

ME Awareness Day 2024

Webinar Event

Saturday, 11 May 2024

Start at 12:00 pm



Program

Speaker	Time	Length	Topic
Opening			
Justin Hogg	12:00 pm	10 min	Welcome. Acknowledgement to country.
Part 1: Understanding ME			
Dr Stanley Du Preez		20 min	Understanding ME: Diagnosis and Misconceptions Stanley will discuss the implications of the misconceptions and stigma surrounding the diagnosis of myalgic encephalomyelitis (ME), emphasising the crucial distinctions between ME and Chronic Fatigue Syndrome (CFS). The presentation will explore the diagnostic principles outlined in the International Case Consensus Primer for Medical Practitioners authored by Carruthers et al. in 2012. Overall, this presentation aims to enhance understanding regarding the diagnosis of ME as a biological illness and foster more effective patient care for people living with ME.

<p>Breanna Weigel</p>		<p>20 min</p>	<p>How ME and Long COVID patient experiences can guide health policy in Australia Breanna Weigel & Rebecca Haddock</p> <p>People with Myalgic Encephalomyelitis (ME) and people with Long COVID experience debilitating symptoms and limitations to their ability to participate in typical activities of daily, working, and social life. Consequently, multidisciplinary care and support is paramount to enable people living with these illnesses to achieve their best possible quality of life and functioning.</p> <p>However, many people with ME and people with Long COVID in Australia face difficulty in accessing necessary services or are deemed ineligible for support.</p> <p>This is largely attributable to a lack of recognition and representation of patients' lived illness experiences at the federal health policy level. Health policy issues across three key areas, including "Identification", "Recognition", and "Consumer Engagement", must be addressed to improve the accessibility and appropriateness of care and support services for Australians living with ME or Long COVID.</p> <p>Specifically, reforms to Australian health policies should ensure: 1) improved public health monitoring of ME and Long COVID; 2) recognition of the disabling nature of these illnesses; 3) collection of patient-reported experience data among these cohorts nationally; and 4) co-production of services with consumers.</p> <p>These recommendations must be prioritised to maximise health outcomes for all ME and Long COVID patients in Australia.</p> <p>These findings have been published as a Health Policy Issues Brief developed in collaboration with the Deeble Institute for Health Policy Research. This publication is entitled "How patient experiences can guide the development of Long COVID health policy" and is accessible via: https://doi.org/10.25916/b246-r560.</p>
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<p>Etianne Martini Sasso</p>		<p>20 min</p>	<p>TRPM3: a potential pharmacotherapeutic target in ME and Long COVID</p> <p>Etianne Martini Sasso, Katsuhiko Muraki, Natalie Eaton-Fitch, Peter Smith, Andrew Jeremijenko, Paul Griffin and Sonya Marshall-Gradisnik.</p> <p>The scientific literature suggested an overlap between Long COVID and Myalgic Encephalomyelitis (ME), mainly due to similar persistent and prolonged symptoms.</p> <p>ME is linked to Transient Receptor Potential Melastatin 3 (TRPM3) ion channel dysfunction and evidence demonstrated in vitro effects of naltrexone hydrochloride (NTX) and potential therapeutic benefits of low-dose naltrexone (LDN).</p> <p>Using the gold standard technique to investigate ion channels, NCNED researchers reported the first laboratory evidence that Long COVID patients have TRPM3 dysfunction, an impaired function already widely proven in NK cells from ME patients. Impaired TRPM3 activity indicates faulty ion mobilisation which consequently impedes adequate cell function resulting in chronic symptoms.</p> <p>Recently, our novel investigation identified that TRPM3 activity is also restored in NK cells from Long COVID patients after in vitro treatment with NTX. Importantly, restoring TRPM3 calcium influx in cells allows cells to function appropriately.</p>
<p>Dr Kiran Thapaliya, PhD</p>		<p>20 min</p>	<p>Brain Changes in ME and Long COVID: A Multimodal MRI Investigation</p> <p>Myalgic encephalomyelitis (ME) and long COVID patients show overlapping symptoms of fatigue, neurocognitive impairment, unrefreshing sleep, physical function, and pain. Studies show that 13-58% of long COVID patients met ME criteria and exhibited symptoms such as neurocognitive impairment.</p> <p>The neurocognitive impairment experienced by ME and long COVID patients could be due to structural and functional changes in the brain regions. This presentation will demonstrate NCNED key findings on brain impairment in ME and long COVID patients using multimodal magnetic resonance imaging (MRI) and will also demonstrate how brain</p>



			impairment is associated with severity measures in ME and long COVID patients.
Break, Q&A		10 min	

