately 50 minutes long for a total time commitment of 1½ - 2 hours. The surveys can be completed at your own pace and with assistance.

By participating in this study, you will provide important information that may help improve education accommodations, healthcare approaches, and quality of life of individuals living with ME/CFS.

If you wish to participate, please click on the following link: [https://trentu.qualtrics.com/jfe/form/SV\\_3I5Mz3E8yccYN3U](https://trentu.qualtrics.com/jfe/form/SV_3I5Mz3E8yccYN3U)

If you consent to participate in the study, you will be asked some questions to see if you are eligible. If you are eligible for the study, you will be asked to provide an email address that the research team can contact you at. Participation is completely voluntary and you can elect to withdraw from the study at any time.

This study has been approved by Trent University Research Ethics Board #29131. If you have any questions about your rights as a research participant, please contact the Trent University Ethics Board by phone at 705-748-1011 ext. 7866 or by email at [annakisiala@trentu.ca](mailto:annakisiala@trentu.ca).

For all other questions about the study, please contact Brian Abernethy at [brianabernethy@trentu.ca](mailto:brianabernethy@trentu.ca).

Thank you in advance for your time and consideration of support for this research.

Sincerely,

Brian Abernethy  
PhD Student  
Trent University  
[brianabernethy@trentu.ca](mailto:brianabernethy@trentu.ca)

Dr. Sarah West  
Student Supervisor  
Dean of Science  
Trent University  
[sarahwest@trentu.ca](mailto:sarahwest@trentu.ca)



## Research Opportunity for Canadian Youth & Young Adults with ME/CFS

### What is the study about?

This study will investigate the effect Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) symptoms have on the quality of life and school participation of young people, aged 14 – 29, living in Canada.

### Who can participate?

Canadian residents, aged 14 – 29, who meet one of the following:

1. Are **enrolled** in high school or post-secondary school and self-report an **ME/CFS diagnosis** or **unexplained fatigue**.
2. Are **enrolled** in high school or post-secondary school and are **without health conditions** (control group).
3. Have **had to withdraw** from high school or post-secondary school due to **ME/CFS** or **unexplained fatigue**.

### Why should I participate?

Your participation will provide important information that might help improve education accommodations, healthcare approaches, and the quality of life of individuals living with ME/CFS.

### What is required?

- Completion of two online surveys approximately three months apart.
- Each survey is approximately 50 minutes in length.
- The surveys can be completed at your own pace and with assistance.

**If you wish to participate or learn more, please click on the following link:**  
[https://trentu.qualtrics.com/jfe/form/SV\\_3I5Mz3E8yccYN3U](https://trentu.qualtrics.com/jfe/form/SV_3I5Mz3E8yccYN3U)



Principle Investigator: **Brian Abernethy**, PhD Student, Trent University, email: [brianabernethy@trentu.ca](mailto:brianabernethy@trentu.ca)  
Student supervisor: Dr. Sarah West, Dean of Science, Trent University, email: [sarahwest@trentu.ca](mailto:sarahwest@trentu.ca)  
This study has been approved by Trent University Research Ethics Board #29131.

## UK MP's Debate ME

On November 19, 2025, a one hour debate on the topic of ME was held at the UK Westminster Hall. This was an opportunity for back-bench Members of Parliament to raise issues and get a response from a government official.

Here are key quotes from two Members of Parliament.



**Tessa Munt MP:** *Despite the devastating toll of the condition, people with ME have endured decades of substandard and sometimes downright unsafe healthcare, with pitifully little funding for research. In spite of the lack of robust evidence to this effect, ME is treated as though the condition is psychiatric.*

*ME and related conditions such as long covid are among the most devastating illnesses of our time, yet they remain some of the most poorly understood and most neglected. Unless we confront this misunderstanding head on, we will never deliver the change that patients so desperately need.*

*I will highlight four areas in which we need to see much more from the Government going forward.*

- *The first area is funding. The case for investment is clear. I urge the Minister to see this not as a sunk cost, but as an investment in a group of people who are desperate to contribute to society.*
- *The second area where I would urge the Government to go further is support for people with severe and very severe ME.*

- *The third area on which I would like to see the Government do much more is accelerating ME research.*
- *The fourth and final point on which I would like the Government to go further is support from wider Departments, particularly the Department for Education and the Department for Work and Pensions.*

