

Getting the Picture

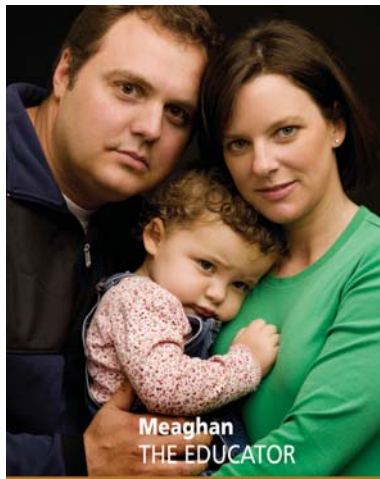
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RELATIONS AND EVENTS MANAGER



Vivian
THE EXPLORER
AND ÉVANGELIST

Brian
THE SCHOLAR-ATHLETE

“The Faces of Chronic Fatigue Syndrome” is creating its own story as it travels the country.



Meaghan
THE EDUCATOR

“Chronic fatigue syndrome is invisible to everyone except the people who have it and the people who love them. I don't look sick, and I balance my symptoms with being a wife, mother and third-grade teacher every day. So some people think the illness is all in my head. But it's not. I want to help educate Americans about CFS so they can go to their doctor for help if they have the symptoms. There is no cure, but there are treatments.”

GET INFORMED. GET DIAGNOSED. GET HELP.



To learn more about CFS, visit www.cdc.gov/cfs

Author Susan Sontag said, “To photograph is to confer importance.” This sentiment rings especially true when considering “The Faces of Chronic Fatigue Syndrome,” the traveling photo exhibit that’s a central element of the CFS public awareness campaign.

More than 5 million people have viewed the exhibit in 20 public venues so far. Among the 5,000 print, broadcast and online stories about CFS published since the beginning of the campaign are nearly 200 stories about the photo exhibit. Even the *New York Times* heralded CFS as “real” in a July 2007 article.

While these stories are vitally important, so are the stories of the exhibit itself, the people photographed in it and those who see it.

“The first merit of pictures is the effect they produce on the mind . . .”

Henry Ward Beecher, 19th-century abolitionist

The idea for a traveling photo exhibit initially came from one of the campaign’s communications firms, Fleishman Hillard, where executives drew on their experience in health care marketing.

“One of our European offices used a photo exhibit for colorectal cancer, a disease that’s not often talked about. They put a face on an illness that people battle and conquer,” says Mike Greenwell, senior vice president for health care and social marketing. “A photo exhibit wouldn’t work for all illnesses. It only works for one that’s ‘invisible,’ that has a stigma, that you can put a face on.”

From this initial concept the CFIDS Association recruited celebrity photographer George Lange—who already knew about CFS and the Association through his friend, fashion designer Kay Unger—and the exhibit began to take shape.

Marcia Harmon, the Association’s communications director, says, “We were intrigued by the idea of adding a photo exhibit to the other campaign strategies. The exhibit, together with the brochures that are available with it, really have helped ‘put a face on CFS’ by showing real people whose lives have been profoundly affected by the illness.”



“The point of photography is to isolate images from context . . . to make them visible in a different way.”

Neil Postman, 20th-century social critic and educator

The people the Association selected to be among the 10 faces that travel the country call themselves “proud and honored” to be chosen.

“I look at my position as an ambassador of patients, so I was thrilled,” says Rich Carson. “I was excited that the publicity would generate more critically needed attention for the disease.”

Meaghan Peterson, appearing with her husband and child, was eager for her portrait to include her family. “I wanted to be seen not just as myself, but as a wife and a mother. Those were two of my greatest accomplishments, because for so long I didn’t know if I would be able to balance a family life,” she says. “It was important to me to be the face of a family living with CFS.”

When Carson and Peterson actually saw the photo exhibit, both remember being startled by its size. Says Peterson, “It’s powerful. It captures the broad spectrum of CFS patients, and the reality of those people is striking when they’re put together. We’re just like any other wife, mother, child, daughter, husband, friend: *we’re normal.*”

Davianne Charles, a CFS caregiver, echoes Peterson. “I have several close friends with CFS and I should know better, but they all look perfectly normal. This is going to let people know that your next-door neighbor could be sick.”

