

**ICanCME Canadian Collaborative Conference
on Myalgic Encephalomyelitis -
*Nothing About Us Without Us***

Schedule:

Pre-Conference Session for Occupational Therapists:

Monday, November 3rd, 1 pm - 3 pm Eastern Time

Poster Presentations:

Wednesday, November 5th 2025, 11:30 am - 12:30 pm Eastern Time

Main Conference:

Tuesday, November 4th - Thursday, November 6th, 2025,
1 pm - 5 pm Eastern Time

Location:

Virtual on Zoom, to increase accessibility
(Zoom link will be sent by email, prior to the conference)

Cost:

FREE for all attendees, to increase accessibility

Language:

In English, with simultaneous translation in French

Main Conference Registration in English:

<https://forms.gle/R8tJgR2x3WBNr9pF8>

Important to note: These sessions will be recorded and will be made available
to review at <https://icancme.ca/research/2025-me-conference/>



WELCOME

It is our great pleasure to welcome you to the Canadian Collaborative Conference on Myalgic Encephalomyelitis (ME) “**Nothing About Us Without Us**” hosted by the Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis (ICanCME) Research Network.

Our comprehensive program brings together leading researchers, clinicians, trainees, patient partners and community collaborators from across Canada and around the world.

Through a variety of themed presentations and panel discussions, attendees will gain insights into Myalgic Encephalomyelitis, its common comorbidities (such as Long COVID, MCAS, dysautonomia, connective tissue disorders, gastrointestinal conditions, and more), and explore the current challenges and opportunities to move ME research forward.

Patient Leaders Explain the Design and Intention of This Conference

Our conference is intentionally designed a little differently and we hope it will complement other events you have attended.

This conference was designed by people with ME (dedicated volunteers) and our ME community’s perspectives are woven throughout the three-day program. The theme of the conference is “*Nothing About Us Without Us*” - a powerful slogan of the disability rights movement, emphasizing that people with disabilities must be involved in decisions that affect their lives.

We believe that “*Nothing About Us Without Us*” is a principle that also needs to be adopted across ME research and clinical care. We feel that lived experience is a vital asset that can bring context and perspective to data and help inform research design, so that we can better address existing gaps and challenges together.

To truly advance ME research and care, we must adopt a **patient-centred, trauma-informed, PEM-knowledgeable** approach moving forward, and lived experience must be meaningfully included for that to happen. This starts with accessibility and inclusion.

Increasing Accessibility and Inclusion

As people with ME, traditional conferences are incredibly challenging to attend and even completely out of reach for many of us. The same is often true for our caregivers and loved ones.

While much of this has to do with the debilitating reality and severity of ME, we have intentionally incorporated accommodations into this conference to increase accessibility and inclusion. Our goal is to enable more people with ME, along with their caregivers and loved ones to participate more fully. We also believe that many of these accommodations will benefit ALL attendees.

- We have eliminated conference fees. This increases access for everyone interested in learning about ME.
- We have eliminated the travel that is often required to attend conferences. This reduces the energy and costs required to participate. Eliminating travel also reduces the risks of infections/re-infections associated with travel and large gatherings.
- We have designed the conference to be shorter (3 half days), with more concise sessions (15-30 minutes) for each topic. The sessions will start a bit later in the day too, to better accommodate attendees.
- We will be recording all the sessions. This provides access post-conference for those who are unable to attend or wish to revisit topics at their convenience.
- We have created a set of expectations, included in this program. These will be reviewed periodically to ensure we are setting a supportive and respectful tone for ALL of our attendees.
- We have included panels at the end of each day to help tie topics together and encourage collaboration and discussion on how to move our research forward more effectively. These will include questions from the audience, using Zoom's Q & A feature, as well as pre-selected questions.

(We ask that you refrain from sharing your personal medical information or asking questions specific to your personal health situation. Please keep questions general. Speakers cannot provide medical advice.)

- This conference program has been formatted to be easier to print. It can also be viewed on your computers, tablets and phones (which should have the option to zoom in or out of the text).

Structure of the Conference

The full agenda and speaker bios are included within this conference program.

Each day will feature a number of speakers (researchers, clinicians and patient partners), focused around three themes:

Day 1 Theme - ***ME Foundations and Current Research Landscape***

Day 2 Theme - ***Reality of Comorbidities and Impact on ME Research***

Day 3 Theme - ***Collective Deep Thinking in ME Research Design***

We have asked all invited speakers to include the following in their presentations:

- Current scientific findings on their topic
- Opportunities to strengthen research design, accessibility and inclusion related to their topic
- Opportunities for repurposing medications or clinical trials (if applicable), related to their topic.

We hope that this design and approach will complement the other wonderful conferences and learning events that have happened recently on this topic.

Building Capacity

This illness demands the brightest minds and most compassionate hearts to build capacity and knowledge, to navigate challenges collaboratively and to drive innovation together. People with ME need answers, care, treatments and a cure NOW.

We extend our sincere gratitude to all speakers, attendees, and partners for their contributions to this important scientific and community-based exchange. We look forward to the insights, collaborations, and future directions that will emerge from this conference.