Part 2: How to care for ME			
Victoria Kalmykova	1:40 pm	15 min	<p>Place for healing - Accessing Psychological support</p> <p>It's not unusual for ME patients to report negative experiences when reaching out to psychological support.</p> <p>The lack of knowledge and understanding of ME among mental health professionals often leads to misdiagnosis and offering inappropriate, sometimes even harmful treatment.</p> <p>Seeing a psychologist or other mental health professional can provide a space for healing through therapeutic relationships that foster safety, acknowledgment, and space for exploration of life challenges and many difficult feelings that ME patients might experience in the process of finding out about their diagnosis and coming to terms with it.</p>
Dr Pete Smith		15 min	<p>Naltrexone – how, when, and why</p> <p>Dr Pete will share his expert knowledge on nonallergic rhinitis and Low Dose Naltrexone (LDN).</p>
Julie Hughes		15 min	<p>Occupational therapy and exhaustion management for ME</p> <p>Julie will share her expert Occupational Therapy knowledge on exhaustion management for people with ME.</p>
Alex Beevers Nicole Roudenko		30 min	<p>How myalgic encephalomyelitis effects activity participation and the services and support occupational therapists can provide to individuals with the condition.</p> <p>Nicole and Alex are presenting their research findings on how myalgic encephalomyelitis impacts activity participation and discussing the services occupational therapists can offer to those affected by the condition.</p>

Raeya Bognar		15 min	<p>Balancing Acts: Navigating Activity Management with ME</p> <p>Raeya will share her expert knowledge on pacing. She will cover details of the following topics.</p> <ul style="list-style-type: none"> • Heart rate monitoring • Heart Rate Variability (HRV) monitoring • Step count monitoring • Vagus nerve stimulation • Workwell Foundation
Break, Q & A		10 min	

Part 3: Lived Experience			
Nicole Roudenko Alex Sandra Chris Mim Bronwyn Carla Gerard	15:20	90 min	Lived Experience Forum Occupational Therapist, Nicole, will chair Lived Experience Forum. She will ask questions to Lived Experience Panel about their valuable insights into their lives and thoughts on living with ME.
Justin Hogg		20 min	Q & A
Closing			
Justin Hogg	17:20	10 min	Closing Speech

Presenters

Presenter	Bio
Host	
<p>Justin Hogg</p> 	<p>Justin Hogg is a governance professional that has worked across a diverse range of industries that has included overseeing teams responsible for billion-dollar business ventures through to working with charities to further their goals. For the past 7 years, Justin has established Right Source, an organisation focussed on providing governance and strategic support to the not-for-profit sector.</p> <p>He is currently a Director of Myalgic Encephalomyelitis Group Australia who's aim is to support those with Myalgic Encephalomyelitis and ultimately establish specialty clinics to provide holistic services for those with ME.</p> <p>As part of Right Source, Justin holds Company Secretary positions with various not-for-profit organisations.</p>
Part 1: Understanding ME	
<p>Dr Stanley Du Preez</p> 	<p>Stanley is the volunteer Community Coordinator for Myalgic Encephalomyelitis (ME) Group Australia.</p> <p>His commitment to patients extends into his work as a resident medical officer with Gold Coast Hospital and Health Service and as a PhD candidate with the National Centre for Neuroimmunology and Emerging Diseases investigating ME. He is also involved in educating future doctors as a clinical lecturer with Griffith University School of Medicine.</p> <p>Stanley is passionate about improving outcomes for people with ME through clinical medicine, research, education, and advocacy. His goal is to become a specialist in immunology and engage other healthcare providers to support ME patients through safe and effective evidence-based care.</p>

Breanna Weigel



Breanna Weigel is a fourth-year PhD candidate at the National Centre for Neuroimmunology and Emerging Diseases, Griffith University.