Cecilia Madigan viewed the exhibit with other members of the Northern Virginia CFS/ME & FMS Support

Group at Union Station in Washington, D.C., in May 2007. “The quality of the photos and the quotations were really powerful,” she says. “Such large photos made me feel somehow connected to the people in them. It was very impressive.”

“A picture is an intermediate something between a thought and a thing.”

Samuel Taylor Coleridge, 18th-century English poet, critic and educator

Indeed, the photo exhibit is a useful intermediary between the skepticism surrounding CFS and stories about the illness in the media. Says Greenwell, “The exhibit makes it easy for the media to shoot and write a compelling story because there’s great imagery to capture. That matters to many media outlets.”

Intensive media outreach to cities and surrounding communities where the photo exhibit has traveled has resulted in nearly 200 stories and interviews with patients, health care providers and other CFS experts over the past year. And encouragingly, journalists are approaching the illness with sympathy and curiosity; their articles reflect a deepening understanding of the struggles of patients and health care professionals in coping with CFS.

This headline from the *Brighton Standard-Blade* in Brighton, Colorado, says it all: “Tired of being tired: Once denigrated Chronic Fatigue Syndrome gains support.” Published in four Denver-area newspapers and on the MetroWest website, editor Kevin Denke’s story presented a moving portrait of CFS patient Craig Horth, weaving basic facts about the illness through Horth’s tale of CFS.

The next stops for “The Faces of Chronic Fatigue Syndrome” photo exhibit are Phoenix, Arizona, from March 6-10 and Tampa, Florida, from April 21-28. Visit www.cfids.org/sparkCFS/photo.asp for a complete schedule.



In New Jersey’s *Star-Ledger* newspaper, writer Carol Ann Campbell presented an overview of CFS, current research into its cause and the debate about whether or not it’s real in “A debilitating condition, an uphill battle: Chronic fatigue is slowly gaining recognition,” a story that ran in March 2007 as the photo exhibit appeared at two locations in that state. She interviewed CFS experts and exhibit participants Brian Bernard and Jackie Niederle. The article was reprinted in eight newspapers across the country, including the *Chicago Tribune* and the *Times-Picayune* in New Orleans.

The exhibit itself is designed to provide enough information to interest people in learning more about CFS and to encourage them to visit the websites of the CDC and Association for more information. This strategy is working. So far more than 130,000 copies of the “Understanding CFS” brochure, brochures for health care professionals and the *CFS Toolkit for Health Care Professionals* have been downloaded or distributed in conjunction with the awareness campaign.

“A room hung with pictures is a room hung with thoughts.” Sir Joshua Reynolds, 18th-century English painter

The photo exhibit also aims to change the way doctors, nurse practitioners, physician assistants and other medical professionals regard CFS patients. To date, the exhibit has been displayed at nine medical conferences, where more than 35,000 health care professionals have had the opportunity to view it.

“We have three to four seconds as people stroll by to catch their attention” at medical conferences, says Terri Lupton, the Association’s coordinator for educational opportunities. “The exhibit’s eye-catching graphics lead them to the toolkits. It adds credibility to the illness and provides an opportunity to say to health care professionals, ‘These are the kinds of people you see every day. Don’t look at CFS as too big a challenge to undertake, look at it as a person sitting in front of you who really needs someone to help with her symptoms.’”

Association marketing associate Kasia Faryna also contacts Area Health Education Centers (AHECs), medical associations, hospitals and medical schools in each location in advance of the exhibit’s display.

“We ask these organizations to let health care professionals know there are free resources available to help with patients who may seek medical attention after viewing the exhibit and picking up a brochure,” she says. “It’s important for medical providers to know there are tools available to help them diagnose and treat CFS.”

And that, says Peterson, is what the exhibit is all about: “I hope that because of this, someone, somewhere, may not have to go through what I went through to get a diagnosis. I hope the general public and the medical community are taking this seriously and that people realize there is help out there.” ■