



## Speaker Bios and Key Messages

### International Forum on COVID Rehabilitation Research

#### Keynote Speaker – Dr. Todd Davenport Back to the Future for Long COVID Research

10:30-11:15am



**Bio:** Dr. Todd Davenport is a Professor and Vice Chair in the Department of Physical Therapy at University of the Pacific in Stockton, California. He earned his bachelor's degrees in Psychology and Exercise Science from Willamette University (Salem, Oregon), Doctor of Physical Therapy degree from the University of Southern California (Los Angeles, California), and Master of Public Health degree from the University of California--Berkeley. Dr. Davenport is a scientific advisor to the Workwell

Foundation and education co-chair of Long Covid Physio. He is completing a Ph.D. by publication with the University of Portsmouth (U.K.), building on his 15 years in ME/CFS research.

#### Key messages from presentation:

- Epistemic humility – the need for patients, researchers, and clinicians to work closely together.
- Special considerations to investigate a disease that breaks many of the rules we thought we knew.
- Balancing the need for specificity (i.e., understanding pathophysiology of specific symptoms and the needs of special populations) with an appreciation for the big picture (i.e., integration across symptoms and systems).

#### Research and Evidence Session Part 1 – Profiling COVID-19 Rehabilitation Research across the Continuum of Care

11:25am-12:30pm



**Dr. Marina Wasilewski** – *Long COVID and Disrupted Biographies: A Qualitative Study of Canadians' Experiences*

**Bio:** Dr. Marina Wasilewski is a Scientist at St. John's Rehab Sunnybrook and an Assistant Professor with the Department of Occupational Science & Occupational Therapy and the Rehabilitation Sciences Institute at the University of Toronto. Dr. Wasilewski's program of research is focused on using social and peer support strategies to optimize the health and well-being of patients and families as they journey across the continuum of care. Dr. Wasilewski applies a patient- and family-centered lens to

her work and uses co-design approaches to engage patients, families, and care providers in health research and service improvement.



**Key messages from presentation:**

- People with long COVID (PWLC) and their caregivers experience disruptions in their personal identities/biographies as a result of the lasting and detrimental impacts of long COVID
- Disruptions entail needing to manage, shift, and adapt daily activities and roles to enable long COVID care and recovery
- Disrupted biographies are underpinned by substantial loss and grief (e.g. loss of independence, loss of identity/personhood, and loss of meaning and purpose in life)



**Dr. Fiona Jones** – *The Listen trial- creating positive rehabilitation connections in the face of uncertainty*

**Bio:** Dr. Fiona Jones is Professor of Rehabilitation Research at St George’s University of London. She has led multiple studies to evaluate self-management approaches within healthcare teams including stroke, acute brain injury and major trauma. In 2013 Fiona set up a social enterprise ‘Bridges Self-management’, which is an approach to self-management co-delivered with people living with complex long-term conditions and used by more than 800 acute and community rehabilitation teams across the UK. Fiona

has expertise in mixed methods and participatory research, co-production, and improvement/implementation science. Her focus is on co-design and working in partnership with patients, families, and clinical teams to develop and implement self-management training, interventions, and resources. In 2021 Fiona successfully gained a £1.1 million NIHR grant for the LISTEN project (Long COVID Personalised Self-management support- co-design and Evaluation). In 2017, Fiona was awarded an MBE for services to Rehabilitation.

**Key messages from presentation:**

- Key learning from a large NIHR funded study currently running in the UK which codesigned and is now evaluating a new personalised support package for people living with long COVID
- Lessons about the key skills and support required by rehabilitation practitioners to personalise and build trust in each rehabilitation interaction
- How to build a ‘collective evidence base’ combining knowledge and expertise from people with long COVID and rehabilitation practitioners.



**Dr. Doug Gross** – *Social Engagement and Employment among People with Long COVID*

**Bio:** Dr. Douglas Gross is a Professor in the Department of Physical Therapy at the University of Alberta. Doug’s scholarship focuses on preventing work disability. This includes evaluating the effectiveness of rehabilitation interventions, investigating determinants of work ability and return-to-work, as well as developing and testing outcome measures and clinical assessment strategies. He has published over 150 articles and contributed to funded research projects totaling over \$25 million, including projects funded by the Canadian Institutes of Health Research, WorkSafeBC,



Alberta Labour and Immigration, among others. He is a Killam Laureate, McCalla Professor, and Editor-in-Chief of the Journal of Occupational Rehabilitation.

