

Organizations Making History

BY CFIDS ASSOCIATION STAFF CONTRIBUTORS

So many organizations support and serve the CFS community and have shaped its history. Here's a brief look at a few that have led the way.

History is often forged through individual effort, but when people come together to support each other and to further a cause, that's where mountains are moved. Powerful organizations are fueled by common goals and common purpose, driven by the shared labor of many, the combined support of all. This is nothing new to the CFS community that has had to band together in diverse ways to push for progress, to share knowledge and to advance research.

As the CFIDS Association marks 20 years of service to the CFS community, it honors the many other organizations making a difference in the lives of people with CFS and related disorders. Here are profiles of seven diverse organizations that have impacted the CFS and fibromyalgia (FM) community on national, state and "virtual" levels. Some played early roles and have dissolved. Others are still around today or have more recently emerged.

Watch the *CFIDSLink* for more profiles of organizations, events and people making CFS history.

Mass Appeal

Big plans and big achievements are the hallmarks of one of the oldest, continuously operating support groups. > > >

National Advocacy's

How do you improve public policy for a complex and sometimes misunderstood illness? By "pricking" the interest of legislators and health officials with sound medical information, powerful personal stories and as much visibility and diligence as you can muster. For CFS, that came in the form of an early advocacy coalition called **CACTUS**, the CFIDS Action Campaign for the United States. Here's how it all began.

In the mid- to late-1980s, there were several advocacy groups working to engage elected officials and policy makers in supporting CFS research. Minnann, led by **Ted Van Zelst**, was the first to address Congress about CFS, building a relationship with U.S. Representative **John E. Porter**, then a junior member of Congress from Ted's Illinois district. **Barry Sleight** ran the CFIDS Information Institute, working in Washington, D.C., to understand federal funding cycles and how to exert pressure.

Meanwhile, the San Francisco CFIDS Foundation—where founders **Jan Montgomery** and **Marya Grambs** applied lessons learned during the city's AIDS crisis—demonstrated leadership with state and local government by building bridges between the lawmakers, public health workers, clinicians and community agencies. They established the first Fatigue Clinic at the University of California San Francisco, staffed by pioneering physician **Dr. Daniel Peterson** and renowned researcher **Dr. Jay Levy**. And they held several roundtable research meetings with high-ranking public health officials, CFIDS researchers and advocates to define priorities and identify funding streams.

In 1990, Montgomery and Grambs were also instrumental in creating CACTUS. They and leaders representing 14 other organizations from across the country, including the CFIDS Association and Mass CFIDS (profiled on page 17), developed the plan for CACTUS and invited advocates to "wage a campaign of advocacy and activism to > >

One of the earliest patient organizations to form in the U.S. was the **Mass CFIDS Association** (then called **Mass CEBV** for chronic Epstein-Barr virus), born in Quincy, Massachusetts, in 1983 when **Bonnie Gorman** kicked off three important efforts: a support group, educational outreach and a media education campaign.

In the years that followed, the organization expanded to a statewide network of

support groups, provided regional medical education with the help of CEBV and CFS experts and worked to get CFS articles in major newspapers. Their own newsletter, *The Update*, which began as 4 pages and grew to more than 40, was published for 20 straight years before shutting down in 2003 due to personnel limitations. Their telephone information line remains active to this day to take calls from anyone wanting to learn more about the illness.

Recognizing early that politics plays a role in disease recognition and research, **Mass CFIDS** was one of the first organizations to push the government for more research funding.

Says current president **Ken Casanova**, “Without such patient advocacy, recognition of this illness and subsequent research would’ve been nearly impossible.” We agree.

Prickly Beginning

bring the reality of CFIDS to national attention.” Ambitious goals, including changing the name of the illness, were outlined. Key responsibilities were distributed among the groups represented on the organizing committee. The *Chronicle* was designated as the national journal of the CACTUS campaign, San Francisco CFIDS Foundation handled national press for CACTUS and provided grant writing and fundraising services, and the CFS Information Institute coordinated federal, state and local legislative efforts for CACTUS.

By mid-1991, leaders recognized that the job of coordinating a dispersed corps of volunteers disabled by CFIDS required full-time attention, and with financial support from organizing member **Ed Taylor** and a few others, executive director **Joan Iten Sutherland** was hired and lobbyist **Thomas Sheridan** was engaged to provide strategic guidance. A September 1991 Lobby Day was held, with the goal of getting CFS recognized in the pending legislation that would direct the National Institutes of Health’s priorities.