ICanCME Conference Planning Committee (in alphabetical order by first name):

Carrie Anna McGinn

Liesl Mulholland

Maeghan Taverner

Sabrina Poirier

Trudy Flynn

ACKNOWLEDGEMENTS

We greatly acknowledge and thank the **Institute of Musculoskeletal Health and Arthritis (IMHA)** at the **Canadian Institutes of Health Research (CIHR)** for providing the funding to make this event possible. Because of their support, we were able to provide this conference for free, which helps reduce barriers to participation for many in our community who need it most.

We want to thank the **Association québécoise de l'encéphalomyélite myalgique (AQEM)** for their financial contribution to our conference, making simultaneous translation possible for our French-speaking attendees.

We want to thank our ICanCME **Director** and **Coordinator** for the support they have provided throughout the planning and execution of this event. We also wish to recognize the wonderful support and guidance provided by **ICanCME's Community Leadership Team** and from the **Working Group on Trainee Development and Medical Education**.

Our heartfelt thanks to each member of the **Conference Planning Committee** for their efforts to secure the funding and execute this important conference.

Thank you to our wonderful **speakers and panelists**, for contributing to our current knowledge and for collaborating with us, to create a meaningful and impactful event.

We extend our deepest gratitude to the **Canadian ME Community** who have inspired and fuelled this work and whose voices help educate on the realities of this devastating illness. A special thank you to those who share their lived experience and energy with our Network, and help inform our direction and decisions.

Finally, we want to thank our **International ME Community** for their continued knowledge, experience, support and friendship, as we continue to build our foundation for change here in Canada. We understand and appreciate the energy it requires to contribute to our efforts and we appreciate each of you for it.



OUR CANADIAN RESEARCH NETWORK

The Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis (ICanCME) Research Network is a national research network of researchers, clinicians, and patient partners working to advance the understanding of ME and its biomedical research.

The ICanCME Research Network was established in September 2019 through a Catalyst Network grant funded by the Institute of Musculoskeletal Health and Arthritis (IMHA) of the Canadian Institutes of Health Research (CIHR). In 2024, it received a commitment for funding for an additional five years, to continue to build capacity.

Governed by a Community Leadership Team and an International Scientific and Medical Advisory Board, the mission of ICanCME is to be the primary resource for initiating, supporting and sustaining innovative and collaborative ME research, designed to benefit the health of all Canadians living with ME and those at risk of developing ME.

OUR SHARED EXPECTATIONS

We want to set expectations for this conference, as we will be bringing together a diversity of perspectives, knowledge and experiences.

We recognize that gatherings like these can be both exciting AND challenging experiences; for researchers and clinicians who are new to this illness and may feel uncertain about where to begin, for those who have been passionately working in ME research or clinical care with people with ME for years, often without the supports and resources they need, and especially for individuals living with ME, their caregivers and loved ones.

To encourage an **inclusive and respectful environment**, we kindly ask all conference speakers and attendees to please:

- Come to this gathering with a humble heart and open mind - ready to learn, to share knowledge and ideas respectfully, to discuss challenging topics with kindness and care.
- Recognize that learned and lived expertise are both valuable at this conference.
- Remember the energy and exertion it has taken for many to be present today.
- Understand that our ME community has endured a great deal of trauma, suffering, neglect, and gaslighting, throughout their experiences with healthcare and research. These challenges persist as they try to navigate countless systemic barriers without the supports and accommodations they need. Due to this very present and ongoing reality, emotions

may flow and tensions may arise. Together we will navigate these conversations with grace, compassion, and a shared commitment to creating change.

- Recognize that for people with ME, their caregivers and loved ones especially, simply being here is an act of courage and commitment. We honour and deeply value your presence. Please feel free to come as you are and rest how/when you need to.

Together, let us set the tone for a conference that centres lived experience and a trauma-informed approach, supports genuine and meaningful contributions, and encourages discussion and collaboration, so that we can move closer to systemic change.

Disclaimer: The content of each presentation and thoughts shared are those of each speaker. These have not been previewed ahead of the presentation and may not reflect the views of the ICanCME Research Network.

SOCIAL MEDIA

Social media can be a valuable tool for sharing information with those who are unable to attend the conference and to connect with other attendees. Boosting each other's stories and knowledge is a great way to show support.

We also recognize that these spaces can be filled with bots, trolling, dismissive and gaslighting comments, especially for those in the chronic illness and disability community.

Please only engage on social media if you feel safe doing so. We will attempt to provide direct updates throughout the conference as well.

The hashtag for this event is **#ICanCME2025**.

ICanCME has a **Twitter** account (@ICanCMEResearch) and a **BlueSky** account (@icancmeresearch.bsky.social).

Note: We would ask that discussions there follow the same expectations as the conference.

PRE-CONFERENCE SESSION FOR OCCUPATIONAL THERAPISTS

Monday, November 3rd, 1:00-3:00 pm Eastern Time

Session Description

This training focuses on occupational therapy practice in the context of post-exertional malaise.

The training will cover topics such as: identifying red flags in referrals, screening for post-exertional malaise, how to work with clients toward stabilizing their energy envelope, how to assess for return-to-work capacity. The training will also provide practical examples of assessment and intervention tools, energy conservation strategies, and communication strategies for reports.