**Key messages from presentation:**

- From the perspective of those with lived experience, symptoms of Long COVID have a fluctuating, rollercoaster-like impact on health, function, and social engagement including employment.
- When navigating Long COVID services within the public health and workers' compensation systems, participants encounter barriers to access around stigma, appointment logistics, testing and 'normal' results, financial precarity, and affordability of services.
- Long COVID rehabilitation services should provide multi-disciplinary, flexible, patient-centred approaches that avoid symptom exacerbation while collaborating closely with workplaces to identify suitable accommodated duties.



**Dr. Kelly O'Brien** – *Conceptualizing the episodic nature of disability among adults living with Long COVID: Findings from an international community-engaged qualitative study*

**Bio:** Dr. Kelly O'Brien is an Associate Professor in the Department of Physical Therapy with cross-appointments to the Institute of Health Policy Management and Evaluation (IHPME) and Rehabilitation Sciences Institute (RSI) at the University of Toronto. Kelly is a Co-Director of the Rehabilitation Science Research Network for COVID in the Temerty Faculty of Medicine at the University of Toronto, and Co-Director of Disability and

Rehabilitation with Long COVID Physio. Kelly is a physical therapist and clinical epidemiologist; she holds a Canada Research Chair (Tier 2) in Episodic Disability and Rehabilitation. Her research is focused on episodic disability and rehabilitation among people living with longstanding episodic conditions.

**Key messages from presentation:**

- Disability living with Long COVID was described by participants in this study as episodic, characterised by fluctuations in presence and severity of health related challenges, which may be unpredictable in nature, occurring both within the day, and over the long-term of months and years living with Long COVID.
- Disability was characterized as multi-dimensional, characterized by physical, cognitive and mental-emotional health challenges, difficulties carrying out day-to-day activities, uncertainty about future health, and challenges to social inclusion which may be influenced by intrinsic (personal attributes, living strategies) and extrinsic (support, stigma) contextual factors over time.
- Uncertainty was a key component of the episodic disability experience as it intersected with the episodic nature of disability, characterised as unpredictability of episodes, their length, severity and triggers, and process of long-term trajectory, which had implications on broader health including the ability to return to employment.



**Dr. Angela Cheung** – CANCOV, RECLAIM, and Long COVID Web

**Bio:** Dr. Angela Cheung is a Professor of Medicine and the KY and Betty Ho Chair of Integrative Medicine at the University of Toronto. She is an Internal Medicine specialist and senior scientist at the University Health Network and holds a Tier 1 Canada Research Chair in Musculoskeletal and Postmenopausal Health. She obtained her MD from Johns Hopkins University and completed her training in General Internal Medicine at the University of Toronto and Beth Israel Deaconess Hospital in Boston, and her Ph.D. from Harvard University.

**Key messages from presentation:**

- Update from CANCOV – a Canadian cohort study of people diagnosed with COVID including clinical characteristics and long-term outcomes.
- Introducing Long COVID Web – a national research network to advance research and clinical care of individuals affected by Long COVID.

## Keynote Session #2 – Best Practices for Community-Engaged Approaches to COVID-19 Rehabilitation Research

1:15-2:15pm

**Aim of Session:** To build research capacity learning from persons with lived experiences about their experiences and perspectives engaging in COVID rehabilitation research, and to discuss recommendations, considerations and best practices for engaging in COVID rehabilitation research.



**Melissa Eagan**

**Bio:** Melissa Egan is the National Lead, Episodic Disabilities at *Realize*. She has worked in the field of health education for over 20 years as a presenter and facilitator, developing and delivering trainings to diverse audiences across Canada. She has experience using community-engaged research evidence to inform policy and believes this is vital in creating lasting practice change and effective KTE tools. Melissa brings a commitment to inclusion, diversity, equity, and accessibility to her work. Melissa holds a BA and a BEd and has recently completed a Masters of Education at OISE – University of Toronto.

**Key messages:**

- Increased accessibility supports for employees and defining Long COVID as a disability/disabling condition
- Use of clear language around Long COVID as an episodic disability
- Work towards addressing the internalized ableism in organizations by developing policy and supports for episodic disability and those living with Long COVID
- Include accessibility/disability in DEI work efforts and priorities



**Susie Goulding**

**Bio:** Susie Goulding from Ontario, Canada, became a Long Hauler after contracting Covid-19 in March of 2020. Realising there was a lack of information available to Covid-19 survivors and a need for a non-judgmental and safe online platform for Long Haulers to congregate and connect for support she founded the Covid Long-Haulers Support Group Canada. Her advocacy work, research involvement and media presence provincially and nationally has connected her internationally with other groups and organizations.



