

Raising awareness about Sjogren's syndrome

October 14 2011, By Angela Hill

Oakland, Calif., physician Sarah Schafer is a trim woman with robust color in her cheeks, bright blue eyes and a pleasant smile. She is the outward picture of health - an image that doesn't begin to tell the inside story.

Schafer, 54, feels bad. Very bad. All the time. Her eyes and mouth are so parched they require the application of drops and sprays nearly every hour of the day. She has severe joint and [muscle pain](#), plus a host of accompanying physical problems including sinusitis, migraines and the worst flulike fatigue anyone has experienced - not the kind that eases in a few days, but that persists on a daily, unrelenting basis.

Schafer has Sjogren's syndrome, a highly underdiagnosed, often misdiagnosed and yet surprisingly common autoimmune disease. Few in the general public were aware of the illness until tennis superstar Venus Williams announced in September that she has Sjogren's and was forced to back out of the U.S. Open because of it.

While no one with the illness would wish it on a worst enemy, many sufferers are, however, glad Williams put a famous face on the problem.

"It's the most common disease that nobody's heard of," Schafer said. "It's very helpful that Venus came forward about it, and maybe now it will get some attention and get the research funding it deserves."

Sjogren's (pronounced "SHOW-grinz") is named for the late Swedish ophthalmologist Henrik Sjogren, who first described the condition in

1933. According to the Sjogren's Syndrome Foundation, roughly 1 million people in the United States - primarily women - have confirmed cases of Sjogren's, but doctors estimate it may affect up to 4 million. It's considered the second most common autoimmune disease after [rheumatoid arthritis](#). In fact, it could be found to be the No. 1 most common if [diagnostic techniques](#) improve, researchers say.

It is a chronic systemic illness, with dry eyes and [dry mouth](#) as the hallmark symptoms. But the syndrome also presents myriad seemingly unrelated problems in varying levels of severity, which account for incorrect and often long-delayed diagnoses. It can be more than six years from the appearance of the first symptoms to a confirmed diagnosis, said Dr. Ava Wu, lead researcher for an international study based at the University of California, San Francisco, which is analyzing the diagnosis and treatment of the disease.

Currently, there is no single test to confirm Sjogren's, but physicians who suspect the syndrome may run blood tests to detect various antibodies such as ANA (anti-nuclear antibody) found in 70 percent of Sjogren's patients, in addition to eye tests to measure tear production.

"A lot of patients definitely fit the listed symptoms, but then we're finding many others who will have autoimmune thyroid issues or pulmonary problems in addition to the fatigue," Wu said. "The umbrella that ties them all to Sjogren's, however, is the dry eyes and dry mouth."

There are also varying levels of intensity, Wu said.

"Some can live very normal lives, while others are quite debilitated," she said. "But there's no increased mortality rate. It's not a death sentence in any way. But it is a life-altering diagnosis."

Researchers believe the cause of the syndrome lies in a genetic

component, but there are possibly environmental or stress-related triggers - such as a major surgery or a death in the family - that can increase severity. Currently, there is no known cure, but early diagnosis and appropriate treatment tailored to each individual may improve symptoms and prevent serious complications associated with the disorder, Wu said.

Prescription medicines for dry eyes and mouth are commonly used. Depending on the symptoms, doctors may recommend anti-inflammatory drugs to help with joint and muscle pain and even steroids or immunosuppressive drugs to treat systemic symptoms.

Sjogren's is considered a "hidden illness" because most who have it appear perfectly healthy, one of the most irritating factors for many sufferers.

"We look well," Schafer said from a sunny office in her home in the Oakland, Calif., hills. Highly sensitive to scents, she opened several windows because a visitor's shampoo fragrance instantly began irritating her throat.

"If someone had a leg in a cast or was losing their hair because of going through cancer therapies, people understand that they're sick," she said. "But people don't get it when you look fine, and they don't understand why you can't do normal things. Even many doctors treat it lightly. Relationships suffer because of this."

Sjogren's is often misdiagnosed as chronic fatigue syndrome, depression, menopause, multiple sclerosis or even hypochondria.

"People think we're just making this up," she said.

Ron Hansman, 67, of Woodside, Calif., is one of the few men diagnosed

with Sjogren's, a fact that doesn't make him feel special - at least not in a good way. Less than 10 percent of patients are men.

"People have various health problems, and they can live with them," he said. "I have friends with heart problems, and they can manage them with medications and live well. I have a friend with diabetes who manages it and lives well.

"I'd love to have diabetes instead of this," he said.

Hansman had a long and successful career as a national sales trainer, speaking in front of groups of up to 300 people. About seven years ago, he began to experience severe exhaustion.

"I'd be running a training sales group, and I'd get so tired, I'd go in the empty training room in the afternoons, lock the doors, put my briefcase on the floor and sleep for a little while," he said.

He was given medications for a thyroid problem, then began to have low-saliva symptoms. He visited many doctors before one about three years ago finally suggested Sjogren's. Hansman, too, is disturbed by the lack of awareness of the disease.

"After the Venus Williams announcement, I decided to let some people know I had it," he said. "I got a note from one woman who said she would pray for my recovery. That was a kind sentiment, but she didn't understand - there's no recovery."

Sjogren's was diagnosed in 1999 for Ina Checkman of Cupertino, Calif., a former schoolteacher.

"I've learned it's all about trying to make wise choices and budget your energy like it's the most precious resource," she said. "With the fatigue,

it's not just a matter of being tired and resting and feeling better. It's like a free-floating cloud over you, hanging there all the time."

Schafer, formerly a public health physician for Contra Costa County, Calif., says she, too, can manage the illness, but it's an all-consuming effort. She's on at least 20 medications and only has small windows of time during the day when she feels well enough to go to the store or do her daily brief swim at the gym.

"I can't go to movies or the theater," she said. "When my son graduated from college in Los Angeles, going on that trip was like preparing to go to the moon. I haven't been able to work in 10 years. I can't do the normal things. I feel left out of life."

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