**Jo Platt MP:** *ME and related conditions such as long covid are among the most devastating illnesses of our time, yet they remain some of the most poorly understood and most neglected. Unless we confront this misunderstanding head on, we will never deliver the change that patients so desperately need.*

*This issue is personal to me. In 2020, I contracted long covid. The infection was mild, but the aftermath was devastating, and it changed my life forever. With long covid, I developed ME, so I know the exhaustion, isolation and gaslighting that patients face. I cannot know for sure why I improved, but I believe that one reason was early recognition. I give a big shout-out to my friend Shelley Guest, who saw that my symptoms mirrored her own. She gave me books; she shouted at me, and told me to pace myself. I am forever grateful to her.*



*That raises a critical question: if diagnosed and supported early enough, could ME's symptoms be managed to the point of recovery or partial recovery? My journey is not over yet. That is why research and recognition are not optional; they are essential.*

\*

**Ashley Dalton**, the Parliamentary Under-Secretary for Health and Social Care, then responded. The government had released "[Myalgic encephalomyelitis/chronic fatigue syndrome \(ME/CFS\): the final delivery plan](#)" on July 22, 2025. It was criticized for not being aggressive enough. Here are some excerpts from her statement:



*For too long, people with ME/CFS have faced stigma, misunderstanding, disbelief and inconsistent care.*

*In July, we published the ME/CFS final delivery plan, marking a significant milestone in our commitment to improving lives. The plan is built around three core themes: boosting research, improving attitudes and education, and enhancing care and support. With a clear commitment to ensure that people with ME/CFS can live as independently as possible and see their overall quality of life enhanced, that plan will help us to take an important step towards achieving that, but we acknowledge that there is more to do. We will continue to build on the foundation of those actions well beyond the publication of the plan. It is the springboard—the beginning, not the end.*

*Research is the key to unlocking better treatments and improving quality of life...Together with the MRC [Medical Research Council], we are actively exploring next steps in ME/CFS research. For example, earlier this month we co-hosted the research showcase event for post-acute infection conditions, including ME/CFS. It brought together people with lived experience,*

*researchers, clinicians and funders to help to stimulate further research in this field. We are now considering the discussions that took place at the showcase to explore the next steps to stimulate further research.*

*The final delivery plan also sets out actions to improve access to specialist services—to provide better support for children and young people, and their families, and to address employment challenges. It aligns with our 10-year health plan, which includes the roll-out of neighbourhood health services, bringing care closer to home and ensuring that multidisciplinary teams can support people with complex conditions such as ME/CFS.*

*Changing attitudes is as important as changing services to many people with ME/CFS who have faced disbelief or stigma. As outlined in the plan, we will address that by launching a public awareness initiative to improve understanding of the condition and the support available. We will work with schools, employers and social care providers to ensure that children and adults with ME/CFS receive the information and support that they need.*

*To support healthcare professionals in diagnosis, as set out in the final delivery plan, the Department has worked with NHS [National Health Service] England to develop an e-learning programme on ME/CFS for all healthcare professionals. The aim is to support staff so that they can provide better care and improve patient outcomes.*

*ME/CFS has been overlooked for far too long. We are determined to change that. To everyone living with ME/CFS and to your families and carers, I say this: we hear you; we value you; we believe you; and we are committed to making the system work better for you and with you. Together, we can build a future where everyone receives the care, respect and support that they deserve.*

\*

Transcript: <https://hansard.parliament.uk/commons/2025-11-19/debates/2CF5B027-60AF-4031-B6B1-A2909CF6A745/MyalgicEncephalomyelitis>

Recording: <https://www.youtube.com/watch?v=wZFEUnjWgOA>

## Scottish MP Writes About ME

Wendy Chamberlain is a Member of the UK Parliament representing the riding of North East Fife in Scotland. She wrote an article which appeared on the “#There for ME” website. Here is an excerpt from “Scotland must step up on ME care and research”. Ms Chamberlain also made a short statement during the Westminster Hall debate.