Breanna's current PhD studies investigate the patient experiences of people with ME/CFS and people with Long COVID in Australia to guide health policy reforms and improve care pathways for patients.

Etienne Martini Sasso



Etienne Martini Sasso is a third-year PhD candidate at the National Centre for Neuroimmunology and Emerging Diseases (NCNED), Griffith University.

E. Martini Sasso holds a Master's in Medical Science, and postgraduate studies in public health and forensic toxicology and her work experiences include areas of pathology laboratory. Her current PhD project focuses on investigating Transient Receptor Potential Melastatin 3 (TRPM3) ion channels function in the pathomechanism of Myalgic Encephalomyelitis (ME) and Long COVID, as well as the potential benefit of Naltrexone (in vitro) and Low dose Naltrexone (LDN) in restoring TRPM3 function and its impacts on the quality of life in patients suffering these illnesses.

Dr Kiran Thapaliya, PhD



Dr. Kiran Thapaliya is working as a Research Fellow in the area of Neuroimaging at the National Centre for Neuroimmunology and Emerging Diseases (NCNED), Griffith University.

His research focuses on investigating brain impairment in ME/CFS and long COVID patients using multi-modal MRI and developing new neuroimaging methods to identify biomarkers for ME/CFS and long COVID.

Part 2: How to care for ME

Victoria Kalmykova



Victoria is a Clinical Psychologist who believes in the power of therapy to transform lives and she is committed to providing a safe and supportive environment for her clients.

Victoria's approach is collaborative, gentle and client-centered. She has 20 years of experience of supporting adults, young people, couples and families and specialises in a variety of psychotherapeutic interventions, with a focus on the brain-body connection, mindfulness-based approaches, and trauma- and attachment-based approaches.

Dr Peter Smith



Professor Pete Smith is a leading allergist in Australia. Pete commenced his medical studies at the University of Tasmania and went on to specialise in paediatrics in Adelaide, before completing his PhD in molecular immunology with Flinders University.

He has worked as an allergy specialist at the Great Ormond Street Hospital for Children in London, and was a senior lecturer at the Institute of Child Health, University College London.

In 2002, Pete set up Queensland Allergy Services in Southport, on the Gold Coast. Here he provides patients the highest level of quality medical care in the diagnosis and treatment of allergies.

Pete is an active member of the Australasian Society of Clinical Immunology & Allergy, and a regular expert commentator in the media.

He is a member of the World Allergy Organization, the American Academy of Allergy, Asthma & Immunology, and the European Academy of Clinical Immunology & Allergy.

He sits on several national and international advisory boards and is involved in medical education, frequently speaking at national and international meetings and conferences.

Prof Pete Smith consults Monday to Thursday.

"Allergy is an exciting profession. If we identify and treat causes, we can dramatically improve peoples quality of life"

Julie Hughes



Julie Hughes has been an occupational therapist for over thirty years. She has a long standing interest in ME/CFS and has worked in this area as both a clinician and researcher. She studied in Brisbane but then lived and worked in the UK for many years before returning to live in QLD in 2017 where she commenced as a Lecturer in Occupational therapy on the Australian Catholic University (ACU) campus in Brisbane. She is the occupational therapy advisor for MEGA.

Alex Beevers



Alex is an Occupational Therapist working for Queensland Health in Acute Mental Health. She graduated with honors, having completed a study on the implications of severe myalgic encephalomyelitis on quality of life and activity participation. Alex is passionate about increasing awareness of myalgic encephalomyelitis within the healthcare systems, aiming to improve services and outcomes for individuals and families impacted by the condition.

