

# National Centre for Neuroimmunology and Emerging Diseases



## December 2023

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## Our Mission

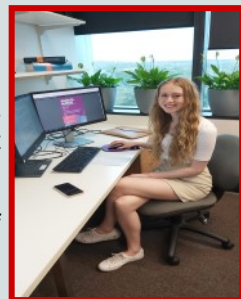
The National Centre for Neuroimmunology and Emerging Diseases (NCNED) is a research team located at Griffith University on the Gold Coast. Led by Professor Sonya Marshall-Gradisnik, the team has a focus on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

Our mission is to translate research findings into preventative medicine, social and clinical care and public health outcomes. By collaborating with local, national and international research institutes, we aim to create sustained improvements in health and health care for not only those affected by ME/CFS but also other immune disorders.



## PUBLICATIONS

Third-year NCNED PhD student, Breanna Weigel, in collaboration with the Deeble Institute for Health Policy Research, published a seminal paper discussing the impact of long COVID on both the Australian healthcare system and Australians living with the condition. The Health Policy Issues Brief is entitled "How patient experiences can guide the development of long COVID health policy". This is the first publication to highlight the role of patient experiences in the development of long COVID health policies in Australia. The Issues Brief also explores the opportunities to address the Australian healthcare system's response to and management of people with long COVID. The Issues Brief has been published on the Australian Healthcare and Hospitals Association's website and is accessible via the following link: <https://ahha.asn.au/.../deeble-issues-brief-no-53-patient...>



## APPRECIATION AND ACKNOWLEDGEMENT OF GRANTING ORGANISATIONS, AGENCIES, BENEFACTORS AND FUNDRAISERS

Thank you to the Stafford Fox Medical Research Foundation, McCusker Charitable Foundation, Mr Douglas Stutt, the Mason Foundation, Ian and Talei Stewart, the Alison Hunter Memorial Foundation, the Blake Beckett Foundation, Mr Adrian Flack, the Buxton Foundation, the Henty Community, Change for ME Charity, ME/CFS/FM Support Association QLD Inc., the ACT ME/CFS Society, ME/CFS and Lyme Association of WA Inc., MERUK, and the National Health and Medical Research Council.

## 2023 RESEARCH, INNOVATION & DISCOVERY (RID) CONFERENCE



The 2023 International ME/CFS and long COVID RID Conference took place on 9 and 10 November at Mantra on Salt Beach, Kingscliff, NSW. The Conference was a huge success and extremely well attended with over 100 participants including speakers from the USA, Canada, Japan, New Zealand, Abu Dhabi and representation from nearly every state and territory in Australia. Participants included researchers, clinical health professionals, health educa-



tors, PhD students and ME/CFS patients from around the country. Invited speakers provided knowledgeable presentations on the overlapping pathology of ME/CFS and long COVID; Ion Channel Physiology Application in ME/CFS and long COVID; MRI Imaging: Neurological Disturbances in ME/CFS and long COVID; Looking to the Future: Innovation and Diagnostics, Clinical Trials and Treatment Outlooks; and Patient Challenges, Impacts and Advocacy. Researchers provided conference attendees with up to date data and an overview of recent discoveries in their field of expertise. We thank all those who attended and hope to be able to provide some of the presentations on our Facebook site for those who were unable to attend. We were heartened by the number of ME/CFS patients who were able to join us to listen to the concentrated research that is being undertaken in the hope of improving their lives.



## CONGRATULATIONS

Congratulations to Ms Rebekah Maksoud and NCNED researchers for their research paper being selected as one of the Editor's Choices for the Journal of Healthcare. This research paper is entitled "Systematic Review of Sleep Characteristics in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome". The paper is available to view via the following link: <https://www.mdpi.com/2227-9032/9/5/568>



Congratulations to PhD student Breanna Weigel who gained First Place for her 3 minute PhD presentation at Griffith University's School of Pharmacy and Medical Science Higher Degree by Research End of Year Symposium for 2023. Breanna presented on 'Illness presentation and impact over time in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Post COVID-19 Condition'.

NCNED researcher Ms Etienne Martini Sasso recently received the Best Early Career Researcher Award at the 3rd ME/CFS and long COVID International Conference 2023: RID - Research, Innovation and Discovery that was held on 9 and 10 November. Congratulations to Etienne on this wonderful achievement. Thank you so much to The Stafford Fox Medical Research Foundation for all of their support.

