

23rd August 2007

The Honourable Tony Abbott MP
Leader of the House, Minister for Health and Aging
P.O. Box 6022
House of Representatives,
Parliament House,
Canberra, ACT 2600

Dear Mr Abbott

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

We recently sought to draw the attention of our State Health Minister, The Honourable Jim McGinty, to the current paucity of services and care provided by our health system to Australians affected by Myalgic Encephalomyelitis, also referred to under the umbrella term "Chronic Fatigue Syndrome". Mr McGinty advised us that our concerns should more properly be addressed to yourself as the responsible government minister.

We request your support for the urgent provision of credible guidelines for diagnosis, treatment and management of ME/CFS to medical practitioners and welfare agencies, the urgent establishment of a biomedical research program into the causes and treatment of the disease and the provision of appropriate support services for those affected, their families and carers.

Our **priorities for action** for which we seek your support are:

- The immediate adoption and distribution of the Canadian ME/CFS Clinical Guidelines and Treatment Protocols (Carruthers et al, 2003) to all General Practitioners and Welfare Agencies
- The establishment of a credible biomedical research program into the causes and treatment of ME/CFS –facilitated through the study of post Q fever fatigue complex.
- Funding for a national telephone information and support line service for patients and their carers based on the Canadian Clinical Guidelines and Treatment Protocols

A Growing Humanitarian and Economic Burden

In 2002 the Royal Australasian College of Physicians estimated there were approximately 140,000 Australians affected by ME/CFS, an incidence greater than either AIDS or lung cancer. Of these it is reported approximately 30-40,000 are so severely disabled by the condition that they are rendered permanently bed- or house-bound unable to perform most basic personal tasks. Recently, the Chief of the US Centre for Disease Control

(CDC) CFS Research Program and others have described the potentially extreme disability associated with severe ME/CFS likening it to Multiple Sclerosis, late stage AIDS or end stage renal failure. The link between infections such as Ross River Virus, Q fever and Glandular Fever and the development of ME/CFS is also well established and the condition is known to affect people of all ages, socio-economic and ethnic groups.

In addition to the obvious humanitarian burden imposed by the illness, more recent studies published by the CDC highlight its growing economic impact. These studies suggest the condition may cost the Australian economy more than \$3.8 billion annually in lost productivity alone

Provision of Diagnostic and Treatment Guidelines

Despite this scenario ME/CFS remains an orphan condition here in Australia, largely overlooked by our health system. In the light of contemporary research findings the diagnostic and management guidelines issued by the Royal Australasian College of Physicians (RACP) to general practitioners in 2002 are increasingly seen as out of date and unfit for purpose; containing amorphous guidance for diagnosis, suggesting increasingly controversial and potentially harmful management techniques and offering patients, their families and carers little if any hope.

In 2003 the Canadian's published their highly acclaimed Diagnostic and Treatment Guidelines (Carruthers et al.) which have been warmly embraced by the ME/CFS community both here in Australia and globally. These guidelines have since been endorsed by both our National Association and our nominated national research body, The Alison Hunter Memorial Foundation. Their adoption here in Australia, or adaptation as has been the case in South Australia, would bring significant and immediate relief to those affected.

We have enclosed a copy of the Canadian Guidelines (abbreviated Overview) for your review and urge their immediate adoption and distribution to General Practitioners and Welfare Agencies in place of the existing inadequate 2002 RACP Guidelines.

Establishing a Credible Biomedical Research Program

A recent report obtained from the NHMRC reveals the lack of relevant biomedical research being carried out into the causes and treatment of post-infective and other forms of ME/CFS. Despite appeals from our National Association adequate funding for ME/CFS biomedical research remains unforthcoming while the minimal funds that have been made available are largely diverted towards unrelated 'fatigue' oriented or psychiatric investigations. These investigations have consistently and over a prolonged period failed to yield any answers or benefit for sufferers.

We request your urgent intervention to establish an appropriate level of funding for ME/CFS biomedical research. In particular we seek to draw your attention to a previous proposal submitted to you in 2005/6 by Professor Barrie Marmion AO and Dr Stephen Graves for the establishment of a Research and Reference Centre for Q Fever and

Rickettsial Diseases -the post infection fatigue complex that follows Q fever and some rickettsial infections representing the best characterised model for the further study of ME/CFS. We add our strongest endorsement to this proposal and urge you to give the establishment of this Centre your immediate and fullest support.

Information and Support Services

Ongoing misunderstanding within the medical community and broader social context renders those affected by ME/CFS, their family and carers largely without support or care, significantly adding to their burden of disability and financial hardship. While timely introduction of the Canadian Diagnostic and Treatment Guidelines will greatly enhance the services offered by our medical and welfare communities, there is an urgent need to establish a professionally resourced national telephone support and information help-line based on these guidelines. We seek your support for the provision of funding to establish this service at the earliest opportunity.

Our Patron, Dr Zeke Pervan, and I would greatly appreciate meeting with you to briefly discuss the urgently needed initiatives highlighted above and to seek your advice on how best to proceed.

Yours Sincerely,

Colin Neathercoat
Management Committee, ME/CFS Australia (WA)
and Director, ME/CFS Australia