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CRUSADE AGAINST CHRONIC ILLNESS

Lawyer Turns Ailment Into Nationwide Cause

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MICHAEL MCANDREWS / THE HARTFORD COURANT

JENNIFER JAFF of Farmington has created a nonprofit foundation to help people deal with chronic diseases.

Jennifer Jaff built a heady law career while fighting bouts of overwhelming nausea, unrelenting fatigue and endless diarrhea from a chronic disease that comes and goes.

Now Jaff, a Connecticut assistant attorney general in the 1990s, is turning the physical lows of an inflammatory bowel disease into fulfilling highs — as a one-woman civil rights crusade for people with chronic ailments.

Jaff was getting sicker again from complications of Crohn's disease in March, when she quit as partner in a Hartford law firm to focus more on the patient advocacy campaign she had already begun.

Working from her Farmington condo, Jaff, 48, launched a website in February, created a nonprofit foundation and recently published an updated guide called "Know Your Rights: A Handbook For Patients with Chronic Illness."

Jaff answers questions and helps patients all over the nation for free in bat-

tles involving health insurance, employment, Social Security, school and other issues related to their diseases. She often triumphs using little-known or ignored parts of laws and motivates patients with passion and compassion.

She has even gotten fundraising help from rock band Pearl Jam, through a connection made by Gloria Steinem. Jaff met Steinem through abortion rights activism.

The patient advocacy cause "is about a group of invisible people who need to be less invisible," Jaff says, her silver-streaked mane shining against an all-black casual outfit. "This is about civil rights and people who need to have their voices heard."

Jaff periodically addresses groups of patients, and coaxes and cajoles them into singing "We Shall Overcome."

And overcome she has. While Jaff was in her late teens, her parents sent her to a psychiatrist for more than a year at the urging of a physician who couldn't figure out what was physically wrong with her.

A dermatologist diagnosed her with Crohn's when, at 19, rashes broke out on her arms and legs, and an ankle blew up to basketball size.

Crohn's has done other odd things, too. In 2002, her body swelled up with water, which turned out to be an endocrine system problem. "I peed out 24 pounds in two days. That's how much water there was," Jaff says.

In just the last four years, Jaff has had four major abdominal surgeries, including operations for two hernias. She has had three staph infections, and life-threatening dehydration and problems absorbing nutrients.

Crohn's causes diarrhea, abdominal pain, rectal bleeding, intestinal blockages due to swelling and scar tissue and can lead to nutritional deficiencies, weight loss, arthritis and skin problems.

Jaff says her Crohn's is not currently "active," but the "remission" is miserable. She opens a kitchen cabinet to display three shelves filled with her medications — currently 18 a day plus supplements.

She still has bouts of diarrhea and says an adrenal problem related to the Crohn's is causing waves of nausea accompanied by a dripping cold sweat and shakiness. As a result, she is afraid to drive farther than Hartford.

She also suffers constant abdominal pain, which she believes is from anchors inserted as part of her last hernia repair.

The fatigue remains as well. "You sleep and you still feel like crap when you get up," she says.

Still, Jaff insists, "I have a great life. Sure, I have my days when I feel sorry for myself, but mostly I feel really proud of myself for dealing with it the way I do."

Her advocacy work especially targets diseases that are characterized by remissions and relapses, as Crohn's is. She doesn't litigate, though she'll refer people to other attorneys for that. Instead,

she wages battles through letter-writing, e-mails, phone, fax and FedEx.

The inquiries have been pouring in — 412 inquiries from the end of February to late July, for instance. Some just seek information, such as how to get health insurance — a tough problem — or how to qualify for Social Security disability.

Others need her to help them wage battles. Jaff has intervened in a wide range of problems that has included insurer denials of treatments, school accommodations for a child with bowel disease, and even an alimony battle.

Jaff has a following of grateful supporters such as Sheila Moore in Phoenix, whose son needed an infusion drug that would have cost more than \$100,000 a year.

Moore's insurer had twice refused to cover the arthritis drug Remicade for her 13-year-old son Jonathan because the drug is federally approved for Crohn's, but not yet for his diagnosis — ulcerative colitis.

"I was at my wit's end; I didn't know where to turn," Sheila Moore says. "It was just amazing what she was able to do."

