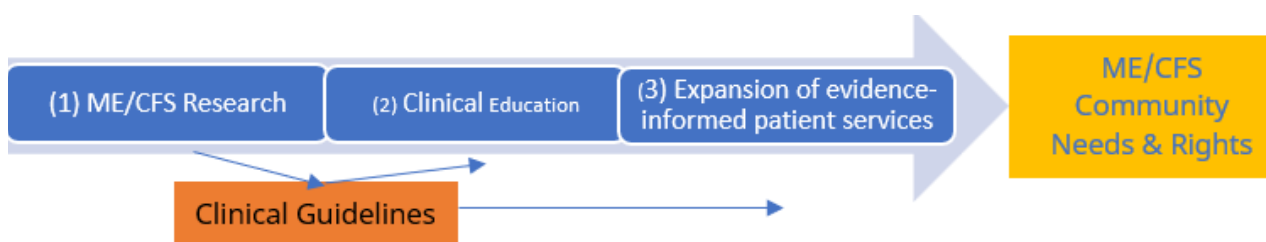


# Outcomes of Parliamentary Friends of ME/CFS Meeting

Addressing the needs and rights of Australians living with ME/CFS

18 November 2024

On 18 November 2024, national ME/CFS organisations came together at the ME/CFS Parliamentary Friends 2024 meeting at Australian Parliament House. The purpose of the meeting was to highlight the needs of the Australian ME/CFS community and the investment needed to address their needs in research, clinical education and increased patient services, underpinned by updated clinical guidelines.



Joined by parliamentarians, clinicians, researchers and the patient and carer community, **Anne Wilson, CEO of Emerge Australia**, introduced the meeting:

*"The voices of the 250,000 Australians living with ME/CFS can no longer be ignored. It is the right of every Australian living with ME/CFS to equitably access best-practice health care and essential supports. No longer can their needs be overlooked".*

## ME/CFS Clinical Guidelines

**The Honourable Mark Butler MP, Minister for Health and Aged Care**, officially opened the event. Anne Wilson thanked the Minister for his leadership in awarding \$1.13 million earlier in 2024 to the National Health and Medical Research Council (NHMRC) to develop new ME/CFS Clinical Guidelines.

**Mr Alan Singh, Executive Director, Research Quality and Advice at NHMRC**, provided an update on the guidelines' progress. Mr Singh confirmed that people with a lived experience of ME/CFS would be recruited to guide development of the guidelines.

*"These evidence-based guidelines will make a profound difference in the early diagnosis and safe management of the condition, based on the latest scientific understanding."*



## Patient Supports

Expert and insightful contributions of lived experience were provided by **Megan & Angus** and **Nicola & Bruce**, and video presentations from **Carla, ME Advocacy Network Australia**, and **Penelope McMillan, ME/CFS Australia spokesperson**. These advocates spoke about the realities of living with ME/CFS and policy changes needed for equitable access to:

- Disability and NDIS supports
- Financial and health sector supports (also highlighted by Dr Mike Freeland)
- Increasing access to allied health services through an increase in the number of MBS-subsidised consultations each year for people with complex chronic conditions and comorbidities
- Increasing the rate of subsidy so people living in poverty can afford much needed multidisciplinary care.

## ME/CFS Research

**Professor Paul Fisher, Chair of Emerge Australia's Medical and Scientific Advisory Committee**, called for greater investment in research to advance our understanding of ME/CFS and identify much-needed diagnostic biomarkers and proven treatment options. This was supported by the **Member for Macarthur, Dr Mike Freeland**, a strong advocate and ally of people living with ME/CFS closed the meeting. **Dr Freeland** emphasised the need for more research, particularly following the COVID pandemic.

## Clinical Education

**Dr Richard Schloeffel, Emerge Australia's retiring Medical Director**, highlighted the need for clinical education, not only when Australia's clinical guidelines are updated, but in the interim period whilst they are developed (up-to three years).

## Closing Commentary

**Friends of ME/CFS Co-Chair, Senator Jordon Steele-John**, apologised on behalf of the parliament for the neglect people with ME/CFS have experienced and strongly encouraged everyone to use their vote to influence the next election:

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*"Use [your] power on election day.  
Let your MPs know that whether or not they are filled with the urgency that is required will determine how you vote."*

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The **Member for Macarthur, Dr Mike Freeland**, closed the meeting.

Emerge Australia thanked **Peta Lange, Chief Counsel, Public Affairs Ogilvy PR ANZ**, for her expert facilitation of the meeting.

## Outcomes

The meeting highlighted the need for the ME/CFS community to be able to access the care, recognition, and support it deserves.

A post-meeting reflection of Australia's national ME/CFS organisations led to their pledge to work together to keep the momentum going during the 2025 federal election year. They gave an undertaking to continue to advocate for investment in a targeted Australian ME/CFS research plan and for the right of every Australian living with ME/CFS to equitably access:

- Evidence-based, best-practice health care and expanded subsidised patient services provided by educated, knowledgeable clinicians.
- Disability and income supports.