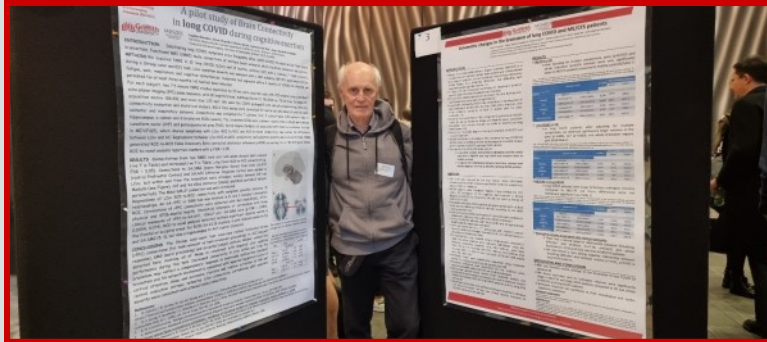


Congratulations to NCNED researcher Stanley Du Preez who was recently awarded a Second Place prize for his HDR Publication at Griffith University's School of Pharmacy and Medical Science Higher Degree by Research End of Year Symposium for 2023. The title of his publication was 'Altered TRMP7-Dependent Calcium Influx in Natural Killer Cells of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients'.



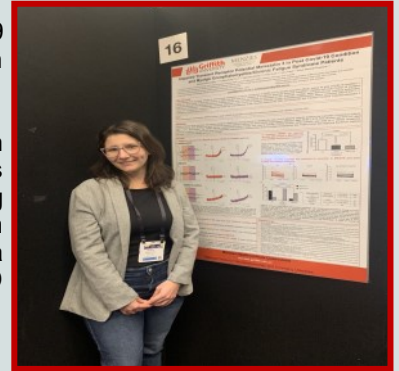
## CONFERENCES

Dr Leighton Barnden and NCNED researcher Maira Inderyas recently presented NCNED MRI research findings at the National Imaging Facility Scientific Symposium 2023 that was held at the University of Melbourne. As NCNED are the national leaders in MRI ME/CFS and long COVID investigations, this Conference provided NCNED researchers an opportunity to showcase their research findings and to explore potential opportunities to apply further medical imaging techniques for future investigations. The National Imaging Facility Scientific Conference highlighted Australia's health challenges, disease burden, neurological biomarkers and neuroimaging in Alzheimer's, epilepsy, traumatic brain injury, other neurological diseases and the use of AI for imaging. Dr Barnden presented two of NCNED's recent studies - altered brain connectivity in long COVID during cognitive exertion and brainstem volume changes in ME/CFS and long COVID patients.



NCNED researchers attended the 3rd Australasian COVID-19 Conference in Brisbane on 27 and 28 July which featured both national and international experts.

The NCNED is honoured to contribute to the growing evidence on the overlap between long COVID and ME/CFS. PhD candidate Ms Breanna Weigel delivered a presentation on the impacts of long COVID on quality of life and the overlap in clinical presentation with ME/CFS. PhD Candidate Ms Etienne Sasso presented a poster on impaired TRPM3 ion channel function in long COVID and ME/CFS.



## ME/CFS MEDIA COVERAGE

- NCNED Director, Professor Sonya Marshall-Gradisnik, was interviewed by SBS discussing the links between ME/CFS and long COVID. You may read the interview via the link: [SBS Interview November 27](#)
- The Capital Health Network, together with two NCNED investigators, Professor Sonya Marshall-Gradisnik and Dr Natalie Eaton-Fitch, invited primary health care providers to a webinar on ME/CFS on 5 October 2023. This educational activity outlined the symptoms and diagnostic features of ME/CFS, the latest research, evidence surrounding Low Dose Naltrexone and the role of health providers in the care of people with ME/CFS.
- The Australian Doctor interviewed NCNED Research Leader and Director, Professor Sonya Marshall-Gradisnik. In this article she highlights the need for new clinical guidelines for ME/CFS and the removal of outdated interventions CBT/GET. Professor Marshall-Gradisnik also highlights that the NCNED scientific discoveries are the first to identify at the cell level the mechanism for calcium impairment via a specific group of receptors in ME/CFS. For further information on this important discovery, please access the link: [https://www.ausdoc.com.au/news/a-key-to-a-faulty-lock-why-aussie-researchers-are-excited-about-naltrexone-for-cfs/?fbclid=IwAR3UhwGgQ8NNnTU7\\_kLkIRt59qU242YRceEK0OeLGgOdZwKNe0vqYIDg4VY](https://www.ausdoc.com.au/news/a-key-to-a-faulty-lock-why-aussie-researchers-are-excited-about-naltrexone-for-cfs/?fbclid=IwAR3UhwGgQ8NNnTU7_kLkIRt59qU242YRceEK0OeLGgOdZwKNe0vqYIDg4VY)
- ABC journalist, Evan Young, interviewed ME/CFS patients to highlight the impact and toll of the daily challenges that ME/CFS patients face. NCNED would like to express their appreciation to Evan Young for this article. [Why myalgic encephalomyelitis/chronic fatigue syndrome is nothing like everyday tiredness - ABC News](#)

**THANK YOU TO ALL OUR SUPPORTERS**