

# People Making History

BY CFIDS ASSOCIATION STAFF CONTRIBUTORS

People make up a community and fuel a cause. We salute all who've worked independently or with others to make CFS history. Here are a few of their stories.

**T**ime marches forward, but history advances only through the actions of dedicated people. Articulate advocates. Caring support group leaders. Innovative researchers. Compassionate medical professionals. Loving friends and family members. Inspired and inspiring CFS patients themselves. Courageous people, with nothing in common but a desire to fight back against a very vexing illness, have influenced the course of history for people living with CFS. As physician Dr. David Bell has noted, "Nearly everything good that has come to people with CFS has come via the support community."

In so many ways, the CFS community has had to bring about its own change—fund its own research initiatives; conduct its own awareness activities; define its own policy priorities. We're still short of a cure, but the horizon is bright thanks to the work of countless committed individuals.

So any look at CFS history must start with the people who've shaped it—in ways both large and small. We'd need a volume the size of the Manhattan Yellow Pages to appropriately acknowledge everyone who has made an impact. Here are a few familiar faces and some new ones too—people whose stories speak to the contributions so many of you have made.

## Young and Inspired

When the time came for Katie Manning's graduation project, there was no question about the topic.

Katie's symptoms had come on suddenly when she was a 16-year-old high school junior in coastal Wilmington, North Carolina. An active, athletic girl who loved soccer and surfing, Katie woke up with a sore throat. Doctors first thought it was mononucleosis, but eventually diagnosed CFS.

Within a month she was in a homebound school program and struggling to keep up with her class work. "I thought I wouldn't miss being in school, but I did," says Katie. "All the stuff I did before I got sick was sort of going on without me, but I was so tired that I couldn't really do anything about it. At least my friends and relatives came by to visit so I didn't feel left out completely."

By the fall of 2006, Katie was a senior with a research paper and related project to develop. She elicited the support of a pizza parlor in nearby Wrightsville Beach that agreed to donate a

percentage of one day's profits to Katie's favorite cause, the effort to conquer chronic fatigue syndrome.

"It took on a life of its own," Katie recalled. "I was expecting to raise something like \$100 or \$200." But even after the designated day, gifts kept pouring in.

To date she's raised \$1,200—all donated to the CFIDS Association to help with education, advocacy and research initiatives. And just as important to her, she's raised awareness about the illness that affected her high school experience so profoundly.

Katie, who turned 18 in April, hopes to study at least part-time at the University of North Carolina at Wilmington this fall. Her health has seen "a whole lot of improvement," but she says, "I know I can't do it all, and I have to pace myself."

Her advice for other teens with CFS: "Don't lose hope. It will get better, even though it feels like it takes forever."

Incidentally, on her graduation project about CFS, Katie earned an A.

