

# GOLD COAST



# UNREST



## You are invited to: **A NIGHT OF UNREST.**

**What?:** We are screening UNREST, an award winning movie from the Sundance film festival and hosting expert guest speakers to discuss research and supporting patients.



*"Twenty-eight year-old Jennifer Brea is working on her PhD at Harvard and soon to be engaged to the love of her life when she gets a mysterious fever that leaves her bedridden and looking for answers. Disbelieved by doctors and determined to live, she turns her camera on herself and her community, a hidden world of millions confined to their homes and bedrooms by ME, commonly called chronic fatigue syndrome." See [Trailer](#)*

**When:** Thursday 12th October, 6:30pm to 9:30pm  
**Where:** The Conference Hall, Southport Church of Christ, 1 Griffith Way (Cnr Olsen Ave)  
**Tickets:** Seats limited, bookings online essential.

Tickets: [bit.ly/unrestgc](https://bit.ly/unrestgc)

## PROGRAM:

- Light refreshments on arrival
- Screening of UNREST, - recently sold out at the Melbourne Film Festival
- Guest speaker Prof. Don Staines, explains the latest CFS/ME break through discoveries from the National Centre of Neuroimmunology and Emerging Diseases. See short article below. (Photo is of Prof Don Staines, centre with Prof. Sonya Marshall-Gradisnik and the NCNED team)
- A panel of lead Gold Coast health practitioners discuss "how we can support patients now".



## Who is affected by Chronic Fatigue Syndrome/ME?

**It is estimated that a quarter of a million Australians of all ages, including children, suffer from CFS/ME ie about 1.2% of the population worldwide.**

Of these people, about 60,000 people are bed or housebound, unable to work or participate in society and reliant on carers. Despite the readily measurable physiological abnormalities, many patients suffer from disbelief, stigma and hence a lack of adequate support from friends, family and governmental agencies.

The USA Centre for Disease Control recently, updated its guidelines for ME/CFS in July 2017, based on an extensive study of the biomedical and physiological research and its own multicentre study. Australian Guidelines remain based on the work of the controversial PACE authors and their colleagues.

## What attendees can expect to learn:

- UNREST, Sundance film: the hidden patient experience, i.e. what happens when the patients leave the clinic and go home, to experience post-exertional neuroimmune exhaustion, and 'crash'. The worldwide impact of this disease, a complex story of hope and resilience.
- Donald Staines MBBS, MPH, FAFPHM, FAFOEM: The latest research advancements and understanding of the pathomechanisms from the National Centre Neuroimmune and Emerging Diseases (NCNED), Griffith University.
- Dr Georgina Gibson MBBS, On the Park General Practice: Measuring orthostatic intolerance (most commonly Postural Orthostatic Tachycardia Syndrome (POTS)), using the 10 minute NASA Lean test, and how to use this information to help patients.
- Mark Barrett B.App.Sc, Physiologic: The use of heart rate monitors and Metabolic testing to help patients, optimise the balance between rest and activity, and for those well enough to add in more activity, to exercise in a way that doesn't make them worse.
- Professor Peter Smith. PROF BMedSci, MBBS, FRACP, Queensland Allergy Services: Allergy, immunity, sensory sensitivities, how serious are these problems and what treatments may help.
- Julie Albrecht. B.Sc. Grad. Dip. Nut. Diet. Cert. Sports. Nut. A.P.D Julie Albrecht and Associates: Eliminating food, chemical and environmental intolerances from the ME/CFS world.
- Dr Dianne Shanely MA, BA PhD, Director of the Psychology Clinic, Griffith University: How, psychological support and advice may help patients cope, with their new identity, post diagnosis.

*Speakers introduced by MC - Adjunct Professor Chris Guiding Arts (Hons), M Business Administration, PhD. Griffith University, Business School. For program updates: please join our Mailings list, (link also available on the ticket booking website.)*

## Short article by Professor Sonya Marshall-Gradisnik and Professor Donald Staines from NCNED:

### ***Recent discoveries in ME/CFS***

*The National Centre for Neuroimmunology and Emerging Diseases (NCNED), Griffith University, has made significant discoveries in the pathomechanism of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). This debilitating illness presents as a multi-system condition affecting almost all physiological systems. It has been difficult to diagnose because of the unknown pathomechanism and the absence of a diagnostic test. Currently the illness is diagnosed by an*

international case definition (International Consensus Criteria or ICC) which is mostly a symptom based definition.

NCNED researchers have identified changes in gene structures called single nucleotide polymorphisms or SNPs, in critical calcium (Ca<sub>2+</sub>) ion channels called transient receptor potential ion channels (TRPs). These changes result in deficits in Ca<sub>2+</sub> signalling, a vital component of cell function. Calcium signalling influences a wide array of cellular activity, such as gene regulation, biochemical function and other second messenger functions.

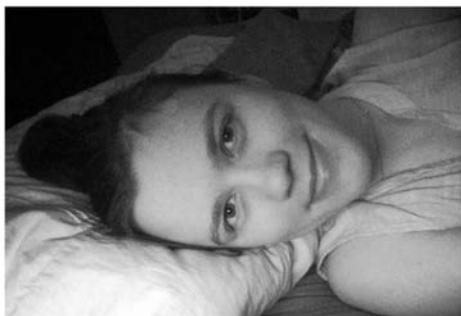
Consequently multiple body systems are affected and likely range from impaired cardiovascular function (such as postural orthostatic tachycardia syndrome or POTS), immune function (such as natural killer cell function), and neurological function. Specifically changes affecting the TRP melastatin family (TRPM) have been shown by NCNED researchers to exist in ME/CFS patients.

NCNED researchers are moving swiftly to investigate the potential application of these discoveries in a diagnostic test and to investigate potential treatments.

### Brought to you by: Young People with ME/CFS on the GC

Ketra and Josh, are two young Gold Coast, ME/CFS sufferers. Josh is 22, with a business degree that he is too ill to use it despite being very motivated. Ketra is 32 and was sailing around the world as a professional sailor/chef before becoming ill, she now lives in Aged Care. They are passionate about spreading understanding and practical support knowledge about this disease.

Thank you for your time. We hope to see you at UNREST.



<http://phngc.com.au/Events/2896.aspx>

Primary Health Network - Healthy Gold Coast