Hi, I'm Shanna Dewsnup. I'm a doctor of audiology. And today, I'm going to be presenting to you on the best hearing technology for individuals that have Usher syndrome. So just a little bit of background on myself. My son was born with a moderate-severe hearing loss. And when he was about 13 years of age, we figured out that he had Usher syndrome.

The reason that I figured that out was that after I had him, I decided to go back to school for audiology so that I could learn as much as I could about hearing technology so that I could help him. And while I was in school studying audiology, we studied the syndromes that were associated with hearing loss.

And Usher syndrome was definitely something that he seemed like he had symptoms of. And so we had his eyes thoroughly tested. And when he was 13, they officially diagnosed him. At that point in time, he was already down to 10 degrees of central vision. So that was when we were getting basically a crash course in how to use a cane, how is he going to learn Braille?

So it was a little bit stressful. And at that point in time, I was already an audiologist. And so I just really focused on, OK, now that the vision loss is known, we really have to focus on his hearing to really try to maximize the hearing that he has so that he can be successful. And not saying you can't be successful if you can't hear, but it definitely helps just navigating around this noisy world we live in when you're able to hear.

So one of the things that I do want to talk about today and just state is that I'm going to be talking about different cochlear implant technologies and hearing aid technologies. And I just want to state that I am not affiliated with any of them. And I'm not being paid by any manufacturer for any of my recommendations in this presentation.

So the information I'm sharing is just based solely on what I have personally found to be the most successful devices when treating individuals that have Usher syndrome. So we, my husband and I own an audiology practicen in Arizona called Happy Ears Hearing Center, and one of our big focuses is working with all of the main manufacturers. So we're not just set on one device. We work with all of them, and that is just so important because it gives people options. And there are so many options out there. And there's also a lot of options, which can really be confusing as well.

So I hope that by the end of my talk today that everybody feels more comfortable with technology
and understanding what's available.

The first thing I wanted to discuss was the difference in the credentials behind someone who treats hearing loss. So I can't tell you how often I have patients come in my office that say, I have these hearing aids. I spent this much money on them, and I can't hear.

And it's so frustrating for me when I see somebody that has purchased something that's not even appropriate for their hearing loss or they've just been sold a device that they should have never been sold to begin with. We have some that should have been recommended a cochlear implant, but somebody thought they would just sell them a hearing aid instead of sending them to the right place.

So I just want to go over the difference, because it's really, really important. And it's important as individuals with hearing loss and vision loss especially to understand who you are going to treat your hearing needs.

So the difference between an audiologist and a hearing instrument specialist. So audiologists are doctorate-level clinicians. So we've completed approximately eight years of education. So four years of doctoral-level education, and audiologists have studied syndromes associated with hearing loss, the anatomy, the acoustics of the ear. There's so much stuff that we study. We study the technology, the implant technology. And it's very, very important to make sure you're going to an audiologist.

A hearing instrument specialist is-- and this is more specifically to the United States, because I know in other countries they might be called a hearing instrument specialist when they're actually a doctor. So it's different in the US. But in the US, a hearing instrument specialist is essentially a salesman.

And so if you see an HIS asked after someone's name or a BC-HIS, that means they're not an audiologist. That just means that they're a hearing aid salesman. So in Arizona, hearing instrument specialists are only required to have a GED. They're not required to have any formal training in hearing whatsoever before they can get licensed to sell hearing aids.

So most of the time, they train under someone else that sells hearing aids, and they teach them the very basics of a hearing test and fitting hearing aids at the most basic level. And a lot of patients that we have come in our office, unfortunately because Arizona is a state that a lot of people retire to, a lot of these patients that are fit by hearing instrument specialists are typically not fit appropriately.

So I just want to educate everybody on that, because when you have vision loss on top of the hearing loss, it's really, really important that you're going to the correct professional to treat your hearing needs.
So being able to hear is so important. And whether you're hearing through a cochlear implant, whether you're hearing through hearing aids, it just opens your world a little bit more. Hearing loss can be very, very isolating for people, especially when they have vision loss on top of it. So I just want to go over some of the things that are just really important to know when you're going to someone to treat your hearing.

