

## Usher Syndrome Coalition | Parent Journey to Pass Hearing Aid Legislation, Diane Wonchoba

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Hello. My name's Diane Wonchoba, and I'm here to talk to you about a journey through hearing aid legislation. I'm from Minneapolis, Minnesota, and I'm the mother of adults. Here's a picture of my family. Cameron, me, my daughter, Alison, my husband, Steve, and our son, Eric.

Just a little background. Here's the timeline. In 1998, our twin boys were born. Here's a picture of my husband holding the boys. It's the president picture with the two babies.

In 2000, the boys were identified as having a hearing loss. And there's a picture of them in their Halloween costumes. And then in 2003, we passed some hearing aid legislation, and that's what I'm here to talk to you about today. And this is a picture of my husband with the boys on their first day of all-day preschool. And it was when they were in all-day preschool that we passed that hearing aid legislation.

Five years later in 2008, we did a hearing aid legislation. We expanded it. And there's a picture of the boys testifying.

And then in 2016, the boys graduated from high school. And then just last year in 2019, the boys were diagnosed with Ushers 2A. And here's the family picture to show that this journey has been a lifelong journey for them. This has been their whole life so far so good, and here we go. Whoopsie.

So I want to talk to you about the hearing aid legislation that I passed. I want to talk to you about the process to get the legislation passed, and then also some lessons that I learned along the way. So there were three of us. This is the tale of three moms.

The three moms are Stacie Leeper. She's from Bemidji, Minnesota, which is in northern Minnesota. Patti Teachout, who is a mom from St. Paul, Minnesota. And then there's me. I say I'm from Minneapolis, but I really truly live in a suburb called Blaine, Minnesota.

Stacie Leeper is really the one who started all of this. She had a two-year-old son with a hearing loss, and she was denied hearing aid coverage. She challenged that denial with her insurance company and brought it to the state attorney general.

The state attorney general responded. He said, listen. We have this law on the books that's been on the books since 1973 that says that an insurance company policy must cover newborn babies up until their age 18 for illness, injury, congenital malformation, and premature birth. That's what the law has

been in Minnesota since 1973.

The attorney general said to the hearing aid provider, you need to cover Stacie's hearing aids, because her son was born with a congenital malformation and hearing aids are the treatment for that. So for her, the attorney general stepped in and got her hearing aids covered.

But the insurance companies weren't going to go, oh. Let's correct this for everybody on our books. It just covered her and no one else. But it was our in. It was our in.

Patti Teachout, at the same time-- all of this is happening at the same time. Patti Teachout had a four-year-old son with congenital hearing loss. Her hearing aids were not covered. She challenged her insurance company and was declined.

She was told by her insurance company that if you want hearing aid coverage, you would have to change the law. So that summer-- that was in the summer. That fall was election season of 2002. Her state senator was door knocking, and she pulled him into her house.

He knocked on her door. Can I have your vote? And she said, come on in. Let's talk. And she sat and talked to him for an hour and a half and explained why her kid needed hearing aids, and why she needed her senator's help to get a law passed.

So Chuck Wiger, a Minnesota state senator which was Patti's senator, won his election. He had been the senator for a long time. This was-- he was a senior member of our state senate. In January 2003, he introduced a bill as an amendment to that 1973 law that specified that hearing aids are a treatment option for children born with a hearing loss. So Stacie's inquiry and Chuck's law now has-- now we're in business.

Then there was me. I had twin four-year-old boys with a sensorineural hearing loss. Our hearing loss was identified at age 2, and all four ears have identical audiograms. Therefore, it was suspected that the loss was present at birth.

The first pair of hearing aids at age 2 were covered, but my subsequent hearing aids would not be. So I knew I had to act. I knew I had to do something. And I was told by my insurance company, same thing as Patti. If you want hearing aid coverage, you would need to change the law.

I didn't know how to do that. What do you mean I have to go change the law? I don't know how to change the law.

So I went to the library. And this is where I cannot sing enough about our public librarians. Because I walked up to our public librarian and I said, I've just been told that I need to pass a law.

And the public librarian said, hmm. Let's see what we can do. She found a book on how to pass a law that was geared towards fourth graders.