Certificates of attendance can be provided for attendees.

Registration:

<https://forms.gle/Pfk65pcrt2b2bkKB7>

Speaker: Melanie Kasner



Melanie Kasner is an occupational therapist with over a decade of experience, currently practicing in the area of ME and Long COVID. Melanie learned of ME not in university, but only when a family member was diagnosed. She is grateful to the ME community for openly sharing their lived experience, which contributed tremendously to her education on the subject.

She is a member of the ICanCME Working Group on Vascular Instabilities and Sleep Disturbances and the Working Group on Trainee Development and Medical Education. She is a member of the scientific committee of the Quebec ME

Association (AQEM) and has collaborated on tools and webinars for its members. Melanie was on the consultation committee for the ME/CFS management and support documents published in 2023 by Quebec's Institut national d'excellence en santé et en services sociaux (INESSS).

POSTER PRESENTATIONS - STARS OF TOMORROW

Wednesday, November 5th 2025, 11:30 am - 12:30 pm Eastern Time

The *Stars of Tomorrow Scholarship* program, launched by the ICanCME Research Network, is an initiative designed to nurture emerging talent in the field of Myalgic Encephalomyelitis (ME). By offering bursaries to graduate students and fellowships to postdoctoral researchers across Canada (and sometimes beyond our frontiers) to support promising Canadian students, the program actively invests in the next generation of scientists and clinicians who will lead the charge in unraveling the complex biology of ME and developing effective treatments.

This effort is crucial for the ME community, which has long faced under-recognition and limited medical support. By fostering interdisciplinary research and drawing new minds into the field, the scholarship helps build a future where those suffering from ME are met with understanding, innovation, and hope.

The poster sessions showcase emerging research, innovative methodologies, and new perspectives that contribute to advancing knowledge in Myalgic Encephalomyelitis (ME).

We encourage all attendees to engage with these presentations (if able), as these discussions are integral to building research capacity and strengthening collaboration across disciplines.

Speaker	Poster Presentation Title	Zoom Rooms
Atefeh Moezzi	The Role of Haptoglobin in the Pathophysiology of Post-exertional Malaise	Room 1
Braeden T. Charlton	An Inability to Recover: Impaired regenerative markers in Long COVID and ME/CFS Patients	Room 2
Corinne Leveau	Exploring the Cognitive Differences Between Myalgic Encephalomyelitis and Long COVID	Room 3
Ghazaleh Azimi	Uncovering the Dual Role of FGF-21 in Myalgic Encephalomyelitis and Fibromyalgia Pathogenesis	Room 4
Yasaman Vahdani	Molecular Insights into a Key Regulator of Autonomic Dysfunction in Myalgic Encephalomyelitis	Room 5
Raminder Kaur	A Multimodal Magnetic Resonance Imaging Study on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: Feasibility and Clinical Correlation	Room 6

AGENDA

Academic titles (e.g., Dr., PhD, MD) have been intentionally omitted from the name listings to maintain a consistent format and to highlight each speaker's contribution equally. Full professional and academic credentials are included within individual bios, as submitted.

Day 1: Tuesday November 4, 2025 (1:00 pm - 5:00 pm Eastern Time)

Theme of the day: *ME Foundations and Current Research Landscape*

Time	Session	Speaker
1:00 - 1:15 pm (Eastern)	Welcome	Alain Moreau, Carrie Anna McGinn, Liesl Mulholland, Maeghan Taverner, Sabrina Poirier, Trudy Flynn
1:15 - 2:15 pm	Keynote Presentation: Women's Health and "Unexplained" Chronic Illness: How Gender Bias Leads to Medical Neglect	Maya Dusenbery, Author of <i>“Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick”</i>
2:15 - 2:30 pm	Exertion and PEM	Todd Davenport
2:30 - 2:45 pm	Skeletal muscle alterations and post-exertional malaise in Long COVID and ME	Rob Wüst
2:45 - 3:00 pm	Cognitive Dysfunction - Lessons We Can Learn from Long COVID	Danielle Beckman
3:00 - 3:15 pm	Rest Break	
3:15 - 3:30 pm	Deep Immune Profiling	Akiko Iwasaki
3:30 - 3:45 pm	Infections and the damage they cause	Amy Proal
3:45 - 4:00 pm	A Canadian Family Medicine Perspective	Daisy Fung
4:00 - 5:00 pm	Q & A and Panel Discussion: Insights and Lessons Learned in ME Research	Amy Proal Daisy Fung Danielle Beckman Maya Dusenbery Rob Wüst Todd Davenport

Day 2: Wednesday November 5, 2025 (1:00 pm - 5:00 pm Eastern Time)

