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Making Insulin Affordable

Its Cost Is Creating a Crisis

By *Fran Quigley*

James Elliott is convinced that the statistics describing the prevalence of type 1 diabetes are misleading. “People say that there is little or no type 1 diabetes in poor countries,” he says. “But that is because all of the people who had it are dead.” Elliott, a health researcher working with Doctors Without Borders/Médecins Sans Frontières and other organizations, has type 1 diabetes himself. As a volunteer advocate with the diabetes patient organization T1International, he and his colleagues confront the often-fatal problems caused by the price of insulin and other diabetes supplies. Elliott’s work recently took him to Cameroon, where a physician shared the story of a young patient’s father happily delivering news. “Did you hear?” the father said with a smile. “Isabelle died!” He was referring to his diabetic daughter (the name here is a pseudonym). The family had struggled to pay for her insulin and equipment, such as syringes and blood sugar test strips. Uneven access to the medicine had often left the young girl quite ill, and its cost when it was purchased had plunged the family into financial distress. “Now we are all able to eat enough,” the father said. “And the other children can get an education.”

Mbolonzi Mbaluka understands. A Kenyan living with type 1 diabetes, he has had to skip insulin injections, sometimes because he could not afford the cost and sometimes because local hospitals ran out of stock. A fellow Kenyan patient recently died after going two months without insulin, which in many countries can cost up to 50 percent or more of the average income. For example, in Brazil, insulin and supplies can cost over 80 percent of an average income. “The insulin and the equipment together are just not affordable for many,” Mbaluka says.

Insulin is a pancreas-created hormone that allows the body to absorb and deploy sugar from consumed food. For people with type 2 diabetes, the pancreas struggles to keep up with the body’s insulin demand, either because the pancreas is not producing enough or because the body has developed insulin resistance. For persons with type 1 diabetes, their body’s immune system has damaged or destroyed the insulin-producing cells in the pancreas. A lack of insulin causes blood sugar levels to rise, damaging the heart, kidneys, eyes, and nerves. Over 400 million people globally have diabetes. Lack of widespread testing makes it hard to apportion the percentages between type 1 and type 2, but the majority of those people have type 2 diabetes. And according to some estimates, half of those who need insulin cannot reliably get access to it. People with type 2 diabetes often need to take insulin shots on a temporary or permanent basis. For people with type 1 diabetes, the equation is much more uniform, and more stark: they must inject insulin in order to stay alive.

The discovery of insulin in the 1920s by a University of Toronto research team is one of history's great pharmaceutical success stories. Orthopedic surgeon Frederick Banting and medical student Charles Best were able to extract insulin from an animal pancreas and inject it into a diabetic human, a groundbreaking advancement that earned Banting the Nobel Prize. Suddenly, a fatal disease became a survivable, chronic condition—as long as the insulin was available to the patient.

The researchers were ideologically opposed to monopoly patenting of biomedical discoveries, but they were eager to see that wide distribution begin as soon as possible. And so, the researchers took out a patent for insulin, which they promptly sold to the university for $1 each. The plan was for the university to partner with pharmaceutical companies that were prepared to mass produce and distribute insulin. (A few decades later, Jonas Salk would famously refuse to patent the polio vaccine.)

For a while, the plan worked. Insulin became widely available and affordably priced. It was even improved upon. Innovations reduced the frequency of needed injections. Soon, the first human insulin and then synthetic insulin, known as analogues, replaced the original animal-extracted version. Yet those changes also caused problems. Each improvement allowed for corporations to take out their own patents on the new versions, and the price began to increase. The far-cheaper former versions of insulin, which experts generally agree were not significantly less effective than the enhanced iterations, disappeared from the market.

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Although the changes in insulin over the years have brought some benefits to patients, some experts say that the insulin producers' tactics have corrupted the original public health vision of the medicine's inventors. "I don't think it takes a cynic such as myself to see most of these (insulin) drugs are being developed to preserve patent protection," Harvard Medical School professor David Nathan toldThe Washington Post. "The truth is they are marginally different, and the clinical benefits of them over the older drugs are zero."

Yet the three main manufacturers of insulin—Eli Lilly, Sanofi Aventis, and Novo Nordisk—have dramatically raised prices on the newest versions. A 2016 study published in theJournal of the American Medical Association showed that the cost of insulin in the U.S. almost tripled between 2002 and 2013, and prices have continued to climb since. A U.S. patient's out-of-pocket cost for a month's supply of Eli Lilly's Humalog can be over $400.

