

HOPE for the **W**earry

In the Pacific Fatigue Laboratory, faculty and student researchers are giving hope to people with debilitating illnesses.

BY LINDA DUBOIS



Maya Sullivan was 22 when she caught a bad upper-respiratory infection. The exhaustion, foggy headedness and flu symptoms hung on for weeks, then months, then years. Doctor after doctor had been unable to help her, some dismissing her illness as depression.

As she grew sicker, she gradually let go of activities, cut her work hours and eventually couldn't work at all. Denied Social Security benefits because medical tests failed to prove her inability to work, she moved numerous times to avoid homelessness.

Sullivan has chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and, sadly, her story is typical. Like so many other CFS/ME patients, she lacked the two things she needed most: hard data proving she was sick, and knowledge of ways she could improve her quality of life.

Today she has them both.

Sullivan, now 36, obtained a referral from her physician and traveled from her Vallejo home in August to the Pacific Fatigue Laboratory (PFL). Operated through Pacific's Department of Sport Sciences since 2007, the PFL conducts a comprehensive disability evaluation. A crucial element is a standard 8 to 12-minute exercise "stress test," but with a key difference that has revolutionized CFS/ME research: patients are retested the next day.

Medical science has shown that, regardless of health level, a person will score about the same each time when taking a stress test two days in a row, says PFL founding executive director Staci Stevens '91, '97. Except for CFS/ME patients.

"Those with CFS/ME are the only patients who score significantly worse the second day," says Stevens. They may suffer as much as a 50 percent drop in their ability to produce energy. Stevens recalls a man in his 20s whose second-day test results were worse than those of a typical 85-year-old. "CFS/ME patients do not recover normally from physical exertion."

From the test results, PFL researchers prepare an evaluation the patient can use to help manage the illness and educate physicians and attorneys. Medical peers who have seen the numbers are astonished.

"They tell us, 'I've never seen this before!'" Stevens says. Follow-up patient questionnaires confirm the test results. "They report things like flu-like symptoms, sore throat; they can't think clearly, they can't sleep, they're throwing up — just horrific things that shouldn't happen after a few minutes on a bike," she says.

"Thank God for the Pacific Fatigue Lab."

— *Maya Sullivan, Vallejo, CA*

"This test is hell on the people who take it," says Sullivan. Five weeks after she was tested, she still needed the aid of a walker. "People should not have to do that in order to get Social Security. But since we do, thank God for the Pacific Fatigue Lab."

Denise King, 44, who's been bedridden for eight years, says it took her five weeks to recover from the test and the long trip from her home in Toronto, Canada.

But both say they'd do it again in a heartbeat.

"It did an amazing thing for me," Sullivan says. "Now I know I really was

as sick as I thought I was. I have a piece of paper that proves it."

Each patient is also counseled on the use of an alarmed heart-rate monitor to help manage exertion levels and prevent a flareup of symptoms.

"I can't believe the tiniest little activities that put me over," King says. "I thought I was pacing myself before, but apparently not."

Now she can get more tasks accomplished without "crashing" by breaking up chores into small steps. If her alarm goes off while she's washing dishes, she lies down for a while before continuing. She's also started an exercise regimen and regained some muscle tone she lost while bedridden.

While King is fortunate to have a healthy husband with a good job and medical insurance, for many, the PFL test can be a financial lifesaver.

"The stories we hear are heartwrenching," Stevens says. "They've burned through their life savings trying to find out what's wrong with them, and they're denied disability." One of the most difficult tasks for people with CFS/ME is providing objective evidence of their illness.

"In my experience," says attorney John Walker Wood, "disability insurance companies often claim that fatigue is just a subjective complaint that cannot be verified or substantiated. Many legitimate claims are denied." Wood and attorney Steve Krafchick specialize in claims relating to disability.

"These lab results make a huge difference," says Krafchick. Both Wood and Krafchick say the PFL test has helped them win many disability disputes.

The PFL is also the only place that offers this comprehensive service, and only two other centers have implemented its exercise testing, one at Ithaca College in New York and one at a university in the Netherlands. Consequently, PFL has drawn patients from across the United States and from countries as far away as Chile and Japan. It has also drawn people suffering

Pacific Fatigue Lab Executive Director Staci Stevens demonstrates the use of a heart rate monitor, which patients can use to manage exertion levels.



from other illnesses, such as HIV, multiple sclerosis and cancer, who increasingly must prove to insurance companies that they can't work.

"We have a reputation that goes beyond the United States, which is quite unusual for a small institution like Pacific," says Christopher Snell, professor of sport sciences and PFL scientific director. Snell and Stevens both serve on the U.S. Department of Health and Human Services' Chronic Fatigue Syndrome Advisory Committee, which makes recommendations that guide the government's response on this important health care issue.

CFS/ME research projects also involve collaborations with Pacific professors in sport sciences, physical therapy, bioengineering and psychology, as well as with researchers from Stanford University, Simmaron Research Inc. and Ithaca College. Both undergraduate and graduate students are involved at each step of the process, working with patients; reviewing medical history; measuring height, weight and blood pressure; conducting the lab testing; and reporting the results.

"I've learned how to work with people and patients," says undergraduate lab assistant Ben Larson '12. "At first I was a little bit shy, but now I've gotten comfortable enough that it's second nature."

Students have also presented their

research at major conferences and before national committees. Larson recently presented his research at the International Association of CFS/ME conference. Harnoor Singh '07 has presented research at the American College of Sports Medicine conference and at the 2009 Meeting of the International Association for CFS/ME, where he was named Student Researcher of the Year.

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*— Staci Stevens '91, '97,
Pacific Fatigue Lab Executive Director*

Singh and Larson say their experiences are invaluable preparation for their future health-related careers. Singh, now in medical school, was particularly affected by patients' frustration at being repeatedly dismissed by doctors. This taught him the importance of being sensitive to patients and listening, he says.

The program has made significant strides in the field despite limited public funding. PFL has received some research grants from the CFIDS Association of America,



Student researchers are involved with patients in every aspect of the testing process.

but for now, patient fees alone cover the \$2,000 cost of the disability testing. The team hopes additional funding will one day make it possible to provide free or reduced-cost testing to patients with financial need.

"I think the biggest thing I get out of this is that we give patients hope," Stevens says. "We change somebody's life, and I think it changes our lives as well."

For information on the Pacific Fatigue Lab, visit go.Pacific.edu/PFL.

More Than Tired: What is CFS?

Chronic fatigue syndrome (CFS) has been called the most common illness that nobody knows about.

Also called myalgic encephalomyelitis (ME), it affects up to four million people in the United States alone — more than AIDS, lung cancer and breast cancer combined — with age of death as much as 20 years premature. It is difficult to diagnose and there is no known cure.

CFS/ME's most publicized symptom is debilitating fatigue, with many patients bedridden. Also, symptoms worsen markedly after minor physical or mental exertion. For a diagnosis, the individual must be sick for at least six months

and, beyond symptoms of persistent physical and mental fatigue, experience accompanying symptoms involving the cardiovascular, immune and central nervous systems.

Some evidence suggests a genetic predisposition or viral connection, says Dr. Christopher Snell, a professor in the Pacific Sport Sciences Department. However, it is not known whether the viruses occur because of a problem with the immune system or whether the viruses are responsible for the symptoms. "It's a chicken-and-egg thing. We don't really know," he says.

For more information on CFS/ME, visit www.CDC.gov/CFS.