Jaff quickly compiled and sent a packet of information for an insurance appeal, including data from the Mayo Clinic. With no word from the insurer, she called a lawyer in the Connecticut attorney general's office who has dealt with insurers and he put her in touch with the company's national medical director. Coverage for Remicade was approved.

Jaff helped Kathleen "Casey" Crowley of Beacon Falls with a student loan matter, but Crowley is even more thankful for the boost to her spirit.

"She gave me back hope," says Crowley, who has multiple sclerosis, lupus and a rare blood disorder. "She gave me back the will to fight. She is a guardian angel."

Jaff, in turn, says she gets a tremendous emotional payback from advocacy and its challenges appeal to her sense of justice. She's incensed, for instance, that the Americans With Disabilities Act fails to protect chronically ill people who can be fired for absences due to their illness.

Before throwing herself into patient advocacy, Jaff had a varied and successful law career. She taught law for a few years and clerked for a federal judge. During the 1990s, she worked in the Connecticut attorney general's office on some high-profile cases involving Medicaid fraud and racketeering, the state's welfare

reform and anti-abortion protests at a women's health center.

Attorney General Richard Blumenthal appreciated her victories and calls her "indefatigable."

"She has a combination of intellectual excellence and legal insight, combined with relentless dedication and energy," Blumenthal says. He isn't surprised that she has embraced patient advocacy.

"She's always been a fighter in the best sense of the word," Blumenthal says.

Jaff left Blumenthal's office in 1999 to work for Planned Parenthood and the National Abortion Rights Action League in Washington, D.C., but left after a year, because she says she was unable to bear in-fighting among coalition members.

Jaff made partner at a Washington law firm but moved back to Connecticut because of a Crohn's relapse. Needing to slow down a bit, she joined the law firm of Killian & Donohue in Hartford but was made a partner and worked 50- to 60-hour weeks because of a big pension case, Robert K. Killian Jr. says.

His partner Thomas J. Donohue Jr. calls Jaff a "razor-sharp advocate" and describes her writing skills as "brilliant."

The same ailments would have shut other people down, Killian says. "She didn't slow down," even when working from home, he says. "Jennifer at half speed is worth most people full throttle."

Jaff says one of the catalysts for her patient advocacy was finding IBDsucks.com — a discussion website for people with Inflammatory Bowel Disease — and answering questions for participants. That snowballed into writing a short primer for the site and then a handbook for people with IBD that she donated to the Crohn's and Colitis Foundation of America, which raised \$20,000 by selling copies.

Jaff is hoping her newest handbooks will help fund her own nonprofit foundation — Advocacy for Patients with Chronic Illness Inc. — so she can continue to expand her advocacy efforts.

She's selling a \$30 edition, written for people with all kinds of chronic disease, on her website at www.advocacyforpatients.org. A special edition with appendices for people with IBD is for sale on the Crohn's foundation website at \$31.50 for foundation members and \$35 for nonmembers.

Just raising money to have the handbooks printed was a chal-

lenge, since her foundation is so new. Donations for the foundation total about \$25,000 so far, including thousands from Pearl Jam auctioning off autographed photos and a concert poster, and sports memorabilia on eBay. Pearl Jam guitarist Mike McCready has Crohn's.

To pay her personal bills, Jaff, who is single, still does free-lance legal work at home and is awaiting payment from a settled class-action lawsuit. She dismisses the idea of going on Social Security disability.

"I absolutely could be on disability. There's no question," Jaff says. "But as long as I have a computer and e-mail and a fax machine, I can do a lot."

Chronically Ill: Their Rights

Jennifer Jaff, an attorney and patient advocate, says chronically ill people should know their rights on health insurance, employment, Social Security, school and other issues related to their diseases.

■ You can extend employer-based health insurance from 18 to 29 months under the federal COBRA law if you were disabled at the time you became eligible for COBRA.

■ If your health insurer refuses to pay for a treatment or service, you are entitled to a copy of everything the company used to make a decision, including clinical criteria.

■ Nearly every major drug company has an assistance program that provides low-income patients with free prescription medication.

■ The leave from work allowed under the federal Family and Medical Leave Act — up to 12 weeks — can be taken a few days at a time, which is useful for people who need periodic medical treatments.

■ A chronically ill child is entitled to an evaluation by the school district and a plan that allows the student to continue school work, even if at home part of the year.