

April 18, 2014

**Open Letter to Dr. Francis Collins
Director, National Institutes of Health**

Dear Dr. Collins:

On behalf of the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME), we thank you for your attention to ME/CFS, and encourage the NIH to continue and strengthen research on this debilitating illness.

Three weeks ago, the IACFS/ME held its biennial research and clinical conference, attracting some 400 professionals and patients to discuss advances in biomedical and behavioral research on the diagnosis, pathophysiology, genetics, and treatments for ME/CFS. The overwhelming consensus from the attendees is that the research efforts, largely supported by NIH, are paying off. We are tantalizingly close to gaining an understanding of potential biomarkers, genetic traits, brain dysfunction, cytokine abnormalities, autoimmune responses, neurological disorders, and treatments. However, we need a special “push” at this time to solve the mysteries of this illness.

We call on you and Directors of key Institutes at NIH to collectively work together to issue a Request for Applications (RFA) calling for R01 and R21 projects related to ME/CFS. At a level of \$7-10 million annually for five years, an RFA would double current funding and bring talented investigators into the field for the first time. The ME/CFS RFA would also dovetail nicely with ongoing NIH initiatives including those related to the brain, big data and transformative research.

We realize the substantial reductions in the NIH budget over the past decade have made it hard to issue RFAs. This is even more reason that we must focus our support on specific targets that are poised to make significant progress in the near future. With ME/CFS related to so many other medical diseases and conditions, support for research on ME/CFS will add to, for instance, our understanding of chronic pain, viral/ bacterial infections, sleep disorders, fatigue,

autoimmunity, and cancer. In this regard, ME/CFS research already has aided knowledge of Gulf War Illness, fibromyalgia, retroviruses, and Lyme disease.

The Trans-NIH ME/CFS Research Working Group members have been helpful in coordinating awareness of the disease at the NIH. However, without financial support, their efforts to enhance applications to study ME/CFS are limited to oral encouragement. We all know that is not enough. The State of the Knowledge Workshop on ME/CFS in 2011 concluded that there is a need for interdisciplinary research, coordination of research, centralized data sharing, and recruitment of additional qualified investigators. The ME/CFS RFA could address those needs as well as the longstanding CFS Advisory Committee appeal for such an RFA.

The IACFS/ME is the largest professional organization in the world with a mission to promote, stimulate and coordinate the exchange of ideas related to ME/CFS and fibromyalgia research, patient care and treatment. Since 1990, IACFS/ME has been advocating for biomedical and behavioral research to develop ways to diagnose, prevent, and eventually cure this disease. Never before in our 20+ years have we seen such advances in research as what was reported at our recent conference. Bioinformatics, systems biology, high throughput technologies, and the microbiome provide new data and approaches to the study of ME/CFS. We are motivated with numerous possibilities, but troubled with the reality of underfunding to reach these goals.

We call on you with a united voice to set aside FY2015 funds at a level of \$7-\$10 million for an RFA on ME/CFS. Please let us know how we can help you make this happen.

Sincerely,

IACFS/ME Board of Directors

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