It's Time for a Change

Should insurers get to decide your medication? **BY DAVE SEMINARA**

WHILE HER COLLEAGUES ARE COUNTING DOWN THE DAYS, Rebecca Alves is one kindergarten teacher dreading the end of the school year. She suffers from a rare autoimmune disorder called Devic's disease and has been told by her insurer that on July 1 it will stop paying for the $12,000-a-month infusions she's been taking for seven years. It will pay for a different treatment, but Alves and her doctor both believe switching could be dangerous. "The medicine has saved my life," says Alves, a 39-year-old mother of a 13-year-old girl. "Without it, Devic's could be fatal within five years."

Like Alves, I live with the fear that my insurer might someday ask me to switch to a lower cost, less effective medication. I have multiple sclerosis and take injections I could never afford out of pocket. And like Alves, I worry that the Supreme Court will overturn President Obama's health care law, returning us to that era when companies could discriminate against the sick. I know from experience: Prior to the law's passage, I looked into buying insurance on the open market—no company would cover me, at any price, because of my existing condition.

The insurance offered through Alves's employer, Hayden McFadden Elementary School in New Bedford, won't pay for her treatments. So she had long been covered through her husband, Derek, who recently retired from the Bristol County sheriff's office. In late 2010, they had to switch to UniCare, the only insurer that said it would cover her treatments. But in April 2011 it denied her claim, saying its previous payments had been a mistake.

Alves says UniCare told her it was stopping because her medication isn't approved as a Devic's treatment by the Food and Drug Administration. Yet many companies that make effective treatments for rare diseases don't seek such backing—the costs are too high for the potential payoff—and the medication UniCare will cover isn't FDA-approved either. (A UniCare spokesman says all medical decisions are based on peer-reviewed scientific literature.)

Since being diagnosed in 1998, Alves has tried various treatments, even chemotherapy, to combat her extreme fatigue, vision problems, and excruciating pain. Nothing worked long term. But her condition markedly improved once she started her current treatment, so she is repelled by the idea of abandoning the one thing that has let her live a normal life.

Alves doesn't give up easily. A Devic's attack once left her paralyzed. Doctors said the condition was permanent, but she was walking again within weeks. After being denied coverage last year, she started a Facebook group, Save Becka, to ask for help. It has attracted more than 2,100 online supporters, many of whom have fought their own battles with health insurance companies. UniCare granted her a

4,000
Estimated number of Devic's sufferers in the US

reprieve that expires at the end of June.

UniCare says it could revisit its decision, but Alves isn't confident it will. She's enlisted the help of her state representative, Robert Koczera, who drafted legislation (H.3641) that would make medical necessity—as determined by the patient's physician, not the insurer—the only criterion for medical coverage. The bill applies only to Devic's disease, but Alves believes it could serve as a model for laws related to other rare illnesses. Her personal crusade has become an effort to increase awareness and options for other sufferers of "orphan diseases."

Alves was a healthy 21-year-old when she got sick. If it can happen to her, it can happen to anyone. And if you get sick, wouldn't you want the right to take the medication your doctor recommends, rather than what your insurer prefers? The Devic's bill is just a baby step, but if it passes, it will once again put Massachusetts in the vanguard of health care reform. And Rebecca Alves can begin looking forward to summer, just like everyone else.

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