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DOCUMENTING YOUR PERSONAL JOURNEY

PRESENTER: TINA CHILDRESS

TINA CHILDRESS: Good morning, everyone. My name is Tina Childress, and I work for Advanced Bionics. And my role is to help recipients, and I love my job. I am also an audiologist. I used to work in the school setting before I joined Advanced Bionics, but I am also a late-deafened adult who has two cochlear implants, and so every time I come to ALDA, I say it's like the mother ship is calling me home. Being able to be around other people who have experienced, you know something similar to what I have.

So what I'm here to talk to you about today is documenting your journey. Why is that important? How you can do it. Talk about some resources, and speaking of resources, on your table in front of you, if you haven't noticed, first you have a flyer about our online community called www.hearingjourney.com, and it is a really wonderful place to talk to people in a very safe format, lots of different topics, and lots of different ideas. You know, a lot of times we don't even talk about implants. We're just finding out about each other.

And the second thing that you have is that spiral-bound journal which we are really excited to be able to provide to you. It has tips on the side, you know, it gives you a little bit of guidance or format for how to document different things going on in your life.

But, obviously, you don't have to follow that format exactly, and I'll show you some of the tools that other people have used and why they've used them.

So this is kind of our agenda for this morning, and the first thing that we're going to talk about is why should you do this? Why is it important to document?

So how many of you got your hearing aid or cochlear implant in one facility and then moved to another facility? When you moved from one cochlear implant center to another one, did you have all of your records with you?

AUDIENCE MEMBER: No.

TINA CHILDRESS: Was it difficult going from one audiologist to another audiologist? Did they just download the programs from your hearing aid to their computer and then just kind of tweak you from there?

AUDIENCE MEMBER: Yes, and I was not happy with that. I didn't like the idea of a computer setting the program for my hearing aid.

TINA CHILDRESS: Yes.

AUDIENCE MEMBER: Those were digital, but I felt that when the audiologist set up the programs themselves, that the hearing aid worked better for me.

TINA CHILDRESS: Right. So it was more a manual kind of setting, list, a lot of hearing aids, and even cochlear implant systems now, they need to be tweaked. And I hope that you have that good relationship with your audiologist that if you need to say, "Oh, it sounds too high pitched," that they can make an adjustment so that you can do that.

Well, I know there are a lot of people that will get a cochlear implant and actually, when I was an audiologist with kids' hearing aids, too, they would move to a different facility and the audiologist would know nothing about their needs, about maybe some of the projection they may have, some concerns. And for people who have cochlear implants, as well as for digital hearing aids, having those numbers can save a lot of time.

I remember when I used to travel a lot around the state and I still had hearing aids, sometimes when you get your hearing aid, they do that skinny little strip printout, and it shows the curve of the way your hearing aid responds. That is very helpful for the audiologist. If your hearing aid were to break down and you were on vacation somewhere and you need to get tweaked again. Maybe your program gets wiped out. And it's the same thing with a cochlear implant. Having those different levels and those different numbers is very helpful

Imagine if it's a little baby, and a baby can't say, "It sounds good or it sounds bad" and they don't have time to work with that family because it's an emergency. Having those numbers is a very important thing.

The other great thing, you know, think of your audiograms. You know, when you go from audiogram to audiogram, sometimes they'll say plus or minus five to 10 db. You know, so let's say from 2004 to 2005, it changed to plus or minus five to 10 db. If that happens every year, and you go back to 1997, you could have been plus or minus five db, and then five years later, it could be all the way down here.

So it's important to have those what we call serial audiograms to see if your hearing is stable or if it's changing and progressing because going from one year to one year doesn't give you everything that happened before.

You know, you go into your audiologist's office, think about the first time that you were diagnosed with hearing loss. You get all of this information. How much of it do you retain? Maybe you pick up certain words. You lose most of it. 40% to 80% is what some of the studies are showing. First of all, you're grieving your hearing if you had normal hearing. And then all of a sudden, you're thrust into this world of technical jargon, of words that you don't understand, like "sensorineural," "decibel," "mild to moderate hearing loss," "conductive hearing loss," "cochlea" "auditory nerve." What do all of those things mean? You're maybe hearing these words for the first time and then you also have to process them.

And other studies are showing if you go to an appointment and you talk to your spouse when you get home, what you may say may not even be accurate. And so it's important to have something written. It's one of the things that I always try to do when I worked with patients was write down immediately the highlights of our appointment, you know, things like, "some of the higher pitches or the treble tone went down a little bit." Or things like "her ears feel full," "she's on antibiotics because she has an ear infection," things like that. And if you've get a fast, progressive hearing loss, many things are changing, and it's stressful, and you're overwhelmed with all of the things going on. So documenting your hearing loss and having that written record is a good thing.