Programming hearing aids in particular should be done with Real Ear Verification. So Real Ear Verification just means that that provider is putting a little microphone down inside your ear while they're programming that hearing aid. Typically, you're going to listen to a speaker, though there's usually a speaker in front of you. And you will listen to it. Say, carrots are part of the parsley family or you might hear just random gibberish coming out of the speaker.

So there's different ways that we check the Real Ear Verification, depending on the equipment the provider is using. But it has to be done with a probe microphone down in the ear. If someone's putting you in a sound booth, and they're just saying listen to some words with your hearing aids on, that is not Real Ear Verification.

So Real Ear Verification is something that we do on babies when we're fitting them with hearing aids, because they can't tell us if the hearing aid is too loud or if the hearing aid is too soft. And it's really the only accurate way to program a hearing aid. So just make sure if you wear hearing aids and maybe you're not hearing very well, that the provider that you're going to has done Real Ear Verification, because it makes a huge difference.

Accessories for hearing aids really enhance the quality of sound. So most hearing technology on the market, whether it's a cochlear implant or whether it's a hearing aid, they have accessories that go with them that help to bring more sound in. So make sure you're going to somebody that has knowledge in different products and that they don't just work with one brand.

Because I see so many people that are just like, oh, they only recommended this brand. And they didn't tell me there was other brands. And a lot of times, the reason why that happens is that particular office or wherever you went to get your hearing aids, that might be the only brand that they sell. And so that's why that's the only option that you got.

So there's different types of hearing loss. And when you have different types of hearing loss, you require different types of treatments. So for someone that has mild to moderate to severe hearing loss, typically in most cases, they're in a traditional hearing aid.
Someone who has severe, profound, or really profound hearing loss, typically those patients are in cochlear implants, unless for some reason they just can't have a cochlear implant. So those are the different options that you have when it comes to hearing loss treatment.

Not all programming is equal. So this is so important too, because even with cochlear implant technology or with hearing aid technology, it's really, really important when you have a vision loss that you're able to hear things going on around you in your environment. So you don't want to just hear what's directly in front of you.

And that's really important too, because if you're walking on a busy street, and someone's coming up behind you on a bike or someone's trying to get your attention, and your hearing devices are saying, oh, there's lot of sound so I'm going to focus on what's in front of me, that's going to actually not help you when you have vision loss. Because you need to be able to hear things going on around you.

So the picture on this slide just depicts that that particular hearing device or the hearing devices this person is wearing are in forward-focus mode. So they're just really narrow focus, like a tunnel, and that's what the hearing aids are focusing on when that noise level gets to be a little bit loud and constant.

Omnidirectional is a configuration where the hearing aids are picking up sound in a 360-degree field around your head. And so if you're walking on that busy street and someone says something behind you, you want to be able to hear them. You want to know that they're there.

You don't want to be startled, and maybe you don't want someone to think you're ignoring them either. And so if someone's coming up on a bike or a skateboard, you want to know that there's somebody coming up on you so you can move out of the way.

Hearing aids and cochlear implants can be programmed to omnidirectional. And for a lot of users that have worn hearing aids before, when you get used to hearing all those sounds in the environment, it's really hard to adjust to new hearing technology, because the new technology has the noise reduction features in it. And when it has noise reduction, everything all of a sudden seems quieter.

And some people that are used to hearing sound, they don't want things quieter. They want to hear what's going on around them. So just make sure that the provider or the audiologist that you're going to knows and understands Usher syndrome.
Because a lot of providers, even audiologists, are guilty of it, just program those hearing aids to that particular manufacturer's proprietary software setting, which is meant for people that are late-identified hearing loss patients.

So those are the people that maybe in their 40s or 50s come in and say, oh, I'm starting to have difficulty hearing. And those are the people that when you give them sound, they don't like hearing all the noise. They don't like to hear all that stuff.

But when you have someone that's more an implant since they were a child or that's worn hearing aids since they were a child, they're so used to hearing the sound in the environment around them that they don't like that noise reduction when it kicks in.

So make sure you're going to somebody that uses Real Ear. Again, that's so important. And make sure that that provider is programming your main program in omnidirectional mode when you have a vision loss, because you need to be able to hear when you're crossing streets. You need to be able to hear what's going on around you.

You can still use noise reduction programs as a second or third program option. You just want to make sure that you have a setting that you can wear when you're in that outdoor environment, in that busy world, so you can hear what's going on around you. So cochlear implants have the same technology. They can set them up the same way.