She said, this might be too simple. And I said, are there pictures? Because that's exactly what I need. I took that book for fourth graders to learn how to pass a law.

Then she also said, you know, I think there's a commission for deaf and hard of hearing in the state of Minnesota. I had no idea. What is a commission? What do you mean? And so she researched that while I was looking through this book.

In addition, part of my research is I was a member of the Alexander Graham Bell association. And they do a weekly-- or a monthly newsletter. And in that newsletter they were talking about-- I think it was Maryland. I'm pretty sure it was Maryland, and I'm pretty sure it was Kentucky had just passed hearing aid legislation.

And they put their names. They put-- they gave those people some props for passing some of the first in the country. And so I literally called them. I looked him up in the phone book and I called those people, and I talked to them about how they did what they did.

So between the librarian and the people who passed in other states, I had some background information. And I went and called our commission for-- our director for the Commission of Deaf and Hard of Hearing. Her name is Mary.

And lo and behold, we do. She's Commission for Deaf, Hard of Hearing, and Deaf Blind. The governor has commissions to oversee areas of interest and develop strategy and advise.

We've heard of these before, right? We know about the commission of baseball. We know about the Food and Safety Administration. We know it about special education.

But I didn't know that there was somebody just for deaf, hard of hearing, and deaf blind. And I don't know what other states do, but I know in Minnesota that's what we do. And at the time back in 2003, it was a one woman show.

Her name was Mary Hartnett. And she was the director back in that time. She had just started. She had been there maybe three years and retired last year.

So I called her up and she said, interesting. Patti just called me, and I think you two need to meet, so let's go have lunch. So back in January of 2003, Mary pulled me and Patti to the state capital in the cafeteria of the basement of the state capitol and we had lunch.

And I truly thought I was going to that meeting and say, hey, Mary, Miss Commissioner, I need you to pass a law to cover hearing aids. And that's what Patti thought we were going to, too. So we sat down and had lunch. It was the first time I had met either one of them. First time any of us had met any of us.

And Mary sat us down and said, I think this is a great goal to pass hearing aid legislation. You're right. We do need to have coverage for hearing aids.

I can get you committee hearings, but you need to go talk to the legislators and tell them your story and tell them why you need this hearing aids. I can't do that for you. You need to do that work.

In addition, I need you to testify in these committee hearings. And oh, by the way, here's this green book. It was about the size of a passport, but it was much thicker. And it's a catalog-- it's a directory of every single senator and representative in the state of Minnesota, what committees they serve on.

And she said, we are going to need to meet in these four committees. And you should start meeting with them right away. And I was-- oh. We're doing this?

I'm talking to these people? How do I do that? What's going on? Mary left, and I will tell you, Patti and I were a little, I would say, upset. Because we didn't know we were signing up for something.

We thought we were asking someone to help us. So I was like, well, if this is what we have to do, and we agreed we would just work it together. Because we were both scared, and we didn't know what we were doing.

So we called-- right then and there, we called the first person on the committee that we needed to go to first and set up an appointment to meet with him. So we met with the senators and representatives. And based on Mary's, this is what I learned.

You need to bring your pictures and you need to tell your story. Start with the senators and representatives that serve on the committees that will need to hear your bill. For our bill it was Health and Human Services and it was Commerce, because insurance companies affect health and human services and businesses.

Eventually, we knew we would need to meet with everyone. Because the goal is we go through committee, committee, and then it goes to the whole floor, so we knew eventually we had to meet with everyone. So we started picking up our pace after we met with the first person.

Let me tell you about that first person. The first person we met with, his name was Senator Metzen. And he happened to be the president of the Senate.

We didn't know that. We just picked the first guy on the list. He was the president of the Senate. And we got there for our appointment, and we could hear him meeting with the previous person.

We showed up in our mom attire, right? We put on a cute sweater. It's January in Minnesota.

We put on a cute sweater. We had her khakis on. Put on a little lipstick. We were ready to go.

We brought our pictures, just like Mary said. And we could hear him chewing out the person that was before us. He was not happy with that person who was before us.

And Patti and I just looked at each other and said, what are we doing? Is this worth it? Why are we doing this?

