Testimony

Khaly Castle

Dear Committee, Government Entities, Medical Community, and Fellow Sufferers:

During the last Committee Meeting in May 2010, we were introduced to Dr. Elizabeth Unger, new acting leader of the Chronic Fatigue Syndrome group at the CDC. Dr. Unger described to us the current and past fieldwork and areas of interest being pursued by the CDC in the CFS arena.

CFSAC Chair Christopher Snell asked Dr. Unger to comment on the use of the current "empirical" definition used by the CDC.

Dr. Unger responded as follows:

*"Yes, and believe me, that's one of the things top on our list is to address this, because largely I think it's our failure to communicate exactly how we use this definition. It is a, it should not have, in my opinion, been called an empirical definition, as it is indeed the same definition as the 1994 international research case definition. As we try to operationalize it so that the diagnostic criteria could be more objectively applied, we made some decisions that need to be validated and need to be fully shown to the community at large.. And indeed the data from the follow up study of the surveillance population in Georgia, that is our first topic of concern to actually present various permutations and selections of cutoff criteria, and how it will affect the patient population that would or would not be classified as CFS.*

*Once we have that completed I think it will be clear whether indeed a full meeting is needed to more carefully debate issues relating to case definition or whether our time together in a conference would be better devoted to other areas of urgency relating to CFS."*

I believe that Dr. Unger was indicating that there is nothing wrong with the definition, it's just that the rest of us are unaware of how it is being used. If this is indeed the case, in my opinion it is high time that we are brought up to date as I would sincerely like to understand how the current case definition is appropriate.

I would like to know if further consideration has been given to the question of whether there is a need to devote a meeting to the case definition issues. It seems to me that a great deal of the discrepancies in how to proceed in research stem from the very root of case definition. In other words, if we don't know what we're looking for, how do we know if we found it?

The 1988 Holmes Definition for CFS stated in part that "*The chronic fatigue syndrome is currently an operational concept designed for research purposes that physicians must recognize not necessarily as a single disease but as a syndrome - a complex of potentially related symptoms that tend to occur together - that may have several causes."*

Dr. Paul Cheney attended the recent international XMRV conference, and reported back to us that

*"Perhaps most interesting of all was what happened with the injection of a bolus of foreign peptides into macaques that had apparently completely cleared the virus from blood. There was a huge reactivation of infectious virus in the blood proving that latent but persistent virus is just below the surface and that XMRV infection cannot be completely cleared from all reservoir sites. The peptide injection mimics an acute infection (? borrelia or the flu), an immunization or even acute mold exposure.*

It seems to me that this may indeed indicate a high possibility that the 1988 Holmes working definition for CFS recognized the complexity of this illness by outlining the operational concept to embrace such a possibility, while the current definition would exclude such a finding based on the idea that flu, borrelia, or even acute mold exposure may be involved.

Perhaps it is time to revisit the beginning, the inception of CFS. What happened that required the CDC to come up with a working definition for an illness that was not yet on the CDC books? What did that original group show clinically? And in retrospect, do they fit the current CDC working model of CFS, or have they been excluded from their own illness? A definition is supposed to describe an entity, not create one.

Thank you,

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