For the drug companies, insulin is a hugely profitable product. Although manufacturers keep the cost of insulin production a tightly-guarded secret, U.S. prices are likely hundreds of times higher than the expense of making the drug. With annual revenues of $31 billion and growing, insulin is one of the highest-grossing medicines in the global market.

But for patients who are dependent on insulin, its cost is creating a crisis—and not just in low-income countries but also in the comparatively wealthy United States. Increasingly, a lack of insurance coverage for the medicine or high-deductible coverage leaves people with diabetes paying as much as half their income for insulin. Patients report skipping doses, injecting expired insulin, and even starving themselves to control their blood sugar. Some patients are intentionally allowing themselves to slip into the life-threatening state of diabetic ketoacidosis just so they can obtain free insulin samples from emergency rooms. Not surprisingly, physicians report seeing more patients in distress because they can't afford their insulin.

Americans with type 1 diabetes are particularly anxious over the likely repeal of the Affordable Care Act, which protects them against coverage denials because of pre-existing conditions and against lifetime caps on coverage. Amy Leyendecker, who lives in Elizabethtown, Kentucky, currently has most of her insulin and equipment costs paid by insurance provided by her husband's employer. But she has been without health insurance before, and is anxious about what may happen when her husband retires in a post-ACA world. "I have a five-month stash of insulin in my refrigerator that a friend brought in from outside the U.S.," she says. "This is life-and-death for me."

THE PUSH FOR LOWER PRICING

Among those fighting for more affordable insulin is T1International. Elliott and Mbolonzi Mbaluka are active members. T1International's founder and director, Elizabeth Rowley, began the organization as a blog, but she quickly discovered that there was a global population of persons living with type 1diabetes eager to connect—and to speak out. One core purpose of the group is to provide a forum for those patient voices. "There are a lot of difficult challenges people with type 1 struggle with," Rowley says. "And number one among those is that the prices for insulin and equipment are just far too high."

Rowley and her colleagues try to channel widespread frustration into focused activism. T1International's detailed toolkit for advocacy includes global case studies of successful campaigns for better insulin access, tactical guidance, and tips on dealing with elected officials—"Sometimes you have to make the politician think it was their idea." They collect data on insulin and supply costs, publish accounts of patient experiences worldwide, and even steer U.S. patients toward the attorneys who have filed a class action suit against the insulin manufacturers. That lawsuit, in the U.S. District Court in Massachusetts, alleges price collusion among the three major manufacturers, citing years of remarkably similar price increases by Eli Lilly, Sanofi, and Novo Nordisk.

T1International's support of that litigation, and its outspoken criticism of insulin pricing, put it squarely at odds with the pharmaceutical industry. That also makes T1 different from most patient advocacy groups. Groups including cancer patient groups and allergy and asthma patient groups have come under criticism for not speaking out in response to drug pricing issues. Most even declined to weigh in even during the recent high-profile Epi-Pen and Martin Shkreli "pharma bro" debates, in which triple-digit drug price increases led to public outcry and Congressional hearings.

In fact, patient groups often vigorously support the pharma industry agenda, while at the same time receiving significant pharma funding. A 2016 report by the U.S. advocacy group Public Citizen revealed that at least three-quarters of the patient groups who actively opposed an Obama administration proposal to reduce Medicare drug expenditures received pharma industry donations. Another study showed that over 90 percent of patient groups participating in a discussion of FDA drug approval reform were pharma-funded. Most patient groups that opposed California's 2016 ballot measure to regulate the medicine prices paid by state government proved to be heavily funded by pharmaceutical corporations.

Not surprisingly, access to medicines advocates report that patient group representatives privately admit that they won't speak out on drug pricing for fear of losing state funding. That fear is well-founded. The U.S. National Multiple Sclerosis Society endured push-back from its pharma funders when it dared to mention concerns over the cost of multiple sclerosis drugs that average $78,000 annually, a 400 percent increase in little over a decade.

