

# Hope for Chronic Fatigue Syndrome

Original source: Stanford Medicine Newsletter 2011, Spring Edition

[http://medicine.stanford.edu/newsletter/2011-spring/DOM\\_NL\\_Spring2011.pdf](http://medicine.stanford.edu/newsletter/2011-spring/DOM_NL_Spring2011.pdf)



Jose G. Montoya, MD, has treated more than 200 people with chronic fatigue syndrome (CFS). The defining symptoms—disabling fatigue, brain fog, muscle and joint pain, impaired sleep, sore throat, and enlarged lymph nodes— indicate that a disease is clearly present. Whatever causes CFS, however, remains a mystery and a troubling concern for patients who suffer from symptoms, which are often inconsistent with what laboratory tests and examinations can actually find. Sadly, this profound dichotomy has led to disbelief among some physicians and members of the medical community as to whether patients are actually sick.

For the past 6 years, Montoya, an associate professor in the division of infectious diseases, has postulated that CFS can be linked to an infection from pathogens such as herpes viruses, *Chlamydia pneumoniae*, tick borne pathogens, or enteroviruses. “We have an increasing number of success stories where patients get better with long-term treatment of the specific pathogen,” said Montoya.

The problem, however, is that these different pathogens often produce the same group of symptoms. “We have the equivalent to pneumonia as a disease in chronic fatigue syndrome but haven’t found the infiltrate yet to objectively say this patient has CFS. We’re still working with the clinical definition and to establish the relationship with the specific pathogens.”

## Ongoing Research

A \$1.4 million grant from the pharmaceutical company that manufactures the anti-viral drug Valcyte has enabled Montoya do a double-blind, placebo-controlled, randomized trial whose results are highly suggestive that patients improve because of the drug and not the placebo.

Additional funds from a generous private donation fuels the search for pathogens in the blood of CFS patients. In collaboration with Ian Lipkin, MD, at Columbia University, and utilizing innovative technologies such as mass tag, PCR, Green chip, or 454 deep sequencing (which have never been tried with CFS patients), researchers may find known or unknown organisms. Montoya also collaborates with other Stanford faculty and the Stanford Human Immune Monitoring Core Facility to analyze the blood through immunological techniques. Several hundred patients are enrolled in these studies.

## The Big Picture

CFS is believed to affect between one and four million Americans and accounts for approximately \$9 to \$18 billion in lost productivity due to illness. Montoya's long-term goal is to eliminate chronic fatigue syndrome. Slowly, he has introduced the condition, which was previously ostracized by academic centers into the division of infectious diseases. He hopes that physicians who treat CFS patients will eventually see it as making a contribution to human health.

"I think the future of infectious diseases is going to be in the challenges posed by viruses, other intercellular pathogens, and chronic illnesses. For these we have poor diagnostics and limited therapies. Connecting an unexplained chronic illness and other diseases with these pathogens will shape the future of our subspecialty. It will expand the therapeutic armamentarium beyond treating extracellular bacteria and fungi to more challenging and unexplained syndromes associated with infection."

## Case study: Living With Chronic Fatigue Syndrome

Tina Caskey is working to improve the quality of life for people with chronic fatigue syndrome. Thanks to her support, there is now a website with up-to-date information and expertise that individuals can bring to their local physicians regarding specific tests, medications, and treatments. Tina has also set up a Good Samaritan Fund at Stanford to assist people with limited funds and no insurance.

"When you're sick, it's important to know the nature of your illness and what you can do about it," said Tina, whose struggles with CFS began in 2003. Tina, who was healthy all her life, received a steroid shot for an injured knee. The Arizona woman who loved to ski, mountain bike, and go backpacking with her family began to fall apart. She was fatigued, dizzy, and experienced tachycardia and signs of the flu. Local doctors had no explanation for her symptoms. She sought medical treatment in Phoenix and at the Mayo Clinic. No one could tell her why she went from being healthy to being sick in such a short period of time.

After the possibility of Lyme disease surfaced, physicians prescribed antibiotics. Tina got better, but eventually relapsed. She read about Jose G. Montoya, MD, and his work using anti-viral medications to treat patients suffering from chronic fatigue. In 2007, Tina began taking the drug Valcyte. Although she is not fully recovered, her health continues to improve. "I saw 17 doctors and Dr. Montoya was the first one to look at the bigger picture. We don't have all the answers, but with treatment, and the right information, people with CFS can live a better life."