

## Transcript: Congress fixed (a piece of) Medicare. It only took a few decades.

**Dan:** Hey there--

On the afternoon of Sunday, August 7, Stacie Dusetzina was sitting alone in her office at Vanderbilt University, where she's a professor of health policy, watching C-Span, and crying.

**VP Kamala Harris:** The question is on passage of HR. 5, 3 76 as amended. I asked for the A's and A's is there a sufficient second? There is. There appears to be. The clerk will call the rule.

**Dan:** The U.S. Senate was voting on the Inflation Reduction Act,

**Mrs. Blackburn. Mr. Blumenthal, Mr. Blunt, Mr. Booker,**

**Dan:** which -- among other things -- lots of other things --

(ducks under...)

**Mr. Cruz, Mr. Danes, Mr. Duckworth, Mr. Durbin,**

**Dan:** Will make it so people on Medicare will pay less for really expensive drugs.

**VP Kamala Harris:** The yays are 50. The NAYS are 50. The Senate being equally divided. The vice president votes in the affirmative and the bill as amended is passed.

**Dan:** There are a bunch of drug provisions in the new law. One that's gotten the most attention is giving Medicare the right to negotiate the price it pays for certain expensive drugs, which doesn't kick in for a few years.

**Dan:** But maybe a bigger deal, and sooner -- by 2025-- nobody on Medicare will have to pay more than two thousand dollars a year for prescription drugs.

Which is a huge deal. It's the main reason Stacie Dusetzina was crying as she watched the Senate take that vote. Because lots of people pay more than that now -- more than a million people every year.

And some pay a LOT more.

Stacie's research shows that the top ten cancer pills cost people on Medicare more than 10 thousand bucks a year each.

That's 170,000 people paying that much each, every year.

And that's just the top ten cancer pills. Those are not the only expensive drugs.

**Stacie Dusetzina:** I think it just basically created a situation where I was thinking a lot, all the time about like, how, how do we help make this better? And it's like, Ugh, so, you know, it creates a little bit of an obsession.

**Dan:** Stacie and her obsession have helped change that situation, change the way Medicare's prescription drug benefit-- called Part D-- will work.

It's an example of how things -- really, really messed up things -- can, sometimes, get better.

This is An Arm and a Leg-- a show about why health care costs so freaking much, and what we can maybe do about it. I'm Dan Weismann. I'm a reporter, and I like a challenge. So my job on this show is to take one of the most enraging, terrifying, depressing parts of American life and bring you something entertaining, empowering, and useful.

Stacie Dusetzina was not born obsessing about Medicare policy. She grew up in a tiny town in North Carolina. Her dad was a welder, her mom home-schooled Stacie and her siblings.

After college, she says she kind of drifted into working in the pharmaceutical industry. And after a few years went for a Ph.D. in pharmaceutical science.

**Stacie Dusetzina:** I was interested in pharmacoepidemiology, quite a mouthful, but like how do large populations use medicine and how does that change with new information

**Dan:** How much drugs cost-- whether people could afford them-- that didn't land on her research agenda until she was already in her first professor job. And read a newspaper story.

**Stacie Dusetzina:** There was a, um, article that had come out, talking about how people couldn't afford this really expensive cancer drug that its price was going up and patients couldn't afford it.

**Dan:** She was like, huh. That makes sense, but there's no data to support it. ... somebody like -- oh, I don't know, a population health scientist, like her, should look into this.

**Stacie Dusetzina:** my colleagues and I produced the paper really fast, cuz we're like, oh, we have access to data to answer this question.

**Dan:** And the findings were pretty dramatic.

**Stacie Dusetzina:** We found that people who had higher costs were 70% more likely to discontinue taking these literally lifesaving drugs

**Dan:** She was looking at drugs that fight a rare cancer called chronic myeloid leukemia. The first one, called Gleevek, came out in 2001, and similar drugs followed. They work, and Stacie says the side effects aren't that bad. She calls them "basically the best cancer drugs that have ever been developed."

**Stacie Dusetzina:** They practically function as a cure. So like the fact that so many people were discontinuing within six months--

**Dan:** And you're supposed to take this for more than six months.

**Stacie Dusetzina:** Oh my goodness. You're supposed to take this for the rest of your life.

**Dan:** And the consequence of not taking it is, the rest of your life is probably going to be a LOT shorter. She says without drugs like these, you're looking at maybe five years to live with this cancer. With them, you're looking at a normal lifespan.

So seeing people not take it because it costs more...

**Stacie Dusetzina:** It's like, that's a nightmare. And the out of pocket costs that we were looking at, some of them were not even that high.

