

# Transcript: Swimming with Sharks

**Dan:** Hey there--

Here is the thing about Lillian Karabaic. I talk sometimes about building a dojo -- like a self-defense training school -- for dealing with the horrible cost of health care? It's a metaphor. A work in progress. A metaphor in progress.

Lillian is a black belt in this stuff. In fact, she's a teacher. I ask her to introduce herself, and she says

**Lillian K:** I'm Lillian Karabaic and I am a podcast and YouTube host that talks about personal finance and unfortunately, a lot of the time that has to do with healthcare.

**Dan:** Lillian comes by all of this so honestly. She's always been good with a dollar. And she's had to be.

One, because she's always wanted to do good things: She spent her twenties working for non-profits, which doesn't pay a lot.

And two, because she's got rheumatoid arthritis. Started having symptoms when she was 18. Couldn't hold a pen.

So, unlike people who are young-and-indestructible, she experienced herself as being pretty destructible. And, as needing to think hard about the financial side of health care.

Especially when she finally got access to a drug called Enbrel.

**Lillian K:** within about three weeks, I went from not able to make a fist, to like 99% symptom-free.

**It was spectacularly life changing for me. I was like, other people live like this,**

**you can just like open door knobs.**

**Dan:** But: Enbrel was not cheap. Lillian says it was 800 bucks a month when she started taking it in 2015. Which, on her income, was a LOT of money.

**Lillian K:** when I went into covering personal finance, I, it just, healthcare is such a large freaking part of it.

**Dan:** And the stakes for her have only gotten higher. Right now, Enbrel's list price is about 12 thousand dollars a month. Yep, it's gone from 800 dollars a month to 12 THOUSAND. It's 15 times more expensive than it was seven years ago. She plans and plans.

She had to pick new insurance recently, and she went over the options with a fine-toothed comb.

In January, with new insurance, she's got a whole routine of chasing the pre-authorization she needs, so when she goes to fill her first prescription of the year, everything's lined up.

**Lillian K:** it's my whole, like, I just, this is every January for me.

**Dan:** It's a lot. Then, in February, this year, a surprise:

**Lillian K:** I just got all of a sudden, a text message from my specialty pharmacy saying that I have a \$3,000 copay. That's not a text message to anybody who wants to wake up to,

**Dan:** Definitely not. And the story behind that text message? It illuminates a TON.

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 Weissmann. I'm a reporter, and I like a challenge, so my job on this show is to take one of the most enraging, terrifying, and depressing parts of American life, and bring you a show that's entertaining, empowering and useful.

And in the last few months -- in an effort to hit that USEFUL part as hard as possible -- I've started putting out a newsletter called First Aid Kit, summing up some of the useful things I've learned in my reporting for this show.

Like, how to pick the least-crappy health insurance. How to avoid getting ripped off on tests like X-rays and MRIs, and last week: How to avoid paying through the nose for prescription drugs.

Which, I have to tell you: It did kind of put my cheerfulness to the test.

Because, I probably don't have to tell you: Pharma, drugs-- it's a big mess.

And handing out advice about it is a classic "First Aid Kit" situation. Like, I can show you where the band-aids are, and a band-aid can definitely do you some good, sometimes. It's good to know where they are.

But a lot of the time, a band-aid just doesn't cut it. I can point you to a website called Good Rx -- you may have heard of it -- and in some situations, it can save you a ton of money, show you how to avoid paying a stupid amount.

Like a generic blood-pressure drug. You go to the wrong place-- like Walgreens, in my area -- you could pay 128 bucks. Or, with an online coupon, you could go somewhere else and pay six dollars and fifty-one cents. That's good to know about.

But that is not the kind of drug that Lillian Karabaic is on.

**Lillian K:** if another person suggests good RX to me, I'm going to throw a fit

**Dan:** Yeah.

**Lillian K:** I would like to put you to the challenge of go look up good RX for.

**Dan:** Yeah.

**Lillian K:** Because the best price I can get with good RX is \$6,000 a month. So

**Dan:** And you know, that IS half of the list price. But not exactly affordable for most of us. Including Lillian.

And: GoodRx is mostly for if you're not using insurance. Lillian puts all this work into HAVING insurance that's supposed to protect her from the wild price of this drug.

And to understand what Lillian is caught up in, we need to zoom out .

