

Armed with hashtags, these activists made insulin prices a presidential talking point

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Hannah Crabtree got active on Twitter in 2016 to find more people like herself: those with Type 1 diabetes who'd hacked their insulin pumps to automatically adjust the amount of insulin delivered.

Soon, though, Crabtree found a more critical diabetes-related

conversation happening on Twitter: rising insulin prices.

Crabtree's mother, who also had diabetes, died in 2006 of complications from rationing expensive insulin. Most people naturally produce the hormone, which helps the body convert carbohydrates into energy. People with Type 1 diabetes don't produce enough, so they need injectable insulin to stay alive.

But the medication has become increasingly expensive. One version rose in price from \$21 to \$255 per vial between 1996 and 2016, for example, and Crabtree had often wondered in the years after her mother died why more people weren't talking about the issue. On Twitter, she found the people who were doing just that.

Crabtree, a 32-year-old accountant in the Virginia suburbs of Washington, D.C., became part of a small group of patient activists who have managed to turn U.S. insulin prices into a kitchen table issue in part through their use of Twitter.

Their activism helped make insulin prices a topic of the 2020 presidential election. And 22 states and Washington, D.C., have now passed caps on insurance copayments for insulin, in addition to a copay cap Congress passed last year for some Medicare patients that went into effect Jan. 1. During President Joe Biden's State of the Union address Feb. 7, he called for capping out-of-pocket insulin costs for all Americans.

But these activists have long called for caps on insulin prices, not just copays, and Biden's measure is unlikely to gain traction in the current Congress, let alone address the broader concerns about the [high prices](#) of many other types of medications that patients struggle to afford. The political intransigence reveals the limitations of Twitter as a platform for patient advocacy, despite recent successes. Some advocates now say they

have scaled back their use of the platform, as trolls grow bolder with Elon Musk now in charge of Twitter and journalists and politicians eyeing other platforms.

"Twitter is a lifeline for a lot of diabetics," said Nicole Smith-Holt, an activist in Minnesota, pointing to the insulin sharing that happens via the platform. "I fear we're going to lose a main resource for a lot of people."

Like others seeking change, such as disability rights advocates and the Black Lives Matter movement, diabetes activists have used social media hashtags to find one another, build momentum, and change the public conversation.

Alice Wong, a disabled activist in San Francisco who helped create the #cripthevote hashtag to give people with disabilities a voice in the 2016 election, said people downplay "armchair activism" as something frivolous and inferior to grassroots organizing.

"But effective activism has to meet people where they are," she said. Despite Twitter's many flaws and accessibility issues, Wong said, it has been a primary way for many people with disabilities to express themselves.

Many prominent voices on what some call Diabetes Twitter have a personal connection to high insulin prices, having struggled to afford it themselves or had family members die because of rationing. Like Crabtree, though, they often joined the online conversation through happenstance, with an everyday gripe about living with diabetes blowing up after strangers retweeted it with the hashtag #insulin4all.

The hashtag was created in part by T1 International, a nonprofit that advocates for people with Type 1 diabetes and doesn't take donations from [pharmaceutical companies](#). The organization was founded in 2014

by Elizabeth Pfiester, who saw a need for an organization directly addressing insulin affordability.

Diabetes activists have sometimes been wary of the standard-bearer organizations, such as the American Diabetes Association and JDRF, formerly the Juvenile Diabetes Research Federation, because they receive money from drugmakers. ADA spokesperson Rebecca Fisher said the organization has supported state and federal efforts to cap out-of-pocket insulin costs. Chelsea-Lyn Rudder, a JDRF spokesperson, said the organization has spent years lobbying Congress and calling on insulin manufacturers, health plans, employers, and the government to take action to lower the cost of insulin.

"Less than one percent of JDRF's funding comes from companies that manufacture insulin," Rudder said, "and these companies have no role in decisions about advocacy and research priorities."

The online conversation inspired one advocate, a Washington, D.C., attorney named Laura Marston, to tell her own story about struggling to afford insulin to The Washington Post in 2016. When Sen. Bernie Sanders (I-Vt.) tweeted a chart from the article and suggested that "the drug industry's greed" was to blame for insulin's rising cost, the stock price of one of the big three insulin manufacturers, Eli Lilly, took a tumble.

A similar scenario played out in November when the company's stock sank 4% the day after a tweet from a parody Eli Lilly account claimed the pharmaceutical giant was making insulin free. Eli Lilly CEO David Ricks told a summit that the prank showed more work needs to be done to lower insulin costs for patients. In both cases, the company's [stock price](#) quickly recovered. Eli Lilly stock is trading around 300% higher now than in 2017.

Eli Lilly did not respond to requests for comment about the role of social media in the national conversation about insulin prices.

Smith-Holt became an insulin activist after she lost her son Alec, at age 26, in 2017 because he couldn't afford his insulin. She started speaking out about insulin affordability to local media, but her advocacy really took off once she joined Twitter.

"There's just no stopping a tweet," Smith-Holt said. "It goes out into the universe and God only knows how many thousands or millions of people see."

Smith-Holt was among a group of activists who traveled to Canada in 2019 to purchase insulin over the counter to showcase the disproportionately high cost Americans pay. During the first trip, dubbed the "#CaravanToCanada," they garnered attention by tweeting about their journey. Sanders later joined them on an excursion to Windsor, Ontario, ahead of a Democratic presidential primary debate in next-door Detroit.

Pfiester pointed to real-world successes the movement has had beyond the copay caps: Since the #insulin4all campaign started, all three major insulin manufacturers have new patient assistance programs to help people get insulin if they are struggling to afford it. Another offline success came in 2020 in Minnesota, where Smith-Holt championed the Alec Smith Insulin Affordability Act, which created an insulin safety net that made insulin available for as little as \$35 for a 30-day supply to people with an urgent need. The program is in place despite a legal challenge from the pharmaceutical industry.

But social media takes a toll on activists. Health misinformation and speculation abound. The open nature of Twitter creates a powerful tool for spreading a message but also an invitation for backlash, trolling, and

vitriol.

"I can't tell you how many times I've been told that I should be in prison because I actually caused the death of my son," Smith-Holt said.

Such venom already gave activists pause about the platform even before Musk bought it and began to remove restraints. Fears it could get worse have led some to leave the platform.

Smith-Holt said she has pared down her own online activism. It could be because of recent changes on Twitter, she said, but she also might just be running out of bandwidth. She works two jobs—for an airline and as a financial aid administrator at a community college.

She's proud of Alec's law, and showing the country that [insulin](#) affordability is an issue for people like her son. But, she said, it never seems to be enough.

"I don't know what it's going to take," she said.

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