Learn the Facts about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Myalgic Encephalomyelitis (ME), commonly referred to as chronic fatigue syndrome (CFS), is a complex disease with an array of debilitating symptoms including extreme exhaustion, orthostatic intolerance, unrefreshing sleep, memory loss, joint pain, inflamed lymph nodes, severe headache, sore throat, neurological abnormalities, and even complete organ system shutdown. The cause of ME/CFS is unknown, and there is no existing cure nor FDA-approved treatment for the disease.

The Numbers
- An estimated 836,000 to 2.5 million Americans have ME/CFS.  
- ME/CFS affects four times more women than men.  
- One quarter of ME/CFS patients will become house- or bedbound in their lifetime.  
- ME/CFS can strike anyone at any time; onset has been reported from ages 10 to 80.  
- ME/CFS costs U.S. taxpayers an estimated $17 to $24 billion each year.

The Reality
- Recovery from ME/CFS is rare, and symptoms often persist for life.  
- Many with ME/CFS have comorbid disorders, such as irritable bowel syndrome, dysautonomia, and fibromyalgia.  
- Patients with ME/CFS have the lowest median and mean quality of life scores of any disease tested, including lung cancer, rheumatoid arthritis, and brain stroke.  

The Needs
- Discovery of an FDA-approved treatment for ME/CFS; if a cure or treatment for ME/CFS were to be found, the U.S. would save $8,675 per patient annually in direct medical costs.  
- Research funding that better reflects the burden of ME/CFS, which would total approximately $250 million per year—more than 46 times the current level of funding.  
- Assignment to a National Institutes of Health (NIH) institute, as ME/CFS is currently the only disease not assigned—this must be remedied to end setbacks in disease progress.  
- Updated protocols on ME/CFS; incorrect information on the website for the Centers for Disease Control and Prevention (CDC), among others, contributes to the misunderstanding, stigma, and mistreatment patients experience.

The Science
- “There are now over 4,000 published studies that show underlying biological abnormalities in patients...It’s not an illness that people can simply imagine and it’s not a psychological illness.”  
  - Dr. Anthony Komaroff  
- “The abnormalities we found provide evidence for central nervous system and neuromuscular involvement.”  
  - Dr. Carolyn Warner  
- “The pattern of focal and lateralized impairments in these patients is consistent with an atypical organic brain syndrome.”  
  - Dr. Sheila Bastien  
- “I have evaluated over 2,500 cases...Half have abnormal MRI scans. 80% have abnormal SPECT scans. 95% have abnormal cognitive-evoked EEG brain maps...80% have evidence of an up-regulated 2-5A antiviral pathway. 80% of cases are unable to work or attend school.”  
  - Dr. Nancy Klimas  
- “…Early ME/CFS cases had a prominent activation of both pro- and anti-inflammatory cytokines as well as dissociation of intercytokine regulatory networks. We found a stronger correlation of cytokine alterations with illness duration than with measures of illness severity, suggesting that the immunopathology of ME/CFS is not static.”  
  - Dr. Mady Hornig, et al.  
- “Patients with ME/CFS have reduced aerobic work capacity compared with normal subjects...Previous studies have shown biochemical and structural abnormalities of muscle in patients.”  
- “Characterizing the molecular basis of this complex, multifactorial disease will yield unprecedented insights into the ‘hardwiring’ of our energy systems, including vulnerabilities, shunts, and short-circuits, with broad implications for other chronic diseases as well.”  
  - Dr. Zaher Nahle