Here's the deal: When you run into problems getting the meds you need at a price you can afford, there are multiple sets of players who are involved here. I'm gonna call them sharks.

Like we're out at sea, with maybe a life-jacket, and there are these multiple sets of sharks who are basically fighting each other, and taking bites out of us.

I mean, for them it's like a game -- they're trying to out-maneuver each other, get more money -- but it all ends up with us getting eaten alive.

One group of sharks, you've probably guessed, are the pharmaceutical companies. Like the makers of Enbrel, raising the sticker price to 12 thousand dollars.

Then there are the insurance company sharks. They'd like to avoid paying those wild prices for those medications.

[I should mention, there's another shark here. A middleman company called a Pharmacy Benefit Manager, which actually does a lot of the insurance company's work, on drug stuff, and takes a cut out of every prescription. I won't go into detail here -- it took me a whole episode to explain their story, and I'll include a link to that episode for you here-- but they're a major shark. Book major profits. To keep it simple here, I'll refer to them and the insurance company as one shark.]

So, the drug-maker sharks set the price super-high. That's their move.

Time for the insurance company's move in the shark game: And they make it against YOU.

They structure your plan so that you have to pay more for those meds. So, maybe you're used to a 10 dollar copay? For some drugs-- especially expensive drugs-- they'll make it more than that. Maybe a LOT more

Take Lillian, for example:

**Lillian K:** So for my drug, I have a 60% co-insurance after I meet deductible,

**Dan:** OK, wait, let's translate that from insurance speak. Deductible. That's the amount Lillian has to pay before her insurance kicks in at all. For her, that's three thousand bucks.

Then, there's co-insurance: One of the RUDE-est pieces of insurance speak. It's my percentage of whatever the cost is. It's like, hey, I'm CO-INSURING myself! So Lillian is co-insuring herself for a drug that costs thousands of dollars a month.

**Lillian K:** So 60% co-insurance is, guess what? That's pretty big.

**Dan:** So, ok. Sucks for us. But the drug-company sharks think it sucks for them too. Because if Lillian doesn't come up with her three thousand bucks, there's no sale. The insurance company doesn't pay anything. The drug company gets zero.

So, here's the drug company's NEXT shark move: They give money to patients, to meet those costs. The coinsurance, the deductible.

Some patients get coupons to give the pharmacist. Sometimes they get grants, funneled through foundations the pharma companies set up just to give people money for drug deductibles and copays.

And no mistake: These programs are a SHARK move.

A Wall Street Journal story documented that with one of these programs-- this one was set up as a foundation, funded by the drug company -- the drug company made back TWENTY TIMES what it put in.

WHOA. I mean, respect to the shark.

So, here is the insurance shark's COUNTER move: It's called a copay accumulator.

This is where the insurance company -- and their pals the pharmacy benefit manager say to me: Hey, Dan-- or hey, Lillian Karabaic-- you've paid your share

when WE say you've paid your share. Like, you personally. We say your share is three thousand bucks.

You got three thousand bucks from somebody else? Great, good for you. But that does. Not. Count. Pay up.

Which is how Lillian landed here.

**Lillian K:** I just got all of a sudden, a text message from my specialty pharmacy saying that I have a \$3,000 copay.

**Dan:** And there's a big question: How did someone as obsessively attentive as Lillian Karabaic get surprised by this? We'll come back to that. It's big.

But first, let's zoom in on a couple of details that Lillian has observed, because hey reveal more moves and counter-moves, by the sharks on both sides, now that the insurance sharks have unleashed their "copay accumulator" strategy.

Starting with: here's how Lillian gets that patient assistance money from the drug company.

**Lillian K:** the pharmaceutical company put money on a visa debit card. And it's, it's in my name. It's an, a debit card in my name

**Dan:** Lillian smells a shark in that.

**Lillian K:** I think it's part of their continued attempt to evade detection by the pharmacy benefit managers, like, they try to make it look like it's Just me paying

**Dan:** just

**Lillian K:** own debit cards.

**Dan:** Yep. Lillian is a hundred percent right about this. The CEO of one of the big pharmacy-benefit managers told reporters these debit cards are part of a cat-and-mouse game. I mean, I call it a shark-and-shark game.

And Lillian is seeing one of the insurance company's COUNTER moves. When she goes to pay for the her meds, the payment portal has a special message:

**Lillian K:** they specifically say, you're not allowed to input a manufacturer card. , even if they are a visa debit card, they say like on the thing, like do not enter this as a card.