Wendy Chamberlain, Liberal Democrat MP for North East Fife

*So, what should the Scottish government do?*

*First, there must be much more investment in research. Without it, we cannot hope to understand causes, develop treatments, or improve services. Funding streams should be ring-fenced and substantial enough to attract high-quality applications.*

*Second, training must be improved across all sectors. GPs, nurses, and other healthcare professionals need to be supported so that they have access to continual, accessible training opportunities to recognise and manage ME. This is particularly urgent given that the conditions overlap with Long Covid.*

*Third, the government must urgently expand access to specialist care. That means supporting health boards to recruit and retain specialists as well as encouraging multidisciplinary approaches. Digital care should be developed to reach those who cannot travel.*

*Finally, there needs to be long-term planning. Piecemeal initiatives and short-term pilots will not deliver the systemic change required. Both the UK and Scottish governments must set out clear action plans, backed by funding, with accountability built in.*

*For too long, ME has been underfunded, under-researched, and poorly understood. Patients deserve better. I will continue to press NHS Fife, the Scottish government, and the UK government to step up. Until they do, I will keep listening to patients, working with charities, and holding those in power to account. For those living with ME in Fife and across Scotland, meaningful change cannot come soon enough.*

The article can be found at <https://www.thereforme.uk/p/scotland-must-step-up-on-me-care>

## Network writes to Ministers

Government fiscal years run from April 1 of one year to March 31 of the following year. In advance of each new fiscal year, government departments discuss their plans and priorities for the upcoming year.

ME and FM are often overlooked in government plans. We therefore wrote to two key ministers outlining actions we would like to see happen in 2026-27. The emails were sent from [President@memfaction.com](mailto:President@memfaction.com) on January 15, 2026. The email to the Minister of Health, the Honourable Marjorie Michel, is on page 7, while the email to the Minister responsible for the Office for Disability Issues, the Honourable Patty Hajdu, is on page 8.

We used some bureaucratic lingo.

\*F/P/T discussions stands for Federal/Provincial/Territorial discussions.

\*The Health Portfolio (reporting to the Minister of Health) includes Health Canada (HC), the Public Health Agency of Canada (PHAC), and the Canadian Institutes of Health Research (CIHR), plus the Patented Medicine Prices Review Board and the Canadian Food Inspection Agency. The Health Portfolio consisted of approximately 12,000 full-time equivalent employees and an annual budget of over \$3.8 billion as of October 2024.

\*NIH is the US National Institutes of Health which, like CIHR, funds research.

## To Canada's Minister of Health

Re: Including ME and FM in Health Portfolio plans for 2026-27

People with ME (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), FM (Fibromyalgia), or both have been receiving inadequate health and social care for a long time. The National ME/FM Action Network hopes that the plans and priorities for the Health portfolio for 2026-27 will include substantial work to address the serious issues faced by the ME/FM community.

On October 21, 2025, we had an on-line meeting with staff in your office. We raised issues that our people are encountering in the health and social system. We focused on ME due to the limited time available. FM is an overlapping illness with similar issues that also need to be addressed. Here is the email we sent to your staff following the meeting:

*Thank you for meeting with us last week (October 21) to discuss Myalgic Encephalomyelitis issues in the health system.*

*ME health policy has been designed around the stigmatizing assumption that ME is not a real illness but instead is due to mass hysteria or faulty illness beliefs. As a result, people with ME have not been receiving the health, social and financial support they need to manage their situation. This has consequences for individuals and their families. It has consequences for the economy since ME often affects people of working age. It also has consequences for the health care system itself - people still come for help but health care providers have little guidance or support to provide the care that people with ME need and deserve.*

*We suggested four specific areas where the Health Portfolio could start – These actions would have value by themselves and would also provide a foundation to enter into F/P/T discussions around ME.*

*We understand that the Health portfolio has many challenges, but we believe that ME has been neglected and stigmatized far too long and therefore deserves attention. We look forward to working with you to make real progress.*

On October 31, 2025, we received an acknowledgement of the meeting but no commitment to action.

Hopefully there will be good news in the government's 2026-27 plans that we can share with the community.

The four specific areas where the Health Portfolio could start are described below.



**Adding ME and FM to the federal government's diseases and conditions website:** There are 243 diseases and conditions on the government site. ME is not included at all. The information for FM is a document published 20 years ago. These situations signal to the ME/FM community, to the health system, and to the wider public that the federal government does not take ME and FM seriously.

