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**From:** ME\_CFS  
**Sent:** Thursday, 24 October 2019 1:49 PM  
**To:** [REDACTED]; 'a.lloyd@unsw.edu.au';  
**Cc:** 'ME\_CFS (ME\_CFS@nhmrc.gov.au)'; [REDACTED]  
**Subject:** CEO Response to ME/CFS Advisory Committee Report [SEC=OFFICIAL]  
**Attachments:** Open letter CEO response Oct2019.pdf

Dear ME/CFS Advisory Committee

I am pleased to advise you that the CEO has now published her response to the *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Advisory Committee Report to the NHMRC Chief Executive Officer - An Open Letter to Stakeholders* (attached) on NHMRC's website at: <https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer>.

Additionally, you may be pleased to know of the recent opening of a Targeted Call for Research to better understand the causes and improve the diagnosis of ME/CFS. The call opened yesterday (23 October 2019) and further details are available at: <https://nhmrc.govcms.gov.au/funding/find-funding/targeted-call-research-mecfs>.

Congratulations on a tremendous effort and thank you once again for your tireless commitment to this work.

Kind Regards

[REDACTED]

On Behalf of the ME/CFS Project Team

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[REDACTED]  
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Research Translation  
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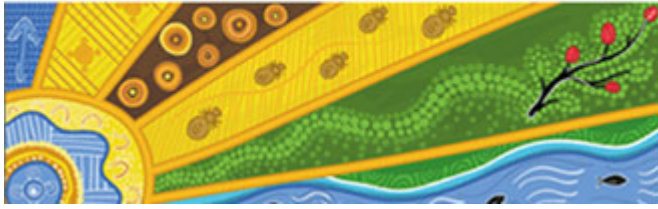
[nhmrc.gov.au](http://nhmrc.gov.au)



BUILDING  
A HEALTHY  
AUSTRALIA

I acknowledge the Traditional Custodians of the lands around Australia and pay my respects to Elders past and Present.

The National Health and Medical Research Council acknowledges the Traditional Custodians and pay our respects to their Elders both past and present.





Dear Stakeholders,

I write to you in response to the *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Advisory Committee's Report to the NHMRC Chief Executive Officer* (the report).

In April 2019, I was pleased to receive the report with the committee's recommendations about research and clinical guidance for ME/CFS in Australia. I would like to thank the committee for its work on this important topic and respond to each of the report's recommendations.

Taking into consideration the report's **Strategic focus one: Research quantity and capacity building** and **Strategic focus two: Improve health services research**, the Australian Government Medical Research Future Fund (Targeted Health System and Community Organisation Research Program) has committed funding toward health economics research. This research will focus on the impacts and costs associated with ME/CFS, whilst enabling better data collection for this complex condition. I understand outcomes for this grant were announced on the Department of Health website on 20 September 2019.

In addition, a Targeted Call for Research (TCR) will be conducted, administered through NHMRC's Medical Research Endowment Account, to the value of \$3 million. The scope of the TCR was informed by the report and will consider the pathophysiology of the condition. The TCR will be announced in late 2019.

As the TCR and MRFF activities are being carried out over the next three to four years, NHMRC will maintain a watching brief on national and international ME/CFS research. After such time, I will consider whether other funding initiatives are appropriate.

In response to the report's **Strategic focus three: Developing health advice**, I have decided that NHMRC should develop clinical guidance on ME/CFS. The report was explicit in this recommendation and reflected the strong feedback provided during public consultation that the current Australian advice, published by the Royal Australasian College of Physicians in 2002, needs to be updated and replaced. We also need to identify a funding source to develop the guidance. It will be important to work collaboratively with health care providers and those with ME/CFS, to ensure new guidance will address the clinical needs of ME/CFS patients and will be effectively distributed to, and implemented by, clinicians.

**Additional committee recommendations:**

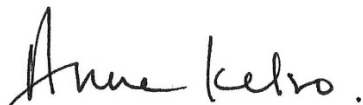
- **Develop Australian research capacity through international collaboration:** NHMRC will continue to monitor international research efforts and how they might interact with Australian research. I will also consider collaborative opportunities for future research funding activities.
- **Establish an Australian collaborative biobank:** I have been informed of recent funding provided by the Mason Foundation, which I understand will contribute \$1 million to support a partnership between La Trobe University, Emerge Australia and the Australian Red Cross Blood Service to establish the first Australian Patient Registry and Biobank for ME/CFS.
- **Raise with the Australian Institute of Health and Welfare (AIHW) collection of prevalence data and burden of disease reporting:** to address this recommendation, I will inform the AIHW Chief Executive Officer of this work and this recommendation.

The committee has also informed me about the reported exclusion of some ME/CFS patients in accessing supportive services such as the National Disability Insurance Scheme (NDIS) and the Disability Support Pension (DSP). I will make sure the Minister for the NDIS and Minister for Government Services, the Hon Stuart Robert MP is aware of this concern.

To obtain a copy of the committees report and its recommendations, I encourage you to visit our website at: <https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer>.

I look forward to seeing the progress of all of these activities over the next few years.

Yours sincerely,

A handwritten signature in black ink that reads "Anne Kelso." The signature is written in a cursive, flowing style.

**Professor Anne Kelso AO**  
Chief Executive Officer

18 October 2019