



# Tackling Price Issues: Bring Patients into the Discussion

DAVID MITCHELL

have an incurable blood cancer. Drugs are keeping me alive. And because my cancer finds its way around drugs, I need new ones. The importance of innovative, affordable drugs is not theoretical for me — it's life and death.

I am very grateful for the drugs produced by the science and research sector in our country. But if my experience as a cancer patient has taught me anything, it has taught me one irrefutable fact: Drugs don't work if people can't afford them.

By now, most of you are familiar with the story of Martin Shkreli, the disgraced drug company CEO who increased the cost of an HIV drug from \$13.50 per pill to \$750 per pill.

You are likely less familiar with stories of Americans suffering every day under the skyrocketing prices of drugs.

Jon Pavlus of Worland, Wyoming, says, "I've had diabetes for 52 years, and in the last six years I've watched my insulin prices go from \$6.75 a vial to \$375 a vial. I can't afford this. I need help."

Angel Porche of Montegut, Louisiana, was diagnosed with rheumatoid arthritis at age 39. Her doctor prescribed Humira to put it in remission, but the drug cost more than she could afford. "So, needless to say, I went without this prescription," she writes. "I was in so much pain because I could literally feel my feet crippling."

These are just two stories from thousands, all across America.

Here is mine: In 2017 alone, my drugs carried a price tag of more than \$450,000.

That's right — nearly half a million dollars'

worth of drugs kept me alive last year.

## A FAITH PERSPECTIVE

Pope Francis, in his 2013 apostolic exhortation *Evangelii Gaudium*, wrote, "Today we have to say 'thou shalt not' to an economy of exclusion and inequality. Such an economy kills."

I agree.

That's why, on Feb. 22, 2017, my wife and I launched a nonprofit called Patients for Affordable Drugs. We take no money from drug corporations or any organizations that profit from the development or distribution of prescription drugs.

I'd like to tell you why I'm trying to do something about drug prices and explore ways to work together with the Catholic health care community to solve an issue with repercussions felt both inside our country's borders and outside, among the poorest and most vulnerable citizens on Earth.

There is hope in the expanding public outrage over drug prices, but to seriously change the broken system, we will need a lot more than angry Facebook posts and news coverage flare-ups centered on smug, convenient villains. Untangling decades of pharmaceutical industry work to build a system rigged in its favor will require a sustained, unified movement. We need action.



Eric Nyffeler

And, the ministry of Catholic health care is in a prime position to take it. Responsible for a quarter of all health care delivered worldwide, Catholic health care is critical in this fight. Faith-based action has been key to success in many struggles for social justice, and the health care ministry's participation can play a key role in this one as well.

#### WHERE WE BEGAN

Even with cancer, I consider myself lucky. I've raised a family. I got to experience a 30-year career in Detroit and Washington, D.C. helping to spearhead public health campaigns like "Click It or Ticket" and "Campaign for Tobacco-Free Kids."

Not only do I have Medicare, but I can afford to purchase Medicare Part B and D supplements, which helps cover the costs of my drugs.

Joining a community of cancer patients, though, I quickly realized not all were as lucky as I am.

According to a 2013 study in *The Oncologist*, almost 1 in 4 cancer patients choose not to fill a prescription due to the prohibitive price. One-fifth take less than the prescribed amount or only fill a partial prescription.<sup>1</sup>

*Kaiser Health News* pointed out that 1.6 million Americans were likely to be diagnosed with cancer in 2017. That means anywhere from 168,000 to 405,000 will ration their drug use.<sup>2</sup>

After Shkreli's story grabbed headlines, I started looking around, wondering who was going to speak up for patients struggling under rising drug prices.

Silence.

In late 2016, I walked downstairs and said to my wife, who is a cancer survivor herself, "Hey, would it be OK if I retire at the end of this year, and we set up an organization to work on behalf of patients to lower drug prices?"

She backed me right away. To get our start, we kicked in some start-up funds and secured funding from the Laura and John Arnold Foundation, a private foundation based in Houston.

#### OUT OF THE SHADOWS

Illness relegates American patients to the shad-

ows. It's understandable. Illness carries incredible burdens beyond the initial shock of any given diagnosis, especially in time and money. This is on top of all of the regular pressures of life: maintaining home, career, family and friendships. It's easy to see why we don't hear more from American patients on the issue of drug prices. They're busy, quietly and diligently, trying to survive.

Our approach to engage patients is threefold. The first task has been to shine a light into the world of the American patient by offering an

**According to a 2013 study in *The Oncologist*, almost 1 in 4 cancer patients choose not to fill a prescription due to the prohibitive price. One-fifth take less than the prescribed amount or only fill a partial prescription.**

opportunity to share the ways high drug costs impact his or her life. Only then can we help policymakers and elected officials understand who is suffering under drug prices and how.

We made it as easy as possible. We reached out through social media to encourage people to come to our new website and quickly collected 8,500 patient stories and 20,000 emails. An interactive map at [www.patientsforaffordabledrugs.org](http://www.patientsforaffordabledrugs.org) shows the issue's scope.

