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CHRONIC FATIGUE SYNDROME

BY JOHN-MANUEL ANDRIOTE

You haven't felt right for months.

You're tired all the time, yet when you try to sleep you toss and turn all night. Your temperature seems to have readjusted itself a few degrees higher than normal. You've gained weight, probably because it hurts to exercise. You seem to forget little things. And then there are those annoying allergies you never used to have. Still, your doctor says there's nothing wrong with you — your blood tests are normal, everything checks out. Be patient, he says. Relax. Maybe it's a little flu. Mono, even. It'll go away.

But it doesn't. Months go by. You see another doctor. And another. Finally you find a doctor who'll admit he watches TV and suggests that maybe you have the same thing Bea Arthur had in last fall's *Golden Girls* two-part season opener, the mysterious malady no one believed because she still *looked* healthy.

So now you've got a name for it. Chronic fatigue syn-

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drome (CFS). You may have heard it called "yuppie flu" and laughed right along with the reporters and doctors who dismissed it as the psychosomatic concoction of stressed-out, upwardly mobile white women. But it's no laughing matter now that you've had to take a leave of absence from your job because you can't get out of bed for days on end. And you're tired as hell of people — including the doctors you've paid to see — telling you it's all in your head.

CFS suppresses the immune system (leading some to call it chronic fatigue and immune dysfunction syndrome or CFIDS), crippling the body's natural defense system. This gives the viruses and various "bugs" we all have drifting around inside us free reign to make life very miserable indeed. Yet unlike AIDS, which virtually destroys the immune system so that you develop life-threatening diseases, CFS is rarely if ever fatal.

CHRONIC FATIGUE SYNDROME

With CFS you suffer a variety of

symptoms besides the debilitating fatigue that gives the syndrome its name. These include: low-grade fever, weight gain, muscle aches, vertigo, sleep disturbances, spatial disorientation, light-headedness, severe nasal and other allergies, painful lymph nodes and difficulty concentrating.

Although it is likely CFS has been around for many years, the federal Centers for Disease Control recognized it as a "real" disease only two years ago and re-dubbed it with its current name. In the past, "the disease with the identity crisis," as *Medical World News* termed CFS after its re-christening, has been known variously as neurasthenia, chronic brucellosis (a fashionable disease among women in the 1940s), hypoglycemia, Epstein-Barr virus syndrome and chronic mononucleosis syndrome. Outside the U.S., it is still usually known as myalgic encephalomyelitis.

With the new name came a more-or-less explicit definition of CFS, intended to eliminate the many people who had been falsely diagnosed as having whatever it was called at the time. CFS

is diagnosed by a process of exclusion; that is, the doctor rules out any other possible explanations for your symptoms until all that's left to explain it is CFS. Assuming you see a physician who knows about CFS—many still don't and continue to dismiss it as a flu or some such—you will be diagnosed with CFS if you've experienced debilitating fatigue that persists over at least a six-month period, if there is no other organic or psychiatric cause (such as cancer, depression or neurosis) and if you exhibit at least half a dozen other minor symptoms associated with the disease.

During the 10 years that Mark Iverson of Charlotte, North Carolina, has had CFS he's watched his life change tremendously. "I went from living the American dream—Harvard Law School, Wharton, the youngest vice president at Barclay's Bank—to having the script of my life torn in half." CFS patient advocates, including Iverson, who is president of the Charlotte-based CFIDS Association, contend that it wasn't until men began to complain to their doctors of CFS-like symp-

toms that the medical profession began to sit up and take notice. Until fairly recently, many more women than men developed CFS—or at least sought medical treatment for it—but current estimates are that at least one-third of the two to six million Americans with CFS are men.

Until men came forward with it, CFS sufferers of the female persuasion were dismissed as depressives and merely told to take a tranquilizer. Marya Grambs, of the CFIDS Foundation, San Francisco, tells of a renowned researcher who studied the blood of 10 female CFS patients. He discounted the women's complaints and said there was nothing wrong with them. It was only when "a man, a tax attorney, complained that he couldn't jog anymore or have sex with his wife that the researcher said, 'Hey, this guy is really sick.'"

Theories abound as to the cause of CFS. Until relatively recently, it was thought that Epstein-Barr virus, which causes mono, was the culprit. But that theory has given way to a host of others—including herpes viruses, the polio vi-

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rus, mycoplasma, spirochetes, or perhaps even an as-yet unidentified pathogen. Though the common belief is that a virus or group of viruses is behind the spectrum of symptoms associated with CFS, most experts now believe there is no single cause, but that CFS may be the result of a confluence of different viruses in the wrong place (from their human host's point of view) at a right time (from theirs). Experts also think there is a triggering agent, a shot heard 'round the body that tells the bad boys to start their nasty work.

