Dear Senator,

We the undersigned scientists are writing to express our interest and enthusiasm for researching myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a common and disabling illness long ignored by our nation’s health agencies.

Many of us have had a very difficult time securing adequate funding. Others have been unable to determine even how to apply for funding, as no institute within the NIH has responsibility for researching ME/CFS. The NIH has responded to requests for increased funding by stating that few researchers are interested in studying the illness.

On the contrary there are Nobel Laureates, several members of the National Academy of Sciences, biochemists, biophysicists, geneticists, immunologists, neuroscientists, experts in public health and infectious disease, epidemiologists, and physicians eager and ready to study this disease, were adequate funding made available. The undersigned are just some of those researchers.

We have so much to learn and large studies are needed to understand how to help patients regain their health. With societal costs in the tens of billions of dollars each year, an infusion of government funding could quickly repay that investment.

Currently, ME/CFS is massively underfunded compared to other diseases of similar severity and number of patients. The NIH allocates just $5 million per year to study this illness, which affects between 836,000 and 2.5 million Americans. Patients suffering from ME/CFS deserve funding proportional to and commensurate with other diseases with similar patient populations. The Institute of Medicine, a special HHS advisory committee, and a recent NIH-appointed expert panel all agree: It is imperative to increase research funding for ME/CFS.

If invited to apply for NIH funding via a new Request for Applications (RFA), we would eagerly submit grant proposals.

Sincerely,

Linda Tannenbaum, Executive Director
Open Medicine Foundation

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