The Myth of "It's All in Your Head"
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DePaul scientists work to unravel the mystery of chronic fatigue syndrome.

By Abigail Pickus
In 1980, a high school English teacher from Wisconsin named Pat Fero went on a trip to England. Healthy and in her 30s, she noticed something was very wrong toward the end of the trip.

“We were in this beautiful countryside, and we went to climb a hill to get a better view of a lake and I just couldn’t do it. I thought, I am really out of shape. I couldn’t get up that hill. My legs hurt, and I was dizzy and short of breath,” recalls Fero.

When she returned home the fever hit.

“I had a 104° fever for a week and a headache from hell. I had extreme pain in my neck and shoulders that lasted another week,” she says.

Over the next few years she got progressively sicker until she couldn’t climb the stairs at school without resting on the landing. Then she was unable to write on the chalkboard. “I would misspell things. I couldn’t form the letters correctly. I would miss words. Day-to-day communication became tough. That’s why I left the classroom. You can’t be in front of 20-some kids and seriously not know what you’re talking about,” she says.

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Mystery Disease

Tragically, Fero is not alone. Using research data developed at DePaul, the Centers for Disease Control and Prevention (CDC) estimates that there are currently more than 1 million people in the U.S. and more than 17 million worldwide with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME)—and these are just the ones who have been diagnosed. (See sidebar: What’s in a Name?)

Often triggered by a virus, this debilitating disease continues to plague people for years with symptoms that run the gamut from nerve pain and cognitive impairments to a fatigue better characterized as bone-crushing exhaustion.

“Don’t use the word fatigue. It’s an exhaustion so severe that you can’t stand up because you feel like you’re going to faint,” says Fero.

Often lumped together with other so-called “mystery illnesses” such as Lyme disease and fibromyalgia, CFS/ME is historically misdiagnosed or underdiagnosed simply because one of its defining symptoms—fatigue—is both commonplace and seemingly benign. Adding insult to injury, CFS/ME is notoriously stigmatized because of its name “chronic fatigue,” suggesting that the patient is merely tired.

But the medical community is baffled, from what causes it to what it really is: A brain disease? A virus? And with federal funding...
for research into CFS/ME improving but still lower than for other major diseases, the quality of life for millions of Americans is left hanging in the balance.

Enter Leonard Jason, a professor of psychology at DePaul, who with his team has been making serious inroads into cracking the code on this mystery illness. “DePaul has been trying to validate the experience of patients with CFS/ME, to find ways to lessen the burden of this illness by reporting on accurate prevalence numbers among adults and children, to find effective treatments and to understand its etiology,” says Jason.

It’s a tall order, but with more than 800 professional publications and 25 books to his name (many on CFS/ME), plus more than $36 million in research grants, Jason and the DePaul Center for Community Research have emerged as leading figures in an area of medicine otherwise shrouded in darkness.

Center for Community Research

Jason has been at DePaul since 1975. Boyish and slender with round wire-framed glasses and a friendly manner, he arrived at DePaul immediately after receiving his PhD from the University of Rochester, having been drawn initially to DePaul because of its values. In fact, his area of psychology—clinical community psychology—has distinctly Vincentian roots with its emphasis on understanding and addressing social problems, particularly for the underserved. It was in this vein that Jason founded the Center for Community Research in 2001.

Jason's initial interest in CFS/ME was personal. In 1989, he was hit with the disease after coming down with mononucleosis, which many researchers now feel could be one of the triggers for the illness. It took him a full year to feel better, and when he did, he started plowing through the meager literature on the disease. What he discovered was that he was in a unique position to make a difference. “It just seemed like there were so many interesting issues with this illness and that I, as a person who had experienced it myself who was also a psychologist with a background in strong research methods, could spend a lot of time making contributions,” he says. He then pursued the matter from all angles, from correcting what he considered to be an inaccurate case definition to countering inappropriate CFS/ME myths from some in the medical community.