So out of all of these devices, how do you know what to get? So I'm going to go into that. There's device brands and then there's also things to consider. So cochlear implant brands, they have on-the-ear processors, which means basically it hangs on the ear and then there's the coil that connects up here. They have off-the-ear processors now. So nothing's on the ear. It's just up here.

Hearing aids, they have the little wire that goes down in the ear that's behind the ear, which is called a receiver in the ear. They have over-the-counter hearing aids. Those are the very cheap, basic hearing aids. And that is definitely something to keep in mind, because I know that's something that keeps being advertised as over-the-counter hearing aids.

They're cheap, they're this, they're that. Be very careful what you spend your money on, because an over-the-counter hearing aid, it's more like a Band-Aid for somebody that has a mild, very easy, slight loss to treat. It's not meant for somebody that has vision loss or someone that needs a lot of other programming capabilities.

So just be careful as you're seeing all these ads come out, because we see them all the time. Make
Sure that you’re doing some research on that and talking to your health care provider, because over-the-counter is typically not what I would recommend for someone with Usher syndrome.

Behind-the-ear hearing aids are more powerful. BTE-style hearing aid with an actual ear mold. So honestly, I know a lot of people like the little wire receiver in the ear style for Usher syndrome. That behind-the-ear style with an ear mold, I just think is-- it’s just a better option for a whole bunch of reasons, but security. It’s molded for the ear. It gives you all that power that you need to hear some of those sounds that are typically hard to hear. You don’t have as much feedback, things like that.

So out of the devices, do you want battery powered or do you want rechargeable? Is it Bluetooth compatible, meaning can you connect it to your phone so that you can listen to music and stream audio and stream phone calls?

And then what kind of accessories does it come with? So a lot of hearing needs come with accessories and same with the cochlear implant processors. So what accessories should you get? What are they? What can they do, things like that. So we’re going to go into that.

So some of the common things that we hear a lot are common complaints with hearing loss. I can’t hear well in noise. I can’t hear conversations in the car. That’s really important for someone with vision loss, because if you’re taking an Uber, if you’re taking a Lyft, if you’re in a taxi, you want to be able to hear that taxi driver. And you want to be able to hear what’s going on in that vehicle.

And so not being able to hear in the car is the big one. I know my son at night, if he takes an Uber, he can’t hear what they’re saying if he’s in the back seat. He has a hard time, and he can’t really see. So it’s definitely, you know, I’m not sure if male, female may feel more nervous than the other, but I know as a woman, I don’t like being in the car by myself in an Uber, let alone if I had problems hearing and vision, I think I would be very nervous myself.

So difficulty understanding television, family members, not being able to hear when you’re in the pool. I mean, the list is here. I mean, I hear it all the time. And so these are things that when you have hearing loss can be very isolating and frustrating. But when you add vision loss to that, it can just be that much more isolating. And so hopefully we can go into some of these accessories, and you guys will see what really will help you.

Three cochlear implant brands in the US. So Cochlear, Advanced Bionics, and MED EL. Cochlear is known for their accessories and their connectivity. So they have the new Nucleus 7 processor, which fits on the ear. And they also have a waterproof case now that you can wear so that you’re able to
wear your processor when you're in the pool. So if you're with friends or family that you're still able to be part of that conversation.

They have a Mini Mic. The Mini Mic 2, it basically just means that somebody can wear it. So if you're in a restaurant, whoever you're with can wear it. It puts their voice right in the processor. And it bypasses the noise. In a taxi, you could ask the taxi driver or the Uber driver to wear it. And then just make sure that you get it back from them.

The phone clip. So phone clips are great for people that don't have smartphones or they don't have a compatible smartphone that can connect to a Bluetooth device for their processor. So that phone clip just acts as an intermediate device so that you're still able to pair to the Bluetooth and still stream music, video, conversation through the phone, what have you.

Cochlear also has a TV streamer. And the TV streamer streams television directly to the processor so that it just makes it clear. It makes it so much clearer that you can actually hear the dialogue. The new Nucleus 7 has a phone app.

So if you have an iPhone, you can change the programs. You can take a look at the battery life. You can adjust your volume. You can connect to your T coil. There's all kinds of things you can do through the apps on the phones now. So that's something that's pretty cool that Cochlear came out with, if you like connectivity.

