Dan: Matthew Lientz was an engineer at Boeing for decades. And not to stereotype engineers or anything, but he's not super-demonstrative. Like, when I ask him to tell the story of how he almost died, this is how he begins.

Matthew: When my merry-go-round started, I was 56 and I'm 72 now.

Diana: Oh, yeah, it was pretty crazy.

Dan: That's Matt's wife Diana. Matt will tell you: He would never have survived the merry-go-round without her. We'll let him get the story going.

Matthew: I worked for Boeing for over 34 years. And one day I had a pain in my lower right side.

Dan: A pal of his had had his appendix burst, a real mess. Matt wanted to avoid that. But, committed Boeing employee, it's not like he was going to clock out early.

Matthew: I sat there all day doing my job and I took the bus home and I decided I was going to go to the doctor .

Dan: A few hours later, he's in the hospital, getting his appendix out. It was messy-- what they call perforated. Matt spent a couple days in intensive care, recovering.

Then, he gets a visit from the surgeon.

Matthew: he asked for everybody else to leave the room except for Diana. And he says, oh, I'm so sorry.

Diana: I'm so sorry. I'm just sorry. And I looked at him for what I said, did you leave a tool in there or something, you know, you forgot to take it out?

I mean, cancer was the last thing in my mind.

Dan: But there it was. Matthew was back in surgery next day, getting a third of his colon removed. Then was chemo. Two flavors. The second one left Matt with neuropathy-- nerve damage. 15 years later, he still can't feel the bottom of his feet, except when they tingle or when the whole lower half of his body feels it's on fire. But at least, the doctors said, they'd cured his colon cancer.

Except, a year or so after the chemo ends, he's got more abdominal pain. And not only is the cancer back, it turns out, it's not colon cancer. It's cancer of the appendix.

Matthew: So then we go about, well, what have you got, doc, what can you do with this?

And he basically said, "well, I don't have any other tricks. this is we would normally refer you to hospice basically leading out to check out time." And we said, we don't really like that prognosis.

Diana: I wasn't ready to be a widow yet.

Matthew: You ready now?

Diana: no, never, never. You're never ready, but you know,

Dan: They were young! They had two young grandkids and a lot to look forward to.

They did some digging and found there WERE other tricks. A very effective treatment. But nobody local-- nobody in their insurance network-- was expert in it.

And their insurance did NOT want to pay for for the out-of-town, out-of-network expert surgeon.

Diana: And that's the first time in my mind that I'd even thought of the possibility that an insurance company wouldn't pay for an operation and it was maddening. I was mad.

Dan: So Diana kept digging, especially in an online chat group for appendix-cancer patients and their families...

Diana: I see there's a woman who's posting who actually lives in Kirkland, Washington and it looks like she certainly knows what she's talking about and I need some advice and I need some help.

Dan: That woman was Laurie Todd. A couple years earlier, she had been exactly where Diana and Matthew found themselves. Same diagnosis, looking at the same treatment, and getting told by her insurance that no way would they pay for it.

She had gone to war, done a ton of research, and written an appeal-- dense with fact, closely-argued-- that made her insurance company change their minds. Since then, she'd helped a few other people doing the same. [You can hear all about that part of Laurie's story in our previous episode.]

Now she's done more than 200 appeals. She says she almost never loses. Matthew and Diana's case was a big one for her-- she learned some big lessons about how insurance actually works, that she's been applying ever since.

Diana and Matthew had a hearing. Laurie was there too. And afterwards, she told them, this scene is gonna be in the movie.

We've got that scene for you, and a bunch of lessons. So get ready. This is gonna be pretty good.

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, depressing parts of American life, and bring you a show that's entertaining, empowering, and useful.

Laurie Todd heard from Diana and Matthew, and she agreed to help them. She started by doing something you'd never put in a movie: reading their benefits book. And she came across some unfamiliar language.

Laurie Todd: I said, this is a self-funded plan, administrator, la la la... And I said, wait a minute. What is that?

Dan: Yeah, what's a self-funded plan? She went down the rabbit hole on Google. Here's what she found. If you're in a self-funded plan...

Laurie Todd: the insurer is no longer insuring you. They aren't actually paying for your medical treatments in a self-funded plan.

Dan: Yeah, I know, right? We spent part of the last couple episodes just getting into this piece of weirdness. For most people who get their insurance from work, this is the deal. The employer IS the insurer.

She brings this finding back to Matthew and Diana. This time it's Matthew who's furious. At Boeing.

Matthew: What you won't cover it after I worked for you for 34 years?

Dan: You know, since he was in his early 20s. Now he's a grandpa.

Matthew: I worked beaucoups millions of hours of voluntary overtime . And you're going to sit there and tell me that after all this time? And my career, in your opinion, doesn't count for squat? I find that, uh, abominable. How's that for a word?

