



# CFS/ME VICTORIA

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Dear Member of Parliament,

With the forthcoming election in mind and the prospect of a new Government being formed, I am writing to you to request that you will work to address the issues facing people suffering from ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome).

The attached document "Key issues facing ME/CFS Communities" provides an insight into this serious illness that affects somewhere between 140,000 and 350,000 Australians. This is greater than either AIDS or lung cancer. Of these, it is reported that some 30-40,000 are so severely disabled by the condition that they are rendered permanently bed- or house-bound, unable to perform the most basic personal tasks. Using USA figures, ME/CFS Australia estimate this condition costs the Australian economy more than \$3.8 billion annually in lost productivity.

The experience of ME/CFS Societies is the past four Howard Governments and advisors have failed to address the key issues related to this illness, or listen to their constituents and consumer groups. This is despite submissions to several Health Ministers and the Federal Government Policy Committee of Health and Aging. Our members report dismay at the callousness shown through receiving the same form letter from their MPs in response to their submissions asking for support and assistance.

The ME/CFS Societies are keen to see the Canadian Consensus Clinical Guidelines used by Australian GPs and other medical professionals. To develop these guidelines, the Canadians took a different approach to development of clinical guidelines to that taken by Australia and the UK in the diagnosis and management of ME/CFS. That is, they **invited** input from 'world leaders in the research and clinical management of ME/CFS patients' to produce a Consensus document.

We would like to see the new Government provide funds for the following initiatives:

1. Establish a research facility and centre of excellence for ME/CFS to address the lack of biomedical research into ME/CFS.
2. Provide every GP in Australia with a copy of the Canadian Clinical Consensus Guidelines.
3. Provide funds and access to expert resources to improve support services to ME/CFS sufferers and their carers, and to raise awareness within the community on management and prevention strategies.
4. Provide basic support and funding to the National Association, ME/CFS Australia. (An example would be the WWDA model of funding).

Yours Sincerely

Simon Molesworth AM QC  
Honorary President