**You have to call us**

**Dan:** They're telling you that they expect you to pay, and if you don't, then you're somehow in breach and they're going to mess with you.

**Lillian K:** Someone's going to come for money for me at some point, but I'm putting it off.

**Dan:** Lillian thinks the insurance folks are paying high-level nerds to sniff out debit cards from the drug company, so if she doesn't tell them, they'll know.

Which is a LOT of levels. And two things here:

One: We checked with analysts-- people who cover the drug industry and the associated insurance garbage. They were like, Yep. Lillian's rights. The insurance folks are totally hiring those nerds to sniff out those debit cards.

And two: Did you notice how in this latest move, the insurance people are putting LILLIAN right in the middle of this? They're saying, "IF this money is from the drug company, you have to call us and let us know?"

I mean, it's bananas.

And, let's get back to that big question: Lillian Karabaic, of all people, got caught by surprise. And not because she hadn't been keeping a careful eye out for this specific problem..

**Lillian K:** um, I called everyone and this. is now the third time that I've switched insurance, where I've been worried about these copay accumulator rules.

**And I have called. Pharmacy billing companies, the salespeople for the insurance I have called like member services to be like, hello. I need to find out how much this drug would be because I'm researching This plan**

**Dan:** ... and I need to know. Does this plan have one of those copay accumulator things? A lot of the time, Lillian says, the people on the phone have no idea what she's even asking about.

So, yeah, this is not a failure on Lillian's part. But you could call it a success on the part of the insurance sharks.

Because Lillian is not the only person looking for this information. There was a team of professionals on the case too, digging into plans across the country. And a lot of the time? They came up empty too.

But they did find out a lot. 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. Kaiser Health News is not affiliated with the health care giant, Kaiser Permanente. We'll have more information about KHN at the end of this episode.

So: Lillian had done her best to find an insurance plan WITHOUT one of these copay accumulator policies. And as she found out, you can't always tell, no matter how hard, and how smart, you work. Ever. Anywhere.

I mean, you might not think there's anybody more-determined or better equipped than Lillian Karabaic to go digging for this information. But how about a team of professionals?

Yep. Lillian passed me a report from a nonprofit group called the AIDS Institute. I talked with the author.

**Stephanie H:** my name is Stephanie Hengst, I am a manager of policy and research at the AIDS Institute.

**Dan:** So, Lillian tried to find out ahead of time if her insurance plan included one of these copay accumulators? Well, Stephanie and her colleagues did the same thing with EVERY health insurance plan on every Obamacare exchange across the country that could possibly have one.

**Stephanie H:** So there were 234 plans we looked through and,



**Dan:** little rueful laugh. Yeah. Like how many, how many of you were there?

**Stephanie H:** uh, three

**Dan:** It took them three weeks. Full-time, three people. They'd done it before, so they had their spreadsheets all set up ahead of time, all the links they used last time in there already.

**Stephanie H:** this year I was thinking, oh, this is going to be quick and easy. And it never is. because links change and information doesn't exist.

**Dan:** it sounds awful. I mean, how do you keep yourself going through that? Like, is there like, just like a shit talking slack channel know, like do you have music that you blast

**Stephanie H:** Uh, probably a little bit of all of the above.

**Dan:** Yeah, and that was just the beginning. Because in about a third of the plans they looked at, the information wasn't online. So they called the 800 numbers.

**Stephanie H:** and then you get into the issue with phone calls of like getting the right person on the line. Who knows what you're talking about. So you spend a lot of time trying to ask the right question in the right way so that you get the right person

**Dan:** Right, which sounds pret-ty familiar to anyone who's ever called their insurance. And guess what? Stephanie and her colleagues weren't always able to get the information they were looking for.

And these are the pros.

**Stephanie H:** this is my job. This is what I do for a living. I understand insurance. I understand the questions. I understand. Yeah. Yeah.

**Dan:** Yeah, and she's got colleagues, with that shit-talking slack channel to egg each other on.

And they're on the clock, not stealing time from something else when they're making these calls.

Those are big advantages when they're asking: Can you tell me does this policy include one of these copay accumulator deals-- this thing where, "my share" of a drug's cost has to come out of my own, personal pocket? Gonna potentially cost me thousands of extra dollars?

And still, dozens of times, they came up completely empty.