**Publishing recent statistics** on ME and FM prevalence and experiences to inform public discussion: We published a statistical study in 2017 that showed that close to a million Canadians reported a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia or both and that the ME/FM community was under-served and in great need. The failure of government to publish more recent information, especially when the number of cases is expected to rise considerably due to COVID, again signals a lack of government interest in ME and FM. [https://www.mefmaction.com/images/stories/quest\\_newsletters/Quest112.pdf](https://www.mefmaction.com/images/stories/quest_newsletters/Quest112.pdf)

**Investigating why ME and FM receive very little research funding:** We have produced statistics that show that ME and FM received very little CIHR research funding considering their prevalence. US studies have found that ME receives very little NIH funding considering its burden of illness. A particular study found that the gender profile of diseases and their prestige or stigma influence NIH funding. <https://pubmed.ncbi.nlm.nih.gov/33232627/>

**Identifying who is responsible for ME and FM disability issues:** Canada's disability system is built around the assumption that disabilities have to be approved by the health system. The health system has been built around the assumption that ME and FM are not real diseases. This leaves people with ME and FM in a terrible position. We need government to sort this out.

## To Canada's Minister for Jobs and Families

Re: Plans and Priorities 2026-27 - CRPD implementation for ME and FM

We hope that the federal government's plans and priorities for 2026-27 will include substantial activity to apply the UN Convention on the Rights of Persons with Disabilities (CRPD) to the ME/FM community in Canada. Step 1 is establishing who in the federal government has responsibility to coordinate and oversee this work in dialogue with the ME/FM community.

The National ME/FM Action Network is a registered charity working on behalf of Canadians with Myalgic Encephalomyelitis ("chronic fatigue syndrome") and/or Fibromyalgia. ME and FM are chronic, disabling medical conditions.

On November 12, 2024, we made a submission to the UN committee reviewing Canada's implementation of the Convention on the Rights of Persons with Disabilities (CRPD). It was posted on the UN website that very day. You can look for it on the UN website but it is much simpler to find it here: [https://mefmaction.com/images/stories/quest\\_newsletters/Quest144.pdf](https://mefmaction.com/images/stories/quest_newsletters/Quest144.pdf)

Our submission started with a quote from a UN website:

*"The Convention on the Rights of Persons with Disabilities, which was adopted in 2006 and entered into force in 2008, signaled a 'paradigm shift' from traditional charity-oriented, medical-based approaches to disability to one based on human rights."*

The federal government's Office for Disability Issues (ODI) has not made the paradigm shift. It listens to the traditional disability community but not to the ME/FM community. We have seen many examples over the last decade including:

- ODI wrote the Accessible Canada Act which addresses issues that are important to the traditional disability community but ignored the issues we raised during the consultation process.
- A former Director-General of ODI told us that ME and FM would be recognized as disabling when the traditional disability community decided to accept them.



Patty Hajdu, Minister for Jobs and Families

- ODI gave responsibility for the Disability Inclusion Action Plan to the traditional disability community who never consulted us even though we were registered as partners on the modernization pillar.
- ODI has not had a substantive discussion with us about the contents of our CRPD submission.

According to a Statistics Canada survey, close to one million Canadians reported that they had a diagnosis of ME, FM or both, mostly women and mostly of working age. That survey also showed that the ME/FM community had high rates of unmet health care needs despite frequent contact with the health care system, and high rates on measures of social distress like unemployment, poverty, food insecurity and social isolation.

People with ME, FM, or both have been receiving inadequate health and social care for a long time. They need government attention. If ODI will not make the paradigm shift and recognize that the ME/FM community is a community needing to be heard and helped, we hope that you will find or create another home for ME and FM so that work can get underway as soon as possible.

Cc Leslie Church, Parliamentary secretary for persons with disabilities

## Disability Skepticism at Provincial Tribunals

Many articles about ME or FM come out of the medical research or medical practice areas. The following article is unusual because it comes out of the legal area. The author, Pascale Malenfant, is a graduate of McGill University Law School. The article was published in October 2025 in the *Dalhousie Law Journal*. As this study will show, tribunals hearing CFS cases seem to ask “can we trust this applicant” rather than “can we help this applicant”.

This article explains disability skepticism as follows. “The medical model [of disability] is inclined to arrange individual disabilities in the form of a hierarchy with respect to legitimacy; thus, disabilities that are poorly understood or do not fit neatly into a medical model (in terms of being easily diagnosable and treatable) are considered less legitimate than others.”