Theme of the day: *Reality of Comorbidities and Impact on ME Research*

Time	Session	Speaker
11:30 am - 12:30 pm (Eastern)	Poster Presentations	Stars of Tomorrow Grant Awardees
12:30 - 1:00 pm	Rest Break (and Speaker Set Up)	
1:00 pm	Main Conference - Day 2 Starts	
1:00 - 1:30 pm	Comorbidities and Less Studied Pathologies in Infection-Associated Chronic Illnesses (IACIs)	Beth Pollack
1:30 - 1:45 pm	ME and Neurodivergence	Jaime Seltzer
1:45 - 2:15 pm	Dysautonomia and Connective Tissue Disorders	Brayden Yellman
2:15 - 2:45 pm	The Science and Art of Caregiving in Severe ME - A Caregiver's Perspective	Ruhi Snyder
2:45 - 3:00 pm	Rest Break	
3:00 - 3:15 pm	Mast Cell Activation Syndrome (MCAS)	Anne Maitland
3:15 - 3:30 pm	Special Considerations for Children and Teens	Sammie McFarland
3:30 - 4:00 pm	Gastrointestinal (GI) Comorbidities	Rebecca Ryan
4:00 - 5:00 pm	Q & A and Panel Discussion: The Reality of Comorbidities and How We Can Better Track, Measure and Treat Them in our ME Population	Anne Maitland Beth Pollack Brayden Yellman Jaime Seltzer Rebecca Ryan Ruhi Snyder Sammie McFarland

Day 3: Thursday November 6, 2025 (1:00 pm - 5:00 pm Eastern Time)

Theme of the day: *Collective Deep Thinking in ME Research Design*

Time	Session	Speaker
1:00 - 1:30 pm	Critical Thinking in Research Design	Todd Davenport
1:30 - 1:45 pm	Cognitive Testing in ME	Jacqueline Becker
1:45 - 2:00 pm	Precision Medicine for ME	Alain Moreau
2:00 - 2:30 pm	Adaptive Clinical Trials and Accessibility in Research Design	David Putrino
2:30 - 2:45 pm	Neuroinflammation in ME	Michael VanElzakker
2:45 - 3:00 pm	Rest Break	
3:00 - 3:15 pm	Patient Engagement in ME Research	Carrie Anna McGinn and Trudy Flynn
3:15 - 3:45 pm	Addressing Ableism/Internalized Ableism in Research and Clinical Settings	Daisy Fung
3:45 - 4:00	Patient Driven Lactate Research in ME	Tess Falor and Isabel Burnett
4:00 - 4:55 pm	Q & A and Panel Discussion: Collective Deep Thinking to Move ME Research Design Forward	Alain Moreau Carrie Anna McGinn Daisy Fung David Putrino Isabel Burnett Jacqueline Becker Michael VanElzakker Todd Davenport Tess Falor Trudy Flynn
4:55 - 5:00 pm	Closing Remarks	Conference Planning Team

PROFILES

All profiles are presented in alphabetical order by first name for ease of browsing. Academic titles (e.g., Dr., PhD, MD) have been intentionally omitted from the name listings to maintain a consistent format and to highlight each speaker's contribution equally. Full professional and academic credentials are included within individual bios, as submitted by speakers.

CONFERENCE PLANNING COMMITTEE PROFILES

CARRIE ANNA MCGINN

Carrie Anna McGinn holds a master's degree in Community Health and has worked for over a decade in the fields of health research and evaluation, in the public and not-for-profit sectors.

As a research professional, she contributed her skills in systematic reviews, grant writing, project management, and knowledge translation to various patient-oriented projects. She also coordinated a centre of expertise which focused on bringing together stakeholders from research, the healthcare system and communities to improve access to healthcare.

Carrie uses her experience of living with Long COVID and Myalgic Encephalomyelitis, to advocate for recognition, research and adapted care for infection-associated chronic illnesses.

She is a member of the ICanCME Community Leadership Team and co-president of the Association québécoise de l'encéphalomyélite myalgique (AQEM). She has co-founded several science-driven provincial and national infection-associated chronic illness groups and is a patient partner for ongoing related Canadian research and initiatives.

LIESL MULHOLLAND

Liesl Mulholland is a consultant and facilitator with extensive experience supporting research, innovation, and knowledge exchange across sectors. She has worked with post-secondary institutions, community organizations, and international partners to design and deliver conferences, workshops, and collaborative initiatives that bring people together to share expertise and advance new ideas.

With a background in law and diplomatic studies, and fluency in English and French, Liesl is passionate about creating inclusive spaces for learning, dialogue, and collaboration. She brings her skills in program development, event facilitation, and community engagement to support the ICanCME conference in achieving its mission of advancing research and care for people living with Myalgic Encephalomyelitis.

MAEGHAN TAVERNER

Maeghan Taverner is an artist and advocate located in Kijipuktuk/Halifax, Nova Scotia.

They are a former member of the ICanCME Steering Committee and now are part of the Community Leadership Team. They have Myalgic Encephalomyelitis as well as a few other rare diseases, so they share expertise surrounding their experiences in inpatient and outpatient settings. They are also the President of the board of directors of Dance Nova Scotia and chair their Accessibility Committee. They hold an undergraduate honours degree in theatre and sociology from Dalhousie University. They were a graduate student in sociology when they developed ME in 2019.

They now dedicate their time to disability advocacy work and hope to create more accessible and inclusive spaces.

SABRINA POIRIER

Sabrina Poirier worked within the private, public and not-for-profit sectors for over 20 years. Her work in politics, education and community development helped shape her perspective and fine tune her approach to meaningful engagement and positive systems change.