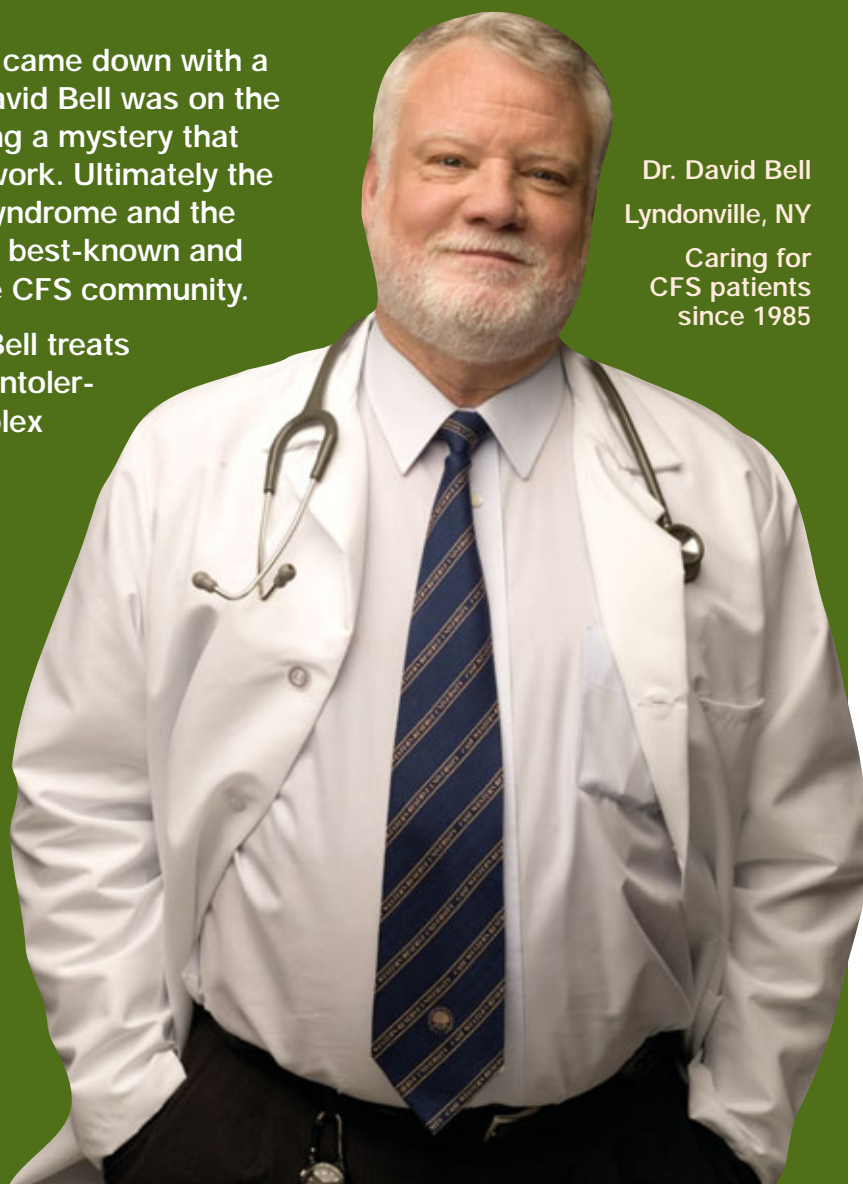
# Medicine Man

When 220 people in upstate New York came down with a puzzling, debilitating illness in 1985, Dr. David Bell was on the job caring for the patients and investigating a mystery that would become a centerpiece of his life's work. Ultimately the disease would be called chronic fatigue syndrome and the doctor would become arguably one of the best-known and most beloved medical professionals in the CFS community.

Today roughly half of the patients Dr. Bell treats suffer from CFS, fibromyalgia, orthostatic intolerance or myalgic encephalomyelitis—complex disorders with overlapping symptoms. So how does this pioneer view CFS and its implications in the medical community?

"I'm convinced that chronic fatigue syndrome and fibromyalgia are treatable illnesses that can be managed successfully. I believe that the medical profession will rise to the task of addressing this illness properly," Dr. Bell shares.

Encouraging words from a man who's been involved since the very beginning. No doubt his own contributions and decades of service will influence the ultimate prognosis.



Dr. David Bell  
Lyndonville, NY

Caring for  
CFS patients  
since 1985

◀ From the  
previous page:  
Katie Manning  
Wilmington, NC

Teen CFS  
advocate and  
fundraiser;



“ CFS took me from helping children in my community to hardly being able to **help myself**. But I keep on top of my congressman to support **the needs** of people with this illness. ”

Carrie Loney, everyday activist  
Sumter, SC



# Tutti per la Causa!

Interviewing Sydney Pollack, Barbra Streisand and Gene Hackman for feature articles published in *Harpers Bazaar Italy*. Producing documentaries and commercials for Italian television. Acting as interpreter for Oscar-winning composer Ennio Morricone and Warren Beatty as they worked on *Love Affair*. Serving as president and vice president of several family-owned companies.

This was Vivian Treves's life. It was fulfilling and it was exciting. She had worked for 20 years to build it. Born and raised in New York by Italian parents who each fled to the United States because of racial laws instituted against the Jews in Italy, Vivian was immensely grateful to the U.S. for taking her family in, and it became her mission to help build cultural bonds between the two countries.

She spent years earning a reputation as a cultural liaison between the American and Italian film industries. When European directors, actors and composers worked on projects with the American film industry, it was Vivian who often served as liaison and interpreter.

"I didn't really think of my life as glamorous," says Vivian. "That was just the career I'd built. But it was interesting, and I enjoyed the creativity and artistry of these giants in the film industry. When I'd work with someone like Morricone as he was creating the *Untouchables* score for director Brian de Palma, I'd be on the phone as their interpreter, in the room for face-to-face meetings and at my office translating all their written correspondence to each other. It was fascinating."