According to Jay Goldstein, MD, director of the CFS Institute in Anaheim Hills, California, CFS *is* in your head — although he contends it's definitely not a figment of your imagination. Goldstein explains that the brain is the major organ most affected by CFS, and because it's so closely interconnected with the immune system, anything that gets into the immune system will affect the brain's functioning and vice versa. "Most of the chemicals made in the brain," he says, "have effects on the cells of the immune system, and virtually all the chemicals we know made by cells of the immune system have an effect on the brain."

Based on his sophisticated brain imaging research using a BEAM scan ("kind of a great grandson of the EEG," he says) Goldstein believes that CFS may be the result of a latent virus or viruses in genetically susceptible people. Exposure to a triggering agent — such as environmental toxins, viral infections, physical trauma or stress — alters the normal secretion of *cytokines*, immune system chemicals that act as a sort of emergency broadcast system allowing cells to tell other cells what to do in case of an infection or other need for immune response. The result is a deregulated immune system unable to provide the level of protection needed to maintain healthy body functioning. But Goldstein notes that because no cells actually are killed "when you do the usual kinds of lab tests that you would do to look for a disease caused by viruses, they will all be normal."

Consequently CFS sufferers may *look* fine even to the trained eye. That has led to dismissals of CFS as an actual disease and its symptoms as anything more than the fevered imaginings of people already disposed to depression and other mental illnesses. Stephen E. Straus, a researcher at the

National Institute of Allergy and Infectious Disease, two years ago suggested in an article that there is a psychoneurotic component to the disease, meaning that the symptoms are at least partly the result of an emotional conflict. Writing in *The Journal of Infectious Diseases* (March 1988), Straus said that because psychiatric evaluations he'd done on CFS patients "reveal that a very high proportion of patients with [CFS] possess histories of depression, phobias or anxiety disorders" he was led to the "inescapable conclusion that psychoneurosis contributes to [CFS]."

Straus's suggestion of a psychoneurotic link in CFS was a triggering agent in its own right. Many patient advocates went ballistic at the idea that precious research dollars would be spent merely to tell them once again that they were only imagining they were sick. In their support groups, newsletters and conferences, they spoke of "two camps" of CFS researchers: those who endorsed Straus's view that they had a psychoneurotic predisposition to getting CFS and those who didn't.

Anthony L. Komaroff, a physician at Boston's Brigham and Women's Hospital, CONTINUED ON PAGE 122

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ham & Women's Hospital and president of the privately organized National CFS Advisory Council, dismisses criticism of Straus's work, arguing that patients have misunderstood what the government-sponsored researcher was saying. Komaroff is widely respected among CFS patient groups because he believes they are suffering with a real disease; he's "on their side." Yet he believes patients must rise above the popular stigma erroneously attached to anything that smells of psychology or mental illness. "CFS," says Komaroff, "like practically any illness has physical and psychological components that need to be taken into consideration." It's naive to think the brain and body are separate. "The mind is a biological organ," he says, adding that "the whole idea that some illnesses are purely physical and others purely mental is not helpful in thinking about human illnesses."

Orvalene Prewitt, president of the National CFS Association in Kansas City, Kansas, says that anger toward Straus and efforts by patient advocates to have him removed from his research post were misplaced. "It can backfire on the support network to have a scientist like Straus fired," she says. "I think it's absurd for the lay community to assume we know scientific and medical things. When a cure is found it won't be found by patients, but by medical scientists." Prewitt concurs with Komaroff: "In research, when you get a disease where you have no idea what its etiology is, you have to look at all possibilities."

Even Straus, criticized so virulently by patients, is looking at other possibilities and seems to have uncovered new evidence that suggests there may be more to CFS than his initial explanation of a psychoneurotic predisposition. In soon-to-be-published research, he compares CFS patients to "classically" depressed patients. And he has found that while patients with classic depression produce an excess of cortisol, a hormone released by the adrenal gland, CFS patients are the oppo-

site, showing a suppressed cortisol level. So the psychoneurotic theory may yet go the way of the many others before it as understanding of the organic aspects of CFS increases.

Of course there's a practical—spelled m-o-n-e-y—side to the physical-mental argument. As Barry Sleight, the only lobbyist in Washington who works on getting CFS funding, puts it, "None of these things operates in a vacuum. Most corporate health benefits provide less benefits for psychogenic disorders." So to say CFS is a psychogenic, or mental, illness could determine whether insurance companies, which already are as reluctant to cover CFS as they are most chronic illnesses, pay for treatment or patients must exhaust their personal resources in the often long and frequently futile search for treatment.

