State of Knowledge ME/CFS Workshop – April 7-8, 2011
Overview Summary

The three main goals of the workshop were 1) to separate what is known (fact) from what is unsubstantiated (hypothetical/theory), 2) identify gaps in knowledge, and 3) identify opportunities for advancing the science related to ME/CFS. Thirty two (32) investigators with expertise in basic, clinical and translational sciences came together for this two day meeting that was seen live by nearly 900 viewers via NIH VideoCast and 100 in-person attendees.

Overall: It is clear there is still much to learn about this illness, and no consensus exists on a cause, diagnosis or treatment.

Case Definition: Current definitions have strengths and weaknesses, and lead to variable diagnoses of research subjects. It is imperative that researchers obtain samples from well-characterized subjects with or without ME/CFS. Although standardization of symptom measurements is important, objective measures and biomarkers are needed to better define a case definition.

Infection: The close temporal relationship of ME/CFS onset to flu-like illnesses suggests an infectious disease etiology or "trigger." A number of microbes, including EBV, herpes viruses, enteroviruses and retroviruses remain candidates as etiological triggers for ME/CFS.

XMRV: There is still considerable debate about the association of this (or any) retrovirus with ME/CFS. The results from large, ongoing NIH-supported projects (NIAID: Lipkin – Columbia Univ; and NHLBI: Blood XMRV Scientific Research Working Group) in the next year or two will help resolve this controversy.

Immunopathology: Understanding the complex interactions within the immune system and among other organ systems is being aided through the use of systems biology analyses (see below). Using immunological data from well-characterized subjects might lead to useful biomarkers of disease. However, immunotherapies employed to date do not provide consistent results and are highly susceptible to variation due to a variety of factors including dosage, timing of administration, and patient selection.

Systems Biology: The incorporation of large amounts of data into computer models of disease may prove to be an approach for studying ME/CFS.

Systems biology can identify distinguishable patterns and networks from complex data which may help identify patients with different forms of disease. Such information could help improve diagnosis, prognosis, and therapy.

Neurology: Research on pain and dysfunction of the autonomic nervous system are providing new avenues for treatment of ME/CFS. Neuroimaging of the brain shows unique patterns of activity throughout the brain in ME/CFS patients, and may help explain, for example, cognitive and sleep disorders.

Post exertional malaise: This appears to be a hallmark of ME/CFS and several studies are studying aspects of this that could greatly help diagnose and treat the most common symptoms of ME/CFS.

Diagnosis: Validated biomarkers might prove to be a key to improved diagnoses.

Biomarkers: Possible candidate markers include cytokine levels, leukocyte function abnormalities, gene expression profiles, cerebral spinal fluid protein patterns, blood oxygen levels and brain images.

Treatment: Current treatments are aimed at symptom management. Both pharmacological and non-pharmacological approaches are being considered, but as yet, there is no consensus on what works best in each patient. No cures have been identified. Better understanding of the etiology and pathophysiology will give insight into appropriate treatments for this illness.

Interdisciplinary Research: The panelists agreed that the illness is complex and ideally suited for an interdisciplinary research approach. The panelists expressed a desire to work together as a network and identify common resources such as clinical (phenotype) databases or biological repositories.

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