# Submission to Federal COVID-19 Response Inquiry

15 December 2023

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**Emerge Australia Inc** is the national patient organisation representing 250,000 Australians with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and an estimated 325,000 Australians who experience Long COVID. While research is yet to confirm the cause of ME/CFS, a majority of people with ME/CFS can attribute onset of symptoms after viral infection[1]. ME/CFS shares many symptoms and biological abnormalities with Long COVID.[2] Research suggests up to 45% of people with Long COVID meet the diagnostic criteria for ME/CFS.[3] The impact of the diseases on carers, families and the economy is identical. To address these diseases in silos is therefore neither cost effective or efficient and ignores learnings from ME/CFS researchers locally and internationally. A lot can therefore be learnt from existing ME/CFS knowledge, without having to 'reinvent the wheel'.

Emerge Australia supports patients via a national telehealth program; undertakes collaborative research (we operate a patient registry and biobank which collects samples from people with Long COVID), advocacy and evidence-based clinical education.

**Key Health Response Measures – National Post-infection Disease Strategy**

Emerge Australia acknowledges that the Federal Government's Long COVID Inquiry found that "there may be a crossover between Long COVID and ME/CFS" and "recommended they be treated separately"[4]. Both illnesses, however, share abnormalities involving the central and autonomic nervous systems, the immune system, reactivation of latent infectious agents (primarily herpesviruses), the gut microbiome, energy metabolism, a hypometabolic state, redox imbalance, and various cardiac, pulmonary and vascular abnormalities. The similar underlying biology of ME/CFS and Long COVID suggest that insights into each disorder will have implications for the other. Research into their pathophysiology has the potential to lead to new strategies for reducing the morbidity of ME/CFS and Long COVID and of similar illnesses that follow a variety of infections[5].

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[1] H. Naess, et al. 'Postinfectious and chronic fatigue syndromes: clinical experience from a tertiary-referral centre in Norway' *Vivo*, 24:2 (2010).

[2] Komaroff AL and Lipkin WI (2023) ME/CFS and Long COVID share similar symptoms and biological abnormalities: road map to the literature. *Front. Med.* 10:1187163. doi: 10.3389/fmed.2023.1187163

[3] C. Kedor, et al. 'A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity'. *Nature communications*, 13:1 (2022).

[4] House of Representatives, Standing Committee on Health, Aged Care and Sport. 'Sick and tired: Casting a long shadow'. Parliament of Australia, Canberra, (2023).

[5] Komaroff and Lipkin (2023)

The similarities of Long COVID and ME/CFS lead to Emerge Australia calling for **a National Post Infection Disease Strategy** to be developed that guides government investment in

- Diagnosis, treatment and management of post-infection diseases such as Long COVID and ME/CFS via development of nationally consistent clinical guidelines
- Education, training, support and resources for GPs and other health professionals
- Collaborative research on the overlaps between Long COVID and ME/CFS, building on ME/CFS research (so as not to re-invent the wheel) including:
    - characteristics, risk factors and underlying pathophysiology
    - how best to prevent, diagnose and treat
    - how Long COVID interacts with, and the similarities of, conditions such as ME/CFS, and overlapping symptoms, including fatigue and reduced exercise capacity.