**Dan:** Some of the people in the "high cost" group in her study were paying just \$75 a month. Or, you know, not paying it, and not getting life-saving medicine.

That paper got some big attention. Like, at a big national meeting for cancer specialists, the president of the group used it as a call to action.

**Stacie Dusetzina:** I wasn't in attendance, but a friend was, and she's like, there was a standing ovation, it was crazy.

**Dan:** Stacie has been looking ever since at how out of pocket costs affect people's access to drugs. She's focused a lot at Medicare's drug benefit, especially with expensive drugs, like cancer drugs.

**Stacie Dusetzina:** And it was so obvious that this is not a benefit that is designed for people who need high priced drugs, but given the prevalence of cancer among older adults, it's like many people when they eventually do develop cancer are on Medicare. And so the idea that you could have such poor coverage was just kind of staggering.

**Dan:** For instance, drug coverage on Medicare Part D, it's actually private insurance: You shop for it, pick the best deal for you. Except...

**Stacie Dusetzina:** I think in 2014 we found that. There are no good part D plans for cancer drugs. They are all uniformly, not generous like you can't shop your way into a plan that covers these better. So that's, that's not great.

**Dan:** Some of her research gets way into the weeds. Other than the result -- people end up paying too much for their medicine-- some of it is way past what I can follow right away. Stacie says, "yeah: this stuff is super-complicated."

**Stacie Dusetzina:** I have spent probably the better part of a decade, like, thinking about this hard and figuring out like over time things that were like, oh, I didn't know. It worked that way. Like, does anybody else actually know it works that way?

**Dan:** No? Time to put out another paper. Pretty much always, the question is: How does Medicare work if you're actually trying to use it for life-saving drugs?

This last spring, Stacie and her colleagues published the results of a really big study. They pulled more 17,000 prescription records from eleven big hospital systems -- all for people on Medicare, all for high-priced drugs for things like cancer -- and looked at whether people ever actually filled their prescriptions.

People on Medicare with super-low incomes get subsidies, and they generally filled those prescriptions. But...

**Stacie Dusetzina:** we found that like 30% of people without subsidies were not filling the cancer drugs that were prescribed to them by their doctors. That is, that's a ton.

**Dan:** For cancer! And there's reason to think that the sample Stacie and her colleagues looked at are folks who would have LESS of a problem than people being treated in other places.

**Stacie Dusetzina:** we're focused on academic medical centers that have very like large cancer programs. They are the specialists in their areas. They have financial counselors and support teams and onsite pharmacies. They have like every tool in the toolkit to help people to take their drugs or get access to drugs. And still we find this massive percentage of people who are not filling them.

**Dan:** I mean, it's shocking-- but also, you know, not that surprising.

**Stacie Dusetzina:** You know, like if you talked to a regular person, and you said, okay, well, these drugs are gonna cost you a thousand dollars out of pocket or two or \$3,000 just for your first month. Like, what do you think would happen? It's like, well, most normal people would be like, uh, yeah, well, how am I gonna fill that?. And so I think that kind of the average person could have told you what I would find in my study before I did my study. Um, that said, it is hard to convince. I guess we'll call them the not average people who are making decisions about policies, how broad of a problem this is.

**Dan:** it's like that very first study she did-- the one where she read a newspaper story and thought, Well, geez, I know how to get the data that could show how big a problem this is. In the last couple of years, this issue Stacie studies has also gotten very personal: Her mom has been fighting breast cancer.

**Stacie Dusetzina:** My siblings and I are in a very good position. We have really great jobs and we could help to cover the cost. But like, you know, your parents are just not gonna be like pro that strategy.

**Dan:** And the complexity of Medicare policy came right into the family's story: The most common kinds of breast cancer are treated with an oral medication: That's Medicare, Part D, prescription drugs, and the price tag is like 15 thousand dollars a year, out of pocket.

But Stacie's mom had a different type of breast cancer-- treated with infused drugs, in a doctor's office. Covered by the \*medical-care\* part of Medicare.

**Stacie Dusetzina:** it really had me thinking. as someone who had already been mad about Medicare part D for a long time, to see like how much relief I felt as a family member, knowing like it was covered, like she could pursue treatment and it would be covered.

And you wouldn't have that additional burden of like having to deal with these huge cost every single month on top of the burden of undergoing treatment for cancer, which is horrible in and of itself.

**Dan:** Stacie published an essay in the New England Journal of Medicine that she says was a little more personal --although it didn't mention her mom at all. It was called "The High Cost of Cancer Drugs Under Medicare Part D." Just the facts. But those facts are wrenching.