And Stephanie says nobody was breaking the law here. She says there IS a federal rule about disclosing these policies-- but only to people who are already signed up with an insurance plan.

**Stephanie H:** So it's too late at that point, if you're shopping for a plan and you want to know.

**Dan:** is like, after you buy the used car, then I will tell you, then I'll give you the mechanics report.

**Stephanie H:** Correct? Yes. That's exactly it.

**Dan:** I mean, hello? Holy crap. But ok, a lot of the time they DID get the information-- they're professionals -- and what they found out was pretty alarming.

In most states, most insurance plans do include these copay accumulators. In some states, every plan includes one.

These are the plans you can buy on Obamacare exchanges, individual coverage. What if you get insurance from work? Stephanie found a study from an industry group show that more than a third of big employers have policies that use copay accumulators.

And that percentage is growing.

So a LOT of us, and more all the time, are at risk of getting caught in this shark-versus-shark game-- where, if we happen to need a really expensive drug, we better have a LOT of our own personal money to burn.

I run my whole shark-versus-shark metaphor by Stephanie to get her read.

**Stephanie H:** you're pretty spot on. I would say, um, we, you know, we use different words, but it's the same exact narrative where, um, patients are caught in the middle between these two massive industries and, . it's the patients who are being hurt because they can't access their prescription drugs. And a lot of these. You know, not just maintenance, drugs, life saving drugs.

**Dan:** Right? I mean, it's not a coincidence that Stephanie did this report for the AIDS Institute. Drugs to treat HIV can be really really expensive. Also drugs that treat cancer.

But these shark games are not exactly front page news. For one thing, they're hard to sum up in a headline.

**Stephanie H:** it's a hard topic for a lot of people to like understand. I mean, insurance is complicated and then when you're finding this tiny little nuanced policy that doesn't affect everybody, but I think it affects more people than we think

**Dan:** Well, it could affect any of us. Right? Like my doctor could tell me tomorrow, like, Hey Dan, you got this funky cancer. I mean, knock wood. I hope that doesn't happen. But I mean, that's, that is why we have insurance.

**Stephanie H:** correct? Yes.

**Dan:** like, if my doctor's like, Hey Dan, you have this funky cancer.

. And I can worry about like, I hope the fucking treatment works and not think about like, I have to remortgage my house.

**Stephanie H:** Yeah. That's the definition of insurance. That's why we have it.

Yeah.

**Dan:** And if the reason we have insurance is to get access to care that we couldn't afford on our own. And for a drug, that doesn't have to be tens of

thousands of dollars. Stephanie's report includes an alarming figure-- she pulled it from a study by a fancy health-care consulting group called IQVIA.

They found that if filling a new prescription means spending two hundred and fifty bucks, seventy percent of people just don't fill it. They walk away, don't get their meds.

That's a lot of prescriptions just not getting filled. A lot.

Which is maybe the point. When we can't afford our "share" of a drug's price ... the drug company doesn't have to shell out for theirs. At all.

They say: These copay accumulators lower the total amount an insurance plan spends on drugs. That's what they're for.

And it's complicated, right? The drug companies are very much a bunch of sharks. They're setting the prices super-high. Remember, Lillian's drug is 15 times more expensive than it was when she started taking it.

[A couple of drug companies funded Stephanie's report, by the way. Because if there's one thing these sharks love, it's pointing a finger-- or a fin, I guess -- at another shark, and saying, "WATCH OUT, THERE'S A SHARK!" I mean, they're always right, which is different than saying you can trust them.]

It's crazy making. The sharks are eating us alive, and they are making wild, wild profits.

I did say, right up top, that going deep on drugs is absolutely testing my usual WTF cheerfulness. Enraging, terrifying, depressing? Yes, yes and yes.

But I've got a few things for you here. Empowering? Useful? Let's give it a shot.

First: When Stephanie Hengst and her colleagues at the AIDS Institute called insurance companies to ask whether a given plan included a co-pay accumulator? They made themselves a how-to, a tipsheet for getting straight answers

**Stephanie H: I put together just like a step-by-step of like, this is how you can try and find it,**

**Dan:** And she's sharing it with us! We'll have a link wherever you're listening. I mean, she's also got caveats.

**Stephanie H:** the hard thing. And the unfortunate thing is there is no ABC process.

**Dan:** I mean, I KNOW, RIGHT? Every stupid call is different.

But a tipsheet by professionals seems like a really valuable thing to have. I will take it.