“It was evident to me that there was a lot of stigma against people who had what’s called chronic fatigue syndrome, which is not a very good term because it is trivializing,” he says. Also trivializing were the treatments recommended to patients. “Here you have these exhausted and sick people, and you basically want them to do exercise and be more active because that’s what you thought would help them,” he says.

An example of a deregulated network in a person with CFS/ME.
It was Jason’s team who coined the term “staying within the energy envelope” as a counter to these popular treatments. In numerous papers, Jason showed that for patients with CFS/ME, pushing too hard leads to serious consequences known among ME sufferers as post-exertional malaise, where the body and brain shut down.

One of Jason’s most significant contributions to the field has been quantifying the number of adults in the U.S. with the disease. “The prevalence rates were not very accurate back in the ’90s when I first started doing research, and the methodology used by the CDC was flawed. At the time, it was considered a rare ‘Yuppie flu’ disease primarily affecting white middle-class women. As a result of this myth, the federal government did not provide a lot of resources for those people who had this illness,” he says.

Throughout the 1990s, Jason and his team conducted a community-based epidemiology prevalence study and came to a staggering conclusion: Instead of 20,000 Americans with this illness, the number was probably closer to a million, and it was actually minorities, particularly Hispanics, who were disproportionately affected by the disease. The CDC has since updated its figures based on DePaul’s research and its own subsequent study. While serving on the CDC’s Chronic Fatigue Syndrome Advisory Committee in the mid-2000s, Jason was able to make recommendations to the Secretary of U.S. Health and Human Services about the research and service needs of this patient group.

Mapping Brainwaves

One sunny, summer afternoon, research scientists Marcie and Mark Zinn were hard at work in the laboratory they fashioned inside DePaul’s Center for Community Research to view images created by quantitative electroencephalography (qEEG) that maps the brain waves of people with CFS/ME. Pointing to two computer monitors displaying a 3D cross section of the brain alongside the EEG squiggles tracking the brain’s metabolic activity, Marcie shows how the technology uses low-resolution electromagnetic tomography (LORETA) software to estimate the sources in the brain causing its dysregulation. It does this all at the millisecond level, the time frame in which the brain actually operates—a vast improvement over the functional MRI, which has a 2- to 3-second delay.

“A normally functioning brain depends on the neurons functioning within a certain time frame. For patients with ME, the neurons are either damaged or dead, which causes cognitive impairments because of the slowed speed and the first part of the processing hasn’t been resolved before they move on to the next,” says Marcie.

qEEG was developed by Clinical Neuroscience Professor Robert Thatcher, who uses it to examine all types of brain injuries; it is also used to study the brains of those with autism and traumatic brain injury. DePaul is the only research center in the world using qEEG to link communication between neural networks and the cognitive dysregulation of patients with CFS/ME. This is something the Zinns hope will change.

“Right now it’s very hard to measure ME, which makes it hard to diagnose. People either have to go to an infectious diseases doctor or [we] have to wait until they’re dead for their brains to be autopsied. One of the things we’re trying to work on is for doctors to use our technology in their offices to help potential patients with ME,” says Marcie, adding that the diagnostic procedures used currently are only accurate in about 50 percent of the cases.

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Leonard Jason
The Zinns began using qEEG in 2001 to study the brain patterns of concert pianists, a profession they both pursued before switching to careers in psychology. They transitioned to studying patients with CFS/ME in 2010 at Stanford University under Jose Montoya, an infectious disease doctor, and have continued their work since joining DePaul in 2015. Marcie is the former director of the center’s cognitive systems neuroscience unit, and Mark is pursuing a PhD in community psychology.

They have studied the brains of more than 200 patients with ME/CFS and have published many research articles on different aspects of the disease. Among their discoveries is that post-exertional malaise is truly all in patients’ heads—just not in the way doctors thought. “Their brain function literally tanks. We can actually see that,” says Marcie. They’ve also seen how CFS/ME patients’ everyday waking brain is drowsy because of too many delta waves.

All these findings have given those suffering from the disease the kind of validation they have long sought. “To see your brain light up like a Christmas tree when you do a simple task really validates what I already know,” says Fero, who came to DePaul to participate in the studies. “I didn’t think I wasn’t able to write on the chalkboard because there was some psychiatric problem. I knew there was something wrong with my brain. These 3D scans confirm that.”

