

Testimony

Jane Clout

One of the roadblocks to progress in ME/CFS research are the poorly defined research cohorts used. What little money is spent on ME/CFS research is often wasted by using a cohort defined by Fukuda, or worse Reeves 2005, or even by telephone interview.

There is also the problem that figures for prevalence vary widely. According to the CDC definition, there may be as many as four million of us. Other estimates are nearer to one million. How terrifying that there may be four million sick people, clamouring for treatment, for the decision makers. Successful treatment research may indicate we need antiretrovirals or amipligen or other expensive meds! Now we know that the CDC figures are bull, but do the DC decision makers?

It seems to me that these two problems, if addressed, would build a firm foundation for future research.

Step One. Random canvas 25,000 citizens with the question "Do you consider you have or have you been diagnosed as suffering with ME, CFS or ME/CFS?"

(I just heard today of a random canvas study of 28,000 people, so I don't see this as too large a beginning. Indeed, any less would not give a sufficiently large final outcome, in all probability)

Step Two. Contact positive responders with a questionnaire to weed out obvious misdiagnoses.

The "If you were well tomorrow, what would you do?" question might be useful here...

Step Three. The remaining positive responders to be seen by Bell/Cheyney/Klimas/other ME docs that know how to Dx, or is there a better way? Obviously, using the Canadian Consensus Criteria.

Outcome: accurate current prevalence, and a well characterized cohort for future studies. With a starting point of 25,000, at the old rate of 0.4%, we should end up with circa 1000 true ME cases.

Others will give you the awful details of how it is to suffer from this disease. You would not want it, but anyone including you could catch it. I have no more mental energy to spend now. Thank you for your work.

Best wishes,

Jane Clout.