

November 19<sup>th</sup>, 2007

Dear David and Vanessa, Australian Liberal Party

**Re: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome ME/CFS**

In Tasmania there is no ME/CFS support team, as in other states of Australia. In the recent past it has been staffed by one person, a chronic fatigue sufferer, with no energy resources. The most active on line support seems to be provided by the one in South Australia. It is administered entirely by volunteers, most of whom are sufferers or family members of sufferers, and financed entirely by membership fees and donations. They are all volunteers. There is no energy for fundraising. Neither is there any contribution from government at any level.

The support group in Victoria sent letters to all sitting Victorian and Tasmanian members of Federal Parliament. Responses to date of both major parties have not been satisfactory answers and were almost identical.

At a forum of federal candidates for Franklin I attended in Kingston last week, I gave each candidate an opportunity to address the inadequacies of the current system. I hoped that by so doing I could help raise the awareness of at least these candidates (especially should they be elected).

Only candidates from parties outside of Liberal and Labor sought to talk with me afterwards. I had a written response from Gerard Velnaar, federal candidate for the Greens Party.

**What do the ME/CFS Societies want to see during 2007/08?**

- Official recognition by the Department of Health and Aging that ME/CFS is a 'disability'
- Improved Australian diagnosis and management of ME/CFS through the use of the Canadian ME/CFS Consensus Clinical Guidelines
- Provision of funds and access to expert resources to improve support services to ME/CFS sufferers and their carers, to fund research into ME/CFS, and to raise awareness within the community on management and prevention strategies
- Provision of funds for core funding for a Research and Reference Centre to study all aspects of Q fever and rickettsial infections and associated post infection chronic fatigue syndromes by Professor Barrie Marmion AO, Q Fever Research Group & Professor Stephen Graves, Australian Rickettsial Laboratory, Hunter Area Pathology Service University of Newcastle.
- Consideration for extra funding for the Menzies Centre's Immunology Division who have had some research projects involved in this area.

Could you please outline for me the steps you and your party will be taking in the new Parliament to assist this hugely disadvantaged group of electors and their families.

Yours Sincerely

Patsy Joan Harmsen

[address supplied]