

## Mediarelease May 12, 2012

### **Eminent Professor and QC demands better research and treatment funding for ‘the most woefully neglected illness in the country’**

Professor Simon Molesworth, QC A.M. is passionate about the organisation he chairs, ME/CFS Australia, and determined to speak out about what he calls the ‘disgraceful neglect’ of the illness he champions, Myalgic Encephalomyelitis (Chronic Fatigue Syndrome). ME/CFS is a neurological disorder causing immune dysfunction that can be extremely severe and disabling. It is estimated that less than 20 per cent of sufferers are correctly diagnosed or receive treatment.

ME/CFS Australia assists sufferers of the disease - estimated at around 180,000 Australians – to receive help, support and advice regarding diagnosis, treatment and access to knowledgeable medical practitioners. Professor Molesworth says the seriousness of the illness is misunderstood by all sectors of the community, including many in the health sector. He believes government and the medical bureaucracy underestimate the impact of Myalgic Encephalomyelitis on sufferers as well as the economic burden on the community. The Professor says perceptions of the illness are simplistic and that there are many aspects of the disease that are simply not known by anyone outside the large community of sufferers and their carers.

*‘For instance, it is a little-known fact that Myalgic Encephalomyelitis (Chronic Fatigue Syndrome) was identified by the World Health Organisation as early as 1969 as a neurological disorder. Yet it is still trivialised by many sectors of the community and sufferers are often stigmatised by being told it is ‘not real’ . Few people understand the real impact of the illness and its sometimes devastating symptoms: that the disease can be fatal; that it can be suffered by children as young as 5. People can suffer from this illness for their entire lives and many are bed-bound, preventing them from participating in work and often resulting in family breakdown, financial hardship and social isolation.’*

According to the Australian Institute of Health & Welfare, the overall burden of disease for Myalgic Encephalomyelitis (CFS) is higher than that of Bi-polar Disorder, Multiple Sclerosis or Motor Neuron Disease and rivals that of Type 1 Diabetes or Hypertensive Heart Disease. The Royal Australian College of Physicians conservatively estimated in 2000 that ME/CFS cost the Australian economy some \$525 million annually. Figures are now estimated at almost \$4 billion.

In Victoria alone about 1,500 calls to the ME/CFS Helpline are received each year, with the most frequently requested assistance relating to difficulties receiving correct diagnosis, effective treatment and support . There are no universally recognised treatment protocols for the illness. The organisation recommends that medical practitioners use the internationally accepted criteria for diagnosis: Myalgic Encephalomyelitis International Consensus Criteria 2011, which can be accessed via their website at [www.mecfs-vic.org.au](http://www.mecfs-vic.org.au)

Professor Molesworth spoke at the Education Seminar organised by ME/CFS Australia held in Melbourne on Saturday May 5 to an audience of over 200 sufferers, carers and medical practitioners and health professionals and educators.

*‘I despair for sufferers. The illness must be given the priority attention it needs for urgently required bio-medical research and treatment. Funding for ME/CFS specific research, diagnostic, treatment and support services in Australia is almost non-existent. Comparable chronic illnesses receive millions of dollars. It’s high time sufferers were given some hope that this inequitable situation will be addressed by governments and researchers in the immediate future’.*

**For further information, contact Alison Copley, CEO, ME/CFS Australia (Vic, Tas,NT) .**

**T: 03 9791 3100**

**E: [Alison@mecfs-vic.org.au](mailto:Alison@mecfs-vic.org.au)**

**W: [www.mecfs-vic.org.au](http://www.mecfs-vic.org.au)**

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**Ethicaltoolbox** Sue Steedman M: 0410 597 646