**Alyssa Minor**

**Bio:** In January 2021, Alyssa was infected with COVID-19 at work. She now lives with Long COVID, POTS, and Myalgic Encephalomyelitis. Alyssa has since supported advocacy projects as her health allows. She is an executive board member of Long COVID Physio; member of the Trainee Development & Medical Education working group with ICanCME Research Network; and former member of the AHS Post-Covid Taskforce. Before becoming ill, Alyssa worked in adult acute care, spanning many service areas, but specifically in Neurology, Neurosurgery, and Neurorehab from 2015-2021. She is originally from Sarnia, Ontario.

**Key messages:**

- The field of research aims to drive positive change, but the way it currently operates falls far short. For best outcomes, the research community must partner with and platform what is already happening out of disabled communities - in this case, out of the Long COVID community. Research improves and advances when lived experience leads.
- Existing knowledge and expertise in the field of post-infectious/post-viral illness (ie. ME/CFS) must inform all Long COVID research or else it risks redundancy.
- Functional improvement is a bonus and not the focus of safe Long COVID rehabilitation. Symptom stabilization is the main goal. Most Long COVID rehab are completely missing this distinction and are applying traditional, progressive rehab approaches which are often harmful in this population.



**Mark Rutledge**

**Bio:** A few weeks after Mark Rutledge, 49, contracted Covid in June 2021, he began to feel debilitating pain. In a few days, the pain worsened and had spread, becoming so excruciating that he was unable to sleep or function. Aside from a prescription for pain medication, visits to his family doctor, an internal medicine specialist and a neurologist over the past few months have brought him no closer to a diagnosis or meaningful treatment.

**Key messages:**

- Empathy, deep listening, and compassion are essential in community-engaged research.
- I want to be engaged in a way that reflects my values.
- Being involved in community-based research provides an opportunity to make meaningful contributions to Long COVID science and advocacy.



**Anisha Sekar**

**Bio:** Anisha Sekar is a member of the Patient-Led Research Collaborative and has been living with Long COVID and associated conditions since 2020. Prior to being disabled by Long COVID, she was a financial technology entrepreneur with over a decade of experience in product management and user experience. She holds a degree in computer science with a focus on statistics from Brown University.

**Key messages:**

- Patients need to be involved throughout the research process.
- An enthusiastic team goes a long way.
- Meaningful, transparent communication helps keep patients and communities engaged.



**Hannah Wei**

**Bio:** Hannah Wei is a co-founder at the Patient-Led Research Collaborative, an international organization of Long-COVID patient-researchers and advocates at the forefront of the Long COVID patient-led movement. Hannah's background is in computer science and leading data-driven products for the technology industry. Before the pandemic, Hannah was running field research in frontier communities of West Africa and Southeast Asia for product innovation teams at Fortune 500 tech companies. She became a Long COVID patient after getting



infected on an airplane in March 2020. Since then, she has dedicated her efforts to running projects PLRC and innovating on the patient-led research model.

**Key messages:**

- Treat patients as whole people and experts of our lived experiences.
- Invite patients early into the research process as key stakeholders; this builds trust and surfaces relevant priorities.
- Co-designing research with patients breaks silos and facilitates effective outcomes.



**Harriet Wright**

**Bio:** Harriet Wright is a Master of Public Health candidate with a focus in Infectious Diseases and Microbiology at the University of Pittsburgh. She obtained a BSc in Health Promotion from Dalhousie University and has lived experience with working in emergency COVID response and as a Long-COVID caregiver. Research interests include public health emergency response, health equity, and Long-COVID rehabilitation and care.

**Key messages:**

- Including multiple disciplines that share same collective goal.
  - Working *with* community members is one of the most beneficial ways to gain understanding of lived experiences. Avoid working *for* a community.
- Sound research methods to effectively study the topic with the population.



**Kiera McDuff (Moderator)**

**Bio:** Kiera is a physiotherapist and is the Program Coordinator for the Rehabilitation Research Network for COVID. She is also the Research Coordinator for the Episodic Disability and Rehabilitation Research Lab. She has a clinical background in ICU and acute care. She is a passionate advocate for the role of physiotherapists in promoting health and well-being of people across the continuum of care.