**Stacie Dusetzina:** it's not even having breast cancer. It's the subtype of cancer that you have that could dictate whether or not you can afford to be treated and that's not where we wanna be. Like that's the whole point of having health insurance is to actually have that financial protection when you need it.

**Dan:** Since Stacie's been studying this, making these arguments, Congress has come close, more than once, to fixing these problems. She remembers a conversation with a friend a few years ago.

**Stacie Dusetzina:** we were commiserating about like how it felt really close that time or it might happen. And someone pointed out like, oh, in the eighties they literally were writing the exact same things, like the same criticisms and stuff like that.

And it was just kind of, um, I don't know, it felt very depressing that like, it basically be my entire lifetime and we are still having the exact same argument without much of a change.

**Dan:** At least, until now. And wait-- the exact some debates were happening in the nineteen EIGHTIES?

Turns out, that's absolutely right. And I got to talk with the eyewitness to end all eyewitnesses to that. Somebody who has been watching this exact argument, in Congress, for the entire time. That's right after this.

This episode of An Arm and a Leg is produced in partnership with Kaiser Health News. That's a non-profit newsroom covering health care in America. KHN is not affiliated with the giant health care outfit Kaiser Permanente. We'll have more information about KHN at the end of this episode.

And speaking of our pals at KHN, one of them is the premiere eyewitness to decades of Congressional debates about Medicare drug coverage

**Julie Rovner:** I am Julie Rovner, I'm Chief Washington Correspondent at Kaiser Health News and host of KHN's What the Health podcast. I've been on this beat since 1986.

**Dan:** That's longer than anybody else. And she has been covering Medicare this whole time.

**Julie Rovner:** basically if you were a health policy reporter in the 1980s and 1990s, Medicare was your beat. I know a lot about Medicare

I learned it all the hard way.

And some of it she learned from watching what happened with what got called the Medicare Catastrophic Coverage Act of 1988.

it was quite, was sort of my first big bill that I covered. And then there was this gigantic backlash and it ended up getting repealed. It's still the only major bill that I ever saw get

repealed.

**Dan:** so it passed and was signed into law. And then the next year a majority of Congress voted to repeal it and that was signed.

**Julie Rovner:** Yes, that's

correct.

**Dan:** Wow.

**Julie Rovner:** Yeah, it was, it was a really big deal at the time.

**Dan:** So here's something I learned from talking to Julie: Medicare originally didn't have what's called an out-of-pocket max. A limit on what you might spend on your own health care in a given year. For ANYTHING. Not just drugs. And it still doesn't. People get private insurance to cover that.

And in the 1980s, Conservative icon Ronald Reagan said, hey: We ought to change that. Medicare should do more for people.

A Democratic Congress said, you betcha. And actually, let's go farther-- let's add a prescription drug benefit.

**Julie Rovner:** which they'd been trying to do for some time because Medicare originally didn't have prescription drug coverage because in 1965, there weren't that many prescription drugs. They weren't that expensive, not a big deal

**Dan:** you were like, yeah, this doesn't cover your penicillin. I'm like, that's all right. It's generic. I'm fine.

**Julie Rovner:** three bucks. I mean, you're probably gonna be able to pay it.

**Dan:** when did we start having drugs that like, people were like, you know, that's kind of a lot. I mean, I really want it, but it's kind of a lot.

**Julie Rovner:** I think we're starting to get some of the newer antibiotics that were more expensive in the early 1980s. And we're starting to see statins become more common. We're starting to get some of these more expensive ulcer drugs. Particularly for older people, drug costs were starting to be a big concern.

**Dan:** And guess who hated the idea of Medicare helping older people with that concern? The drug industry. Which sounds bananas, like: Hey, the government is gonna help people pay for our expensive product. Boo! Well . . .

**Julie Rovner:** this is my favorite quote ever written about the drug industry and its involvement, uh, in, in Medicare. And it's from the New Republic in 1989, uh, written by a guy named Philip Longman

and he said that the drug industry opposed the prescription drug provision, quote, out of the reasonable fear that if the government were paying for all these drugs, it might wanna have some say over how much they cost

**Dan:** The drug industry lobbied hard against the bill, but it passed, it got signed. So then they fed a sneaky campaign to turn people against it.



**Julie Rovner:** you know, this was, there was no internet yet, but you'd be surprised at the misinformation that got out about this.

**Dan:** There was a kernel of truth: These new benefits were gonna be paid for by taxing seniors directly for the first time. Regular medicare gets funded by payroll taxes on workers.

It was like 800 a year, and only for wealthier seniors. But

**Julie Rovner:** these groups were saying you're gonna have to pay thousands of dollars and Lower income seniors were gonna have to pay thousands of dollars. None of which was true. I mean, there was just an enormous amount of bad information. And as it turns out, some of this had been planted by the prescription drug industry, which didn't like the part of the bill that was going to, to start a drug benefit.