And the person before us left and was in a full suit with the polished shoes. And there we are in our mom clothes. And the secretary went in to Metzen's office and said, your next appointment's here.

And he went, oh, for crying out loud. Who wants something now? Everybody wants something. Oh, well, sure. Send them in. And he was just so annoyed.

We walked in and he invited us over to his couch. And we sat down, and we showed our pictures. And we told him how it was important to us to have hearing aids.

His whole demeanor shifted. It was night and day. He listened to us. He looked at our pictures.

He said he's not used to regular people coming in and talking to him, and that's why he became a senator. He wants to help regular people, but everyone who comes in and talks to him are people working for a lobby. And so it was so refreshing to see two regular moms coming in to talk about our story.

And he said, you will have an uphill battle, but I will help you in any way I can. And he sent us on and so-- he gave us encouragement. He said we were doing a great job presenting our case, and he sent us on our way.

So we were so grateful, but it was scary at the beginning. And when you meet with everyone, the goal here is to get to a committee hearing. Mary is the one that set up those committee hearings, and she set up who would testify in those committee hearings.

She got Stacie to talk about how the attorney general said this should be the law. She got an audiologist from the University of Minnesota talking about how hearing aids can help kids. And then she had me and she had Patti talking about how our insurance companies told us that they would not cover hearing aids and that we had to go pass a law.

So that was kind of our series and our message. And she said bring our boys. The parents in Maryland told me, bring your kids. Have a show, bring your kids, and so we did.

And my little boys, they were 4, about to turn 5. They sat on each knee and they were wiggly the whole time. And the whole time the senators in that committee were eating it up. They were just smiling at how wiggly my little boys were.

And the chair of that committee, Senator Anderson, she said to me, she said, did the boys want to testify? And I asked them. I said, do you guys want to say anything?

And Cameron was a little gun shy, but Eric, he said, what do you want me to say? I said, well, do you like your hearing aids? And there he was, a four-year-old little guy.

He got up. He leaned his elbows in and he talked in the microphone. I like my hearing aids. And that's when all the lobbyists said, that's it. We lost. And that was the end of it.

What's so hard about these testimonies is the opposing view. The opposing view got up there and for us, it was all the insurance companies. There was a representative from Blue Cross, and a representative from Health Partners, and a representative from United Health.

And all-- there were like six of them. And each of them testified that basically said, if you cover-- if you mandate hearing aids, you're going to destroy all the businesses. That was their argument.

And they were polished, and they were-- and all I could do was sit on my hands. I couldn't do anything. So when you testify, you really need to share with them. You need to know what the other team is going to say, and you need to be able to address that in your testimony, which I had.

At the time there was a Johns Hopkins University study that said a hearing aid mandate would add \$0.06 to your policy per year. I said, for \$0.06 per year, can't we help my kids? So can you imagine

how powerful that was to bring my little boys and tell them for six-- really? We're talking about \$0.06 here.

So we had to go through these hoops. For ours, because it was insurance, we had to go to through Health and Human Services. We had to go to Commerce, and then it had to go to the Senate floor.

We passed 60 to three. One of the three was my own senator. Can you believe that? That's another story I'll tell you for another time.

But anyway, then it also had to go to the House. It had to go to the House Health and Human Services, the House Commerce, and that's where we stopped was at the House Commerce committee. I testified in all these committees.

We had the same show for all the committees, and Mary was the one who answered all the questions that any of the legislators had during that time. But we testified and presented our case in each of those committees. But in the House Commerce committee, Mary went to the chair of that committee. His name was Representative Greg Davids.

He's still there today. He is a great guy, although he says some controversial things. Mary asked him if we could have a hearing in the Commerce committee.

And he said to her-- this is private, behind closed doors-- do you want a hearing, or do you want your bill to pass? And we're like, well, we want our bill to pass. He said, you're not going to get the votes in my committee. I can tell you that right now.

And if I bring it to my committee, it will kill it. It will be done. You won't get anywhere.

He said, how about we include this bill in the omnibus bill? OK. Mary knew what a omnibus bill was, but I didn't. Remember, I'm like the fourth grade book.