Ms Malenfant took on a challenge -- to examine how administrative tribunals decide whether or not to approve disability support payments for applicants with illnesses that are poorly recognized by the medical system. She refers to poorly recognized illnesses as “hidden” illnesses.

She focused her study on people applying for financial support on the basis of Chronic Fatigue Syndrome. She notes that “those with CFS (as well as their caretakers) have described facing significant skepticism when sharing their condition with others, as they are often labeled as lazy, hysterical or psychosomatic.”

She chose two administrative tribunals to review, the Ontario Social Benefits Tribunal and the Tribunal administratif du Québec. The Ontario tribunal hears appeals from people who applied to the Ontario Disability Support Program and were turned down. The Québec tribunal hears appeals from people who applied to the Québec Pension Plan and were turned down.

Tribunal decisions are published on-line. She identified decisions that were published between 2013 and 2023 and contained the key word phrase “chronic fatigue syndrome” in English or French. She then went through those cases, selecting the ones where CFS was a factor in the decision and removing those where CFS was just casually mentioned. She ended up with 142 cases from Ontario and 89 cases from Québec.

She came up with a methodology for reviewing how each of the decisions was made. She would look at how the

decision maker relied on

- the documentation (notably medical records and activity logs),
- the testimony of the applicant and witnesses at the hearing, and
- the demeanour or comportment of the applicant at the hearing.

The author found that medical documentation was important in both provinces, but she found that the Québec tribunal paid stricter attention to the medical documentation than the Ontario tribunal did. She attributed this in part or in whole to the qualification criteria in the legislation, with Québec’s criteria being much more medically based than Ontario’s, and Québec requiring essentially permanent disability versus Ontario allowing for shorter term approvals. This shows that the design of income support programs affects how decisions are made.

The author also found the Québec tribunal to be less flexible than the Ontario tribunal when considering activity records of applicants. The author noted: Further, decisions from the Québec tribunal in particular relied heavily on the stereotype that disabled persons are incapable. Where claimants exhibited behaviour outside of this perceived norm, they were rendered suspect. In more than a dozen unsuccessful CFS cases, activities such as driving, traveling, moving independently, exercising, gardening, caring for one’s own children, walking one’s dogs, or volunteering in organizations related to their disability were scrutinized as inconsistent with their claim of being unable to hold any “gainful employment.”

When it came to testimony at the hearings, the author found that both tribunals were on the look-out for evidence of malingering. Some decisions started off by saying that there was no evidence of malingering which showed what the decision-makers were looking for exactly that.

When it came to demeanour, applicants were watched closely. If they showed few signs of CFS such as loss of concentration, they might have overstated their condition in their application. If they showed too many signs of CFS, they might be exaggerating their condition at the hearing. They were also expected to display at least some frustration with their condition.

When it comes to solutions, the author suggests that applicants think about their documentation, their testimony and their demeanour. More importantly, she suggests that

the following systems changes are needed:

- better access to healthcare for people with hidden and hard-to-diagnose illnesses
- clearly legislating that disabled individuals' own perceptions of their impairments be given the same investigative weight as medical evidence regarding the severity of their disability
- clearly articulating to adjudicators the importance of and methods for considering a claimant within their own circumstances

We would add one more – better access to legal support.

Pascale Malenfant, “Seeing is Believing: Identifying the “Ideal Manifestation of Hidden Disability” in Ontario’s and Quebec’s Social Benefits Tribunals” (2025) 48:2 Dal LJ. <https://digitalcommons.schulichlaw.dal.ca/cgi/viewcontent.cgi?article=2282&context=dlj>

## Contested and Neglected: Severe ME/CFS

This study came out of the Sociology Department at Georgia State University in the US. The study looks at social media postings of people with severe ME/CFS to learn about their experiences. The study finds them to be both physically incapacitated and socially invisible.

The authors describes three contributing factors to this social invisibility:

Contested legitimacy: The authors note the disbelief about ME/CFS in the medical profession. They explain that a medical diagnosis “works beyond a mere label, but conveys a socially embedded process that shapes how an illness is understood, accepted, and treated. People with ME/CFS, therefore, lack not only the legitimizing power of a diagnosis but also the relief of medical treatments or access to disability benefits... Having a valid diagnosis offers a socially accepted reason for affected individuals to not entirely fulfill social roles, whether as employees, society members, or family members. Lack of a legitimate label results in stigmatization and blame for no longer being a productive member of society.”