**Dan:** And this worked. People showed up to confront their members of Congress, pissed.

**Julie Rovner:** There was a very famous, demonstration in Chicago, Dan

Rostenkowski, the. the. Then chairman of the house ways and means committee. Um, there were, there were seniors who draped themselves across the front of his car.

**News archive:** Seniors, chase Rostenkowski down Milwaukee avenue and surrounded his car. One woman stood in front of it, refusing to move as the car inch towards her...

**Dan:** I was a kid. I remember the headlines. Rostenkowski was a giant political figure in Chicago. Him getting stopped in traffic by a bunch of pissed-off old people was huge front page news.

**News archive:** He's supposed to represent the people, not himself.

**Dan:** I mean, I had no idea what it was about at the time. But members of Congress did. They repealed the whole thing by the end of the year.

And I asked Julie: If the drug industry didn't want Medicare to pay for drugs, why didn't they focus on lobbying and stirring people up to just repeal the drug part?

**Julie Rovner:** Because that was really popular. I mean, people wanted the drug coverage, it was easier to undo the rest of the bill that was being paid for by these extra taxes

**Dan:** And Julie says those extra taxes were unpopular, even if a lot of people got the facts wrong. There was a precedent being set: Medicare services being paid for by old people. Maybe \*eventually\* more old people would be on the hook for more.

**Julie Rovner:** So there were, there were a variety of things that that got this repealed, you know, you cannot say it was all the drug industry, but you can definitely say that drug industry had a hand in it.

It was a long time before Congress made changes like that. In the 1990s, Bill and Hilary Clinton invested all their political capital in an effort to fix more than just Medicare-- and got flattened.

Then in 2003, Republicans had control of the White House and both houses of Congress, and they decided to do something they knew people would thank them for: Add a drug benefit to Medicare. But ...

It happened in negotiation with the drug industry, because one of the things that, uh, they had discovered that the Democrats had discovered in 1993 and 1994, is that if the drug industry is not in the tent, they're gonna blow up whatever you're trying to do.

**Dan:** So the government wouldn't be able to negotiate prices for the drugs it was gonna be paying for.

There were other compromises too, especially: the benefit was gonna be limited. It had actual gaps in it, built in. There's a thing people call the Donut Hole-- to this day! Until this new law kicks in over the next few years-- where: once your drugs cost a certain amount, you have to pay thousands of dollars completely on your own before Medicare comes back and picks up anything for your medicine.

**Julie Rovner:** It's like, Yeah, we have this Medicare drug coverage, but it doesn't work all that well for a lot of people. It was designed as a political compromise, not as a workable plan.

**Dan:** And it was specifically a political compromise with the drug industry and its lobbying arm, which is called PhRMA. Which, after the bill passed, executed an impressive flex.

**Julie Rovner:** Fun fact, the chairman of the house, energy and commerce committee, Billy Tonkin, went on the following year to resign from Congress and become the head of PhRMA.

**Dan:** Yeah, what!?! This is the dude who WROTE the Medicare-drug bill. Which starts to answer the question: If this was so messed up for so many people, why did it take 19 years to fix?

And about the compromises with industry. There was also a big compromise with the insurance industry: the drug benefit, Medicare Part D, is structured as private insurance. You pay for it out of your pocket. All these compromises add complexity, for all of us.

**Julie Rovner:** It gets really confusing. Before my mom died, she had basically four different insurance policies she had regular Medicare-- Medicare part A and part B are slightly different.. She had a Medicare supplement, so it would cover most of her out of pocket costs and provide her an out of pocket cap. She had to buy extra insurance to do that. Then she had a separate part D drug plan with its own deductible and its own coverage.

**Dan:** I will spare you the head-spinning details. I tell Julie, she's reminding me of a big reason we haven't looked at Medicare yet on this show: Because it is SO complicated.

**Julie Rovner:** It's just a mess to try to understand it does not end up with a, a streamlined program that's easy for its end users.

**Dan:** Yeah, we'll be coming back to Medicare. But this is why Stacie Dusetzina has had to work so hard to wrap her mind around how Medicare works -- or doesn't -- for regular people. And how to find the data that demonstrates it.

Meanwhile, Julie's been watching the action-- and inaction -- on Medicare drug coverage in Washington.

There were patches-- the sort of things people like Stacie finds the big gaping holes in -- but nothing... well, nothing that the drug industry actively opposed.

Until now. Just barely.