Vivian continues, "It was a period in my life when I was working 40- to 70-hour weeks. I was based in New York, but traveled extensively. I'd be in London working on a project. Then I'd be crisscrossing the globe—from Paris to Sao Paulo to Hong Kong to Sydney—in 26 days to shoot a promotional film for American Express TRS. Then I'd be in the office of the Treves Group, our family-owned business, which served as a major distributor of international magazines and newspapers. Then I'd be traveling to see friends and family. It was a time of incredible vigor and professional accomplishment for me."

That all ended in 1993 when Vivian, then 43, returned to New York from a brief business trip to

Europe. What seemed like a bad case of jetlag or a virulent type of flu took hold of her and wouldn't release its grip. It was the beginning of a 14-year journey with chronic fatigue syndrome that continues today.

The early years were the worst. Her symptoms were so severe that many weeks Vivian never left her home. Finding the energy to wash her hair or the clarity to read a newspaper article were major victories. On top of dealing with life-changing, debilitating symptoms that made her career and social life things of the past, Vivian had to come to terms with the psychological impact of having a chronic illness.

The **injustice** of not being believed and the stigma attached to CFS, especially in the early '90s, made me **howl with rage**.

Her disbelief gave way to grief, then anger. "I couldn't accept that I had CFS. My condition was so grave that it was incomprehensible to me. Then, when I began to talk about it to colleagues and medical professionals, the injustice of not being believed and the stigma attached to CFS, especially in the early '90s, made me howl with rage."

The first three years were a long nightmare. So profoundly ill that she sometimes couldn't lift her head from the pillow, Vivian was terrified that she wouldn't have the strength to get better or to find resources or treatments that might help. That's when she discovered the CFIDS Association. "The Association was a lifesaver for me. I discovered that there was a place that offered accurate, reliable information, a place that made me feel like I wasn't alone, a place where people worked every day on my behalf. With every available scrap of energy I had, I used the resources of the Association to read about the research findings, possible causes and treatment options."

Vivian was so grateful that she vowed that if she every recovered enough to help someone else as the Association was helping her, she would lend whatever

resources she had—her time, her talents, her financial means—to aid the cause.

It took about six years for her to partially recover. She gained back some of her function, thanks to the help of New York clinician Dr. Susan Levine and treatments like acupuncture, mild graded exercise and a change in diet. And she made her peace with the illness, thanks to the help of psychologist Dr. Laura Monserrat and the friends and family who stuck by her.

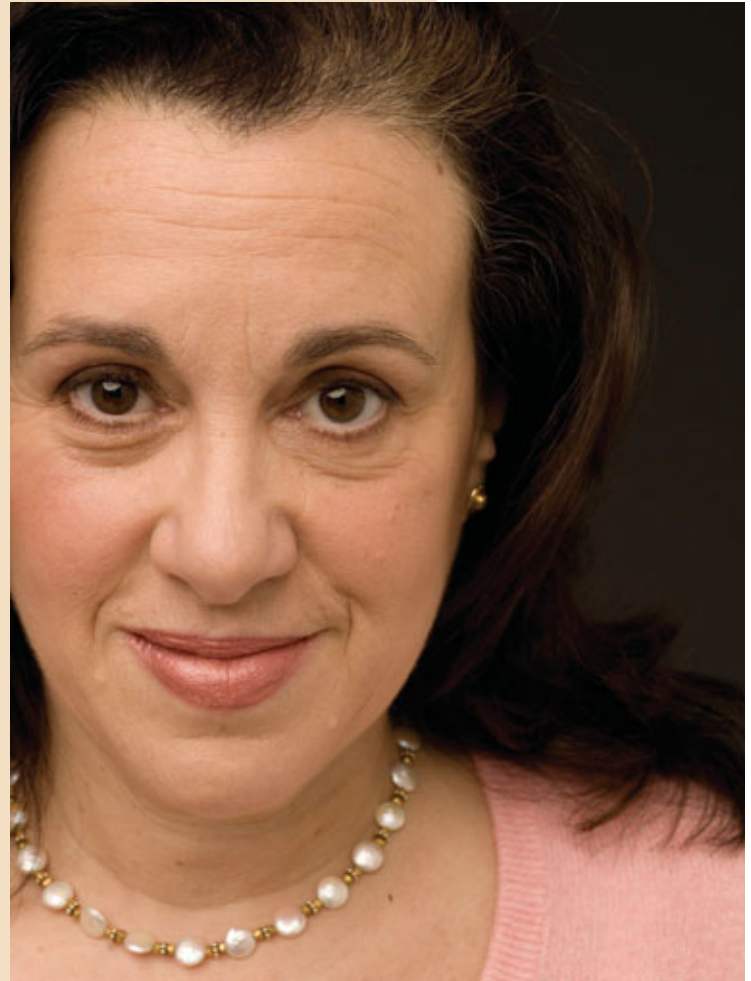
Then she kept her vow. First, she made annual donations to the CFIDS Association and she helped Kim Snyder as she worked on the documentary *I Remember Me*. Today she is a spokesperson for the national CFS public awareness campaign, having participated in the photo exhibit that's currently traveling across the country. And she is one of the greatest champions of MyCause, the Association's online fundraising tool, having raised more than \$5,900 for CFS initiatives from family and friends.

