Hey there. There's gonna be some cursing in this story. So, if there's little kids with you right now, maybe save this one for later. Up to you.

OK, here's the show:

It's raining for a second just as I get to Stephanie Wachs's house in Houston.

DW: Stephanie HEY! SWW: Hey, great to meet you

And it takes a minute for her to get the dog quiet so we can talk.

DAN: Hi SWW: Hi DW: Thank you. SWW: Of course. I love inviting strangers into my house. It's my favorite thing.

I'd first talked with Stephanie because she's a little bit famous. She published a book last year about grieving her brother, who died of a drug overdose. (And he was a little more famous-- her brother was a writer and producer on Parks and Recreation. Harris Wittels. When he died, it made news.)

And now -- not coincidentally-- she's making a podcast about the opioid epidemic. That's how we ended up talking the first time. It's got people like Sarah Silverman and Aziz Ansari in it, who loved her brother, and it's good.

But I didn't fly to Houston to talk about that.

I came to Houston because Stephanie had told me this story: How she lobbied the Texas legislature to make insurance companies cover hearing aids for kids. She's got a hearing-impaired daughter.

And I was like, that's a hell of a story.

And just before I came, Stephanie sent me some links for background. I'd seen most of them before, but one was a video from some group called Let Texas Hear-- it's got her and her husband, telling their story, making a pitch.

SWW and MIchael: My name is Stephanie Wachs. I'm Michael Wachs. We're married. We have a daughter. Her name is Iris.

It's pretty slick. There's a really nice logo, there's experts

MOORE: I'm Dr. Scott Marquardt. Uh, I'm the current president of the Texas Academy of audiology.

There's a slick logo, a cast of thousands-- well dozens-- chiming in at the end,

SWW/MW: LET TEXAS HEAR!

RANDO FAMILY 1: Let Texas Hear!

RANDO FAM 2: Let Texas Hear!

Etc.

the whole thing.

And I was like, Oh, this may not be the story I was hoping for. This looks like the hearing aid industry, or whatever, orchestrated some campaign. And she's just one of the people they got to be in their videos and go to the capitol. That's how this works.

But the answer was no, no, it wasn't.

That video was made by a friend of hers. The slick logo? Stephanie's husband designed it.

This story's the real thing.

This is An Arm and a Leg, a show about the cost of health care. I'm Dan Weissmann.

And on this season, we are focused on what I'm going to call self-defense. What we can do for ourselves and for each other, right now.

Because I've gotta tell you. The cavalry isn't coming. As I make this season there are presidential candidates talking about big plans to change American health care.

But the way I see it: nothing's changing any time soon.

Let's say your dream candidate gets elected, along with their dream congress, and they pass your dream legislation, and they do it in the first hundred days.

Well, let's forget about the ODDS of all that happening for a second. Let's talk about the timing. A hundred days into the NEXT presidential administration is like springtime 2021.

And even if we're looking at a CRAZY, schedule, like World War II mobilization -- it's a couple of years after THAT before anything takes effect. 2023? That would be SUPER Crazy.

And -- in a world where any of us-- or anyone we love-- could wind up with some kind of serious medical/financial mess, like anytime... that's a long time to wait for the cavalry.

So this season, we're going after stories about what's possible, right now.

That includes stories about fighting off bills that don't seem right-- I've got one woman who is kind of a ninja at this-- and exploring what is and isn't possible to fight. We're we'll have a feature called "Can they fucking do that?" That's gonna be pretty fun.

[MUSIC OUT]

And this story, about Stephanie Wachs, begins five and a half years ago, when Stephanie's daughter Iris was born. She's awesome.

SWW: I know every parent thinks that their kid is just marvelously beautiful. But she was a truly gorgeous newborn baby.

The docs had to take her out a little early-- C-section -- but she's great.

everything was fine. She started nursing immediately, like already super starring.

... and -- this isn't super-memorable for MOST parents-- but it turns out hospitals run a million little tests on newborns.

