

May/June 2011

The Hon. Mark Butler MP  
Minister for Mental Health and Ageing  
PO Box 6022  
House of Representatives  
Parliament House  
Canberra ACT 2600

**RE: Funding for Research and Treatment for Myalgic Encephalomyelitis**

Dear Minister,

I am writing to you in your capacity as the Minister for Mental Health and Ageing, Minister responsible for the National Health and Medical Research Council (NHMRC). As a sufferer of Myalgic Encephalomyelitis, otherwise known as Chronic Fatigue Syndrome (ME/CFS), I seek your support to significantly increase funding for biomedical research into this illness and the provision of ME/CFS specific services and support.

ME/CFS is a severely disabling chronic illness, estimated to affect up to 180,000 Australians.<sup>1</sup> The majority, like myself, have had their working and personal lives destroyed. The most severely affected are bed-bound or housebound, and the illness can be life threatening.<sup>2</sup> It strikes people in the prime of life, with few achieving full recovery and most losing years or decades of their lives. Children are also struck down with this condition.

The Australian Institute of Health and Welfare estimates the overall burden of disease associated with ME/CFS is higher than that of Bipolar Disorder, Multiple Sclerosis or Motor Neuron Disease, and rivals that of Type 1 diabetes or hypertensive heart disease.<sup>3</sup> This analysis accounts for the different death rates between illnesses and is based on a highly conservative estimate of the prevalence of ME/CFS. Yet this illness remains marginalised by its misleading name and stigma.

Multiple studies show the majority of people with ME/CFS are unable to maintain full-time employment and 20% to 40% are unable to work at all.<sup>4,5,6,7,8</sup> The annual economic cost to Australia associated with the condition is estimated at almost \$4billion,<sup>9</sup> not taking into account lost quality of life, disruption to education, impact on families, and the mental health consequences of this chronic illness.

Despite this situation, patients remain without medical treatment, meaningful medical research funding or appropriate support services. Most comparable illnesses receive millions of dollars annually in medical research and support services from the Federal government, while ME/CFS has received little more than \$100,000 per annum in the past 10 years.<sup>10</sup> This is shocking. ME/CFS is by far the most neglected of all chronic illnesses by government and the research and medical communities.

In April 2010 the Australian Red Cross banned all people who have ever suffered from ME/CFS from donating blood due to concern that they may carry an infectious retrovirus.<sup>11</sup> This appropriate concern for the rest of the community highlights the serious nature of this illness, yet it prompted no commensurate response into research or treatment for sufferers of the condition.

We patients are desperate to recover our lives and once again become active and productive members of the community. Yet we continue to struggle daily with this devastating illness without hope or effective treatment. I therefore strongly urge that you redress the imbalance in research and service provision funding by supporting:

- the allocation of five million dollars annually to ME/CFS research
- prioritisation of physiological research that seeks to identify the cause(s) and successful treatments or cure for ME/CFS
- the use of the Canadian Diagnostic Criteria and, where appropriate, the identification of further sub-groups for research purposes
- the expediting of research into the role of infectious agents in ME/CFS
- the participation of patient organisations and ME/CFS doctors in determining research directions
- and the provision of ME/CFS specific support services for patients across Australia.

Thank you for your consideration of my letter. I look forward to your response. I would appreciate if you could also cc a copy of reply to Penny Abrahams, CEO, ME/CFS Australia, PO Box 7100 Dandenong 3175.

Yours sincerely

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#### References:

1. Health Policy Unit, Royal Australian College of Physicians (RACP) 2002, 'Chronic Fatigue Syndrome Clinical Practice Guidelines 2002', *Medical Journal of Australia*
2. Boulton N. for Invest in ME, 2010, *Lost voices from a hidden illness*, 2nd edition, Wild Conservation Press, UK.
3. Begg et al 2007. *The burden of disease and injury in Australia 2003*, Australian Institute of Health and Welfare, Canberra. <http://www.aihw.gov.au/publication-detail/?id=6442467990>. [Annex Table 3: Disability-adjusted life years (DALYs) by age, sex and cause, Australia 2003].
4. Reynolds et al 2004, 'The Economic Impact Of Chronic Fatigue Syndrome', *Cost Effectiveness and Resource Allocation*.
5. Jason et al 2008, 'The Economic Impact Of ME/CFS: Individual and Societal Costs', *Dynamic Medicine*.
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7. Bombardier and Buchwald et al 1996, 'Chronic Fatigue, Chronic Fatigue Syndrome, And Fibromyalgia: Disability And Health Care Use', *Medical Care*
8. Lloyd et al in 1992, 'The Economic Impact of Chronic Fatigue Syndrome', *Medical Journal of Australia*
9. Productivity loss based on Reynolds et al 2004, assuming similar percentage productivity losses per person with ME/CFS in Australia in 2010. Direct health costs per person based on Lloyd et al 1992 indexed by ABS Health CPI. Prevalence estimate 0.7% Australian population (RACP 2002).
10. National Health and Medical Research Council 2011, 'NHMRC Research Funding Datasets Based On Burden Of Disease And Health Issues', viewed April 2010 <http://www.nhmrc.gov.au/grants/dataset/issues/index.htm>. [Excludes research into exercise physiology and general fatigue, as such research is not specific to ME/CFS]
11. Australian Red Cross 2010, 'Blood Service Updates CFS Donor Policy', Press Release viewed April 2011, <http://www.donateblood.com.au/media-centre/latest-national-news/blood-service-updates-cfs-donor-policy>.