## Research Evidence Session Part 2 – Profiling COVID-19 Rehabilitation Research across the Continuum of Care – Rehabilitation Approaches

2:30-3:30pm



**Dr. Stacey Skoretz** – *Unravelling the pandemic complexities of swallowing and communication following invasive ventilation*

**Bio:** Dr. Stacey Skoretz is an Assistant Professor and Director of the Swallowing Innovations Lab (Si-Lab) at the University of British Columbia. Her aim is to enhance health outcomes for critical illness survivors following dysphagia through her research on aerodigestive tract biomechanics, biomarkers, clinical practice patterns, patient perspectives, and guideline development for those following

supportive ventilation. Si-Lab is funded by the Canadian Institutes of Health Research, Canada Foundation for Innovation, and BC Knowledge and Development Fund. In 2020, Dr. Skoretz received the prestigious Michael Smith Foundation for Health Research Scholar Award – an award for exceptional, early career researchers.

### Key messages from presentation:

- Impaired airway protection during swallowing is associated with more complex and severe otolaryngological, respiratory, and physical manifestations following severe COVID-19.
- Risk stratification along with proactive and standardized multi-disciplinary assessments of swallowing and communication following invasive ventilation improves patient health outcomes.
- The roles of speech-language pathologists are still poorly understood across the healthcare system – how we navigate future care delivery for swallowing and communication can be informed through the lived experiences and resiliency of patients and front-line clinicians.



**Dr. Michelle Kho** – *COVID and Post ICU frailty and quality of life*

**Bio:** Dr. Michelle Kho is an Associate Professor in the School of Rehabilitation Science. Her research focuses on effective and creative methods of physiotherapy such as in-bed cycling, to help patients stay as strong as possible while they are in the intensive care unit (ICU). She is also a clinician-scientist who cares for patients at St. Joseph's Healthcare ICU. Michelle holds a Tier 2 Canada Research Chair in Critical Care Rehabilitation and Knowledge Translation. As our population ages and the demand for critical care increases, Michelle's rehabilitation research may help improve function and quality of life in

ICU survivors.





**Jessica DeMars** – *BREATHE: A mixed-methods evaluation of a virtual self-management program for people living with Long COVID*

**Bio:** Jessica graduated from the University of Alberta in 1998 with a Bachelor of Science Degree in Physical Therapy (with distinction). She practices cardiorespiratory physiotherapy in a private practice setting. With the onset of the COVID-19 pandemic, Jessica quickly recognized the implications of Long COVID

on the population and has pivoted to creating programming that delivers the best available evidence for both those living with Long COVID and health care professionals working with this population. She has become an ally and an advocate, taking on the role of Co-Director of Advocacy for the Long COVID Physio executive board. She has developed several courses and webinars on Long COVID to assist with knowledge translation to allied health professionals.

**Key messages from presentation:**

- Virtual, multi-disciplinary, group-based self-management is a feasible, safe/tolerable and acceptable format for people living with Long COVID
- A virtual, group-based format may improve self-efficacy to manage chronic illness and reduce social isolation
- We may need to rethink what we consider rehabilitation, and how we deliver it to people living with Long COVID



**Dr. Simon Décary** – *Integrating Rehabilitation in Care Models for Long COVID: third update of a living systematic review*

**Bio:** Dr. Simon Décary is assistant professor of rehabilitation at University of Sherbrooke in Québec. He is involved in Long COVID research since April 2020 having received national grants to study rehabilitation care models. This work led to co-authoring care model recommendations for the World Health Organization Living Guidelines. In Quebec, he is a scientific consultant for the Ministry of Health to support the

implementation of a 20M\$ provincial network of post-COVID clinics. In March 2023, he became the co-lead for Long COVID Web with Dr. Angela Cheung, a 20M\$ investment from CIHR to coordinate Long COVID research across Canada.

**Key messages from presentation:**

- Three years of international evidence propose that rehabilitation professionals are key to achieve integrated care models for Long COVID.
- While initial rehabilitation interventions focus on safe approaches such as pacing, emerging adapted specialty approaches are developing within care models. Future work will standardize rehabilitation outcome measures and practices for this population.



**Dr. Jill Cameron** - *Co-Designing Person and Family Centered Care for Long COVID*

**Bio:** Dr. Jill Cameron is Professor and Vice Chair Research in the Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute in the Temerty Faculty of Medicine at the University of Toronto. Her primary research interest is to understand the experiences and needs of family members who assume the role of caregiver for individuals with

disability. Dr. Cameron aims to enhance models of health care delivery such that caregivers receive timely and relevant support across the care continuum. Ultimately, her research aims to enhance the health and wellbeing of people affected by disability and their caregivers.

**Key messages from presentation:**

- Consider the complexity of meeting the needs of diverse patient and family populations
- Consider other models of care to integrate patient and family support across the illness trajectory