

# The CFIDS Association of America

*Working to conquer chronic fatigue and immune dysfunction syndrome*

## **PRESS RELEASE**

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## **CFIDS Association Launches New Research Initiative for Chronic Fatigue Syndrome Today**

Charlotte, North Carolina - November 7, 2007. The CFIDS Association of America today launched a new initiative to advance research in the field of chronic fatigue syndrome (CFS) and accelerate progress in developing treatments for this illness. The research initiative is designed to build a new model for bridging the gap between CFS science and medicine, and it includes a campaign to raise one million dollars over a one-year period to fuel the program. This is the largest CFS research campaign to date in the United States.

“This new program represents a visionary approach to CFS research that has applications for many fields of science,” says Dr. Suzanne Vernon, who will lead the program as the CFIDS Association’s new scientific director. “There has been tremendous progress made by CFS researchers around the world in the last decade, and we now understand an enormous amount about the pathophysiology of CFS, and about the body systems that are broken or altered by this disease. But what is lacking is a mechanism for sharing this progress and information not only among investigators spread out across the globe who are working in disparate fields, but among health care professionals and patients.”

Vernon, who has 17 years of experience as a microbiologist at the Centers for Disease Control and Prevention (CDC), and who led the Molecular Epidemiology Program in the CDC’s CFS research group from 1997 to 2007, says this mechanism isn’t all that’s been missing in the world of CFS science. A whole network is needed.

“There has been no organization, academic institution or agency that has taken on the enormous task of bringing all this information together, connecting the dots and forging new collaborations across the globe,” said Dr. Vernon. “Because of the enormous progress made in recent years, this is a critical time for determining CFS research needs and directions—decisions that will have implications that will be felt for decades. The CFIDS Association is really on the cutting edge in recognizing the need to bridge the gap between CFS science and medicine, and for taking the leadership reins to start building the framework for that bridge in a way that has the potential to catapult the field forward.”

A million-dollar fundraising campaign for CFS research is part of the new research initiative. “The pace of progress we’re making is too slow and we need an infusion of funds to move the field forward faster,” says Kimberly McCleary, president and CEO of the CFIDS Association.

Specific elements of the new CFIDS Association research initiative include:

- Revamping the Association’s own research grants program, which has funded \$4.8 million in research so far, in order to expedite progress in the search for biomarkers, treatments and a cure
- Building strong collaborations with CFS researchers across the world to identify synergies, gaps and opportunities that warrant higher priority
- Developing new opportunities for scientists to share ideas, knowledge and data to advance the field
- Surveying other fields of research for findings and scientific approaches of potential relevance to CFS
- Securing a new infusion of federal research funding for CFS
- Attracting new investigators from a number of disciplines to the field of CFS research.

Dr. Vernon believes that the research advances made in recent years should give all CFS patients hope, which has therapeutic value of its own. “But with this new initiative, within a few years we want to be able to

offer more than hope to patients and their families, whose lives have been so altered by this debilitating illness. We want to be able to offer effective treatment interventions. Until we have a cure, that's the next important step."

Benjamin Luft, MD, a professor and infectious disease specialist at SUNY at Stony Brook, said today that the CFIDS Association's research initiative and "the appointment of Suzanne Vernon to lead the program is a coup for both the Association and all who care about understanding and treating this elusive condition. Dr. Vernon's work at the CDC demonstrated a unique capacity to bring together various disciplines to understand chronic fatigue syndrome. This work serves as a paradigm for understanding diseases that are caused by multiple factors. Ultimately this knowledge is our best hope for effective therapy."

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### ***About the CFIDS Association of America***

The CFIDS Association was founded in 1987 to stimulate high-quality CFS research, improve the ability of health care professionals to diagnose and manage the illness, secure a meaningful response to CFS from the federal government, provide educational information for patients and their families, and build widespread public awareness of CFS. The organization has invested more than \$25 million in education, public policy and research and is the largest charitable funder and advocate of CFS research in the U.S.

### ***About Chronic Fatigue Syndrome (CFS)***

Chronic fatigue syndrome (CFS), which is also known as chronic fatigue and immune dysfunction syndrome (CFIDS), affects more than a million Americans. Historically, CFS has been difficult to diagnose and treat because there is no diagnostic test and no therapy that treats the illness at its core, instead of simply treating the symptoms. Diagnosis and treatment are further complicated because the symptoms and severity of CFS can vary considerably, both over time and from patient to patient.

CFS is characterized by at least six months of profound, incapacitating fatigue and postexertional relapse—a worsening of symptoms following physical or mental activity. Other defining symptoms include impaired memory or concentration, sleep problems, muscle pain, joint pain, headaches, sore throat and tender lymph nodes.

To learn more about CFS, visit <http://www.cfids.org/cfs>.