

# To Our Health

One advocate's battle against insurance companies and a culture of denial.



I shouldn't overstate the importance of Jennifer C. Jaff to our nation's health-care system. She is, after all, only one person, and a very ill person at that. She leads an organization that employs a workforce of two, not counting the full-time lap sitter, a cat named Emily.

Jaff seems anonymous, hidden away in a Farmington condo, and, by physical necessity, is seldom seen in public. Aetna doesn't invite her to cocktail parties; Joe Lieberman's staff hasn't asked her to drop by to discuss the chaos in health care. ("My relationships with those folks," she reports, "are a bit strained at the moment.")

And yet there are thousands around the land who know Jaff's name and how to find her, because they rely on this infirm 52-year-old lawyer as their lifeline. One of them is Mike McCready, from Seattle. The name may be familiar to you, because he is a member of the rock group Pearl Jam, which has sold 60 million albums worldwide but could not have addressed the health issues of its lead guitarist without Jaff's help.

McCready writes in the foreword of Jaff's new book *It's Too Hard to be Sick In America: Stories of Chronic Illness*, about how he came to know her. A mutual friend knew they both suffer from Crohn's disease. McCready

was instantly taken by Jaff's knowledge of patients' rights and passion for helping others.

In Jaff he met a woman who is intimately aware of what it means to live with a body that doesn't work. "I'm an expert at being sick," she says. With Crohn's and also gastroparesis, she must prepare her table without fruits, vegetables, whole grains, chicken or beef ("All the healthy stuff, I can't eat"), and can never stray far from a bathroom. She lives with nausea, diarrhea, fatigue, and the effects of eight abdominal surgeries and 15 medications per day.

In spite of all this, she has proven tireless, except on weekends, when, resting from the rigors of fighting for the rights of clients, she seldom gets out of bed.

It was McCready who pressed Jaff to start her nonprofit, Advocacy for Patients With

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Chronic Illness Inc., and who over its five-year existence has helped bankroll the organization as well as Jaff's efforts on behalf of patients who can't carry out the fight against an impenetrable system on their own.

McCready writes that while he was happy to support Jaff's nonprofit, "I never thought I would need Jennifer's services myself." He is at the top of the music world, but to his health insurer he was just another name on a form. His doctor had wanted to double the dosage of a drug he was taking. The insurer denied coverage, arguing that the prescription was

beyond the normal dosage guidelines.

Here was a problem a great number of Americans face. They have a chronic illness and painful symptoms. Their doctors prescribe medication. Insurers deny coverage for a variety of reasons. So what can they do? For one thing, they can call Jaff, as McCready did. She pressed the insurance company by bombarding it with medical records and legal arguments drawn from another book she had written, *Know Your Rights: A Handbook for Patients with Chronic Illness*. Now the musician gets the medication he needs.

McCready, obviously, could have come up with the thousands necessary to pay the retail price. Almost all other cases, however, are taken on behalf of people who must choose between finding relief and paying the rent.

Some clients are unable to get treatment for pre-existing conditions or are fighting to get disability benefits. Others are trying to convince reluctant employers to grant or extend medical leave. Too many have no insurance at all. A few of Jaff's clients are profiled in *It's Too Hard to be Sick In America*. (This book is free; *Know Your Rights* is sold for \$30 to help subsidize the organization, which doesn't charge for its services.)

Here is a capsule of the story of "Wendy" (all the names are changed). She is in constant pain from Crohn's disease and fibromyalgia. The only drug that controls the debilitating symptoms is Actiq, approved by the FDA for cancer treatment. Her insurance company refused to cover "off-label" usage for Wendy's illness, even though it works for her. She had to buy Actiq on her own, whenever she could afford to. When the money ran out, she became desperate. She wrote two bad checks on closed accounts—then faced two felony charges.

What Wendy did was illegal, of course. But these are the choices that many people face in a system rigged against them. It seems barbaric to Jaff that it has come to this: desperately ill people going up against companies that have the luxury of time, companies which can string out appeals that, to them, are painless while to the patient, they can be

deadly. Indeed, Jaff is not reluctant to use the term "getting away with murder" in regard to the insurance companies. She certainly felt this way when one of her clients died during the appeals process.

She knows there are honorable people who work for these companies, but believes that the system itself is out of balance. Instead of a doctor having the authority over the welfare—and perhaps survival—of the patient, it is a nameless bureaucrat who decides, one whose loyalty is to the company's bottom line.

Jaff, then, had high hopes as the House and Senate passed versions of health-care legislation over the winter months. She read every word as if she were consuming a Dan Brown novel.

No, the proposals—so watered down—didn't thrill her, but at least they would help reign in insurance companies. It didn't bother her that, under the proposed legislation, her own policy, a "Cadillac Plan" that now costs her \$15,000 a year, would be taxed. It is necessary, she reasoned, for the greater good, an ideal that seems lost in the political atmosphere of "What's in it for me?"

Her sentiment is aligned with the Rev. Martin Luther King Jr.'s, whose words are imprinted on the sweatshirt she was wearing the day I visited: "Of all the forms of inequality, injustice in health care is the most shocking and inhumane."

What a crushing moment, then, when the Massachusetts special election to fill the seat of the late Sen. Ted Kennedy reduced the chance for sweeping health-care reform in Washington. From her blog the next day:

"Sen. Kennedy said over and over that hope endures and the dream never dies. But now his Senate seat will be used to kill the dreams of 30 million people who would have had insurance if health reform were passed. And I still will have nothing to offer the people who call me, desperate for answers. The stock prices of health-insurance companies skyrocketed yesterday on the belief that health reform would die, and it looks like they were right."

Yet two days later she regained a sense of optimism, writing that congressional reconciliation could produce a reasonable compromise and that "we musn't retreat."

Indeed, her life story demonstrates this can-do attitude again and again. If, after all, doctors had had their way, Jaff would never have gone to law school. They warned that, given her condition, it would prove too demanding. But she attended Georgetown anyway—chugging Mylanta and taking time off to be fed intravenously in a hospital so her inflamed bowels could rest.

There has been little rest since. And there likely won't be until the Washington establishment also chooses a path of courage and compassion. ■