Unfortunately, CACTUS didn’t survive long enough to realize the potential of the organizing committee’s initial “prickly” plan. Burnout and funding challenges claimed Sutherland and Sleight, tensions between groups and individuals consumed limited energy and resources, and in early 1992 CACTUS dissolved due to a lack of capacity to execute its initiatives. But the roots of this advocacy effort had nonetheless taken hold.

The CFIDS Association, at the urging of Van Zelst and Taylor, accepted responsibility for leading national advocacy efforts and continuing the work Sheridan had begun on the NIH Revitalization Act. To this day, Sheridan, the Association and thousands of volunteer advocates lobby our national leaders and health officials for improved public policy and increased research attention for this illness.

“Support groups have strengthened advocacy on the local, grassroots level where national organizations can’t specifically focus. They also give patients a local connection with other patients.”

- Mike Munoz, president of Rocky Mountain CFIDS/FMS Association

ProHealth is unique in the CFS world: a commercial enterprise that also generously disseminates vast amounts of free research, advocacy and support information to CFS patients and their families.

From its 1988 beginning selling nutritional supplements, ProHealth has demonstrated a commitment to CFS and FM patients, becoming a resource not only for products, but for information and community, too. Perhaps as significant, its audience may comprise the largest CFS-related network worldwide. The company's website hosts five million visits a year, research and clinical articles, an e-newsletter and active message boards on a variety of subjects.

Founder Rich Carson was just 23 years old when CFS sidelined his sales career and sent him in search of researchers and clinicians who might explain the chronic Epstein-Barr virus diagnosis he received in 1981, before there was anything called chronic fatigue syndrome. After leading a local support group, Rich started ProHealth to share information about the nutritional supplements he found helpful in treating his symptoms. And he put his charisma and sales skills to use as a fundraiser, establishing contacts with high profile people with CFS connections. ProHealth reports having raised and donated more than \$2.6 million to support CFS and FM research through organizations including the CFIDS Association of America and the National Fibromyalgia Association.

Rich and ProHealth are now on the front lines of a new initiative—to change the name of CFS. In January 2007, Rich assembled a group of expert CFS clinicians and researchers who suggested using the term ME/CFS (or CFS/ME). Soon he'll announce a group of respected advocates who'll help educate and familiarize others with the new term.

Even with all his accomplishments through ProHealth, Rich states, "Changing the name chronic fatigue syndrome is by far the most important endeavor I've ever undertaken."

That's no small statement from the man who put in the effort and dedication to build a commercial success like ProHealth.

Offering Help

In the heart of Utah sits an organization with a heartfelt mission to help patients get better care

OFFER, the Organization for Fatigue and Fibromyalgia Education and Research, holds monthly education meetings, organizes provider and patient conferences, hosts an informative website and publishes a monthly newsletter. With no paid staff, it operates on the energy of a working Board of Directors and chronically ill volunteers assisted by a few healthy participants. And other than a handful of gifts, it runs on numerous small donations from people with CFS and fibromyalgia (FM). That, and the personal dedication of its directors, including principle founder **Dr. Lucinda Bateman**.

Dr. Bateman, an internist with a clinic dedicated to treating fatigue and fibromyalgia, began her medical residency with a quest for treatment know-how to help her sister Shauna who was plagued by debilitating, mysterious symptoms now all too familiar. From this experience grew a desire to bring knowledge to other health care professionals and to help patients get vital medical information and care.

OFFER is nationally respected for its conferences that are focused on bringing family practice doctors and internists into the service of people with CFS and FM. As many as 550 health care professionals and 1,300 patients and family members attend these events.

According to Dr. Bateman, "OFFER has filled a gap that couldn't be met by consultation and individual patient care. It's helping patients and health care professionals conquer CFS and FM by networking, education, advocacy and research."

And no history of OFFER would be complete without acknowledging three other compassionate people who contributed to the fabric of what OFFER has become. First, **Marie McDonald** and **Jan Racine**, who for 12 years led a Salt Lake City support group that became a precursor to OFFER's monthly education meetings. And especially **Dr. Deborah Robinson**, who treated some 3,000 people and was a founding OFFER Director before her death in 2005.

Commerce & Compassion

Internet **Ready** Delivering communication and community

Nowadays, we tend to take the Internet and e-mail for granted, but back in 1996, the personal computer was just becoming commonplace in homes throughout the industrialized world. Meanwhile, within the world of CFS, research and opinions about the illness were a topic of intense discussion. And where these two worlds intersected, a new project was formed that today remains a prime information source for CFS patients, their families and other interested parties.