Gendered stigma: “Many individuals with ME/CFS, as well as those with fibromyalgia, chronic pain, and now Long COVID—report not being heard or taken seriously by medical professionals, and feeling medically gaslit by accusations of malingering or exaggeration...Those with feminized contested and often energy-limiting conditions are especially vulnerable, as their illness narratives are

frequently suspected of being emotionally charged and unreliable.”



Systemic marginalization: The article observes that disability support systems were built around visible, consistent and easily-classifiable impairments. The article notes that disability activism is crucial in fighting for more inclusive benefits for those with contested illnesses. “Yet, ME/CFS and chronic illnesses alike are also marginalized by the disability community, which has historically sought to distance disability from illness.” The article observes that “bringing ‘unhealthy disabled’ individuals into the advocacy is thought to compromise the idea that ableism is the problem, not bodies...” In its advocacy work, the National ME/FM Action Network has encountered reluctance to talk about ME and FM issues from the disability system, and from the recognized disability community as well.

The authors then turn to recommendations:

- greater biomedical recognition of the condition, including identifying underlying biological mechanisms and diagnostic tools that can help validate the illness in both clinical and policy settings and possibly offer effective treatments
- listening to and respecting patients and confronting the gendered history of ME/CFS
- reliable, accessible institutional supports.

They conclude with the following statement referring to the patients with severe ME/CFS in their study:

“These individuals are not invisible by choice; they are rendered invisible by systems that refuse to acknowledge their existence and suffering. Listening to their voices is a moral imperative, a research necessity, and a first step toward justice.”

Bitá Nezamdoust, Erin Ruel: Contested and neglected: Social and medical marginalization in severe Chronic Fatigue Syndrome:

<https://www.sciencedirect.com/science/article/pii/S0277953625010974>

## Germany to Fund Post-infectious Disease Research

The German Federal Government, and in particular the *Federal Ministry for Research, Technology and Space* (BMFTR), has committed a total of €500 million (€50 mln/year) is to be spent on research into

post-infectious diseases in 2026-2036.

500 million euros is the equivalent of \$800 million Canadian. Canada's economy is about half the size of the German economy. Thus, that would be the equivalent of Canada dedicating about \$40 million per year to post-infectious disease research over the next decade.

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# MEMBERSHIP APPLICATION or RENEWAL FORM

## NEW MEMBERSHIP or RENEWAL fees

*For online application and renewals go to  
**MEFMaction.com***

**ANNUAL MEMBERSHIP FEE :**  
\$30.00 per year including quar-  
terly newsletter Quest

**IN ADDITION,** I would like to  
donate \*\$\_\_\_\_\_   
to help with the many  
projects of the National ME/FM  
Action Network.

*\*Tax Receipt issued for all donations*

### TOTAL PAYMENT:

\$\_\_\_\_\_

### PAYMENT OPTIONS

- Cheque  
*Please make Cheque Payable to  
the:*  
NATIONAL ME/FM ACTION NETWORK
- VISA
- Master Card
- Other \_\_\_\_\_

Card Number:  
\_\_\_\_\_

Expiry Date:  
month \_\_\_\_\_ year \_\_\_\_\_

CVV \_\_\_\_\_ (3 digit code on back of  
card)

Name on Card:  
\_\_\_\_\_

Signature:  
\_\_\_\_\_

**I would like to be a member.**  
**Please waive the annual fee.**

Date: \_\_\_\_\_

Name / Organization  
\_\_\_\_\_

Contact Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

City \_\_\_\_\_

Province/State \_\_\_\_\_ Postal Code/Zip \_\_\_\_\_

Country \_\_\_\_\_

Email \_\_\_\_\_

Phone \_\_\_\_\_

Website \_\_\_\_\_

- Please send news updates to my email address
- Do not** send news updates to my email address

- Please send an electronic version of the Quest newsletter
- Please send the Quest newsletter to my mailing address

### MAIL FORM & PAYMENT TO:

**NATIONAL ME/FM ACTION NETWORK**  
**200 - 38 Auriga Drive**  
**Ottawa, ON K2E 8A5**



## THANK YOU FOR YOUR SUPPORT!

*CREDIT CARD TRANSACTIONS CAN BE MADE BY PHONE*  
*Our phone number is 613-829-6667*