Sabrina is a co-founder of the ICanCME Research Network, the Chair of its Working Group on Trainee Development and Medical Education and a member of the 2023-2025 Community Leadership Team.

From 2018-2021, she served as a Research Ambassador for the Institute of Musculoskeletal Health and Arthritis (IMHA) at the Canadian Institutes for Health Research (CIHR) and from 2020-2023 as a Community Advisory Committee member for the NIH-funded Collaborative Research Centers Network in the US. She is currently collaborating with the US National Institute for Neurological Disorders and Stroke (NINDS-NIH), Research Triangle Institute (RTI), and other subject matter experts as a member of the Common Data Elements (CDE) Teams for PEM and Cognitive Testing.

Sabrina uses her knowledge, skills, expertise and personal experience as an individual living with ME (and several common comorbidities), in the fight to have the illness understood, cared for, researched and removed from the shadows once and for all.

TRUDY FLYNN

Trudy Flynn is a medically retired nurse from Nova Scotia. She is also a patient partner who has been involved in patient engagement work for over 14 years. Trudy has lived with

Fibromyalgia for over 30 years and was a caregiver to a daughter and husband who were both diagnosed with ME. Trudy has stayed involved in the ME community since that time.

Trudy is the Chair of Fibromyalgia Association Canada, did work with the Maritime SPOR Support Unit and is a Patient Engagement Research Ambassador alumnus, who helped develop patient engagement modules at CIHR-IMHA. Trudy is currently doing work developing training modules at Can Train and working on various Research projects across the country. Trudy was a member of the ICanCME Steering Committee and is currently on the Community Leadership Team.

SPEAKER PROFILES

AKIKO IWASAKI

Akiko Iwasaki, Ph.D. is a Sterling Professor of Immunobiology at the Yale University School of Medicine. Her research focuses on the mechanisms of immune defense against viruses at mucosal surfaces, which are a major site of entry for infectious agents.

Professor Iwasaki received her Ph.D. in Immunology from the University of Toronto and completed her postdoctoral training with the National Institutes of Health before joining Yale's faculty in 2000. She has been a Howard Hughes Medical Institute Investigator since 2014.

Professor Iwasaki has received many awards and honors including Forbes 50 over 50 Innovation 2024, TIME 100 Most Influential People 2024, TIME 100 HEALTH Most Influential People Affecting Global Health 2024, and the Else Kröner Fresenius Prize for Medical Research 2023. She was elected to the National Academy of Sciences in 2018, to the National Academy of Medicine in 2019, to the American Academy of Arts and Sciences in 2021 and was appointed President of American Associations of Immunologists (AAI) in 2023.

Professor Iwasaki has been a leading scientific voice during the COVID-19 pandemic and is also well known for her Twitter advocacy on women and underrepresented minorities in the science and medicine fields. She was named to the 2023 STATUS list of the ultimate list of leaders in life sciences.

Professor Iwasaki is the director of the Center for Infection and Immunity and is at the forefront of several long COVID investigations including the Mount-Sinai Yale Long COVID study, Yale LISTEN study, and Yale Paxlovid trial.

ALAIN MOREAU

Professor Alain Moreau holds a PhD in Microbiology and Immunology from the Université de Montréal, where he is a full professor at the Faculty of Dentistry (Stomatology) and the Faculty of Medicine (Biochemistry and Molecular Medicine). He served as Research Director at CHU Sainte-Justine (2013-2016) and led the Canadian Oral Health Research Network (2016-2022).

Since 2019, he has directed the CIHR-funded ICanCME Research Network on myalgic encephalomyelitis and serves on the Open Medicine Foundation's Scientific Advisory Board. An international expert in musculoskeletal genetics, his work has led to 73 patents. Dr. Moreau co-founded Inception Therapeutic Inc. to develop diagnostics and treatments for arthritis and complex diseases.

AMY PROAL

Dr. Amy Proal is a microbiologist and the President of PolyBio Research Foundation: a non-profit studying how viral, bacterial, and parasite infections contribute to human chronic disease and aging processes. She conceptualizes and coordinates collaborative research projects among scientific teams studying infection-associated chronic conditions such as Long COVID and ME/CFS. In that capacity she directs PolyBio's Long COVID Research Consortium: a scientific collaboration to rapidly study Long COVID biological drivers, with a focus on the persistence of the SARS-CoV-2 virus in tissue.

Dr. Proal also serves as Scientific Director of the Mount Sinai Cohen Center for Recovery from Complex Chronic Illness: a clinic innovating medical care and clinical trials for patients with infection-associated chronic disease. She holds a Bachelor of Science in biology from Georgetown University and a PhD in microbiology from Murdoch University in Australia.

ANNE L. MAITLAND

Anne Maitland, MD, Ph.D. is the Director of the Ehlers Danlos Syndrome Institute, at Medical University of South Carolina, and an Associate Professor in the Department of Medicine, Division of Rheumatology at the Medical University of South Carolina.

