

S.B. man helps raise awareness about chronic fatigue syndrome

HILDY MEDINA, NEWS-PRESS STAFF WRITER

May 26, 2006 12:00 AM

If there's one message Rich Carson would like to get across to fellow sufferers of the hard-to-diagnose chronic fatigue syndrome, it's that the disease is real and treatable.

"There is a name to this disease that may be destroying their lives, and they can seek effective treatment," said Mr. Carson, who in 1988 founded Santa Barbara-based ProHealth, in part to share his extensive research on what was then a little-known disease, and also to sell supplements.

Nearly 20 years later, Mr. Carson will be part of one of the first national campaigns to raise awareness about CFS, which experts believe afflicts at least a million Americans, most of them women.

Mr. Carson, 49, is one of 10 people featured in a traveling photo exhibit funded by the U.S. Centers for Disease Control and Prevention. "The Faces of Chronic Fatigue Syndrome" is scheduled to launch June 7 in Washington, D.C., and will then embark on a cross-country tour.

The Santa Barbara resident has raised some \$2.5 million for chronic fatigue research, and his Web site, www.ProHealth.com, is one of the leading resources for information on CFS and fibromyalgia, a disease with related symptoms.

"He's one of the pioneers who got involved with this (disease) through his own experience and took on the challenge of trying to bring researchers together during a time when very little was known about CFS," said Kim McCleary, who heads the CFIDS Association of America, the campaign's organizer. "(Mr. Carson) took something that devastated his life and future expectations and turned it into a commitment and a cause that he's been involved with for the whole time he's personally had to deal with (chronic fatigue syndrome)."

In 1981, at the age of 23, Mr. Carson awoke one morning with severe flulike symptoms. Several months later, he was too sick to work and had to quit his job and move in with his parents.

"The best analogy is feeling extraordinarily hung over, because you felt so ill, so toxic and so sick," said Mr. Carson. "It's more than just the fatigue. The name chronic fatigue syndrome doesn't do the disease justice.

"One of the best days of my life was when I found out there was a name to the disease," said Mr. Carson, who learned about chronic fatigue five years after experiencing his first symptoms.

The syndrome, which has no known cure, is characterized by debilitating yet unexplained symptoms that include fatigue, muscle pain, sore throat, insomnia and impaired memory.



"The illness was first recognized in the late 1980s, and despite more than two decades of basic and clinical research and at least 3,000 peer-reviewed papers, we're still learning a lot about it," said Dr. William Reeves, chief of fatigue syndrome research at the CDC.

Chronic fatigue is difficult to diagnose because its symptoms are similar to those of other ailments like fibromyalgia, depression and lupus.

A federal study released last month has linked chronic fatigue sufferers to specific genes. The findings are significant because the genetic link will help doctors diagnose the illness and come up with more effective treatments.

About 80 percent of people suffering from the disease do not know they have it. "A lot of CFS patients suffer in silence," said Mr. Carson.

The former long-distance runner says his symptoms have subsided significantly thanks to a regimen of nutritional supplements -- which his 25-employee company sells -- and trying to lead a stress-free life. "I had to reach a certain type of accord with myself; I needed to live within certain guidelines and not overdo it."