

National Centre for Neuroimmunology and Emerging Diseases

March 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.

SAVE THE DATE

The 3rd ME/CFS and long COVID International Conference will be held on the Gold Coast on **15 and 16 November**. Please check our website and Facebook page for details shortly.

NCNED ANNOUNCES 2023 CLINICAL TRIAL

NCNED Researchers, in collaboration with Dr James Jarman and Professor Eric Visser of St John of God Hospital, will embark on a clinical trial to investigate the treatment of long COVID using Low Dose Naltrexone (LDN) made possible by the generous grant provided by Mineral Resources. This 12 week Phase 1 Clinical Trial is expected to commence in the coming months.

LOCAL MP VISITS NCNED

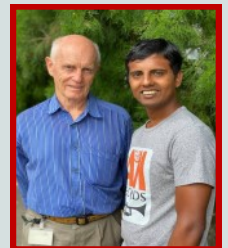


The NCNED recently welcomed Mr [Sam O'Connor MP](#) to our research facilities at Griffith University on the Gold Coast. NCNED researchers Dr Natalie Eaton-Fitch and Dr Kiran Thapaliya provided Mr O'Connor with an update on the latest ME/CFS and long COVID research while facilitating a tour of our research laboratories. We are grateful for all of the support Mr O'Connor has shown not only to our research, but also the ME/CFS community.

PUBLICATIONS

Thapaliya K, Marshall-Gradisnik S, Barth M, Eaton-Fitch N, Barnden L - Brainstem Volume Changes in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and long COVID Patients, *Frontiers in Neuroscience*, 17, 2023.

<https://www.frontiersin.org/articles/10.3389/fnins.2023.1125208/full?fbclid=IwAR1pqRs-Cy1cpi7jcoGtzgq5Kd3SZgcJChsRdn-Qdote9ihOmmS6S2l3o80>



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, Mr and Mrs 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.

ME/CFS MEDIA COVERAGE

Extensive TV, radio, newspaper and internet coverage including ABC, Channel 10, Channel 9, Channel 7 and Sky News Live featured nationally and internationally on 14-16 March following NCNED's recent publication:

<https://www.frontiersin.org/articles/10.3389/fnins.2023.1125208/full?fbclid=IwAR1pgRs-Cy1cpi7jcoGtzqg5Kd3SZgcJChsRdn-Qdote9ihOmmS6S2l3o80>

Lead author Dr Kiran Thapaliya and the NCNED team were able to highlight ground-breaking results from MRI imaging examining overlapping neurological, autonomic, pain and post-exertional systems in ME/CFS and long COVID patients.

American Neurological Association recently interviewed NCNED researchers Professor Sonya Marshall-Gradisnik and Dr Kiran Thapaliya for a Podcast regarding ME/CFS in the Age of long COVID. You may listen to the Podcast using the link: https://myana.org/education/podcast/ana-investigates-myalgic-encephalomyelitis-age-long-covid?fbclid=IwAR3oZZX9NxdnI6vKbjqxXdikWIEpki_APDj5Z-Z-e7abtcf4UtBVfEDsE

CONGRATULATIONS

Breanna Weigel, one of 5 researchers chosen nationally for an AHHA internship, has recently concluded three weeks in Canberra engaging patients in the development of health policies. Breanna has also had the opportunity to meet with health bodies and attend the public hearing for the ongoing long COVID and repeated COVID-19 infections inquiry.

Breanna was featured in the March newsletter for the Deeble Institute for Health Policy Research. In the article, Breanna shares her experience of working with the Deeble Institute and Australian Healthcare and Hospitals Association to develop a Health Policy Issues Brief about the role of patient engagement in health policy for Australians living with Post COVID-19 Condition. The article can be read via the link below:

<https://ahha.asn.au/deeble-institute-scholar-highlight-2?fbclid=IwAR36fr3xyVnuugHQ37KMYq-hZUSlutSsOo6mWGJdoaSYV3nD7Wlhj4wqXAI>



CALLING FOR NATIONAL PARTICIPATION

Brisbane, Queensland

NCNED is inviting patients formally diagnosed with ME/CFS and healthy controls (aged between 18 to 65 years old) to participate in continuing research using magnetic resonance imaging (MRI) of the brain. Interested participants will be asked to undergo MRI scanning with an advanced ultra-high field MRI scanner for 45 minutes (7 Tesla) followed by an additional 30 minutes (3 Tesla). The MRI Scanner is located at the University of Queensland, St Lucia so participants need to be able to travel to Brisbane to complete the scan. In addition to this, participants will complete 7 questionnaires for evaluation of fatigue symptoms, life quality, etc; wear a blood pressure cuff on their arm for 24 hours; and wear an activity monitor on their wrist for 3-4 days to record physical activity, heart rate and sleep/wake information. Please see inclusion criteria on our Facebook page.

SE Queensland, Northern New South Wales

NCNED is inviting patients formally diagnosed with ME/CFS and healthy volunteers (aged between 18 and 65) to participate in an upcoming investigation to continue NCNED research in the area of calcium channels, signalling and pharmaceutical intervention. Immunological dysfunction is a consistent feature of ME/CFS and many patients report onset following an infection. Further, there is significant overlap with chronic fatigue (CF) and post-viral syndromes (PVS). Transient receptor potential (TRP) ion channels have been implicated in the pathomechanism of ME/CFS and recent data suggests this channel provides a potential therapeutic target and may benefit ME/CFS patients. This project aims to investigate the role of ion channel dysfunction in ME/CFS and PVS patients and potential diagnostic and therapeutic drugs. The study involves a donation of 84ml of blood and completion of an online questionnaire. Please see inclusion criteria on our Facebook page.

Australia Wide

While TRP ion channel dysfunction has been reported in ME/CFS patients, researchers continue to learn more about the structure and genes encoding for TRP proteins. NCNED is recruiting participants around Australia who have been formally diagnosed with ME/CFS and healthy controls (reporting no health concerns). Eligible participants must be able to travel to pathology collection centres including Queensland pathology, Sullivan Nicolaidis Pathology, QML Pathology, Australian Clinical Laboratories, Melbourne Pathology and Clinipath Pathology to donate 14ml of blood. The inclusion criteria are as follows: (i) aged 18 to 65 years; (ii) non-smoker; (iii) no current diagnosis of other chronic illness (e.g., autoimmune, cancer, cardiovascular disease, or diabetes); and (iv) not pregnant or breastfeeding. Sample donation appointments are ongoing and will be arranged in stages according to location.

People with ME/CFS have a lower quality of life (QoL) when compared with healthy individuals and other chronic illnesses. However, illness presentation and QoL are yet to be investigated over time. Further, there is a significant overlap between ME/CFS and Post Viral Fatigue Syndromes (PVS), like long COVID. Therefore, this project aims to follow people with ME/CFS and long COVID over time to observe changes in symptom presentation and QoL. Further, we aim to make comparisons with other multi-systemic illnesses, such as Fibromyalgia (FM), Multiple Sclerosis (MS), and Rheumatoid Arthritis (RA). Inclusion criteria includes: (i) aged 18 to 65 years; (ii) non-smoker; (iii) history of malignancy within past 5 years, (iv) not diagnosed with an autoimmune disease, (v) not pregnant or breastfeeding. This study involves completing three online questionnaires every six months. Please see our website for more details.

If you are interested in being part of these studies or would like more information, please contact NCNED on 07 56789283 or email ncned@griffith.edu.au.