Her career has long been driven by curiosity about the neuro-immune axis and its dysregulation in disease. She was introduced to the spectrum of neuro-immune dysregulation, as she witnessed the HIV and asthma epidemics unfold in her hometown, in the 1980s. Nowadays, Long COVID exemplifies acquired neuro-immune dysregulation, which follows infection by SARS CoV-2 and impacts 7% of the US population; and, children as well as adults with connective tissue disorders, such as Ehlers-Danlos Syndromes (EDS), face neurodevelopmental challenges and heightened sensitivity to environmental exposures,

which reflect chronic dysregulation of the autonomic nervous and immune systems, respectively.

In collaboration with Drs. Norris, Gensemer and Patel, Ehlers-Danlos Syndrome Institute (EDSI) will become a model of innovative care for complex medical disorders, amidst a sea of siloed healthcare.

Dr. Maitland serves on committees addressing mast cell activation disease (MCAD), Health Care Disparities and Integrative Medicine of the American Academy of Allergy, Asthma and Immunology. She also serves on the scientific faculty for the Mast Cell Disease Society, the Ehlers-Danlos International Consortium and the Chiari Syringomyelia Foundation.

In addition to the Medical Society of the State of New York and local allergy/immunology societies, she is also:

- a Fellow of the American College of Allergy, Asthma and Immunology
- a Fellow of the American Academy of Allergy, Asthma and Immunology
- a past Chair of the Allergy/Immunology Work Group of the National Medical Association.

Her clinical and research efforts focus on increasing access to Allergy/Immunology Specialty care as well as the diagnosis and management of immune mediated disorders, including Mast Cell Activation Disease. Recent publications highlight immune dysfunction in patients with Ehlers Danlos Syndrome and dysautonomia, including chapters in the book, *Symptomatic, Transforming Ehlers Danlos Syndrome*, and the recent publication from National Academy of Sciences, *Engineering and Medicine*, entitled *Selected Heritable Disorders of Tissue and Disability*.

BETH POLLACK

Beth Pollack is a Research Scientist in the Department of Biological Engineering in the Tal Research Group at MIT, where she leads research on ME/CFS and on the overlaps and shared pathologies among infection-associated chronic illnesses. Her work focuses on understudied pathologies that significantly impact patients, with the goal of accelerating knowledge, clinical research, and treatments. Beth is also a visiting scientist at the Fred Hutch Cancer Center.

She is currently a collaborator on several clinical studies on infection-associated chronic illnesses. She also serves as a Long COVID subject matter expert on two NIH RECOVER working groups focused on Long COVID therapeutics and clinical trial design.

Beth was chair of the NIH ME/CFS Research Roadmap subgroup on Less Studied Pathologies, where she led work on less studied pathologies as part of co-designing a national

research plan for ME/CFS. She was also previously a senior researcher at Harvard. In 2024, Beth was named a United States Leader by the Obama Foundation.

Beth is committed to increasing understanding and awareness of ME/CFS, Long COVID, and complex chronic illness, and has been widely quoted in media, including interviews with the The New York Times, The Atlantic, The Guardian, NPR, and other publications.

BRAYDEN YELLMAN

Dr. Brayden P. Yellman, MD, is a board-certified physician in internal medicine and rheumatology. He earned his B.S. in Biology from Washington University in St. Louis and his Doctor of Medicine from the University of Texas in Houston, followed by a residency at Exempla Saint Joseph in Denver and a rheumatology fellowship at the University of Pennsylvania in Philadelphia.

Joining the Bateman Horne Center in 2019, Dr. Yellman has focused his work on advancing clinical care, education, and research for ME/CFS, fibromyalgia, Long COVID, autonomic dysfunctions, mast cell activation, and other infection-associated chronic conditions.

He is dedicated to improving patient outcomes through his clinical expertise and research collaborations while enhancing provider understanding of these complex, multi-system illnesses.

DAISY FUNG

Daisy Fung is a family physician in Edmonton, Alberta, with a diverse practice that includes a clinic population spanning new-born to geriatric and palliative patients as well as home visits for house-bound patients (including patients with intellectual disabilities, spinal cord injuries, and more). She is an Associate Clinical Professor at the Department of Family Medicine at the University of Alberta, teaching medical students and residents from multiple programs who have an interest in community care.

Most importantly, she is a mom of four kiddos ages 6, 8, 10, and 12, a fur mom of a 6 year old cat and 13 year old rescue pup, and partner in crime with her husband Christopher.

After contracting COVID in 2020 and subsequently developing Long COVID, she has started to advocate for patients not only with the same syndrome but also the misogyny and stigmatization of chronic illness, mental health, and post infectious syndromes by our healthcare system and society.

DANIELLE BECKMAN

Danielle Beckman, PhD is a neuroscientist interested in neurovirology and neurodegenerative diseases. She has a master's in Biophysics and a PhD in Biological Chemistry. Currently, she is a project scientist at the California National Primate Research Center, coordinating the development of novel monkey models for neurological diseases such as Alzheimer's and neuroCovid. She is also part of the Long Covid advisory group of the World Health Network.

DAVID PUTRINO

Dr. David Putrino, Ph.D. trained and worked as a physiotherapist in Australia before completing a PhD in Neuroscience and moving to the US to work as a researcher. He is currently a Professor in the Department of Rehabilitation and Human Performance at the Icahn School of Medicine at Mount Sinai in New York City and is the Nash Family Director of the Cohen Center for Recovery from Complex Chronic Illness.