Dan: It's also, honestly, kind of intimidating for Laurie. She's been up against insurance companies more than half a dozen times by now. She's used to winning with them. But this is something different. This is Matthew's employer. And that employer is Boeing.

Pretty big opponent. You know the Fortune 500? That year, Boeing was number 28.

By this time Matthew's surgery is coming right up. Laurie drums up a written appeal, gets denied. There's one avenue left. An in-person hearing. With Boeing VPs at the table, along with insurance-company reps. There'll be lawyers on speakerphone.

Laurie Todd: So at this point, I'm thinking this is a ginormous situation mushrooming into an even bigger one.

Dan: And the hearing is in like two days. Surgery is supposed to happen he following week. Laurie isn't sure she's actually up for it. At this point, she's dong all these appeals for free, nobody's paying her anything. but she can't say no. She writes two speeches. One for Diana, and one for herself.

Laurie Todd: I said, I'm going to, I'm going to be the secret weapon.

Dan: Night before the hearing, she emails Diana her speech. Diana prints it out, reads it over, goes to bed-- and goes to work in the morning. Yeah, she and Matthew are both going to work the day of the hearing, taking care of business. Diana practices the speech one time, at a park near her job.

Diana: I did my presentation to the trees. And, uh, said my prayers and said, okay, you know, I'm going to speak and out's going to come, what they need to hear. I came back to our house. And, you know, freshened up, Laurie showed up and away. We went, it was just boom, boom.

Dan: It was the first time they'd met Laurie in person.

Matthew: We had a good coach and this was fourth quarter and, and five minutes left.

Laurie Todd: We sat down at the table kind of synchronizing watches and whatnot, and Matthew piped up and he said, wait a minute, I'm the patient?

Do I get to say something too? And I said, yeah, sure. I said, Matthew, you're an engineer and I want you to talk like an engineer. I said, no emotion, no angry, no pissed off.

Matthew: Did I do it?

Laurie Todd: Aeah, you absolutely did beautifully.

Dan: OK, that's getting ahead of ourselves. After the break, we're gonna basically take you inside that conference room. Because those speeches Laurie Todd wrote for herself and for Diana? She still has them. And we'll be hearing her and Diana read aloud from them-- for the first time since that day. That's right after this.

This episode of an arm and a leg is produced in partnership with Kaiser health news. That's a nonprofit newsroom that covers healthcare in America. Kaiser health news is not affiliated with the health care giant Kaiser Permanente. We'll have a little more information on Kaiser health news at the end of this episode.

Diana, Matthew and Laurie drive together to the hearing at the insurance company headquarters.

Laurie Todd: and it was like a gleaming three story spaceship out there. And I said look at that, that's where your monthly premiums are going.

Dan: They get name tags. And they get told. Wait here.

Laurie Todd: So finally, a gal came and ushered us up to the top floor and we walked up to these two massive doors, which then swung open. And we looked in on the biggest hugest conference table you've ever seen in your life. And all these women dressed in business attire, staring at us.

Diana: they really didn't say much. They just said, okay. Kind of like the floor's yours

Dan: Matthew was up first.

Diana: both Lori and I knew our speeches, but we had absolutely no idea what Matthew was going to say when he was going to say it or what

Matthew: I winged it. I just spoke from the heart and, uh, what it was like to be denied and what it was like to be just a pawn in a big game

Dan: He called the company's decision extremely cruel. He'd put in 34 years. He said this didn't seem like a great way to get and keep loyal workers.

Laurie remembers he wrapped up by saying he just wanted to be able to retire, ride his bike, tend his garden and see his grandkids grow up.

Diana: Matthew leading it off was powerful. What he shared uh, really set the tone for Laurie in my speeches

Dan: Diana talked for fifteen minutes, and she just laid out all the facts.

Diana: Matthew was diagnosed with appendix cancer in August of 2005,

Dan: including the misdiagnosis.

Diana: Appendix cancer is not colon cancer and it should absolutely not be treated like colon cancer. Matthew underwent six grueling months of chemotherapy

Dan: And the further misdiagnosis later when Matthew's cancer came back and he started feeling lousy again

Diana: And neurologists told Matthew that it was all in his head. And so he prescribed him an antidepressant

Dan: building the case: We tried things your way. And when we found the treatment that would work, you denied it, saying it was investigational.

Diana: I will prove that this assertion is not supported by facts.

Dan: And that Blue Cross Blue Shield-- which Matthew's plan is part of-- has paid for this exact procedure *before*. From out-of-network docs.

Diana: All that we ask is the same consideration and coverage, which has been given to other blue cross blue shield members.

Dan: But Blue Cross Blue Shield is a "family" of companies. Had THIS one, in Washington State, called Regents, ever paid for it? Diana had put that question to an online support group.

