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A Letter to the Honourable Kathleen Sebelius, U.S. Secretary of Health and Human Services

Health and Human Services' Contract with the Institute of Medicine to Create New definition of ME and CFS

Dear Secretary Sebelius,

Invest in ME is a UK charity campaigning for biomedical research and better education for myalgic encephalomyelitis (ME) and currently initiating high-quality biomedical research into ME.

Invest in ME wish to support the statement signed by 50 clinicians and researchers [1] who are involved in ME or CFS related research and in the treatment of patients.

They urge the HHS to adopt the Canadian Consensus Criteria instead of starting yet another expensive and time consuming consensus process for defining new clinical diagnostic criteria for ME and CFS.

The importance of correct guidelines for diagnosis and for research is something for which IiME have argued for a long time. The deleterious results of not using up to date guidelines for diagnosis and research is easily seen in the UK where the ineffectual NICE guidelines are ignored and the fiasco of the PACE trial shows clearly how money can be squandered on flawed research.

The Fukuda definition is out of date.

The Canadian Consensus Criteria (CCC) are more modern, recognises core features of ME, and is in use.

It would seem to be a far better use of public funding to try to replicate or validate some of the promising research into ME in order to find objective markers and then revise a whole new set of criteria based on these findings.

We believe this statement from experts on ME sums up exactly why there is no requirement or value in contracting the IOM to waste time, energy and resources producing an inferior and likely unrepresentative definition of ME -

“ME/CFS patients who have been disabled for decades by this devastating disease need to see the field move forward and there is no time to waste. We believe that our consensus decision on a case definition for this disease will jump start progress and lead to much more rapid advancement in research and care for ME/CFS patients. We look forward to this accelerated progress and stand ready to work with you to increase scientific understanding of the pathophysiology of this disease, educate medical professionals, develop more effective treatments, and eventually find a cure. ”

We support this statement completely.



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The lesson learnt from the previous exercise whereby the IOM changed Gulf War Syndrome into Chronic multi-symptom illness is one which overshadows this new attempt to redefine ME.

The debacle from the IOM's redefinition of GWS will not be allowed to be repeated for ME.

That will be unacceptable.

The concern over this new IOM contract is from patients – the very people whom your department should be helping, those who are least able to help themselves and whose health needs protecting.

We have a parallel in the UK where a government organisation (supposedly independent) – NICE – performed a flawed and ultimately tawdry attempt at forcing a pre-determined and unfit set of guidelines for ME onto patients and healthcare professionals.

This organisation was taken to a judicial review – by patients.

The NICE guidelines are in tatters in the UK – useless for both healthcare professionals and patients alike. It would be tragic if you did not listen now to patients and experts who state that they do not want this IOM contract.

It seems apparent that the Institute of Medicine (IOM) lacks the necessary expertise to take on the job of correctly defining ME.

The CCC is in use and form a valid basis for evolution.

The proposed contract for the IOM to develop a new guideline will use scarce funding which could in fact be used to perform biomedical research into ME.

“Beware of false knowledge; it is more dangerous than ignorance” – that quote from George Bernard Shaw would characterise the perverse decision to contract the IOM to redefine ME.

ME patients have, more than most, suffered for a generation from flawed approaches and the vested interests of non-experts.

For once it would be refreshing for a government organisation and official to listen to patients.

It is, after all, what government is intended for – to serve the people.

Yours Sincerely,

The Chairman and Trustees of Invest in ME

References:

1]

<https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%20final%2010-25-13.pdf>