And they also have a basic remote control. So that's for someone that maybe doesn't have a smartphone. They don't want all the bells and whistles. They just want it to be simple and easy. That remote control is just a very simple remote control, and it makes it easy. All of the cochlear implant processors have a battery option as well as rechargeable option. And the new Nucleus 7 is a smaller, slimmer product. So it's not as big and bulky as some of the older implants that Cochlear had.

Cochlear is also compatible with ReSound hearing aids. And so certain ReSound hearing aids allow for bimodal streaming, which basically means that if you have a hearing aid on one side and the implant on the other, you get sound in stereo at the same time. So that way, you're not just streaming television to one ear. It's actually streaming to both at the same time.

Cochlear also has an off-the-ear processor, which basically means it doesn't sit on the ear. It just sits on the magnet. And they also have a waterproof case for that as well. They have a simple remote assistant. It's still compatible with the Mini Mic, the phone clip, and the TV streamer, like the previous version.
And it also has a simple remote control. So this has the wireless capability. It only uses disposable batteries. So it's not rechargeable, and it only has a remote control option. So it doesn't have an app or anything that connects to a smartphone.

Advanced Bionics has the Naida Q90 on-the-ear processor. They also have a waterproof case so it can be worn in the pool. And then the Naida Q90 now has what's called the Naida Connect, which is a Bluetooth device that you attach to the battery door. And it allows you to connect to a smartphone through Bluetooth and also through the TV connector.

It also has a compilot accessory, which is worn around the neck. And that pairs to a TV station that connects to your TV. The nice thing about the compilot, even though you have to wear it around your neck, is that it has tactile switches on it. So with vision loss, it's a little bit easier to navigate.

And it has an audio port on the bottom of it so you can plug it into any type of audio source. So if you're having trouble hearing someone or maybe you're in a big meeting and you need to plug into a telecoil or you need to plug into something to be able to hear what's going on in the room around you or what the speaker is saying, these are great for that.

The Phonak devices are compatible with the Advanced Bionics devices. So that also allows for bimodal capabilities, just meaning that you're going to get it in stereo. And Advanced Bionics connects to the Rogers system, which is something that Phonak has, which is like an FM system but is now available for adults.

FM systems really help to enhance speech in noisy environments. And basically, they have a little Roger desk, which is shown on the right side at the top of the slide. And you can put that on a table and aim the microphones at different people who are talking or have them aim the microphones for you if you can't see the lights very well. And that just allows you to hear their voice over restaurant noise and things like that. So we can set those devices up to block out all the noise or to still allow some of that noise to come through.

Advanced Bionics also has the Neptune processor, which is waterproof and takes a normal battery. So it also can take a rechargeable battery as well. And it has tactile controls. So there's different switches you can attach to the top of that Neptune that allow you to feel the Volume button, the Program button, On and Off, et cetera.

It has visual indicators, and it also has acoustic indicators. It also has an audio jack. So that's something you can plug into at conferences or plug into a computer, anything that you want to
stream through an audio chat. It has removable controls.

And the nice thing about the Advanced Bionics products is that if you wear two processors, if you have one for each side, if you accidentally put the wrong one on the wrong ear, they will automatically reprogram themselves so that they're still correct. So it's a pretty cool feature that they have and something that I think is great, especially for kids, if you accidentally get them mixed up.

MED EL has great cochlear implant products as well. Their product is called the Sonnet II. It's worn on the ear. It has a volume control that's automatic, directional microphones, which just means that that's the type of microphone technology that helps you to hear better in noisy situations. Wind noise. It also has a waterproof water wear accessory so you can wear them in the pool. It's rechargeable, and it has an audio link that connects to the phone and other devices.

MED EL products are meant to be simple and easy. They do have a remote control with tactile buttons, which is great for people that have visual loss. But they are meant to be more automatic and hassle free.

So if you're one of those people where you don't want all the accessories, and you don't want the connectivity and capabilities with all the different devices that go along with it, then this one's more simple and easy. So if you have a smartphone, if you like to be connected to TV and other things like that, then some of the other implant companies are better for that type of setup.

The Rondo II is the MED EL off-the-ear cochlear implant processor. It's wireless. It has a Bluetooth neck loop that you can connect to with the audio in it. So you could directly plug that in as well. It has automatic volume control. It's water-resistant, rechargeable. It has wireless charging. So you actually just basically set it on a little dock and it charges itself. And then hearing loops with direct audio inputs.

