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1 February 2019

The Hon Josh Frydenberg, MP,

Federal Member for Kooyong,

Treasurer of Australia,

PO Box 6022,

House of Representatives,

Parliament House,

Canberra, ACT 2600

The Hon Greg Hunt, MP,

Federal Member for Flinders,

Minister for Health,

PO Box 6022,

House of Representatives,

Parliament House,

Canberra, ACT 2600

Dear Mr Frydenberg and Mr Hunt,

**PRE-BUDGET SUBMISSION 2019-20**

Thank you for the opportunity to make this submission.

I write to request that the 2019-20 budget includes sufficient spending to enable implementation of all recommendations in the National Health and Medical Research Council (NHMRC) Draft Report on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) to The NHMRC Chief Executive Officer dated December 2018, and copy attached [[1]](#footnote-1),[[2]](#footnote-2).

Particularly I ask that you consider:

1. $8.5m of additional annual funding from NHMRC grants[[3]](#footnote-3).
2. $13m of additional funding from the Government’s $1.3 billion Health and Medical Industry Growth Plan, announced in the 2018 – 19 Budget[[4]](#footnote-4)
3. $790m of additional Health funding from total Federal Budget - estimated annual expenditure on Health of $78.8 billion for 2018-19[[5]](#footnote-5).
4. In addition to this I submit that the total disease burden of ME/CFS is greater than just making an equivalence from the proportion of people afflicted. Up to 25% of patients with ME/CFS are so severely affected they are bedbound or housebound, with most unlikely ever to return to work full time. These patients also have an above-average vulnerability to self-harm [[6]](#footnote-6). Recent research has found that people with ME/CFS are more disabled than people with Multiple Sclerosis, with relatively less time spent at work and lower income [[7]](#footnote-7).
5. Spending $10m in the upcoming 2019-20 budget would be fully paid back to the budget if only 1.3% of those with ME/CFS make a substantial recovery. This is an exceptionally low threshold for financial break-even[[8]](#footnote-8).
6. Spending $10m per annum offers an exceptional potential “payback” to the budget: if spending $10m per annum can help just 5% of those with ME/CFS to recover, then the payback to the budget would equal $38.7m per annum, or 3.9x benefit versus cost.
7. If spending $10m per annum helps just 10% of those with ME/CFS to recover, then the payback would be $77.5m per annum or 7.8x benefit versus cost.
8. The Federal Government has spent less than $100,000 per year over each of the last 18 years on research into ME/CFS via the NHMRC [[9]](#footnote-9). This is less than 0.02% of total NHMRC grant spending [[10]](#footnote-10), despite the fact that around 1.0% of Australians struggle with ME/CFS.
9. I respectfully submit that this is 50 times less than a ‘fair go’, based on the number of Australians who have the illness, and how serious and debilitating it is.
10. Up to 240,000 (1.0%) of Australians have ME/CFS, according to the estimates in the NHMRC Draft Report (NHMRC Draft Report page 15).
11. Up to 60,000 are bedbound or housebound (NHMRC Draft Report page 15) and largely dependent on carers. Many of these patients are isolated and subsequently vulnerable to all the serious health problems, including cardiac disease and self-harm, which are known to be involved in loneliness and isolation.
12. Up to 148,000 are unemployed.
13. Up to 180,000 women have ME/CFS in Australia, making ME/CFS a serious womens health concern.
14. Preliminary research reports from the USA and UK note that ME/CFS patients are at serious risk of self-harm and suicide. Potential for suicide was indicated at a ‘sevenfold’ increase in a UK study[[11]](#footnote-11) and at 17-18 times increase as compared to national averages, in a USA study [[12]](#footnote-12),[[13]](#footnote-13).

The NHMRC report into ME/CFS is excellent work by Government. It is the most up to date and comprehensive report on ME/CFS prepared by a Government and an expert advisory committee in over two decades. I believe that this report is a prudent starting point for spending decisions.

**Please allocate 2019-20 budget spending to enable implementation of all recommendations in the National Health and Medical Research Council (NHMRC) Draft Report on ME/CFS to The NHMRC Chief Executive Officer dated December 2018, copy attached.**

**I understand EMERGE Inc, the national community service and advocacy charity for ME/CFS, also has made a submission and it contains more detail in support of similar recommendations.**

Yours Sincerely,



Bill Ranken

1. NHMRC Draft Report submitted as supporting doc; p23 has details of recommendations. [↑](#footnote-ref-1)
2. Please note the report is in draft form pending public consultation closing 18 February 2019. See https://consultations.nhmrc.gov.au/public\_consultations/mecfs-2019a [↑](#footnote-ref-2)
3. NHMRC Annual Report 2018, p119, total NHMRC grants in the 2017-18 year were $848m. [↑](#footnote-ref-3)
4. Budget Paper No. 2, 2018 – 19, p116 –20 [↑](#footnote-ref-4)
5. Table 8, Summary of Expenses – Statement 6, Expenses and Net Capital Investment, Health, Budget Paper No 1 2018-19 [↑](#footnote-ref-5)
6. Bedbound / housebound and unemployed numbers from NHMRC Report page 15. Self-harm data see para D5 herein [↑](#footnote-ref-6)
7. Kingdon C C, Structural Status and Wellbeing of People With ME/CFS Compared With People with Multiple Sclerosis and Healthy Controls, Pharmacoeconomics Open 2 – 381, 2018 [↑](#footnote-ref-7)
8. Only 619 people need to recover out of 48,000, or 3,097 out of 240,000 (reflecting the prevalence range of 0.2 – 1.0%). Payback figures are of course indicative-only and require appropriate qualification: they are based on $765m annual cost plus the additional $10m annual spending cited in the example. [↑](#footnote-ref-8)
9. Ministerial correspondence 1 May 2017 - letter from the Hon. Greg Hunt. [↑](#footnote-ref-9)
10. NHMRC Grants Funding 2000 - 2016 Summary. [↑](#footnote-ref-10)
11. Kaupur, N et al in The Lancet 2016 p1596 [↑](#footnote-ref-11)
12. p4-6 Dimmock E M et al, Estimating the Disease Burden of ME/MECFS in the United States and its relation to research funding, Journal of Medicine and Therapeutics, DePaul University Chicago, USA,  Vol 1 pp 1–7, 2016 [↑](#footnote-ref-12)
13. NB the authors note that results were ’rough estimates’ and ‘first approximations’ with low sample size. [↑](#footnote-ref-13)