

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 *Bugsy*. 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 fled to the United States after her grandfather died in Auschwitz during World War II, 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 they called to serve 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 his 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 filming a commercial. 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 ever 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 Vivian 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, deep tissue massage and mild graded exercise. And she made her peace with the illness, thanks to the help of psychologist Dr. Laura Montserrat and the friends 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