

Testimony

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In 1988, the CDC named a disease that for the past 100 years had been called a variety of things including Akureyri Disease, Iceland Disease, a disease simulating poliomyelitis, myalgic encephalomyelitis, benign myalgic encephalomyelitis and epidemic neuromyasthenia. Not only could the name not be agreed upon; but also this disease defied definition. “It” defied definition because attempts at each outbreak failed to isolate an infectious agent and failed to identify signs that could be objectively measured. Each outbreak however left in its wake a number of people who did not recover from the acute infection and were left with a number of vague and nonspecific symptoms that included pain and fatigue.

For the past century, fatigue has defied definition. And today, despite sophisticated molecular devices and system biology perspectives, fatigue has no objective markers. Therefore, a disease that is described by non-specific symptoms should not be defined by those same ill-defined terms.

Further, the requirement that has person must be sick for at least 6 months – whether defined by the 1994 or the Canadian criteria – must be abolished. This 6 month diagnostic lag decreases, if not diminishes, chances of identifying perpetrating agents.

To the NIH, we should not have to wait for reports, more meetings and pronouncements to have sufficient grounds for NIH to act. According the NIH RePORT more than \$150 million has been spent on direct or relevant research on CFS. NIH has spent much more to develop the infrastructure and tools necessary for partnerships and collaboration. Dr. Italo Biagioni of Vanderbilt gave an example of one such NIH-sponsored initiation called REDCap (Research Electronic Data Capture; www.project-redcap.org). REDCap has more than 100 standardized and validated instruments including ones many of us have used in our own research freely available to consortium members. REDCap is free and a turnkey approach that could jumpstart a clinical and research network for CFS.

The CFIDS Association has funded research for the past 20 years. Our funding policy encourages the use of community determined standards, collaboration and sharing. In 2008, we funded 6 investigators that was a network of more than 23 investigators at 10 institutions. This isn't rocket science. There only has to be the leadership and the will to get it done.