Diana: within an hour. I received a reply. We heard from the family of Jennifer.

Dan: Jennifer has Matthew's exact same diagnosis, and his exact same insurer: Boeing's self-funded plan, run by Regents Blue Cross.

Diana: I was shocked. Regents had told me they had never paid for this before. And yet here we are. We just found someone that you currently are paying for. And if you didn't know you're paying for this, I suggest you look through your files.

Dan: At this point, Diana recalls, the woman who was chairing the meeting started doing exactly that.

Diana: She starts thumbing through every single paper she had. . She was looking to the person to her right. She was looking at the person to her left.

I thought, okay, we've got them on the run there.

Dan: Diana wasn't done. Jennifer had waited too long, and she was unlikley to live. And she was spending months in the hospital, racking up bills that were way more than this surgery-- bills that her insurance, Matthew's insurance, Boeing, would pay.

Diana broke down all the numbers-- how much Matthew's surgery would cost. The fact that Blue Cross had a contract with the hospital. So the surgeon's fee was just about the only issue, financially speaking.

Diana: I regret the urgency of the timing, but we have been consistently and continuously delayed ever since we first requested this treatment over a month ago, we need to have this process completed by the close of business tomorrow as Matthew scheduled in Washington, DC, just six days from. Thank you very much for your attention and consideration of our case.

Dan: Pause. And then up pipes Laurie Todd. The secret weapon. She'd been sitting there unannounced, looking like a friend who'd tagged along to give moral support.

Laurie Todd: I believe that I have something to add to this discussion. I was diagnosed with appendix cancer in March, 2005.

Laurie Todd: If I had done what my insurer told me to do, I would be in the nursing home by. With no stomach, no colon on intravenous nutrition, dying, a hideous and protracted death from appendix cancer.

Dan: But here she was, looking pretty healthy.

Laurie Todd: I run a mile a day. I see no doctors. I take no medications. I'm fine.

Dan: She also said the "end of life" care she would've needed -- frequent doctor visits, long hospital stays-- would've cost a ton more than her surgery.

Laurie Todd: I figure I've saved my insurer, at least \$1.5 million by now. They should give me a medal.

Dan: She's like: We all want a good outcome here, and it also happens to be cost effective.

Laurie Todd: I moved heaven and earth to save one precious life, my own, and I will do the same for Matthew because his life is as precious as mine. Thank you

Dan: Boom. Then came the part Diana had been dreading: Time for the lawyers to ask questions. Lawyers at the table. Lawyers on the phone from Idaho, from Oregon.

Diana: So there were no questions at the board table, but so then she starts asking like, Oregon, do you have questions, Idaho?

Do you have questions? I mean, there was a pause. There was none. They had no questions.

And that also looking around as I was actually even giving this speech, I saw some of the ladies there having tears in their eyes and I thought, you know what?

We're getting to them. We're getting to their hearts. And they really were listening . then afterwards, when we got up to leave, a number of them came up, gave Matthew a hug.

They gave me a hug and, um, you know, I thought, wow, I think something powerful has just happened here.

Dan: They didn't get an answer right away, of course. They said they needed one by close of business the following day. And that's when it came. The answer was yes.

In the fourteen years since then, Laurie Todd has gone on to help hundreds of other people with similar appeals. Still, she finds it emotional to relive this particular day.

Laurie Todd: it doesn't get any more real than that. What we did, it's real. And now we get to feel it again from the perspective of 14 years later.

Diana: It's what we hoped and dreamed for 14 years ago. This is the moment that we were looking forward to, that we could share our story, that we could, you know, tell people what, what we went through.

The outcome could have been so different. And then you fast forward to say, look at these 14 years that we've gotten, it's just really a blessing

Dan: Matthew's clear: He owes his life to Diana, for finding the treatment, for finding Laurie

Matthew: I was in no shape to do this kind of internet searches. I was kind of like a wimp on the couch

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Dan: Fourteen years later, he's got the things he told those Boeing executives he wanted: A chance to work his garden. Ride his bike.

Matthew: with the neuropathy. I still ride bike, not near as often. I still have a John Deere. I try to maintain five acres and still, uh, have grandchildren to take care of

Diana: One is a junior in college and the other one's learning how to drive a car.

Matthew: I've been waiting to get to the golden years. I haven't figured out what age that is because I haven't seen the gold yet.

Diana: It's out in that five acres somewhere

Matthew: There's gold out there somewhere. Yeah.

Dan: Years after his surgery, Matthew still sees an oncologist every once in a while, just to check. So far, so good. No new cancer. He says on a recent visit, he asked the doc a pointed question.

Matthew:, I was curious like, how many patients have you had with this variety of cancer? And he says, "Uh, 30. Maybe 30." And I says, "Well, out of that, 30, how are they all doing?" And he says, "Well, they're all dead except for you."