Cochlear implants have hearing aid components as well. So all three of the manufacturers have an acoustic component. And what that means is that if you still have usable hearing after you have surgery to get a cochlear implant, they can put the hearing aid component on that implant.

And you can still hear through it like a hearing aid with some of those natural sounds that you were used to before. But then the implant is giving you the high frequencies or whatever sounds you were missing.

So we have some amazing surgeons in Arizona that-- it's amazing. We see audiograms before and
after surgery that look almost identical. So they've been able to preserve a lot of that residual hearing, and it's not like it was in the past when you get cochlear implant surgeries, where the ear would just be wiped out.

So the electrodes are smaller and sleeker. And they don't damage the cochlea as much when they're doing the surgery. And so a lot of that hearing is actually able to be preserved. So that's pretty awesome.

So for people with Usher syndrome, my personal top-four choices four hearing aid brands are Starkey, Oticon, Phonak, ReSound. And I'm going to go into why that is. So Starkey is an American-made manufacturer. They're based out of Minnesota. And they have a new product out, which is called the Livio Edge AI. So AI for artificial intelligence.

So they have a couple really new innovative products out right now that I really like, especially for people that have Usher syndrome, that I just think they're just amazing. So they have the OrCam or the MyEye2. The MyReader2 for people who are blind. So basically, it attaches to the glasses. So if you have a pair of glasses on, you can attach it to your glasses.

And the smart camera on that little device takes a picture of the text or whatever object is in front of you, and it streams the audio directly to your hearing aids. So it's only compatible with the new Livio Edge AI hearing aids, but because of the artificial intelligence, it actually reads from that camera. And it reads and communicates with your hearing aids.

So that was something that I just thought, wow, that is awesome. Like, the technology just blows me away sometimes with how things are changing. But Starkey has definitely got some really cool things coming our way.

They have a little remote microphone, which also you can have somebody wear, whether they're someone presenting. You can have it connect to your phone through Bluetooth if you need to. So these hearing devices are meant for people that have moderate, up to I would say severe to profound hearing loss.

They have a rechargeable option, and they do connect to smartphones. So you can use the app on the phone to answer your phone calls, to adjust your volume, change your programs. It's just, it's really cool. And then they don't have a behind-the-ear style with an ear mold, but they do have a power ear mold that's integrated into that little wire that goes in the ear.

That's depicted at the center, at the top of the screen. And that is something that they can make an
ear mold of your ear and build specifically for you so that that hearing aid is strong enough and that there's not the risk of feedback.

On the very top right of the screen is the table mic. So this is a brand-new device. I've tested it out in a really, really busy expo hall, and it works amazing. So the little lights on the top switch around. So it has an automatic mode, where you can put it on the table in a noisy restaurant or in a big expo hall, and if people are talking with you at the table, it automatically shifts the microphones around to whoever's talking.

And so that goes directly to your hearing device. And it actually has more microphones built into it than the Phonak Roger Select. So the Roger Select, I was a huge fan of for a long time.

I was not a huge fan of the price tag. So the Roger Select devices from Phonak are pretty costly. They range from $2,000 to $3,000 just for that little device. Starkey's table mic is about $400. So it's much cheaper. It has actually more functionality, I feel, than the Roger device has at this point in time.

So just another really cool app that-- or cool device that you can use with your hearing aids to help enhance sound. So these hearing aids also have Bluetooth capabilities. They have a Find My Hearing Aid function, and they also have a caretaker app, which is nice if you have a spouse or somebody that, you know, for safety issues, if you want them to also have access to the app for your hearing aids on their phone, they can have access to that as well.

It can also-- one thing with this brand, their AI devices can transcribe conversation into text that can be saved in the app. So if you're wanting to record something, and you're just not following along as fast as you'd like to be, you can actually record it and play it back to yourself later. So I just think that's amazing. And it's just a really great product from Starkey.

Oticon is another brand that has really great power behind-the-ear products. So their new Xceed line is actually stronger than the Phonak Naida. So Phonak is known for their power products and they've always had Phonak Naida BTE hearing aids. My son has worn them for years. Oticon came out with their product, which is called the Xceed.