An omnibus bill is at the end of a session. They call it the garbage bill. It's got all the things in there. Everything that we didn't get to vote on individually gets put in the omnibus bill. It's all encompassing.

And it's kind of a negotiating power between the two parties. Like, I'll give you this if you give me that. And we'll include that all in this one bill.

Our hearing aid bill got put in there, so we never did go to that Commerce committee hearing. And when it went to the floor, it was passed unanimously. Because by the time it gets to voting, everyone is like, OK. We're getting this because of that.

And truly our hearing aid bill was never part of that negotiation. It was just added in there. So we took it. It's now law, so there you go.

So the bill passed in 2003. All children born in Minnesota would get their hearing aids covered every three years at the same rate as all other parts of their insurance policy. So if your insurance policy was an 80-20, your hearing aids would be covered 80-20. If your insurance policy was \$500 deductible, you would have a \$500 deductible.

And because this law that we were piggy backing off said until you're 18, we had to include that until you're 18. Because really, truly, we were just an amendment to that 1973 law.

Then we went back to work, because now we needed to prove that kids are getting a hearing loss when they're born. So then we went and said, let's pass universal newborn hearing screening. And we passed that in 2007.

Most hospitals before that were doing that. In fact, when my boys were born in 1998, they were born in March. Had they been born in August, they would've had that newborn hearing screening.

Because they weren't, we didn't get identified till they were two. So that was a bummer. But now in Minnesota, all babies-- all hospitals are doing that.

And then in 2008 we went back, and by then we had five years under our belts. So now we have data, right? We know how much does it really cost to cover hearing aids for an insurance policy.

What is the effect? When we get a kid wearing hearing aids from newborn, how does that help them through education and things like that? So in 2008 it was way easier to say, let's just cover all kids.

Now what we're really running into is in 2021, we're still working on now expanding that to all people, not just kids. And that's going to be a tougher deal, because it's not piggybacking on existing law. It's like a whole new proposal. But I will tell you without that 1973 law, we would've had nothing. That Attorney General did a huge favor for us.

When we met Mary for that lunch, she sat us down and said, this is great. I believe in you guys. You can go do this. But honestly, we've been trying to get hearing aid passed for 10 years and have gotten zero progress. Zero. And so the fact that we were able to do this in one legislative session was amazing. That was unheard of.

So let me talk about insurance mandates a little bit. So now we have an insurance mandate that says,



hearing aids have to be covered. But that doesn't mean that your insurance policy will cover hearing aids, because there are two different types of insurance policies. One is a fully insured policy. The other is a self-insured policy.

Fully insured policies, they have to follow the mandate. And usually, it's smaller companies, and it's always government entities that have to follow the fully insured policy. What it means to be fully insured is that when you pay your premium for your insurance, that money goes into a pool of money at the insurance company. And the insurance company takes care of everything.

They take care of the administration of the insurance. And if you break your arm, they're taking money out of their pool of money to go pay the hospital bill. That's fully insured.

Self-insured does not have to follow insurance mandates. Usually larger companies are self-insured. So at the time I worked for Wells Fargo, and we were a self-insured company. So all this work and it did not affect my insurance policy.

Because what a self-insured policy is, is Wells Fargo is primarily a bank, a financial institution. But what they do is they will hire an insurance company like a Blue Cross to administer the paperwork, but they keep their pool of money at Wells Fargo. So they keep the money at the larger company.

So if you break your arm, it's the employer who is paying the insurance company-- or paying the hospital, not the insurance company. They're self-insured. So self-insured policies don't need to follow the mandates, and that's one of the arguments the insurance companies go for is because like 30% of the people who have coverage don't even come under the law.

But here's what happened. When the law goes into effect, it normalizes it. Before this, nobody had insurance for their hearing aids. No one.

Now it's still limited, but you might start seeing. In Minnesota, a lot more people are, for sure. We do now-- at Wells Fargo, we do now have hearing aid coverage, not just for kids but for everyone. We do-- my husband works for a different company. At his company, they do.

Back in 2003, no one did. So making it normal helps your cause. That's my argument for doing it.

Anyway, OK. Let me talk about my lessons learned. Have you ever noticed that presidential elections have a really high turnout, but if a president's not running, the turnout for voter engagement is low?