Since the beginning of the COVID-19 pandemic in 2020, David has been recognized globally as a leading expert in the assessment, treatment and underlying pathophysiology of Long COVID. His team has managed the care of over 3000 people with Long COVID, ME/CFS and chronic tick- and vector borne illness and have published multiple peer-reviewed scientific papers regarding these diagnoses.

In 2019, he was named "Global Australian of the Year" for his contributions to healthcare.

ISABEL RAMIREZ-BURNETT

Isabel Ramirez-Burnett, President, CEO, and founding member of Renegade Research, pivoted from a medical career disrupted by ME/CFS to become a Systems Engineer. Now a board-certified health and wellness coach (NBC-HWC) and Autoimmune Protocol Certified (AIP-C), she also directs Remission Biome, Renegade Research's flagship project, and co-founded Renegade Medical Coaching.

Isabel's scientific passion fueled an early career in pharmaceuticals and medical devices. Driven by over 40 years living with ME/CFS, she embraces innovative scientific paradigms. Harnessing her systems expertise and autodidactic scientific knowledge, she aims to decipher the complexities of multi-system chronic illness. Her path has transformed into a quest, driving her, as a leader, to transform research frameworks, improve patient outcomes, and unite clinicians, researchers, and other champions. Her motto is *Exponential Decay of Suffering!*

JACQUELINE BECKER

Jacqueline Becker, Ph.D. is a clinical neuropsychologist, Assistant Professor of Medicine, and health services researcher in the Division of General Internal Medicine at the Icahn School of Medicine at Mount Sinai. She completed her doctoral training at Fordham University in New York, her residency at Harvard Medical School/Massachusetts General Hospital, and her clinical neuropsychology postdoctoral fellowship in the Department of Neurology at Northwell Health.

Her research focuses on cognition in the context of chronic medical conditions, and most recently in people with Long COVID and other infection-associated chronic conditions. Dr. Becker is MPI of NIH's RECOVER-Neuro, a multisite randomized controlled trial (RCT) to treat cognitive dysfunction post COVID-19. She is also PI of a NIH/NIMH RCT to treat cognitive impairment in people with Long COVID and comorbid depression, PI of an Alzheimer's Association/National Academy of Neuropsychology award investigating the neuropsychological effects of COVID-19 in older adults from underserved populations. In addition, she is co-investigator of various Long COVID initiatives, including an Agency for Healthcare Research and Quality (AHRQ)–sponsored project integrating primary and Long COVID care to improve outcomes for minoritized adults in New York City.

Finally, Dr. Becker has been an expert panelist and keynote speaker for SAMHSA's Policy to Action-Long COVID meetings for three consecutive years, a member of the National Academies of Science, Engineering, and Medicine's Committee on the Long-Term Health Effects of COVID-19 and Implications for the Social Security Administration, and she is Chair of the NIH/NINDS Cognitive Assessments CDE ME/CFS Working Group and Chair of the International Neuropsychological Society's NeuroCOVID special interest group.

JAIME SELTZER

Jaime Seltzer is MEAction's Scientific Director, a Biochemistry Research Affiliate at Stanford University, and a TIME 100 Health awardee recognized for her work on infection-associated chronic diseases ME/CFS and Long COVID.

She has served as a subject-matter expert for CDC, WHO, NIH, and Cochrane Review, integrating biological sciences, clinical, pedagogical and advocacy backgrounds. She has co-authored critical clinical guidelines with Mayo Clinic, led education initiatives, developed disease management guides for laypersons, working to transform ME/CFS clinical and research approaches through the power of patient-centered data. Seltzer lives with ME/CFS: experience guides her work.

MAYA DUSENBERY

Maya Dusenbery is a journalist, editor, and author of *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*.

Maya has been interviewed about gender bias in the medical system on *Fresh Air*, *Good Morning America*, and countless podcasts, and regularly gives talks on the subject to students, health care providers, and patient advocates. Her freelance writing has appeared in many publications including the *New York Times Magazine*, *Scientific American*, *The Atlantic*, *Mother Jones*, and *Cosmopolitan*.

A Minnesota native, she now lives in Portland, Oregon.

MICHAEL VANELZAKKER

Dr. Michael VanElzakker is a neuroimmunologist and neuroscientist whose research includes complex chronic illness following infection, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and post-acute sequelae of COVID-19 (PASC or Long COVID). These conditions are both often biologically subtle, despite their profound impact on patients' lives.

Dr. VanElzakker began his research career in neuroendocrinology, gaining extensive wet lab experience in biological sample collection, processing, and assays. His PhD training centered on neuroimaging and blood-based research in PTSD, while his interest in ME/CFS was fueled by a close friend's illness and ongoing personal engagement with patient experiences and literature.

Rather than joining an existing group, his postdoctoral fellowship involved establishing a neuroimaging lab for ME/CFS from the ground up. With the rise of Long COVID, his research on complex chronic illness has become even more urgent. He has a particular interest in improving research methodology to reduce variability across studies and improve pathogen detection.

Dr. VanElzakker is also co-founder of the nonprofit PolyBio Research Foundation and is active in scientific outreach, advocacy, and education.