"I think of it as a responsibility and a privilege to help the CFIDS Association with its work. It costs money to send out information packets to patients around the country, to maintain the websites, to organize Lobby Day, to pay talented staff to do vital work that patients can't do for themselves. In my bleakest years, I got most of my CFS information and inspiration from the CFIDS Association. It's important for that work to continue for others.

"Now, with the provider education and with the public awareness campaign, this illness is finally being recognized and validated in a way it never has before. It took the Association years to fight for the government to fund this campaign. That, too, must continue."

Vivian is still not fully recovered. She hasn't been able to read a novel in 14 years because she still doesn't have the concentration and memory needed. Instead of jetsetting around the globe for her career, she can take on only one or two small projects a year without risking a relapse, and even then it takes her three months to recover from a three-week venture. She reserves what energy she has for her five-year-old daughter Allegra and for helping aid the CFS cause.

And she dreams of a day when she'll be able to contribute even more to the work of spreading CFS awareness not just in this country, but globally, especially in her beloved Italy.



**Vivian Treves**  
 East Hampton, NY  
 CFS spokesperson;  
 MyCause activist;  
 Association member  
 and donor

“ Support groups give people with CFS a voice and a place to share. **Living with CFS** helps me understand how members feel and what needs I may be able to serve through the group. ”



Susan Midcap, CFS support group leader, Hartville, OH

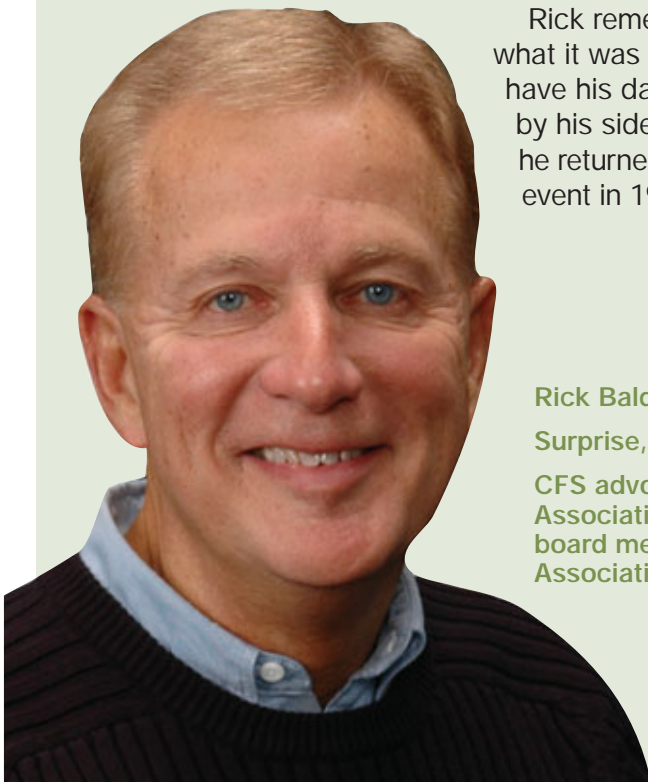
## Father and Advocate

“I was eager to make a difference,” recalls Rick Baldwin, dedicated father and determined CFS advocate. “My daughter, Allison, had been sick for more than two years, and we’d spent that time looking for a knowledgeable doctor and some sign of recognition of CFS by medical authorities. It wasn’t there.” Disappointed by what he found, Rick looked for a way to raise awareness.

Enter Lobby Day. “I found the CFIDS Association on the Internet and was intrigued by the opportunity to make an impact in Washington, D.C.” Allison was too ill to go that year, but Rick decided to go anyway, in her place. That was back in 1998, and he hasn’t missed one since. In fact, now he holds the record for the most Lobby Days attended.

