# ME Awareness Day 2025
# Webinar Event
# Lived Experience Forum

Saturday, 31 May 2025
Start at 3:00 pm (Qld time)

## Program

| Forum | Time | Length | Topic |
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| **Opening** | | | |
| **Nicole Roudenko**<br>• MEGA – Volunteer team member<br>• Queensland Health - Occupational Therapist (Honours), Bachelor of Science | 03:00 pm | 20 min | **Welcome.**<br>**Acknowledgement to country.**<br>**Housekeeping**<br>**Introduction to Panel**<br>**Ice Breaker** |
| **Lived Experience Forum** | | | |
| **Q & A with Dr Todd Davenport PhD** | 03:20 pm | 40 min | **Panelists ask questions about Post Exertional Neuroimmune Exhaustion (PENE) with Special Guest, Dr Todd Davenport PhD.** |
| **Panelists share their Lived Experience** | 4:00 pm | 55 min | **Focus Topic: Post Exertional Neuroimmune Exhaustion (PENE)** |
| **Closing** | | | |
| **Nicole Roudenko** | 4:55 pm | 5 min | **Closing** |

# Participants

| **Participants** | **Bio** |
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| **Moderator** | |
| **Nicole Roudenko**<br> | 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 Queensland Health.<br>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. |
| **Special Guest** | |
| **Dr Todd Davenport PhD**<br> | Dr. Todd Davenport is a tenured Professor and Chair of the Doctor of Physical Therapy program at the University of the Pacific. A graduate from USC with further advanced qualifications and training from UC Berkeley, and the University of Portsmouth, he leads teams across, physical therapy, public health, and complex chronic illnesses like ME with an interest in PEM/Neuroimmune Exhaustion and preventative health care. His work continues to drive innovation in clinical education, interprofessional collaboration, and advocacy.<br>In addition to research on PEM Dr Davenport serves as an editorial lead across the Cardiopulmonary Physical Therapy Journal, Journal of Orthopaedic and Sports Physical Therapy, and Pacific Journal of Health. He is also active in community health and youth programs. |

| **Panelists** | |
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| **Sandra**<br> | Sandra has a background in IT, Complementary Therapies and Vocational Training. Life was vital before ME developed in 2012 after a virus. An attempt to return to work faltered, social activities and hobbies fell away.<br>With no education of PENE and appropriate pacing, her health worsened. It took five years to a clear diagnosis then living within her energy envelope became her goal. She slowly stabilised but has remained in the moderate spectrum.<br>Understanding the history of ME and following the biological science (with preference for the International Consensus Criteria) are very important to her.<br>Sandra is passionate about learning from mistakes of the past and forging new care pathways. She is excited by MEGA's vision for a multi disciplinary clinic and supports the organisation as energy levels allow. |
| **Margaret**<br>**"Margie"**<br> | Margie lived an active and healthy life until recent years.<br>A registered nurse, Margie is passionate about her family and caring for others.<br>She has battled three life-threatening illnesses—Encephalitis, Severe ITP, and Severe Legionnaires' Disease—but considers living with Myalgic Encephalomyelitis (ME) her greatest challenge.<br>Unlike her previous conditions, ME is poorly understood and lacks treatment, requiring Margie to research and educate others.<br>Living with ME has required major adjustments. Margie is unable to work and has difficulty with most tasks. She is very grateful for her husband's significant support.<br>Involvement in a support group has provided helpful information, connection, friendship and a sense of purpose.<br>Despite limited energy and the constant threat of Post-Exertional Malaise, Margie continues to advocate for ME awareness. |

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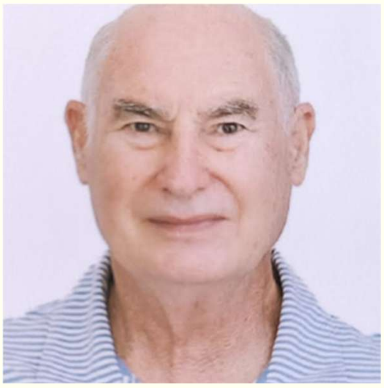
| **Howard**<br> | Howard is a retired professional who contracted ME at the age of 55 in 2003. I spent the next 3 years in bed, looked after by my elderly mother. After many years, I was approved for the Disability Support Pension, and then I transitioned to the Age Pension at 65, allowing me to travel overseas freely.<br>With the return of my health, I embarked on a new chapter of my life. I spent seven fulfilling years in Thailand, got married, and led a vibrant life running a Creche in Chiang Mai. However, my health took a turn, and I had to return to Australia in 2024.<br>Rejoining the Bayside ME support group was a turning point. It not only helped me but also allowed me to help other sufferers by sharing my journey, providing a sense of reassurance and support.<br>My dedication to the cause led me to write reference material for the group and advocate for the establishment of a dedicated ME Clinic in Melbourne, a crucial step towards better support and understanding for ME patients. |
| **Tracey**<br> | Tracey has lived with ME for 19 years but was only diagnosed in 2022 and spent the next 2 years house and bed-bound with severe ME. Over the past 9 months Tracey has managed to find some treatments that have given her small but significant improvements in capacity. She now prioritises spending time with her family, learning to paint with watercolour, and advocating for people living with ME, mainly via her blog 'Not Just Tired' on Facebook.<br>Prior to having severe ME, Tracey worked in leadership roles at TAFE NSW, loved long walks in nature, yoga, tennis, netball, and swimming, as well as reading and weeding the garden. |
| **Adrienne**<br> | Adrienne comes from a family profoundly impacted by myalgic encephalomyelitis (ME), particularly on my maternal side. Severity ranges from relatives who are 100% bedbound—living in silence and darkness, unable to speak or eat unassisted—to those who can work but must strictly manage activity to avoid post-exertional neuroimmune exhaustion.<br>Our lives have been transformed by the research and guidance of the WorkWell Foundation, whose science-based approach has helped us manage our illness, halt further decline. I'm honoured to be part of this panel and especially grateful to Dr. Todd Davenport for his critical work. |

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| **Melanie**<br> | Melanie Foulkes is an Autistic counsellor, educator and creative who has lived with mild to moderate myalgic encephalomyelitis since 2018.<br>Though currently on leave from private practice, Melanie remains committed to advocating for a future where all therapists are equipped to support individuals with ME and related conditions. She is particularly interested in the impacts of PENE/PEM on mental health.<br>Melanie is grateful to rest and pace on Malanbarra Yidinji Country in Far North Queensland where she enjoys picturesque views of Bunda Djarruga Murrgu (Walsh's Pyramid) from her window. Currently mostly house/bed-bound and a wheelchair user, she holds hope for a day when she can go hiking in the rainforest again. |

**Myalgic Encephalomyelitis**
Group Australia

REGISTERED CHARITY
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