It turned out that patients really wanted to talk about the way drug prices hurt them. We listened to what they said to make sure our actions reflect their concerns, amplifying their voices however we can.

Second, we are educating them. Unbiased information hasn't been made available about how monopoly drug corporations and various actors in the drug supply chain are driving up drug costs. Patients have been told they need to fund research if they want cures. But no one tells them what to do when the research results in treatments costing hundreds of thousands of dollars per year. The Patients For Affordable Drugs education component includes everything from interactive online seminars about activism to a monthly newsletter in which we try to make the economics and politics of drug pricing something the average person can understand and then act on.





Third, we seek to mobilize patients to bring about federal and state policy changes that relieve their suffering and to warn against those that won't. One action encouraged patients to write to President Donald J. Trump, asking him to let Medicare negotiate for lower drug prices. In another, we flew a patient named Ann Neilson to Washington, D.C., to speak with her members of Congress about the high cost of drugs and push for passage of the CREATES Act, a bill introduced in 2017 by Sen. Patrick Leahy, D-Vt., to promote competition in the pharmaceutical market and "to facilitate the timely entry of lower-cost generic and biosimilar versions" of drugs.<sup>3</sup> The bill was referred to the Senate Judiciary Committee, where it remains as of February 2018.

We also are urging Congress to conduct an investigation into anti-competitive behavior and price-fixing by the primary manufacturers of insulin — Eli Lilly, Novo Nordisk and Sanofi. We want Congress to enact legislation to require full price transparency from all players in the insulin supply chain, including drug makers, pharmacy benefit managers and insurers. This could include incentives to encourage additional competitors to enter the market or regulation to ensure current companies aren't abusing the system. Nevada offers a bipartisan model law to ensure a vibrant, competitive insulin market that serves consumers instead of drug corporations and distributors.

At the state level, our organization brought Victoria Steussel to the California State Capitol to advocate for SB17, a drug pricing transparency bill. California Gov. Jerry Brown signed it into law in October 2017. Colorado is modeling its upcoming drug pricing transparency reforms on California. We're active there, too.

I have testified before three Congressional committees and before a Food and Drug Administration and Federal Trade Commission panel. Without us, these panels are dominated by industry representatives, academics and economists. We all must work together to solve the drug pricing issue, and patients deserve a seat at these tables, too.

#### THE CATHOLIC HEALTH CARE COMMUNITY

It's so important to us that the Catholic health care community be a part of making a case for the ethical and moral issues connected to drug pricing. And so, I am asking you to join us. Prescription drugs are, for people like me, a matter of life and

death. The Catholic Church, of course, has a deep commitment to life.

There are ways to help.

First, invite your communities to visit our website, [www.patientsforaffordabledrugs.org/share-your-story/](http://www.patientsforaffordabledrugs.org/share-your-story/). There, they can share their story about drug costs or leave contact information. We don't sell it and we won't abuse it. But, we will tell them how to participate in the fight to lower drug prices. There are a range of options for getting involved.

Activists can join our email list, follow us on Facebook and Twitter. Those who wish to be engaged at a higher level can sign up for our patient advocate program and work with our growing team of dedicated organizers. We know how busy patients are and will make civic participation as pain-free as possible.

You might also consider bringing this article to your priest or faith leader to see if the moral imperative of fair drug pricing could be a focus in your faith community.

We must achieve the balance of affordability and accessibility while maintaining that robust research and development pipeline and a fair profit.

I am an optimist.

I think it comes with having an incurable cancer. And I have faith that, together, we will find a way to lower drug prices.

**DAVID MITCHELL** is president and founder of Patients For Affordable Drugs, a bipartisan national patient organization in Washington, D.C.

#### NOTES

1. S. Yousuf Zafar et al., "The Financial Toxicity of Cancer Treatment: A Pilot Study Assessing Out-of-Pocket Expenses and the Insured Cancer Patient's Experience," *The Oncologist* 18, no. 4 (2013): 381-90. <http://the-oncologist.alphamedpress.org/content/18/4/381.full.pdf+html>.
2. Liz Szabo, "Sticker Shock Forces Thousands of Cancer Patients to Skip Drugs, Skimp on Treatment," *Kaiser Health News*, March 15, 2017. <https://khn.org/news/sticker-shock-forces-thousands-of-cancer-patients-to-skip-drugs-skimp-on-treatment/>.
3. *Creating and Restoring Equal Access To Equivalent Samples Act of 2017*, S 974, 115th Cong., 1st Sess. [www.congress.gov/bill/115th-congress/senate-bill/974/text?q=%7B%22search%22%3A%5B%22s974%22%5D%7D&r=1](http://www.congress.gov/bill/115th-congress/senate-bill/974/text?q=%7B%22search%22%3A%5B%22s974%22%5D%7D&r=1).

JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

[www.chausa.org](http://www.chausa.org)

# HEALTH PROGRESS®

---

Reprinted from *Health Progress*, March - April 2018  
Copyright © 2018 by The Catholic Health Association of the United States

---