So, that's one.

Two: This may be an instance where the government steps in and says: Hey, sharks, that game is too freaking rough.

These copay accumulator programs have only been around for a few years. But already, a dozen states have banned them. Others are considering it. I'll have a link to a report showing which states are which.

If yours isn't one of them, you might want to call your state rep, or do a little Googling to find out what's shaking in your state.

Now, as we've discussed, most people who get insurance from work, that insurance is actually regulated by the feds, not by states at all.

And federal regulators have been considering a ban on these programs too -- at least for drugs where there's no generic. They've been waffling -- Stephanie's frustrated -- but maybe we can help them get off the fence. I've asked Stephanie to keep us posted on how.

But this is a big problem. Right now, there's no way to be informed, organized, and determined enough to avoid getting caught. If there were, Lillian Karabaic would have found a way. And if there were a way to wriggle out of this trap, she's the one I'd pick to find it. She's been putting in the time. I asked her: How much? She was like...]

**Lillian K:** here, we can run the report, right.

**Dan:** Hm.

Because, yeah: She uses time-tracking software.

**Lillian K:** It has been okay. So it has been nine hours and 32 minutes in the past two weeks that I have spent on healthcare admin, which is mostly being on phone calls.

DAN: And she's gonna be putting in more. She's gotten the insurance company to open up a "claims audit." That's still in the works. She doesn't expect it to work.

**Lillian K:** I'm kind of delaying the inevitable, at least long enough to apply for a credit card that has a decent point sign-up bonus. So at least I can get something out of this entire situation.

**Dan:** And have the satisfaction of giving these folks the hardest time possible.

**Lillian K:** And I won't die without this drug. I will slowly degrade, but I will not die.

**Dan:** I mean, Lillian says she's gonna be OK financially too.

**Lillian K:** No one should be crying me a personal river about this. I can make it work, but I am also.

Fairly unique in how much of an emergency fund I have, because I am very paranoid partially for reasons like this.

**Dan:** I mean, yeah. I mean, you're, the personal finance equivalent of a prepper,

**Lillian K:** Yes. correct. I have, I have like a two year emergency fund. Um, and that has a lot to do actually with knowing how much my drugs cost and how expensive it is to get my drugs.

**Dan:** But no mistake. This is bad. She says her arthritis has been flaring up big-time since this started. She's frustrated. And not just for herself.

**Lillian K:** Cause it's, there's so many other people that are going to be screwed over by it.

**Dan:** Yeah. There are a LOT of people with a lot less time, energy, know-how, and financial cushion than Lillian Karabaic. I mean, that's pretty much everybody. And millions of us have serious, even deadly conditions that require medicine that -- at U.S. prices -- pretty much none of us can afford to pay on our own.

This is one of the reasons I say: We can't win them all. But we don't have to lose them all either.

Coming up next time on An Arm and a Leg, closing the justice gap.

Like, say some hospital is suing you for a bill ... that you don't even owe.

**Rohan: if you can't afford a lawyer and you probably can't find a free one because there's not enough supply of help that's available, you, are out of luck.**

That's Rohan Pavuluri -- he runs a non-profit that's got a plan to help. Except what they're proposing to do? Train some non-lawyers to at least give you some tips? It's technically a felony.

He's got a plan for that too. First step: Suing the state of New York. He wins that, there's 49 more. I am pretty excited about it.

That's next time, on An Arm and a Leg.

Till then, take care of yourself.

This episode of An Arm and a Leg was produced by me, Dan Weissmann, with a LOT of help from Emily Pisacreta, and edited by Marian Wang. Daisy Rosario is our consulting managing producer.

Adam Raymonda is our audio wizard. Our music is by Dave Winer and Blue Dot Sessions.

Gabrielle Healy is our managing editor for audience. She edits the First Aid Kit Newsletter.

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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, 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 [arm and a leg show dot com slash Kaiser](http://armandalegshow.com/kaiser).

Diane Webber is national editor for broadcast at Kaiser health news; she is the editorial liaison to this show.

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And I mentioned our First Aid Kit newsletter? Where we're writing down some of the most useful information we've found in our reporting for this show? You might want to subscribe. You can do that-- and read everything we've written so far-- at [arm and a leg show dot com slash, newsletter](http://armandalegshow.com/newsletter).

Thanks!