SWW: They are like, 'Oh, I'm here to do this. Oh, I'm here to test this.' So, you know, and you're just 'like, fine, poke and prod, whatever.' So they come in and they say, we're going to do her newborn hearing screening. And I think I was like literally in the bathroom and I was like, just do it. I, you know, whatever. I don't care.

And they're like, Hey, she didn't pass, but a lot of C-section babies don't pass the first time. We'll run the test again tomorrow.

SWW: Fine. She kept, they come back tomorrow, they test her again. Again, she doesn't pass. And at this point I like started Googling

They test her again, THIRD day, doesn't pass.

They're like, look: Come back in a couple weeks for a follow-up, but hey: 95 percent of babies like this, they ace the follow-up. So don't worry about it.

And she gets home, and baby Iris seems fine. There's a loud noise, she responds. Great.

But two weeks later, they're like: Your baby has mild hearing loss -- and she's gonna need hearing aids her whole life.

... oh, and here's a great big packet of stuff about all the ways kids like yours will struggle

SWW: academically they miss, you know, up to 50% or more of what's going on in a classroom.

And it's not just the classroom.

SWW: There's things called incidental listening, which is how most babies learn language? They're overhearing conversations. Children with hearing loss have trouble with that. If you're not looking directly at them, they have trouble knowing that you're talking to them.

Which-- like, imagine that on the playground.

They get a referral to a nice audiology center. Iris gets hearing aids at six weeks.

And this is where Stephanie and Mike find out that hearing aids are not covered by insurance. They're considered cosmetic, which is insane, but they are, it is.

SWW: And the hearing AIDS cost \$6,000 minimum, a pair minimum and they last about three to five years. They're like little computers. So you think about a lifetime of that. I don't do math...

But it seems like it would add up. Meanwhile, there's other stuff going on.

SWW: Our house had this mold infestation. We had to move into my parents' like 1500 square foot apartment. We were all on top of each other with a newborn. It was hell.

SWW : It blurs together honestly. Cause it was just like a fucking, you know, tidal wave of bad news. [laughter]...

And some of it is not funny even in retrospect.

SWW: The same exact time that we, um, moved out of my house, my brother went to rehab for the first time.

He was addicted to opiates. Six months later, back in rehab because now he was shooting heroin. When Iris is a year old, he's back in rehab. A few weeks later, he checks out and immediately ODs and dies.

SWW: Like I was in truly crippling depression. Yeah.

Today, four years later, Stephanie says Harris's death has defined her entire life.

Everything she's done-- the book, the podcast, the whole deal -- is because of him.

Later in our visit, she's giving her baby a bath-- Harry-- named after Harris-- she brings up advice her brother gave her. I can hear it in her voice, how much she misses him.

SWW: It's like my primary relationship in my life. But the kids help...

I mean, she's saying this while she's giving her baby a bath.

But yeah: Stephanie's kids are going to be 30 before she has spent as much time with them as she spent with her brother.

So yeah. It's a rough time.

SWW: so my, yeah, so my crippling depression, uh, translates into action

She starts writing like crazy. That turns into the book.

And, about a month after Harris dies, she finds this Change.org petition that says, it's messed up that they don't cover hearing aids in Texas. And the state legislature should change it.

SWW: And I signed the petition and then I was like, who's running this thing?

And she finds out that it's like one audiologist and one mom.

And she's like, let's saddle up. I'm in. Let's do this.

And it's not about her family's finances. They actually lucked into a grant that gives hearing aids to parents of infants with mild hearing loss, and covers Iris's speech therapy for a year and a half.

The problem isn't financial need. It's personal.

SWW: I needed a place to put a lot of my inability to bring my brother back, my inability to change the fact that my daughter couldn't hear. Like all of these things happened at once that I couldn't fix.

And so here she goes.

First thing she finds out: It's late. It's past the middle of the legislative session in 2015, and this is where she learns:

There's a million steps. More than you'd think. So they're WAY behind.

Here's how the Texas legislature works.

You start in the House. Get assigned to a committee. If you pass there, the bill goes to a CALENDAR committee, which basically just decides are we going to schedule this to be heard on the floor? A lot of bills die right there-- and if it doesn't die there, and DOES pass in the house, the whole thing happens again in the state Senate.