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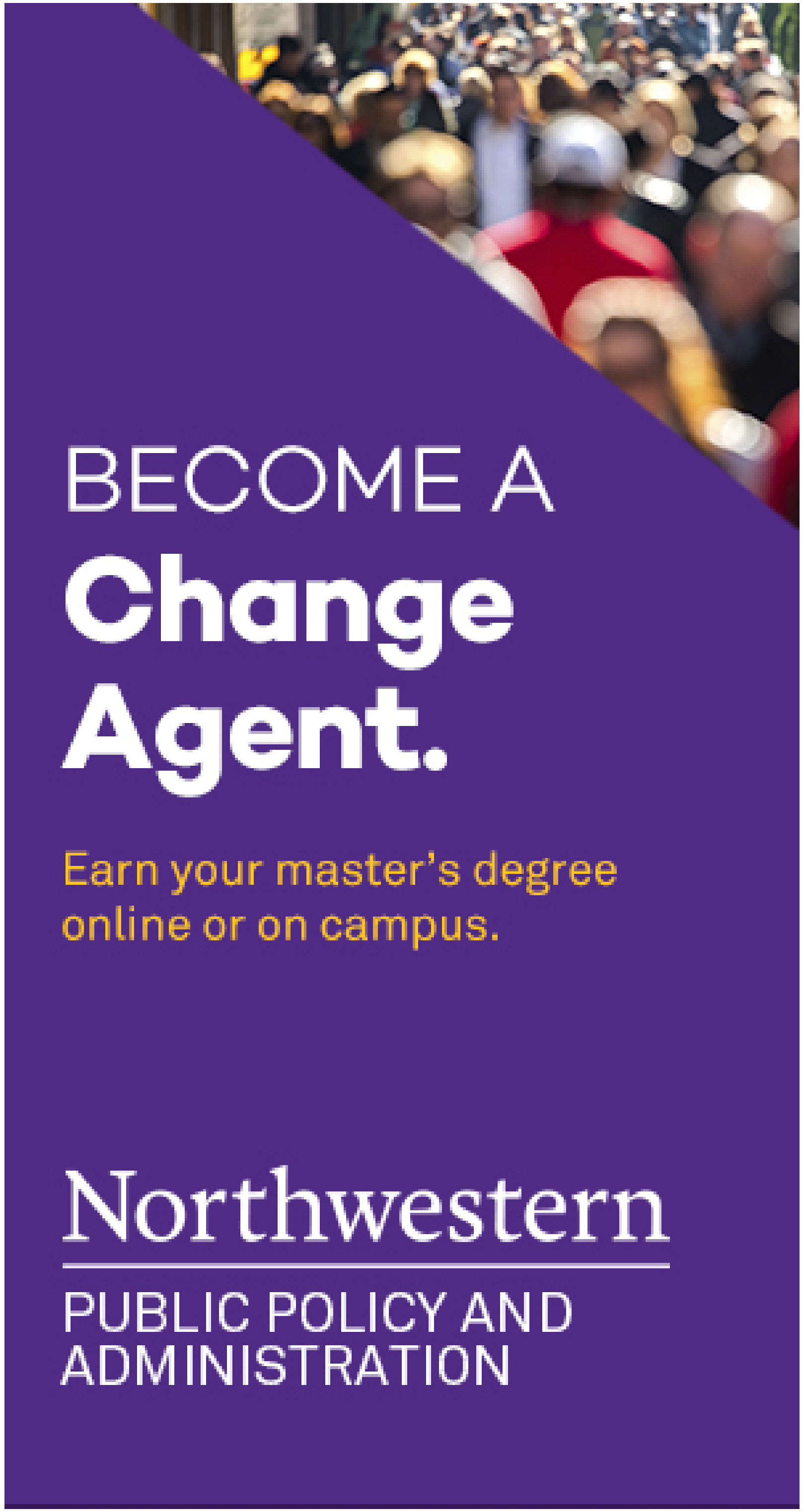

For patient groups, the pharma industry is the best source both for operational funding and the drug donations that can be shared with desperate patients. So most groups choose to accept the funding and devote themselves to patient education and direct aid, muting any criticism. T1International made the choice to favor advocacy, but it was not an easy one. Elliott recalls an early board meeting where he argued for a focus on patient service mission instead. “I am glad I was outvoted,” he says now. “T1 fills a much-needed need in the diabetes patient community.”

T1International refuses on principle to accept pharma industry donations. “Even if they don’t force you to take certain positions, it is human nature not to want to bite the hand that feeds you,” Rowley says. But that choice has implications. Although pharma-funded organizations such as the International Diabetes Federation and the American Diabetes Association are well-staffed, T1International gets by with an all-volunteer workforce, anchored by Rowley’s 40-plus hours of unpaid labor each week.

She and other volunteers continue to spend those hours ratcheting up the pressure on lawmakers and companies to address insulin pricing. They push for congressional hearings on the alleged industry collusion, expose the limitations of well-publicized corporate drug donation programs, and build a social media community around the theme of #insulin4rall. And they are giving voice to the argument that essential medicines should be once again a public good, not a for-profit commodity. “It is a tragedy that a drug like insulin, invented by people who were motivated by a goal of access to all, is so clearly unavailable to so many,” Elliott says. “People are dying, and that is a status quo no one can defend.”

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