**Julie Rovner:** this was not an easy bill to get through. I mean, it, this was definitely hand to hand combat.

**Dan:** And Julie says: The drug industry lost a round. That doesn't mean they're done fighting.

**Julie Rovner:** It is a long game. I'm gonna watch it. I plan to watch it for a long time.

**Dan:** Back to this round and what it means. Of course it wrapped with Stacie Dusetzina alone in her office, watching C-Span and crying. She was alone, but not completely alone.

**Stacie Dusetzina:** you have your different chat groups like your academic friends chat group, who really has been in it with you for the ups and downs.

**Dan:** Right, Stacie's NOT the only person whose work helped make this happen. She's got a lot of colleagues and collaborators

**Stacie Dusetzina:** We're like texting with each other and, you know, we've had these same support groups for years, as we've felt like it was really close to happening. And then like it didn't, and there was also crying, but different crying

**Dan:** she'll see some of those collaborators later this month-- at a big ceremony, celebrating the bill's passage, at the White House.

**Stacie Dusetzina:** I got a save the date from the president. Like, you know, that's, that's pretty cool. I was like, I definitely feel like I've peaked.

**Dan:** She figures there will still be lots of messed-up things to investigate for the rest of her career. But seeing this change also makes her feel good about her role running Vanderbilt's PhD program in health policy.

**Stacie Dusetzina:** I bring people into the field and to be able to say like, sometimes it actually does change. And I've always said, you know, like policy's a long game. Like your job is to generate evidence, like keep on generating evidence and you will often feel like it's going nowhere because it's not the right political moment. But I think to be able to show students that like, you can still make a difference, even if it takes 40 or 50 years.

**Dan:** I absolutely do not want to wait 40 or 50 years. I don't think any of us does.

And for some people, even waiting two or three years for this new law to fully kick in is too long.

On Twitter, one woman responded to Stacie's thread celebrating the new law, "Sad I won't make it that long, and that my man will have to work while I die so I can have his insurance." She's got breast cancer.

But she agreed that this WILL help a lot of people once it's in place. She wrote "I'm working for those that come behind me."

So, I am so glad that Stacie Dusetzina and her colleagues have hung in there, that they continued to generate evidence. Because this is a pretty big freaking deal, and I'm pretty sure it wouldn't have happened without them.

Next time on An Arm and a Leg, we'll talk about one thing that didn't make it into the bill the way some people had hoped. Here's a clip from a rally in late July:

**Insulin4All activist 1:** We need action on insulin now,

**Insulin4All activist 2:** our fight literally means life or death.

**Dan:** The Inflation Reduction Act does help some people who need insulin: For people on Medicare it'll limit copays to \$35 per month.

But there was also an effort to extend that copay cap to people with regular insurance. And that failed.

But producer Emily Pisacreta, who lives with type 1 diabetes herself, will bring us a story that may provide some reason for optimism. States like California say they're taking matters into their own hands. Here's California Governor Gavin Newsom.

**Gov. Gavin Newsom:** it's happening. California's gonna make its own insulin,

**Dan:** For real? Emily's got the story in three weeks.

Til then, take care of yourself.

This episode of an arm and a leg was produced by me, Dan Weissman, with help from Emily Pisacreta and edited by Afi Yellow-Duke. Daisy Rosario is our consulting managing producer. Adam Raymonda is our audio wizard. Our music is by Dave Weiner and blue dot sessions.

Gabrielle Healy is our managing editor for audience Bea Bosco is our consulting director of operations. Sarah Ballema is our operations manager.

This season of an arm and a leg is a co-production with Kaiser health news. That's a nonprofit news service about healthcare in America. It's an editorially independent program of the Kaiser family foundation.

Kaiser health news is not affiliated with Kaiser Permanente, the big healthcare outfit. They share an ancestor. The 20th century industrialist Henry J Kaiser.

When he died more than 50 years ago, he left half his money to the foundation that later created Kaiser health news.

You can learn more about him and Kaiser health news at [armandalegshow.com](http://armandalegshow.com) slash Kaiser.

Diane Webber is national editor for broadcast at Kaiser health news. She's editorial liaison to this show.

KHN also brings you JULIE ROVNER's podcast What the Health-- where Julie sorts through the latest on health policy and politics from Washington DC, along with other super-smart reporters and other guests.

Thank you to public narrative. That's a Chicago based group that helps journalists and nonprofits tell better stories for serving as our fiscal sponsor, allowing us to accept tax exempt donations.

You can learn more about public narrative [www dot publicnarrative dot org](http://www.publicnarrative.org).

And those donations support this show. If you're not a donor. We would love to have you. come on by to [www dot armandlegshow dot com](http://www.armandlegshow.com), slash support. Thank you.