

Meet Suzanne Vernon

BY MARCIA HARMON, DIRECTOR OF COMMUNICATIONS

Last year the CFIDS Association began exploring a new approach to its role in fostering research. With \$4.8 million in Association-funded studies since 1987, and many more millions pumped into research through our advocacy work, we sought a new strategy to complement those efforts. In November the Association embarked on our most ambitious CFS research initiative to date—an expanded research program to accelerate the discovery of biomarkers, better diagnostics and more effective treatments for CFS.

To fuel this program, the Association launched a \$1 million fundraising campaign, the largest CFS research campaign to date in the United States. And to lead the program, the Association recruited Suzanne Vernon, PhD, as scientific director. It will be her task to help us chart a brand-new trajectory and move us to our ultimate destination, with whatever divergent explorations or course corrections are needed along the way.

Vernon has 17 years of experience as a microbiologist at the Centers for Disease Control and Prevention (CDC), where she helped identify viral markers that predict cervical cancer before moving into the CFS research group at the agency in 1996. She led the CDC's chronic fatigue syndrome Molecular Epidemiology Program for the past decade, and her team was one of the first research teams in the world to apply human genomics and genetics to identify biologic and diagnostic correlates of CFS.

Vernon recently sat down for an interview that reveals her incredible expertise, enthusiasm for the tasks ahead and commitment to “translating” CFS research for the people who need it—not just fellow researchers, but medical professionals and patients.

***Q** In the past 20 years, more than 3,500 peer-reviewed papers about CFS have appeared in the scientific literature. But for many patients, particularly longtime ones, their day-to-day lives haven't significantly improved. And some patients are sicker today than ever. Why should the CFS community be excited about where CFS science is today?*

A There has been tremendous progress made by CFS researchers around the world in the last decade. We now understand an enormous amount about the pathophysiology of CFS, and about the body systems that are broken or altered by this disease. This was crystallized for me at the IACFS/ME conference in Ft. Lauderdale in January 2007, where multiple presentations showed just how much we know about the pathogenesis of CFS, especially compared to when I first started in the field in 1996. All this research has given us a strong foundation, a solid knowledge base to work from in the future.

But what was also clear to me at the IACFS meeting is that we really need to use this hard-won information about all those broken body systems, and use the genomic information we now have about CFS. The science is very strong. Where we are weak is in bringing all this information together and connecting the dots. I saw the coalescing of all these various research groups and findings, and I wondered: Who is going to bring all this information together? Who is going to use it to make it have an impact?

We're at a crossroads. It's time to move the entire field forward by encouraging the kind of collaboration and communication among scientists that propels research to the next stage, and it's time to spearhead empiric diagnostic efforts and new treatment interventions.

Q *You were at the CDC as the team leader of the Molecular Epidemiology Program in the CFS research section. Why didn't you stay there to engage in this challenge?*

A During the past decade, I've had the opportunity to work with an incredibly innovative laboratory and computational research team at the CDC, and I value the time I spent there. But for me, the next big challenge is focusing on how we effectively intervene to control and treat CFS. I realized this was going to be very difficult as team leader in a molecular epidemiology setting, so I began looking at opportunities elsewhere to be engaged in this next critical step.

Q *Why did you pick the CFIDS Association when there were so many other opportunities open to you?*

A The timing was perfect. The Association was looking for a scientific director because the organization had come to the same conclusion I had—that there's a void that needs to be filled, a gap between the science and medicine. There has been tremendous progress made by CFS researchers around the world. 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 various fields, but among health care professionals and patients.

I was very impressed that the CFIDS Association was preparing to launch a new research initiative to fill that void. And I recognized that this organization has been spearheading the education and awareness efforts for CFS, and it has been a leader in funding CFS research for the past 20 years. So joining the Association is the perfect marriage for me.

Q *Does a patient advocacy organization have any business setting itself up to fill that void, to connect those dots, to influence the course of CFS research?*

A Absolutely. If we don't take on this role, then who will? 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. Because of

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SUZANNE VERNON, PHD
Scientific director, CFIDS Association of America

the 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.