Dan: And from the way that doctor answered Matthew and Diana's next question, it sounded like none of them had gotten the treatment Matthew got, from a surgeon who specialized in it.

That conversation is the ultimate vindication of the fight that Matthew and Diana and Laurie undertook. It's a stark reminder of how high the stakes were.

And it illustrates the lessons they all took away. You have to fight for your own life. You can't rely on the system to watch out for you.

Matthew: a very important aspect that other people need to learn is the doctor tells you something, doesn't make it into gospel

Dan: Mathew's doctors told him at the beginning that he had colon cancer, when he didn't. When his cancer came back, they told him it was in his head, prescribed him antidepressants. The testimony Laurie Todd wrote for Diana to give in that hearing unpacked a lot of medical mistakes.

That's one part of Laurie's method: Document that you've tried things their way, and you've done your own homework.

You heard how emotional those appeals were, but what you might not have noticed was how carefully structured the argument was. Diana's testimony was primarily a recitation of facts, carefully arranged to make a point.

If you caught our last episode, you might remember hearing Laurie say

Laurie Todd: Every insurance appeal is a contractual dispute.

Dan: And one important underpinning of her method is: You're illustrating to the other side what your argument would sound like if this ever went to court.

Laurie Todd: there's no law that says any employer has to pay for your kid's brain surgery. And so we're out in the wild west here, but the only thing they're somewhat afraid of is liability

Dan: Like if they said no to that brain surgery, and your kid died, and there's this whole record where they denied treatment after you'd made this kind of case? She says: hinting at what that lawsuit would look like? that's what gets results.

Laurie Todd: And you have to be very subtle about how you hint at it, obviously,

Dan: Subtle because the other side—whether it's your insurance company or your employer— has access to a lot of lawyers. You're not trying to pick a fight... until you know exactly how you plan to win it.

Look, Laurie Todd's strategies fill two whole books. She's built them by winning hundreds of these cases.

And even though I hope most of us will not be in the kind of extreme fights that she takes on, her insights are valuable for all of us. I hope we'll hear from her again and again.

Meanwhile, for next time, we're going to talk about something a little more here and now for a lot of people: Picking insurance. It's November, which is open-enrollment for lots of people-- time to pick insurance for next year.

Which is why our newsletter, First Aid Kit, is basically spending all month unpacking the things I've learned over the years about insurance-picking.

And as I've been writing these installments, I've been talking to some top insurance nerds, and learning more.

Like for instance: You're scoping out an insurance plan to see if it covers your doctors? TAKE A SCREENSHOT. File it away someplace safe.

So if your insurance ever says, "What? Aw, no, we don't cover that doc..."

Sabrina Corlette: If you have that screenshot, many insurance departments will go back to the carrier and say, Aw, you got to pay Dan's bill.

Dan: That kinda stuff. A whole bunch of it. That's Sabrina Corlette from Georgetown University, one of those top insurance nerds I've been talking with.

If you're not subscribed to First Aid Kit, you are right on time. We published the very first installment this week, and it's an intro: You are all caught up. — You can check it out-- and sign up to get First Aid Kit sent straight to your inbox—at arm and a leg show dot com, slash newsletter. That's arm and a leg show do com, slash newsletter.

Meanwhile, we'll bring you some of the freshest insights in our next episode.

We're able to do this because YOU have been supporting us. And right now is the perfect time to do it: In November and December, a campaign called NewsMatch will match every dollar that you pitch in.

In fact, if you make a monthly pledge-- say, five bucks a month-- they'll match a full year's worth upfront. Yep. You pledge five bucks a month, they give us sixty bucks.

It is the sign of a true member of the Arm and a Leg squad to take advantage of a truly good deal-and to support good things -- and this is a chance to do both at the same time.

The place to go is arm and a leg show dot com, slash support.

Arm and a leg show dot com, slash support.

I'll catch you here soon. Till then,

Take care of yourself.

This episode of An Arm and a Leg was produced by me, Dan Weissmann, with 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 from Dave Winer and Blue Dot Sessions.

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Kaiser Health News is not affiliated with Kaiser Permanente, the big healthcare outfit. They share an ancestor. This guy, Henry J Kaiser. He had his hands in a lot of different stuff.

Really different. Poured concrete for the Hoover Dam, and a whole bunch of basements in California. Smelted aluminum. Built ships. Owned a bunch of early TV stations.

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 arm and a leg show dot com slash kaiser.

Diane Webber is national editor for broadcast and Taunya English is senior editor for broadcast innovation at Kaiser Health News. They are editorial liaisons to this show.

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And BIG thanks to everybody who supports this show financially. Time to shout out a few folks who have come aboard or increased their donations during NewsMatch to help us capture those amazing matching funds: [names redacted.]