And they get one victory-- the bill comes out of the first committee, but then the clock runs out. There is no time to even get through the calendar committee.

And in Texas, when the clock runs out, it's a long time before you get another shot. That legislature spu-lits.

SWW: Texas meets every two years, their legislature meets and for six for six months. So you've got like this very small window to get something done. And so, um, yeah, it's, it's, it's wild and crazy.

DW: I'm from Illinois, and our political culture... is famously fucked up, but I mean, ... I know the Texas is fucked up, but that's pretty fucked up.

SWW: Texas is fucked up

I'm like, that means your next shot was two years away. What kept you going for two years?

SWW: I'm competitive. I'm like, I'm like, we didn't win. There wasn't any question that we would do it again. There was no question.

Which I love.

So there's not much to do for a while. But she's keeping a Facebook group going and stuff. And so a year and a half later, January, 2017 -- the Texas legislature is starting up again, and she's ready.

And by this time, the audiologist who started the whole thing is being treated for cancer and can't even participate. And one of the other moms has kind of fallen away, but she, but Stephanie finds two other moms and it's the three of them -- they drive the whole thing through the Texas legislature with not that many other people

This was not some highly orchestrated campaign by the hearing aid industry to get something done.

This wasn't the hearing aid industry pretending to be a giant army of moms.

It was three moms pretending to be a giant army of moms, which is pretty awesome.

Time to get Iris from school.

SWW: You're going to get into my minivan.

DW: Totally..

SWW Turn this Bad Boy on...

We keep talking. It's spring 2017. The moms just pushed. They got through, the committee in the house and they got through the calendar committee and they got through the house floor---

And once they cleared the house, Stephanie says the insurance industry backed off.

Because, she says, they did the math. One, this was getting real, no longer something you can quietly kill in committee. And two, not THAT many kids need hearing aids. For the insurance industry, the money involved wasn't huge.

SWW: So do we really want to be like the reason why kids are not getting this coverage? And so they sort of softened

Of course now the bill needed a sponsor in the Senate, and they get one: a SUPER-conservative Republican: Lois Kolkhorst. Here's a snippet from <u>a campaign ad</u>:

KOLKHORST AD: The disaster on our border cannot be under-estimated. Our sovereignty and our secrutiy are at risk. I'm Lois Kolkhorst, and I'm not willing to give up one inch of Texas to the drug cartels and the traffickers. Not. One. Inch.

Which is exactly what they need: Republicans run the Texas legislature.

SWW: (<u>39:27</u>) if we had like sponsors of the bill who were Democrats, the bill wouldn't have made it. It just wouldn't have, you know, so you end up like getting into bed with people who were like, they're the worst, you know, and like, but they're actually not the worst. I had my mind opened a bunch.

And Senator Kolkhorst has a profoundly deaf niece with a profoundly deaf daughter. It's a match.

And so Stephanie and these moms, they keep doing their thing. Stephanie brings three year-old Iris to the Capitol a bunch of times, in her little cowboy boots.

SWW: And we walked around those hallways to every office and she shook their hands and said, hi, my name is Iris and these are my hearing AIDS. And I love them and I use them to hear. She loves her hearings aids, she's obsessed. They have glitter on them, they're awesome.

And it's overwhelming, it's tiring.

SWW: You're constantly just like bugging everyone, you know, like please call a please text, please call, please email. You know, you're just like become this broken record. And everyone's on the internet asking for shit that they want

But the bill is moving. And then this weird thing happens, which is they run into resistance from a really unexpected place. And it looks pretty serious. Like, the day before their big hearing in front of a senate committee, suddenly everything looks like it's up in the air.

Stay with us

[DING]

AD BREAK

This season of An Arm and a Leg is a co-production of Public Road Productions and Kaiser Health News, a non-profit newsroom that covers health care in America. Kaiser Health News is NOT affiliated with the giant health care provider Kaiser Permanente. We'll have a little more on Kaiser Health News at the end of this episode.

["DING"]

Ok, Stephanie's going to tell me about how this new, surprising resistance threatened her whole effort...