I was recently reading an article in *Scientific American*, which said science that benefits humanity is a combination of data, the hypothesis and the narrative. What's often been missing from science and medicine is the narrative. Too often that narrative is delivered only in articles that take a hard-core scientist to understand and at conferences that are usually attended by a relatively small group of experts.

Our challenge with the new research initiative is to find ways to deliver that narrative to the masses. We need a powerful “CFS narrative” that translates information: 1) for investigators working in various disciplines who may not be aware of research findings that have a bearing on their own CFS research; 2) for researchers in other fields whose work may have applications for CFS; 3) for health care professionals who don't have the time or the inclination to read dense, hard-core CFS studies and translate what effect the science has on the medicine; and 4) for patients who are impacted by this illness every day.

Q *What are the most significant challenges the CFS field faces in the immediate future?*

A One of our major challenges is engaging investigators in CFS and bringing them into the field. We need an

ROLE OF THE SCIENTIFIC DIRECTOR

The post of scientific director was created to enable the CFIDS Association to advance CFS research at a faster pace.

Specific priorities that Vernon will address include:

- Revamping the Association's own research grants program, which has funded \$4.8 million in research so far, to expedite progress in the search for biomarkers, diagnostics and treatments
- 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
- Assisting in efforts to secure a new infusion of federal research funding for CFS
- Attracting new investigators from a number of disciplines to the field of CFS research

ON THE JOB, ON THE ROAD

In her role as scientific director for the Association, Suzanne Vernon, Phd, has hit the ground running, literally—making trips to scientific meetings, visiting with researchers and sharing CFS science with public policymakers. Here's a sample from her first-quarter itinerary:

- Presented CFS findings at a scientific meeting at the Banbury Center in NY.
- Made onsite visits to research facilities of Drs. Shungu and Mathew and Dr. Lipkin.
- Met with health appropriators and policymakers in Washington, DC
- Will attend NIH conference in March on PROMIS initiative to improve clinical research tools
- Will give a CFS talk at NIH Integrative Neural Immune Network series.

infusion of fresh talent from a number of disciplines. We have some of the best researchers in the world doing immunology research on other diseases. How do we bring those researchers into the CFS field? We have some of the most amazing neuroscience—brain science—going on in this country. How do we get those people interested in pathway components of CFS?

Another hurdle is that we need an infusion of money at the National Institutes of Health to help advance CFS research. The amount of funding the NIH currently provides for CFS is simply not commensurate with the public health burden this illness places on Americans.

And we need to share data. One of the most satisfying experiences of my career came from sharing the incredibly extensive data set that the CDC's CFS research group collected. This kind of data sharing was new to the CDC, but it led to C3, the CFS Computational Challenge. This resulted in the April 2006 publication of 14 CFS research papers in *Pharmacogenomics*, giving CFS a kind of exposure it had never had before. C3 and the *Pharmacogenomics* papers were the culmination of years of work—epidemiological, clinical and genomics research—that was brought together by an amazing group of 25 investigators. It was a beautiful example of how sharing information and engaging new people can really advance the field.

We need a data-sharing process for CFS. The NIH now has a data-sharing policy, and other agencies may follow suit. As part of our new research program, I think the CFIDS Association can be instrumental in establishing a data-sharing mechanism for CFS. In the long run, this will help create a culture that will be emulated by other fields, and I think it will make an enormous difference in the progress we can make.

Q *What are you most excited about as you take on your new responsibilities as scientific director?*

A I'm incredibly excited about having the opportunity to talk to people whose lives are affected by CFS, and to talk with the medical professionals who care for them. It's important for people to understand how the science impacts the medicine, and I can help further that understanding.

When we started the human genome efforts at the CDC, we were really on the front edge of that wave, and we were emulated by a lot of people. Similarly, when the articles in *Pharmacogenomics* were published, it was unprecedented to look at an illness by bringing all these disparate pieces together in a systems biology way. Now, I'm happy to be on the cutting edge of translational science, which is not only the next challenge for me, but the next challenge for science in general.

Q *What key goals do you think are most important for the CFIDS Association and the CFS field over the next 5 to 10 years?*

A 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 physicians tools to objectively diagnose, then effectively treat, this illness. We want to help physicians take some of the guesswork out of diagnosis and management. Until we have a cure, that's the next important step. ■