For Marcie, who also suffers from the disease, focusing on the brain is a significant step in the right direction particularly because blood tests cannot detect CFS/ME. “Just because a doctor doesn’t find any indicators of illness in a person’s blood doesn’t mean they aren’t sick. It just means they aren’t looking where the problem is,” says Marcie.

The Invisible Demographic

“I really don’t want to die, but it’s really hard to call this living,” says CFS/ME patient Jennifer Brea in her chilling documentary, “Unrest,” which documents just how widespread—and debilitating—the disease is. Some of the most heart-wrenching stories in the film are about young people who have spent most of their formative years bedridden. It turns out that children are the most invisible demographic to be hit by CFS/ME. Only Jason and his team are putting a number on this phenomenon. They are currently wrapping up a rigorous study of 10,000 children to estimate its prevalence among youth.

“Sometimes there are children who are functioning at a very high level and then all of a sudden something happens—there’s an accident or there might be some type of virus, we’re still trying to understand...
What’s in a Name?

In the second half of the 19th century, a new epidemic spread across the country: Women of the upper and middle classes were taking to their beds with fatigue and weakness. It was neurologist George Miller Beard who gave this condition a name: neurasthenia. He blamed the malady on the modern predicament of “American nervousness.”

Despite a rash of outbreaks reported around the world beginning in the 1930s, it wasn’t until a 1955 outbreak in London that this mystery disease was given a more scientific diagnosis: myalgic encephalomyelitis (ME), which means inflammation of the brain.

But the Centers for Disease Control and Prevention (CDC) reversed all that in 1984 after yet another outbreak in Lake Tahoe, Nev., when they dubbed the condition chronic fatigue syndrome (CFS).

“When we gave medical interns the name ‘chronic fatigue syndrome’ with a prototypical person with this illness versus a medical sounding term (myalgic encephalopathy), we found there was judgment when they saw ‘chronic fatigue’ because it seemed psychological. If you called something chronic cough syndrome, they’d say, ‘So what? Everyone coughs.’ But if you called it bronchitis or emphysema, then people would say, ‘This is important,’” says DePaul Psychology Professor Leonard Jason, who is a leading authority on CFS/ME.

That’s why so many patients prefer the term myalgic encephalomyelitis. “Are we getting closer to a breakthrough?” Jason asks. “I think so, yes.”

On the Brink of a Breakthrough

Answers are exactly what people like Fero need. “I am almost 69, and I’ve had this for more than half my life,” she says. She’s buoyed, however, by a changing tide of events, from an emboldened sense of advocacy among patients through the power of social media to the growing number of institutions working to find some answers. Stanford University, for example, has created both an initiative to study CFS/ME and a CFS research center under the direction of Ronald Davis, a professor of biochemistry and genetics whose son has a severe case of the disease.

“That is an exciting study as we are getting close to finding out some kind of answers,” adds Katz.

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that—and then their functioning goes down considerably. Their parents and school officials often think, ‘Is this child just malingering?’ Unless there is an ally to help the child, the child could easily get stigmatized for this condition,” says Jason.

In another prospective longitudinal study, Ben Katz, a professor of pediatrics at Northwestern’s Feinberg School of Medicine, is partnering with Jason to look at the link between mononucleosis, which is triggered by the Epstein-Barr virus, and CFS/ME in youth. The study looks at which percentage of those who develop mono will go on to develop CFS/ME and why. “About 5 percent of all kids who go to college will get mono before they graduate, and about 12 percent who get mono will meet criteria for CFS/ME six months later,” says Katz. “Why do most people recover? Nobody knows the answer, and that’s why we decided to study college kids. By enrolling people when they’re healthy, you can see if they get mono and why some recover and some don’t.”

Data collection to estimate the prevalence of CFS/ME among youth will be completed in 2019, and soon after, papers will be submitted for publication, according to Jason. The results of the mono-CFS/ME study will also be released in 2019.

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