Oh, wait. We've arrived at Iris's school. No more cursing for a while.

SWW: Oh, there she is... She's looking at you. Who is this? This is a strange man. I said, yeah, you said it would be with me.

I get Iris to show me her hearing aids. They really do have glitter on them.

IRIS: Um, I can hear with the, with them out. I just can't hear very well

For most of the next five hours, Stephanie keeps telling me the story while she:

Shleps Iris home, gets an iPad in front of her, gets chicken nuggets and apple pieces and Thomas the Tank Engine in front of baby Harry, and eventually gets around to bath time, dinner with Mike and bed for the kids.

Before dinner there's some playtime in Iris's bedroom-- there's unicorns and rainbows everywhere.

And Iris drags in a full-size guitar from another room

[IRIS/GUITAR STARTS HERE]

and serenades the rest of us.

IRIS: This is my uncle Harris's guitar. This is, it was my mom's brothers. Uh, he died. We are very sad.

[IRIS STRUMS MORE...]

We left you hanging: Who suddenly hated Stephanie's bill?

The deaf community.

As Stephanie describes it, the deaf community in Texas happened to be involved in another legislative fight at the same time, which was super-contentious.

Briefly, there's an idea that deafness is an *identity*, and there's a culture to be part of. Hearing aids, cochlear implants-- you could say they're taking something away.

And in the other fight, deaf folks with this perspective were fighting with -- among others -- the chochlear implant association.

Folks in that fight see that Stephanie's bill involves tech like hearing aids and implants in some way, and there's... suspicion.

Stephanie and the other moms worked hard to get up to speed, and make nice, and clear things up.

They were like: Honest, our bill doesn't mean anybody HAS to get hearing aids or implants. Just that if you want them, insurance can't say no.

But when the first Senate committee hearing rolls around, it's still not clear that everybody's comfortable.

And THEN, day before the hearing, Stephanie and her family are all at the swimming hole in Austin. It's the middle of the afternoon and Stephanie is in her swimsuit Stephanie gets this note from one of her allies-- works for the speech center where Iris gets therapy.

SWW: So this woman emails me from the center. Hello Stephanie. Hello Stephanie. Exclamation Mark.

She's like: There could be a problem.

SWW: Texas association of the deaf just posted a call to action to attend the hearing and asked everyone to sign up to testify

Testify AGAINST stephanie's bill. And in the fight around the other bill, the deaf community has turned people out in force.

It raised questions about what kinds of opponents might show up? Deaf folks? People from the business community who just hate government mandates?

Stephanie's ally has an idea: Like, how about: The bill's sponsor gets to talk first at any of these hearings. Maybe Senator Kolkhorst could address any potential opposition right up top. And here are some things that she could say.

SWW: I forward this. Yeah. In my bathing suit at the swimming hole...

... to the senator's chief of staff. Chief of staff writes back.

SWW: I emailed him at 3:51, he wrote me back at 4:06 "Sorry, can you clarify? I'm not exactly clear what you're asking."

And Stephanie's like

SWW: "Sorry!" Exclamation mark. This is me writing him back at 4:16.

She tries to clarify.

SWW: Hope this makes more sense.

And the guy does not write back.

And so the next day, time for the hearing--

SWW: We had no idea. Like we had no word from her. We didn't know if she'd gotten this message what her plan was

And they don't know: Who's going to be there from the deaf community? How pissed off might they be?

So they're sitting there with their allies, in these t-shirts that Mike designed (turns out he's a graphic designer-- who knew?)

**

Oh, by the time Stephanie gets to telling me this part of the story, Mike has just come back from putting the baby to bed.

SWW:Remember how anxious we were. Cause like they didn't get back to us about it and so she sits down, she's like gives this testimony about how much it means to her personally.

Actually, I've seen the tape. And Senator Kolkhorst starts with the kind of dry recitation you might expect-- what the bill would do, who it serves. And then...

Kolkhorst: I will tell you on a personal note, members, um, I'm so proud today to have my, uh,my niece who was born profoundly deaf to my family and the struggle that we went through and the blessing that she has been to our family.

