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NEW INITIATIVE FUELS FIGHT AGAINST CHRONIC FATIGUE SYNDROME

Partnership among leading researchers seeks to improve understanding of controversial disease

New York, NY – The newly formed Chronic Fatigue Initiative, Inc., a nonprofit organization, today announced a novel collaboration that brings together medical experts from the world's leading research institutions, including Columbia, Harvard, Stanford and Duke Universities, to identify the causes and treatment of Chronic Fatigue Syndrome (CFS), a debilitating illness that affects more than one million people in the United States. The initiative's comprehensive strategy includes funding for an epidemiology study, already underway; a well-characterized cohort recruitment; a pathogen discovery and pathogenesis study; and a Mechanism of Illness grant program that will fund additional research.

The exact cause of CFS – which afflicts patients with overwhelming fatigue and cognitive difficulty – has eluded researchers since it was first identified in 1985. Chronic Fatigue Initiative, headquartered in New York City and funded by the Hutchins Family Foundation, seeks to jumpstart and to sustain critical research by providing investigators and academic institutions with access to funds and a mechanism to ease collaborative study, enabling the best minds to drive new solutions.

The Chronic Fatigue Initiative-funded Epidemiology Project, led by the Harvard School of Public Health, aims to identify a large sample of men and women with CFS and to study their environmental exposures as well as their blood samples from before and after the time they became ill. The study will draw on epidemiologic data from three separate HSPH studies, including more than 20 years of longitudinal bio-samples from nurses and other health professionals, providing invaluable clues to environmental as well as biological risk factors for CFS.

"The Nurses and Health Professionals cohorts provide a unique setting for the investigation of CFS, because the participants in these investigations have provided detailed information on their lifestyle and medical history longitudinally for over two or three decades," said Alberto Ascherio, M.D., professor of epidemiology and nutrition at HSPH and leader of the Chronic Fatigue Initiative-sponsored epidemiology study. "A large proportion of these participants have provided blood samples, in some cases before the onset of CFS. We expect that this investigation will provide new insights on possible risk factors for this potentially debilitating condition."

Chronic Fatigue Initiative will also recruit a well-characterized cohort of CFS patients – 200 subjects who truly have the disease plus 200 healthy controls nationwide – from whom biologic samples and clinical data will be collected, ultimately enabling the discovery of pathogenic pathways. The biologic samples,

collected by clinicians from selected sites around the country, will be stored in a central bio-bank located at Duke University. The bio-bank will be accessible to researchers around the world for future study.

“A database administered at Harvard Medical School will link clinical data from the cohort to the biologic samples in the bio-bank. Together, these resources will form a unique foundation for the discovery of pathogens and pathogenic mechanisms in CFS and the identification of patients who will most likely respond to specific treatments,” said Nancy Klimas, M.D., professor of medicine, psychology, microbiology and immunology at the University of Miami School of Medicine and the principal investigator for cohort recruitment.

Following cohort recruitment, creation of the bio-bank and population of the database, W. Ian Lipkin, M.D., a prominent virologist and director of the Center for Infection and Immunity at Columbia University, and Mady Hornig, M.D., principal investigator for pathogen discovery and pathogenesis at the Center for Infection and Immunity, will lead a pathogenesis study that seeks to uncover novel viruses implicated in the disease. The team will use new techniques that allow up to 20 pathogens to be searched simultaneously.

“We are eager to join Chronic Fatigue Initiative in bringing the full measure of our resources to bear on the challenges of this debilitating syndrome that robs individuals in the prime of their productive years,” said Dr. Lipkin.

Chronic Fatigue Initiative will also offer grants, housed under the Mechanism of Illness program, to fund new research guided by five or six general hypotheses formed by a scientific advisory board of leading scientists and clinicians.

The first of many grants to be funded by the Mechanism of Illness program is the *Hutchins Family Fellow for Infectious Disease*. This year’s inaugural recipient, Claire Gordon, M.D., will work under the direction of Scott M. Hammer, M.D., professor of epidemiology and chief of the Division of Infectious Diseases at the NewYork-Presbyterian/Columbia University Medical Center. The pair will collaborate closely with Drs. Lipkin and Hornig on the pathogen discovery and pathogenesis study.

“The gift establishing the Hutchins Family Fellow in Infectious Diseases as part of the Chronic Fatigue Initiative is visionary,” said Dr. Hammer. “Training dedicated, talented young physicians in pathogen discovery and state-of-the-art care and treatment of related patient populations will produce advances that will ultimately lead to defining and defeating chronic fatigue syndrome and the morbidity it causes.”

“As more policy makers and industry experts grasp the full scale of CFS, we believe they will more likely respond in kind and increase efforts to promote research surrounding the disease,” says Scott A. Carlson, Chronic Fatigue Initiative executive director. “By simultaneously seeking to understand the causes of the illness and the breadth of our population affected, Chronic Fatigue Initiative aims to build awareness and reduce social stigma connected to CFS, ultimately improving patient lives in a comprehensive way.”

For more information, please visit www.CFInitiative.org or contact info@CFInitiative.org.

About Chronic Fatigue Syndrome

Chronic Fatigue Syndrome is a debilitating disease characterized by overwhelming fatigue often aggravated by physical or mental exertion. It does not improve with rest. The exact causes of CFS have yet to be identified and diagnostic tests do not exist. According to the CDC, symptoms for diagnosis must include severe fatigue along with at least four additional symptoms ranging from cognitive difficulty to sore throat and muscle pain. A patient is diagnosed only once all other treatable conditions are ruled out and symptoms have persisted for more than six consecutive months. In many cases, these symptoms persist for years or decades.

CFS affects more than one million people in the United States – more than multiple sclerosis, lupus, or lung cancer, according to the U.S. Centers for Disease Control and Prevention.

About the Chronic Fatigue Initiative

Chronic Fatigue Initiative is a science-based 501(c)(3) nonprofit organization fostering and supporting collaboration among the world's leading medical research, treatment and public health organizations in understanding the causes, therapies and epidemiology of Chronic Fatigue Syndrome.

Through a unique private funding strategy, Chronic Fatigue Initiative brings together a variety of scientific and academic partners to ensure that the best minds can collaborate and drive new solutions. By simultaneously seeking the causes and treatment of CFS and leading research to understand the breadth of the affected population, Chronic Fatigue Initiative aims to build awareness, reduce social stigma connected to the disease, and improve patient lives in a comprehensive way.

Participating institutions include the Center for Infection and Immunity at Columbia University, Harvard School of Public Health, Stanford Medical School, Harvard Medical School, Duke University, Brigham & Women's Hospital, Massachusetts General Hospital, University of Miami and University of Utah.

About the Hutchins Family Foundation

Chronic Fatigue Initiative is funded by the Hutchins Family Foundation, a private family foundation that has grant programs to expand research and community initiatives in public policy, education and public health throughout the United States.