“You hear a lot about the empowering effect of Lobby Day, but I’m here to tell you that it’s true. To be part of the process, influencing lawmakers’ actions, was so powerful. I knew I wanted to do it again the next year and hoped that Allison could experience it too.”

Rick remembers what it was like to have his daughter by his side when he returned for the event in 1999.



**Rick Baldwin**  
 Surprise, AZ  
 CFS advocate;  
 Association  
 board member;  
 Association donor

“We were walking through the tunnels under the Capitol building when we saw our senator, Joe Biden, walking toward us. We stopped him and introduced ourselves. He really engaged with us, asking what he could do to help. It made a huge impact on Allison and me. After that, we received newspaper clippings about CFS from his office, with short notes of support.”

A move to Arizona last year means that Rick now has new members of Congress to educate.

But educating people about CFS isn’t new to Rick. Early on, he helped lead a large support group and attended as many federal meetings about CFS as possible. He placed pamphlets about CFS under windshield wipers of cars parked at a local mall and gave radio and newspaper interviews about the illness.

Having spent 11 years working to raise awareness, Rick found the November 3, 2006, national press conference particularly meaningful. “It was a powerful moment. We have a lot of people’s attention now and must continue the momentum of the national campaign.” In fact, Rick relishes the opportunity to spread the good news at this year’s Lobby Day on May 15. “Progress in scientific efforts and awareness will energize our advocates and those whose support we seek,” he predicts.

Thinking about the current environment, he also recognizes the challenges. “We’re competing with a lot of other causes for government dollars. We’ve got to attract researchers to study CFS even though it’s not yet a well-funded field.”

Rick was elected to the Association’s Board of Directors in 2001, and he’s been a steady force through times of change and transition. But for Rick it all comes back to making a difference. “I witnessed the struggles Allison has encountered since falling ill at age 16. I want to make life easier for other teens and young adults with CFS, as well as their families.”

Through his history of advocacy, this energetic, enthusiastic and caring father has recruited many others—on and off Capitol Hill—to greater levels of support for the cause.

# Assisting the Field

Dawn LaBarbera doesn't have CFS. She doesn't have a family member with CFS. In fact, she didn't even know anyone with the illness when she decided to take a CFS training course for medical professionals organized by the Association back in 2001. But that first day of training had a profound impact that's motivated her to educate other physician assistants (PAs) about this illness.

"I was surprised by how many of the people at that training event had CFS themselves and how severely it had affected their lives. I couldn't get over how one formerly prominent surgeon could barely pass the course materials to me. It was eye-opening how CFS could debilitate this surgeon to such a degree."

As chair of the department of physician assistant studies and an associate professor at the University of Saint Francis, Dawn now educates PA students annually about CFS, hoping to improve the care patients receive.



**Dawn LaBarbera**  
Fort Wayne, IN  
CFS advocate  
in the medical  
community;  
CFS educator

## The Spirit of Giving

**Beth Levine**  
Richmond, VA  
Former support  
group leader;  
Association  
member and donor



Beth Levine sees her service to the CFS community as a duty both to others and herself. While she tends to downplay her own generous contributions, she's adamant that "we need to up the ante to get more researchers involved in our cause, and to move forward at a healthy pace to find a cure."

Her symptoms came on suddenly. One day she was meeting with a prospective client and realized she couldn't stand up. Debilitating migraine headaches followed. After making the rounds to countless doctors, CFS was finally diagnosed. By 1994 she sold her business and retired.

Eager to help others with the illness, Beth ran the CFIDS Association of Virginia until the work became too much for her limited stamina. When that organization folded into the CFIDS Association of America, Beth was invited to serve on the Board of Directors.

Having since cycled off the Board, Beth now fills her time playing with her three beloved dogs, enjoying her grandchildren and helping friends who are facing similar physical challenges. "I do what I can for them on days that I'm up to it, and they reciprocate on the days when *they're* up to it."

"This has been a long road, and it's not the way I thought I'd end up," Beth says. But she's well enough now to travel a bit, making accommodations for her need to rest frequently.

Her motivation to make regular and generous gifts to the CFIDS Association is simple: "There's a sense of wanting to find a resolution to this thing, to move people to find a cure. I contribute because I want a cure, I want to make it better for me and everybody else with this illness. It's very frustrating when you see all the money going to other diseases . . . I want to see us get our fair share. We can beat this thing!"