REBECCA RYAN

Dr. Rebecca Ryan, BMBS (Hons), FRACP, is an Australian Gastroenterologist and Hepatologist specialising in the management of POTS, MCAS, hEDS, and Long COVID, with a distinctive focus on the Gut-Brain Axis.

Dr Ryan delivers care for complex cases through a holistic, science-driven approach-integrating genetics, diet, exercise, stress, and inflammation to address Functional Gastrointestinal Disorders.

She is recognised for multidisciplinary collaboration and her commitment to advancing understanding of gut-brain interactions in Tifecta patients and post-viral syndromes.

ROB WÜST

Dr. Rob Wüst is an assistant-professor at the Faculty of Behavioural and Movement Sciences at the Vrije Universiteit Amsterdam. His research group investigates skeletal and cardiac muscle metabolism and function.

His recent interests include skeletal muscle adaptations after bed rest, in collaboration with astronauts from ESA and NASA and after acute and chronic inflammation. Recent work focuses on skeletal muscle abnormalities and exercise responses in patients with diabetes and Long COVID, which has led to a lot of international media attention.

To better understand how muscle metabolism changes under different conditions, muscle biopsies from humans, mouse models, immunofluorescence and electron microscopy and various cellular and molecular techniques are used. The research is funded by ZonMw, and various European and American (patient) organisations for diabetes, Long COVID and ME/CFS.

RUHI SNYDER

Ruhi Snyder is an interdisciplinary researcher and systems scientist. For two decades, Ruhi studied sleep, shift work and circadian rhythms. In 2011, she initiated a decade-long pioneering self-case study “The Slow Violence of Shift Work”. This investigated the role of self-regulation, exercise, diet, nutrition, and shift schedules in mitigating shift workers’ skewed circadian rhythms. The study posed more questions than it answered, especially around the “fallacy of the individualism and individual responsibility” in a system that is antithetical to life, health, and wellbeing. It also took a deep dive into how society and systems view motherhood.

She is the founder of “ruhislleep” and “Naptor” - dedicated to advocacy and public education. She is also the host and the creator of Sleep and Society Podcast. Through the lens of biomedical sciences, the humanities, economics, and human rights, these platforms examine the science, nature, and importance of what it means to be human in our 24/7 society.

For the past four years she has been providing care to her loved one with very severe ME. Her current focus is on the care and treatment of severe to very severe MECFS and Long COVID.

SAMMIE MCFARLAND

Sammie McFarland is the founder of Long Covid Kids and Friends, the first global charity dedicated to supporting children and young people living with Long Covid. Inspired by her and her daughter's experience with the condition in 2020, she transformed personal adversity into a movement that now supports over 11,000 families worldwide.

Despite living with Long Covid herself, Sammie works alongside children and young people to ensure their voices shape research, policy, and healthcare. She has co-authored several research papers and contributed to international collaborations advancing understanding and support for paediatric Long Covid.

Her leadership has been recognised with the Self Management Resource of the Year Award from the Scottish Alliance (2022) and as a Coronation Champion by the Royal Voluntary Service (2023). Sammie has presented at national and international conferences, including the first International Meeting on Long Covid in Children in Rome, and provided written and oral evidence to the UK COVID-19 Inquiry.

She has contributed to expert groups including the NIHR Expert Group on Long Covid, the NHS Long Covid Task Force, and the WHO Expert Panel on Post-COVID Conditions, and continues to share lived experience with organisations including the WHO, the Rehabilitation Science Research Network for COVID, and the Clinical Post Covid Society.

TESS FALOR

Tess Falor, PhD, is the Founder and Chief Scientific Officer of Renegade Research. With an undergrad degree in Aerospace Engineering and a PhD in Earth and Planetary Science from UC Berkeley, she developed a strong foundation in systems thinking and innovation. At NASA's Jet Propulsion Laboratory, she helped take bold mission ideas, considered impossible to build by many, and make them reality. While in academia she built scientific instruments and analyzed data from Mars.

Her aspirations of leading space missions and becoming an astronaut were halted by complex, chronic illnesses. She left aerospace and launched the Remission Biome project. As a passionate advocate for transparency and collaboration in science, she integrates her technical expertise with lived experience pushing forward coordinated N-of-1 trials and community-driven protocols.

TODD E. DAVENPORT

Todd E. Davenport, PT, DPT, PhD, MPH, FAPTA, is Professor and Chair in the Department of Physical Therapy at University of the Pacific in Stockton, California.

He earned bachelor's degrees in psychology and exercise science (sports medicine) from Willamette University, Doctor of Physical Therapy from the University of Southern California, Master of Public Health from the University of California at Berkeley, and Doctor of Philosophy in Sport, Health, and Exercise Sciences from the University of Portsmouth.

Todd is a volunteer scientific advisor to the Workwell Foundation and Chair of Long Covid Physio. His primary research focus involves the systems-level physiology and clinical recognition of myalgic encephalomyelitis and ME-like conditions.

Dr. Davenport is the grateful recipient of several distinguished teaching, research, and service awards. He is designated as a Catherine Worthingham Fellow of the American Physical Therapy Association, which is that organization's highest membership honor.