She says her niece-- and the niece's daughter, who was also born deaf-- will speak later. The daughter got cochlear implants when she was just a year old.

Kolkhorst: She speaks as well as we do and is the most incredible thing I've ever seen. So I'm sorry for the emotion today. I'm so proud of them

SWW: Oh my God. Not a dry eye. Every up, every Senator was crying. Remember?

MW: I think we were crying. It was legitimately intense.

SWW: But it was like that tactic of like get her niece to get up and also represent the deaf community. Yeah. Slam dunk. Three-pointer.

Mike: That's good politics.

SWW: I mean, holy shit.

Mike: Like Stephanie said, it's a slam-dunk, three pointer.

And the deaf community? No show of force. One deaf person speaks against the bill.

AND the bill passes the committee unanimously. It's passes the calendar committee, it passes the Senate and the governor signs it. It becomes law.

I thought it was a pretty good story.

By the time it's done, Iris is begging her mom to come do bedtime.

SWW: Go, go, go, go, go, go, go, go, go, l'm coming in five minutes. Okay. I promised you pinky swear. Five minutes.

IRIS Set her

SWW: Alexa, set the timer for five minutes.

But it's longer. Because we need to talk about what it means.

Because this is just one battle in a huge fight-- right? The big picture?

I mean, last year, Stephanie's family spent more than 20 thousand bucks on health care. All in.

And that's not counting the new hearing aid Iris needed, and the special bluetooth part, which is extra, that lets her teacher wear a mic in class just for Iris.

After insurance, that stuff is still like 10 thousand bucks. Except Stephanie found another grant -- from the ELKS-- and got it paid for.

SWW: This is why, this is why I wanted to pass the bill because I'm like, I am savvy and I'm scrappy and like my kid's not gonna fucking need anything. But that is not normal. That is not a normal response because people are fucking busy or they've got, you know, 17 jobs and like mouths to feed and like people, like nobody has the time for this or the energy or whatever. And I just feel like, I don't know, I just, I'm a fighter, I'm just, I have a fight, I have a fight in my soul

SWW: And it's interesting because I am like super fucking negative and cynical. You know, my disposition is like very, like I said, I'm a glass half empty kind of girl, but I feel like,

SWW: I don't know, like I must have some sort of some sort of like hope or positivity or something in my body because I do feel like activism as possible and people can make change.

DW: And you did it

SWW: with a lot of help. Yeah. But like we did it. Yeah.

DW: But you decided to make it happen. And with his tiny, like I was like, Oh was because I was like, Oh there's the hearing aid industry was doing this -- and you just appeared in some videos. Like no, this was you.

SWW: My friend Jeremy did it for a \$50 gift card. Yeah.

DW: But you know you did this and it's possible that like, I think for our, you know, this is the question of like what does it take? And this is a lot is what it takes does. But it also is interesting how we think of, I think of the political forces I think of like everything's so fucked up, giant industry. It's a fifth of the economy or set of industries. How can possibly up against them, but like they're, you just did it. Yeah. Like without really anything dry. You didn't, you didn't have a network TV show. Um, yeah. I didn't even really have like a substantial following. I don't think that at the time. Yeah. He hadn't published your book yet. You're not always podcasts. You're, no, you're just, you're normal lady. I'm just, I'm just a house. I'm just a housewife. Just a ball. I now that's a pretty face.

SWW: Yeah. No, I, I mean, yeah. Yeah. I mean, you can, you can, like, it takes, it takes a little bit of like craziness I think. And it takes like, I think the timing has to be right. The team has to be right.

SWW: Um, you gotta have the will, you've got to have like the, the reason for like, for us, like the reason was a very strong, yeah. Our kids and other people's kids, but kids.

DW:And you did in Texas.

SWW: Yes. Damn straight. I'm kicking you out of my house. [inaudible] 15 years. Oh my God. I thought I was moving in, but I don't have a hotel tonight. Yeah.

Stephanie Wittels Wachs is the host of "Last Day" -- that's a new podcast about the opioid epidemic. It starts with the story of her brother Harris Wittels and then expands way, way out. It is funny, and super-sad, and super-smart.

