

12 October 2009 To CFSAC meeting October 2009 From Mr Anthony Foran, Melbourne, Australia

I'm a patient from Australia diagnosed with ME/CFS since 2001. The CDC's work or rather lack of it in relation to proper investigation into this illness also affects many thousands here. Hence my testimony to you today. I do not apologise for being direct.

The CDC in the wealthiest country in the world, the United States of America, is looked to by many but has provided very little help in relation to the millions of dollars that you have spent on CFS. With the amount of money available you should be leading the world in research and be a guiding light for help and hope. Instead you are left behind, towards the rear in the search for answers, scorned, ridiculed and ignored. Much smaller, private institutions, researchers and individual doctors around the world are the real leaders in biomedical research and treatments that actually help patients with ME/CFS. This is a shame upon you.

The CDC's empirical definition defines nothing and has proven even more unhelpful in defining any patient group. It simply must be abandoned. Continuing its use will provide no answers and consign the CFS program to even further irrelevance. We will have no genuine help from the CDC if this definition is continued to be used. Adopting something like England's NICE guidelines would also be destructive. The emphasis on spurious treatments such as exercise and behavioural therapy are limited at best and actually found to be harmful to very many patients. The negation of biomedical testing and therefore proper medical treatment from that system is appalling. That outcome cannot be acceptable to anyone, especially to doctors who have taken the Hippocratic oath. How can you possibly endorse this? The internationally known and respected Canadian Guidelines of 2003 are clearly more helpful and should be adopted. That step would be greatly welcomed by doctors and patients in the USA and around the world.

Dr Reeves and others who have actively mismanaged the CFS program, I ask you to continue your careers elsewhere, to resign your post and move on. If it were within my power I would demand it. For years now you have proven you cannot help us, so you can at least get out of the way for those who can. The health of millions has no room for your personal beliefs that have so comprehensively failed us. You have wasted millions of your country's taxpayer dollars and far too many years of patient's lives. You must accept significant blame for the ongoing pain, suffering and indignities of at least one million people in your country alone. Please just go. Now.

I hope that we can see a new age of enlightenment shine on this maligned disease so that hope and successful treatments are able to be spread widely and with much needed speed. Change is desperately needed.

Mr Anthony Foran

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