It's our local elections that have the most direct impact on your life. So I would say maybe we should

start paying attention to those local elections. That's what I learned.

I didn't know that my government was there to work for me. Who calls their attorney general when they're told no? I wouldn't have. I can't believe Stacie did. What an amazing effort.

Who pulls their senator into their kitchen when they're door knocking and says, no. This is what I need you to do for me. Patti did that. I was like, wow.

And I didn't know, and now I know, that I can go talk to every single legislator, not just mine. Mine, the person that I voted for, didn't even like my law. But I went and talked to every single-- and there's 200 people I talked to. Took me three months.

It was a lot of work. But you know what? If my senator doesn't serve on a committee, then I need to go talk to that committee people that it matters.

Writing letters, they matter. So while Patti and I were the ones knocking on doors every day at the state capitol, literally, we would talk to each other more than we talked to our own husbands on some days. We engaged the letter brigade.

Stacie was up in Bemidji, getting her northern Minnesota people going. Mary was engaging her contacts. We were engaging our contacts, and we started letter writing campaigns.

So that when we went and knocked on a door, one of the senators from the highest educated, most engaged, highest voter turnout region in Minnesota, she said, oh. I got 11 letters on this issue and that's significant. 11 letters for that Senator was a significant wake up call to them that it mattered.

So your one letter matters to those senators and those house of representatives. Please write those letters. You may not be able to go knock on doors, but you can write a letter.

The other thing I learned is I didn't know there was a commission that represented people who needed that help. Now she's one of my best friends. But if-- I don't know what every state does, but if you have a need-- and I brought this up because at the last conference, people were talking about how there's needs, laws need to be changed. And talking to the commissioner is a great start.

What can you do? Maybe you can't go and talk to everyone. Maybe you can't testify. But maybe you can learn about what laws are going on, and what you can do to write a letter, have a stand on it. Who's going to support this?

And then I will say the most important lessons, the number one top lessons, and then after this I

became a teacher so that I could teach this to students, is that the character of the legislator is far more important than party affiliation. I don't care if you're Republican or Democrat. I care if you want to listen to what I have to say, and I care if you can gather that information and form an opinion that's besides your knee jerk reaction.

I had Republicans who wouldn't listen to me because insurance mandates are not a thing Republicans are super excited about. I had Democrats who wouldn't listen to me because they already were going to vote yes because it's helping deaf kids. So both of them, I didn't respect because they didn't listen to me. I want someone who's going to listen and gather the information to make an informed decision.

I would also say, don't let the perfect be the enemy of the good. When I did all that work, it was for a very small group of people. It was for kids born with a hearing loss. But that opened the door enough to get to the next level, to get to the next level, and hopefully we'll keep going. But what we've done has helped.

And then the last lesson, the last and most important, is if not you, then who? I talked to Patti more than I talked to my husband during that time of my life. I said, Patti. I can't keep doing this. We've got to do this now.

I said, I'm missing dinner time with my family. I'm missing stories with my kids. I can't let all of this be for naught. We got to just do it and do it now.

Staci lived six hours away from the state capital. She couldn't come down every day to talk to people. She needed us to do that. So if not us, then who was going to do it? And if you have an issue that needs to be addressed, if not you, then who?

So my last thing I wanted to say is we're new to the Ushers family. We were just diagnosed last year. And I will tell you, I want to give you this information. My boys just graduated from college this month, May of 2020.

And I wanted to tell you that because I remember when we were diagnosed with the hearing loss, it was very scary. We would research stuff on the internet, and it's scary to think about. And then we just got that Ushers, the vision piece, added on last year.

And, again, the prognosis was like, I don't understand it. And not understanding is what makes it scary. So I know there are families out there who are new that were like us a year ago. And while we still have our moments of uncertainty, you know, celebrate what's going right.

For us, the boys graduated this year. Eric is a civil engineer from North Dakota State University, and Cameron is a computer scientist from the University of Minnesota. And they have a very, very bright future ahead of them.

So thank you. I'm always helpful with people who are trying to work through the legislative process. Please connect with me, and we can talk. I don't have answers, but I do have encouragement. And I thank you for your time.