

As president of the IACFS/ME, I thank the CFS Advisory Committee for this opportunity to present testimony on behalf of my organization. Six months ago the three major CFS scientific advocacy groups, the IACFS, the CFIDS Association of America, and this committee all recommended new, open-minded leadership at the CFS research program in the Centers for Disease Control. We commend this bold and important action by the CFSAC.

Despite this unprecedented consensus, the CDC has shown no indication of changing its CFS program leadership. This is surprising given its track record to date. After 25 years (and over \$100 million) of CDC research, chronic fatigue syndrome remains a stigmatized illness without substantive progress on public health policy or objective diagnosis and treatment. And their new 5 year \$25 million plan fails to inspire any confidence that change will occur.

In fact, the consensus recommendation of these scientific advocacy groups was based on dissatisfaction with the CDC's ill-conceived and impossibly far-reaching 5 year research plan. President Obama said in his inaugural address: *The fundamental question of our time, is not whether government is too big or too small, it will be whether it works.* The CDC is the world public health authority; It can certainly provide more effective leadership in this poorly understood domain.

I am speaking not only for my organization but for several prominent biomedical scientists whose opinions should be considered in our ongoing efforts to effect change. These individuals were unable to speak today.

Gudrun Lange was a member of the distinguished external review panel that in 2008 evaluated the CFS program at CDC; She asked me to read this quote:

"I am very disappointed that CDC has not been more proactive in implementing important suggestions made by peer reviewers. The committee recommended that CDC, as the lead health agency dealing with CFS, establish closer relationships with other traditional public health agencies to further promote CFS as a significant health concern. This includes using public service announcements to alert the public about CFS as an important health issue. In addition, it is rather surprising that CDC has not shown any initiative to address obvious research questions posed by the H1N1 epidemic. Why are we not surveilling the population for post-infectious fatigue following H1N1?"

Distinguished UK scientist and geneticist, Jonathan Kerr, expressed the following:

Research output on CFS from the CDC in the last 5 years has been principally in the areas of gene expression and mutation. These studies used patients who did not attend CFS clinics and were not diagnosed by recognised CFS clinicians. A microarray was utilised which did not represent the entire human genome (yet such an array was available at the time). But, at no time were the microarray gene profiles confirmed using real-time PCR, a standard procedure in microarray studies because the arrays are very sensitive but not very specific. The findings of these papers do not lead anywhere and were not followed up by CDC. They do not provide insights into pathogenesis, nor do they indicate candidate treatment targets. The authors made no effort to explain their work in context of the available CFS gene expression literature.

Recommendations

Although the CDC program has ignored the views of scientific advocacy groups, their CFS program will not go forward without challenge. Nor will this widely supported protest be

confined to one meeting of this committee. We ask the CFSAC to support us in our ongoing efforts. We respectfully recommend the following:

- A continuing critical focus on the CDC chronic fatigue program during this and subsequent meetings until the leadership is changed.
- A new scientific forum at the CFSAC that allows biomedical scientists who wish to speak at the meeting the opportunity to do so. This is important because prominent scientists and clinicians who attempted to register to speak 3 weeks in advance of this meeting were wait- listed.
- Permission for non-US biomedical experts in CFS to participate in these scientific forums. They are not permitted to speak now. Given that there are so few CFS experts worldwide, we need informed views to make informed recommendations.

If we the CFS scientific community remain united in common purpose we can lead the way to major new public policy initiatives and research programs that advance the recognition and understanding of this still poorly understood illness.

Thank you.