Parliamentary Friends of ME/CFS Launch Speech

I too acknowledge the traditional owners of the lands on which we meet and pay my respect to elders' past, present, emerging and to those in attendance today.

A very warm welcome to all our members of parliament and their advisors, members of our ME/CFS community whether here or online, members of the clinical fraternity, departmental representatives and invited guests. I particularly give special thanks to **Senator Jordan Steele-John and the Member for Calwell Maria Vamvakinou** for stepping forward to be Co-Chairs of the ME/CFS Parliamentary Friends Group. Thank you on behalf of us all.

Emerge Australia believes that today marks the beginning of a new era of working with all stakeholders and government, providing an opportunity for the ME/CFS sector to unite and focus on the critical work before us, to ensure that 'people with ME/CFS stop being left out'.

As CEO of the national patient organisation that delivers clinical education, patient support, biomedical research and advocacy for policy change, I welcome the opportunity to actively participate in this ME/CFS Parliamentary Friends Group and to harness its support to bring about much needed change.

As you all know:

- Approximately 250,000 Australians are living with or impacted by ME/CFS.
- 75 per cent are women and 25 per cent are housebound or bedbound.
- The estimated cost to the Australian economy of ME/CFS is $14.5 billion annually.
- Research indicates 70% of this estimate was due to loss of income, 24% due to direct personal out of pocket costs and 6% incurred as a cost to government and the health care system.

It has been predicted there will be more than 400,000 people developing Long COVID with the same impacts on patients and the community **as ME/CFS.** Whilst there are overlaps and similarities in symptoms, the impact of these post inflammatory diseases that lead to disability and an inability for patients to get on with their lives **must be addressed**.

ME/CFS is a complex, debilitating, multisystem disease. For a majority of patients, ME/CFS develops after contracting a viral or bacterial infection. Formerly healthy, thriving active achievers, **people** with ME/CFS live with a range of debilitating symptoms including post-exertional malaise, cognitive impairment, reduced energy and an inability to function at pre-illness levels.

It is not uncommon to hear patients with severe ME/CFS describe their lives as 'a living death'.

The burden of disease for ME/CFS is significant because the disease is so disabling and prevalent. People living with ME/CFS have just as poor or poorer employment, social and physical health outcomes as many other diseases.

For a person with ME/CFS, every aspect of life is impacted by their symptoms. Even those who are moderately unwell are often socially isolated, unable to work and often require assistance with activities of daily living. This has significant implications for the Australian economy and for the individual, with many ME/CFS patients and their carers living below the poverty line. Despite the severity and prevalence of ME/CFS, the lack of biomedical understanding of the disease has contributed to an entrenched misunderstanding and disbelief of the disease and patients by medical practitioners.

To reduce the impact of this burden, a number of systems and policies need to change. This change must bring proper recognition, research and support to the large cohort of people with ME/CFS. Emerge Australia has identified the following priority actions to increase support for people living with ME/CFS, and post-infection disease:

Our first is GP Education

We need to educate doctors to diagnose ME/CFS and provide evidence-based support to patients. Evidence continues to indicate that people with ME/CFS are dismissed by many health practitioners. Patients experience stigma that impacts their health and well-being and undermines prevention, early diagnosis, management and improved health outcomes. There is no designated specialty in ME/CFS, so diagnosis and management usually take place in primary care. Doctors, nurses and allied health practitioners need to be supported by information, education and tools to deliver early diagnosis and effective management.

Our second is Clinical Guidelines

ME/CFS Clinical Guidelines need to be funded and the time is NOW – funding clinical guidelines is the domain of Government - **please**! Yet calls from patients, clinicians and researchers continue to fall on deaf Government ears. Australia's outdated and redundant clinical guidelines developed in 2002 fail to keep our community safe and fail to reflect scientific advances in the pathology of ME/CFS and place Australia well behind other countries including Canada, UK, US, Netherlands, Finland, Norway and New Zealand among others. **The lived experience of a quarter of a million people impacted by ME/CFS, and their hard-working clinical teams are hindered by the ever-present hurdles resulting from a lack of direction.**

Our third is Optimal Patient Referral Pathways

As with other disease areas, the patient needs to be at the centre of their care decisions. We need Optimal Patient Referral pathways to be developed linking **primary care** to the **for-purpose community sector** where patients are able to be supported by nursing and allied health professionals. Much can be achieved utilising specialised multi-disciplinary Telehealth Services and to that end I gratefully acknowledge the modest federal government support that my organisation receives.

Our fourth Research

At a time when unprecedented funds are expected to be poured into Long COVID research via the MRFF, I note recommendation 8 of the Inquiry into Long COVID **recommends that funding be made available for ME/CFS research and patient support and that this funding be allocated in consultation with peak bodies for ME/CFS, noting the recommendations of the ME/CFS Advisory Committee's 2019 report to the National Health and Medical Research Council.**

The complex nature of ME/CFS has created challenges for researchers. The diagnosis and treatment of ME/CFS for individuals is confounded by the extensive range, disparity and dissimilarity of presenting symptoms. A lack of sustained ME/CFS research funding continues to significantly hamper progress towards identifying clinically applicable biomarkers, effective treatments or a cure.

There has been widespread acknowledgement that more fit for purpose research is urgently needed to fill gaps in our biomedical understanding of the disease, its etiology, pathophysiology, diagnosis and treatment.

Our fifth priority is Advocating for policy change – NDIA/NDIS
Access to the NDIS is a major issue for those severely impacted by ME/CFS.
Patients tell us they are constantly having to prove legitimacy, despite ME/CFS being more disabling than many other chronic health conditions.

- Patients experience a **lack of knowledge of ME/CFS which impedes access**.
- There is a lack of specialists.
- GP evidence is often not regarded as sufficient to approve NDIS claims
- Finding a GP with sufficient knowledge and experience in managing people with ME/CFS can be extremely difficult.

For those able to gather the required documentation **ME/CFS is misunderstood by NDIA assessors.** Assessors are not assisted to understand the disabling and often delayed nature of post-exertional malaise (PEM), or other disabling symptoms of ME/CFS, because there are no ME/CFS specific assessment guidelines.
The application process is incredibly costly and stressful.
And for those not accepted onto the NDIS, other support options are sorely lacking.

Finally, today is just the beginning!

- **To all here today – it's time!**
- **It's time for unity of purpose amongst patient and clinical groups**
- **It's time for the voices of people with ME/CFS to be heard!**
- **And it's time for the priorities the ME/CFS sector has been long advocating for, to be recognised by Government, be funded Government and included in health policy.**

People with ME/CFS matter.
Their voices need to be heard and acted upon
To not do so creates a human rights issue and continues to 'leave people out'.

Ladies and gentlemen – it's time.