Nicole Roudenko



Nicole has a background in Immunology. She worked in diagnostic pathology and research as a senior scientist at the Royal Brisbane and Women’s Hospital, the Gold Coast University Hospital and Mater Public Hospital. Nicole specialised in the immunophenotyping of hematopoietic malignancies, HIV and immunodeficiencies. After 20 years in the science field Nicole had a desire to connect more with the people she was impacting. She retrained in occupational therapy and graduated with first class honours in 2023 and currently works for OccAssess Pty Ltd. Her honours research into the lived experience of severe ME prompted her desire to improve healthcare services in Australia for people living with ME. Nicole has a passion to destigmatise ME through education and training of the condition for individuals, their families, other healthcare professionals and the broader community. Nicole believes every person with ME has the right to a timely diagnosis and the support to enable a life with meaning and purpose. Nicole’s family, husband, three children and fluffy white cat – PhilCat, bring her the most joy in life. Otherwise, any outdoor activities, cooking and discovering new people/places is how Nicole likes to spend her spare time.

Raeya Bognar



Raeya is an Exercise Physiologist who has a background in Pilates, Yoga, Meditation & Health Coaching and uses these skills with her holistic treatment approach. Raeya comes with personal experience of complex invisible illnesses from her teens and early adulthood that drove her goals and passions towards helping others.

She knows what it's like to have these illnesses, and how much the right help and right team can make such a difference. Raeya enjoys working with paediatrics and neurodiversity most, and has a special interest in chronic fatigue syndromes, dysautonomia and hypermobility spectrum disorders.

Raeya enjoys outside time, exercising, reading and audiobooks, and socialising with loved ones, oh, and dogs too. To recharge, Raeya likes to have quiet time to herself, sometimes exercising, sometimes reading, sometimes outside time. She's also now kept on her toes with her little girl who generally keeps her busy but smiling.

Part 3: Lived Experience Forum

Sandra

An ME patient, sudden onset after a virulent virus in November 2012.

Previously, an active, fit and professional 48 year old, I became instantly so ill, I was never able to return to full time work. After 6 months convalescence, tried to get back on the horse and attempted part time work of 12 hours per week for a couple of years but ultimately became unable to work at all.

Successfully applied for Disability Support Pension and no longer able to afford my life, moved from Sydney to the Central Coast in 2015.

With proper diagnosis and understanding that my illness is Myalgic Encephalomyelitis, not post viral fatigue or chronic fatigue syndrome.

Through education, I have been able to stop the decline in health by avoiding Post Exertional Malaise PEM, stabilise and maintain a baseline of moderate ME. This requires being approximately 85% homebound and living life small in my local area.

I do enjoy riding my mobility scooter around the waterways and use some of my spoon/energy allocation towards advocacy. I want to help others avoid the traps I fell into and hope to see medical education rolled out and support for patients be built.'

Chris

Chris is a Senior Industry Fellow with the Bankwest Curtin Economics Centre, a position he holds in conjunction with being Research and Policy Development Leader at the Western Australian Council of Social Service (WACOSS). Chris brings to BCEC a wealth of experience in industry, government and community engagement and his appointment provides the Centre with extensive networks at both state and federal level, and will continue to develop BCEC's stakeholder engagement and collaboration activities.

Chris is the Chair of the Green Institute Board and sits on various advisory committees including the National Consumer Roundtable on Energy, the State Emergency Management Recovery Sub-committee, the National COSS Network Policy advisory committee, the Alcohol Advertising Review Board and Social Reinvestment WA among others.

Prior to his current roles, Chris has been a Senior Policy Advisor to federal politicians and worked in communications at a number of WA universities. Chris has a background in the social sciences and humanities, including science communications and multi-media production, and is commencing a PhD looking at social investment models, early intervention and the role of community-controlled services in reducing the number of children in state care.

Mim

My study and work commitments came to a halt when my ME became severe. Now my days are spent in bed managing my healthcare and NDIS supports.

	<p>On my best days I enjoy making art and having bedside visitors. I am someone who likes dreaming and I value the collective power of community.</p>
Bronwyn	<p>I'm 48yo & was diagnosed with ME/CFS when 26yo.</p> <p>Over the next 5 years I got back to about 95% function but in 2009 after a couple of very active years I relapsed. I had to give away my work as a brewer in 2013 & have been severe since 2016. 95% bed bound & in long slow decline.</p> <p>With NDIS support for last 3yrs I can now leave the house, on my own, 1-2 times/month for a few hrs.</p>
Carla	TBC
Gerard	TBC



**Myalgic
Encephalomyelitis**
Group Australia

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