Wherever you're listening to this podcast, we'll have a link to "Last Day" in the description for this episode of An Arm and a Leg.

If you're listening to this show for the first time-- WELCOME! You can find more about us at Arm and a Leg Show dot com. And of course you can subscribe wherever you get podcasts.

I'm gonna plug an app from the podcast company Acast-- they're distributing An Arm and a Leg this season, so we like them-- but you do you.

Just go subscribe-- and while you're there, why not leave us a review?

And actually, if you are digging the show, there is one super-special thing you can do for us RIGHT NOW.

A website called Discover Pods has a kind of people's-choice awards for podcasts, and this show is a finalist in TWO CATEGORIES.

One is best new podcast, which I am pretty psyched about.

But the SUPER special thing is: Somebody nominated us in the best True Crime Podcast category. And we are a finalist.

Which is genius. Or, as the person who tipped me that we were nominated said: So funny and yet not funny at all.

I mean this show has no cops, no prosecutors, no defendants-- as far as I know, the things we document here, like the price of Insulin, don't actually break any laws.

Which, you might say, is the real crime here. And it's not exactly victim-less.

So. I really. REALLY. Really want to win this award.

And I need your help. Wherever you're listening to this show, there should be a link to the awards, where you can vote. Please, please please do it.

And: Tell everybody you know. You can find the link at our website too, and a whole spiel about why we ought to win. Arm and a leg show dot com.

Go there, follow the link, vote for us-- and then tell everybody you know to do the same thing.

If you think the way we deal with health care in this country is a crime, then LET EVERYONE KNOW.

And if you're good at Twitter or Instagram or whatever, just go hype the heck out of this.

We're at arm and a leg show, dot com. You'll find other cool stuff there too. Head over there, vote for us, and spread the word. THANK you. You rock.

Next week on An Arm and a Leg: My neighbor the health-care ninja. Meredith Balogh wrote to me last year. She's survived for years and years as a type 1 diabetic-- often with no health insurance, and never with a lot of income.

She's learned how to work the system to get the help she needs and to make sure she doesn't pay more than she's supposed to. It hasn't been easy, and it takes a lot of time, but here's one thing she's figured out:

MEREDITH: (<u>58:24</u>) There's only three things that you're fighting as far as something that you can possibly recognize and have any control over. You're looking for comp problems with competence, problems with greed and problems with maliciousness. And luckily most things are incompetence.

Meredith's amazing story, and more of her secrets-- to navigating the cost of health care and maintaining your sanity-- next time on An Arm and a Leg.

Till then, take care of yourself.

This episode was produced by me, Dan Weissmann. Our editor is Ann Heppermann, our consulting managing producer is Daisy Rosario. Our music is by Dave Winer and Blue Dot Sessions. Adam Raymonda is our audio wizard.

Thanks this week to Stephanie Wittels Wachs for inspiring -- or is it gently shaming -- me into finally starting to post transcripts of this show to our website. Her baby Harry is deaf in one ear, she and her family are learning American Sign Language, and she posts transcripts of her show. I figure we can do it too. Arm and a leg show, dot com, slash: transcripts.

This season of An Arm and a Leg is a co-production with Kaiser Health News-- a non-profit news service about health care in America that's an editorially-independent program of the Kaiser Family Foundation.

Kaiser Health News is NOT affiliated with Kaiser Permanente, the big health care provider-- they share an ancestor, and that's all. This guy Henry J. Kaiser was what people used to call an Industrialist. He built ships, made steel, smelted aluminum, poured a LOT of concrete. He was like a mid-twentieth century Elon Musk.

Henry Kaiser died more than 50 years ago. The health care provider and the newsroom named after him are offshoots of totally different little projects he created on the side.

It's a fun story-- you can check it out 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.

Finally, thank you to some of our new backers on Patreon-- I literally could not make this show without you. Pledge two bucks a month or more, and you get a shout-out right here. Thanks this week to:

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Thank you so much! Seeing you come in and support this show makes me feel SO good. It's like

Stephanie: Yeah. Slam dunk. Three-pointer.