The SP and the UP, so super power and ultra power. And I actually have a few cochlear implant users that prefer this particular product over the other products, because of the amount of power they can get out of it. So if you're one of those people that you want more power, you want more volume, and it's just maxing out that hearing aid, this is a really great option.
And it also has Bluetooth capabilities so you can stream television to it. You can stream Bluetooth from your phone. You can stream music, and you can also connect to a little mini mic connect clip, which can also be worn by somebody and put that sound directly in your ear. So if you're not quite a cochlear implant candidate, these are amazing devices.

And Oticon is also known for their spatial sound. It's a function that actually automatically adjusts so that you're still able to hear in that 360-degree field around you but still focuses and pulls some of that information that's really important out of that sound as well. So these have been really, really successful for individuals that have Usher syndrome. And so far, we just have been really happy with their products. They're a great company. They stand behind what they do. Their customer service is amazing.

So in the past, I wasn't a huge fan of Oticon when it came to fitting people that had severe high-frequency hearing loss, because they would whistle a lot. But they fixed that. It's not an issue anymore, and these power products are really, really good hearing aids.

Phonak. So Phonak finally, they came out with their Marvel line last year, which is a really great new direct to Android, direct Bluetooth device. But they just came out with the Naida M Super Power. So for those people that love Phonak products, and they love the Naida hearing aids, which a lot of people do, they now have that Naida Marvel product, which connects directly to your smartphone. And it allows for remote and telehealth appointments.

So we can actually patch in and program those hearing aids without you even needing to come in the office. So when you have a vision problem, sometimes that's kind of nice, because you don't have to hitch a ride or take a taxi.

We can actually just do it remotely with you. Those particular hearing aids connect directly to the Roger devices now. So you don't have to have a battery door boot that you have to attach to the hearing aid in order to connect to it.

And then Phonak also has a newer product called the Partner Mic, which is similar to the other microphones that the other companies have. And it has noise reduction built into it, and it's meant for somebody to wear. So that's another really great product for people that have trouble in noise and just want to be able to their spouse or significant other or friend.

Their friend can wear that, and it puts their voice directly into the hearing aids. They also have a TV streamer, which was shown on the Advanced Bionics page. And it's the same thing. It wirelessly sends
the TV to the hearing aids.

And ReSound. So ReSound is another great product which connects to cochlear products. Their new Enzo Qs are their power behind-the-ear hearing aids. And they're meant for people that have moderate to profound hearing loss. And these particular devices connect through an app on the phone. They also connect wirelessly with all of the same streaming devices, whether it's a microphone, the phone clip, or the TV streamer.

And they have app controls, FM capability, and direct streaming. So the nice thing about ReSound products is you don't have to wear anything around your neck. It's just a wireless direct signal. So ReSound products, again, are compatible with Cochlear-branded implants. And so if you have a Cochlear-branded implant, you're probably going to lean a little bit more toward the ReSound hearing devices if you want to be able to hear in stereo.

So success with hearing devices. There are so many options for hearing aids and additional accessories that really, really enhance the sound quality for everybody. The hearing provider you see is so important. It's the most important part of your hearing journey. So make sure you're going to someone that is an audiologist that works with all of the brands, that doesn't just work with one brand.

And someone that understands Usher syndrome or understands the vision loss component, because it's so important when you're having your hearing devices, whether it's a cochlear implant or hearing aids programmed, that those are being programmed appropriately for you and for your needs.

So make sure if you have a cochlear implant even if you think your map sounds great, go in for your annual checkups with your audiologist. Ask about technology. Ask about the accessories. They're always changing, and there's always new things coming out that just really enhance your ability to be successful in so many different situations and to be able to get out there in the world and not isolate yourself from certain activities because of hearing. So with everything that's out there right now, there's just so much that you can do to really, really enjoy life and enjoy that sound quality of what's going on around you.

So if anyone has questions, please email me, message me. If you have questions about technology, if you're not sure who to go to where you live, I am on a blog with a lot of audiologists. So if you're stuck or you're just not happy with what you have, I will definitely try my hardest to direct you to somebody that I know is a good provider that would really be helpful for Usher syndrome or the vision loss component with the hearing loss.
So thank you for your time, and I've added all of the links for the cochlear implant companies. If you have questions about their products or their accessories, please click on the link. It will take you to their website, where they have literally everything listed out.