

ABN 61 012534794 Charitable  
Collections License Number 20372

11th May 2007

The Honourable Jim McGinty  
Minister for Health  
4th Floor, London House  
216 St George Terrace  
Perth WA 6000

Dear Mr McGinty,

### **Myalgic Encephalomyelitis Chronic Fatigue Syndrome (ME/CFS)**

We seek to draw your attention to the current paucity of services and care provided by our health system to people affected by Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome. We request your support for the urgent provision of credible guidelines for diagnosis, treatment and management to medical practitioners and welfare agencies in Western Australia as well as the establishment 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 in Western Australia
- The establishment of a professional part-time (2 days per week) information, support and outreach service for those affected, including their families and carers.

### **A Growing Economic and Humanitarian 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 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 severe disability associated with severe ME/CFS, likening it to Multiple Sclerosis, late stage AIDS or end stage renal failure.

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 approximately \$3.8 billion annually in lost productivity alone. The link between infections such as Ross River Virus, Q fever and

Glandular Fever and the development of ME/CFS is also now well established and the condition is known to affect people of all ages, socio-economic and ethnic groups.

### **Diagnostic and Treatment Guidelines for Practitioners**

Despite this scenario ME/CFS remains an orphan condition here in Australia, largely overlooked by both our health system and government. In the light of contemporary research findings the guidelines issued to general practitioners in 2002 are now hopelessly out of date; suggesting increasingly controversial and potentially harmful management techniques and offering patients, their families and carers little if any hope. Federal funding for research to identify the cause and a cure for post-infective and other forms of ME/CFS remains meager, despite repeated appeals from our national executive.

Yet in 2003 the Canadian's published their highly acclaimed Diagnostic and Treatment Guidelines (Carruthers at al.) which have been warmly embraced by the ME/CFS community globally. Their adoption here in WA, or adaptation as has been the case in South Australia, would bring significant and immediate relief to those affected. We have enclosed copies of both the Canadian and South Australian Guidelines for your review.

### **Information and Support Services**

An estimated 8,000 West Australians affected by ME/CFS along with their families and carers remain largely without support or assistance in coping with this devastating illness. In addition the more severely affected may experience extreme isolation and deprivation - the current environment of misunderstanding in both the medical and social contexts significantly adding to their burden of disability and financial hardship. We seek therefore to establish on a part-time basis a professional resource to provide support to patients, their families and carers. This service, in conjunction with the adoption of the Canadian Guidelines, would handle the growing number of requests for information and management advice and also act as an 'outreach' service to those most seriously affected and isolated by their condition.

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