And that search can lead far and wide. Only one thing is certain, and that is that each patient's treatment needs are different. Goldstein says, "Since each person's immune system is unique, to treat the disease adequately both doctor and patient have to be somewhat persistent to try and find the right combination of treatments that will deal with the particular problem."

Ward Karns was a 37-year-old mechanical engineer for IBM in Palo Alto, California, when he started to get headaches, sore throats, and, within six months, nightsweats, fevers and swollen lymph nodes the size of grapes. Now Karns was no slouch: He skied, played golf, rode a bike, took aerobics classes and played sports in addition to a demanding research job. But within eight months, he couldn't figure math problems, he couldn't drive, and he spent three months in bed. He was fortunate to hook up with Dr. Daniel Peterson, one of the medical heroes of the CFS "movement" because of his pioneering work on the disease, who has treated him with everything from vitamins and minerals to intravenous acyclovir. Karns has also tried drugs from Mexico, organic germanium, antifungal drugs and intravenous gamma globulin. As he says, "It would be easier to list the drugs I *haven't* tried." He even tried wrapping himself in an elec-

tric blanket and sweating out a couple gallons of water in an effort to rid himself of whatever is making him so sick for so long. Through it all, he's had company in all the failed attempts at finding a cure: His wife also has CFS.

Forty-six-year-old Larry Habluetzel, a banking broker in Kansas City, Kansas, thinks he's been somewhat more fortunate than most in finding effective treatment. Habluetzel, whose athletic 15-year-old son Chad came down with CFS a month after his father, was properly diagnosed and got early treatment from an infectious disease specialist. Because he had a holistic-type approach to health, he was open to trying an acupuncturist, taking vitamins and minerals, listening to relaxation tapes and generally trying to exert mind over matter. Like many other CFS patients, Habluetzel believes that stress played a major role in his developing CFS. "Most people I see with [CFS] are 'type-A' people," he says. "I've never seen any laid-back people get this."

Ernie Tubb was hardly what you'd call a laid-back kind of guy. Besides lifting weights five days a week and running three or four days a week, he played handball in between. But Tubb knew something was wrong in October 1986 when he was so exhausted he could barely move around his office at New York City's Hunter College. He went from doctor to doctor to doctor and from expert to expert. They all recommended a psychiatrist. Finally he found a CFS support group to which a doctor gave a speech about his own home-brewed CFS treatment of *abesonine mono phosphate*, which he claimed aided the body's cells by energizing them to destroy the virus that presumably had invaded them.

And it worked for Tubb. Though he still can't train as he did before, he works out three days a week, benching an admirable 300 pounds, in addition to a 20-minute cardiovascular workout on a bike or treadmill.

Bob Landau, 34, who leads the support group Tubb attended before he recovered, says, "As more papers are published in medical journals, you see more scientists from the National Institutes of Health and the Centers for

Educating yourself, and your doctor if need be, about CFS may not cure you, but it will let you make informed choices about treatment options and what level of activity is appropriate for your particular situation. The three national CFS/CFIDS patient groups gladly send out reams of information for the asking. They may be reached as follows:

Chronic Fatigue Immune Dysfunction
Syndrome Society
P.O. Box 230108
Portland, OR 97223
503-684-5261

Chronic Fatigue and Immune
Dysfunction Syndrome Association
P.O.Box 220398
Charlotte, NC 28222
704-362-2343

National Chronic Fatigue
Syndrome Association
919 Scott Ave.
Kansas City, KS 66105
913-321-2278

Disease Control doing credible [CFS] research." Unfortunately, "it doesn't filter down to the local general practitioner on the corner," although he notes that he now has a list of some three dozen specialists in the New York/New Jersey area alone to which he refers patients. For his money, he thinks that pediatricians are among the best and most sensitive in treating CFS because of what he describes as their "greater powers of observation," which enable them to diagnose children's illnesses based on subtler, perhaps more intuitive, clues. "Medicine is as much an art as it is a science," he says.

Whether it's an art, a science or a little of both, Landau says people with CFS "are all waiting with bated breath" for medical researchers finally to discover conclusively what causes the debilitating, long-term illness. Meanwhile, after having CFS for nearly six years, he believes that "you have to have a good sense of humor to cope with this because those who are dependent and wait to be over the illness take the longest to get over it." ■

John-Manuel Andriote is a freelance journalist in Washington, D.C.