Enter **Co-Cure**, an international Internet project created to “communicate and cooperate for a cure.” Founded by **Donna Tabish**, **Katherine Carrington** and **Wanda Tilley** along with the help of people like **Margaret Bailey** and **Arie van Buuren**, Co-Cure utilized emerging LISTSERV(tm) technology to use the Internet and e-mail to disseminate information about research findings and treatment options, as well as provide a forum for anyone interested in CFS and/or fibromyalgia.

Says current Co-Cure manager **Ray Colliton**, who came to the project in February of 1997, “It was a time in which hope for research discoveries was running high. Co-Cure was launched as a reliable source of information about CFS and fibromyalgia research and medical advice and to provide a way for various groups to announce their events and ask for assistance with their projects.”

It has also become a sounding board for many issues pertinent to the patient community. In fact, the Co-Cure archive reads like a history of the CFS world over the past 11 years.

Not an organization, per se, but an Internet-based project, Co-Cure started with about 200 subscribers and now has 2,500, plus many more readers who receive the information through automated downloads called RSS feeds. Any reader can post information, and the project is maintained by a collection of moderators from around the world.

But there was a time when the future of Co-Cure wasn't as certain. Colliton describes that in 1998, when the last original founder had to leave the project, the other moderators had some concerns about what might happen next. Would people continue to post messages? Could Colliton and the others handle the website? They held their breaths for a few days, but much to their delight, postings continued to flourish and, most importantly, the project continued to operate completely by consensus—a concept that's at the core of Co-Cure's philosophy.

Shares one of Co-Cure's subscribers, **John Herd**, “Untold numbers of bridges of communication among patients and patient organizations have been formed because of information that Co-Cure has distributed.”

According to Colliton, that's just the point. “Information is power,” he says. “Providing information that's accurate, and as complete as we can make it, to the patient community is a way of empowering everyone.”

“Empowerment, respect, dignity and safety—the life net to a very unkind world that doesn't embrace CFS and other neuroendocrineimmune disorders in the way that it should. That's what organizations like ours provide.”

- Marly Silverman, founder of P.A.N.D.O.R.A, a patient alliance headquartered in south Florida.

Instituting Success

When the Whittemore Peterson Institute for Neuro-Immune Disease opens in Reno in 2009, it will be the first center of its kind—combining clinical care, research and education for CFS, FM, Gulf War Illness, multiple sclerosis and autism. Founders **Annette and Harvey Whittemore** and **Dr. Daniel Peterson** have attracted support from the federal government and the state of Nevada, as well as individuals, to make this dream a reality.

Blueprints have been drawn for the facility to be housed within the University of Nevada Medical School’s Center for Molecular Medicine, and models for delivering comprehensive patient care are being developed. Several research collaborations have

begun and priorities for future projects are being shaped by the Institute’s Scientific Advisory Board.

With the goal of translating progress from “bench to bedside,” this unique institution promises to advance our understanding of CFS and improve the care that all CFS patients receive.

Scientifically Speaking

The **International Association for CFS/ME (IACFS/ME)** was founded in 1990 by researcher **Dr. Dharam Ablashi** and patient advocate **Orvalene Prewitt** and was chartered in 1992. Back then it was called the AACFS, the American Association for Chronic Fatigue Syndrome. Though the name may have changed, this organization’s purpose has been constant.

At its first meeting, the Board of Directors set forth goals to bring together researchers, clinicians, health care professionals, CFS support groups and patients so that all could learn more about this illness through discussion, research and education—with special emphasis on educating physicians to diagnose and treat CFS patients. This, at a time when CFS was not recognized by most physicians despite being recognized by the CDC and NIH.

In the years since that first meeting, the IACFS/ME has reviewed research, fostered scientific collaborations and produced biannual conferences bringing the leading CFS researchers and medical professionals together to share their expertise. The most recent conference—the organization’s eighth—held in Fort Lauderdale, FL, January 2007, featured record attendance, an impressive array of presentations and a budding convergence of scientific findings. Hundreds of researchers, medical professionals and CFS patients from around the world convened at the event, further reinforcing the shift from an American association to an international one.

One can only imagine what’s in store for the future as medical and scientific collaborations emerge under the encouragement of this global organization, currently presided over by **Dr. Nancy Klimas**, a highly respected and admired CFS researcher and clinician herself.