I have also known of people that will actually also go and videotape their appointment so that they're sure they know what's happening, especially if an interpreter is involved.

Or they may carry a tape recorder with them so that they can keep a document of what happened.

Another reason is that you are the expert about your own hearing loss. So you need to know what's happening to you, not getting it secondhand through someone else. How many of you go to your appointments with a friend or a spouse or someone else?

I remember when I started losing my hearing, and it got really bad towards the end. I didn't trust my own hearing to understand what the audiologist was saying. So I always made sure to bring my husband with me so that he could be my second pair of ears. He would be able to perhaps remember things that I couldn't remember or perhaps that I missed.

And do you guys keep records of your audiograms or any of those things? I have a box about this high full of all of my records, you know, my immunization when I got my cochlear implant, my mappings, my manuals, you know, all of those things is very helpful to me. But it can be overwhelming having all of that material.

The other thing that I've done is I have scanned anything that was not electronic and burned it to a DVD and put it in a lock box, in case of fire. Because if all of that stuff got damaged, then there would be no one else that would have that. This is just, my way of protecting my records.

They have new things like the memory stick that you can put in your computer? There are services out there now where you could put medical records on a USB drive and just carry it in your purse. Some people are like, "I don't want to carry this equipment. What if the wrong person got a hold of this?" What if you're on a bunch of different medications? It would be nice, if you have seizures or something like that, and you became unconscious, that the emergency medical technicians would know what your medications are on.

Sometimes I've gone to appointments and they can't get my chart in time from the main hospital. So it's nice to have some records from at least the previous appointment to show my audiologist.

And also we talked about what happens if you move from one location to another how nice it is and how much easier it is for both of you if you are able to have some of your records from your previous provider.

Acknowledge your accomplishments: I'm going to pass around a book right now. I have a book that I created when I got my second cochlear implant. And it's kind of about my hearing journey, you know, which is the topic of this. It shows my surgery, a couple of mappings, but it also shows some of the things that I am able to accomplish and that I'm very proud of with my cochlear implants and, you know, different things that I've done.

You know, a picture is worth 1,000 words, and with digital cameras now, so many people just have these memories just holding, and there are ways that you can use that creatively for yourself, for your family, to kind of share your triumphs, you know, over your hearing loss or ways that you've coped. Acknowledging your accomplishments is another reason to document.

I'm going to share some stories with you of some people that have documented their journey and reasons that they did it.

Deb McClendon, you may have met at the at the Advanced Bionics booth. “While we were out of town my map got wiped out. Though I found an audiologist to map me, my clinic was closed” -- that's another thing, what if your clinic is closed? “It took hours to map from scratch, and it still didn't sound like my old map.” That could also be the same thing that would happen to your hearing aid, if it's not programmed the way that you're used to. You were talking about it being automatic versus the audiologist kind of adjusting it. It may not sound right.

Another story: “Our surgeon changed practices and we wanted to go to his new clinic. When we called to get the files transferred, they said everything had been lost.” they had to start from scratch. Debby, the mom to these two teenagers, these kids were diagnosed at birth, “when this happened they lost 10 years of records.”

AUDIENCE MEMBER: My hospital told me they're not required to keep records more than 10 years.

TINA CHILDRESS: Is that what they said?

AUDIENCE MEMBER: I was asking about something that was 15 years ago, and they said “we're only required to keep records for 10 years.”

TINA CHILDRESS: That's another great reason to keep your own records—if they do have that cutoff point. I go to a family practitioner, and I can't imagine what it would be like not having stuff as a senior citizen from, when I was a young adult, and not having that history. Thank you for bringing that up. That's another great reason.

Journaling: My biggest mistake was to not journal. The information is so important down the line because one forgets so much. To be able to reflect back on where you came from to the progress that you have achieved would be amazing to say the least.

There have been so many memories, but did I write them down? No. Again, my number one recommendation to anyone is journal. I remember when I got my first implant; it was right around when e-mail was becoming more prevalent. And I look back to some of those thoughts and feelings that I had as someone experiencing a progressive hearing loss, compared to where I am now, and I think oh, my goodness. I have come such a long way. I have learned so much. I forgot sometime -- it's so nice sometimes to go back and remember some of the things that you heard for the first time. I mean, do you guys remember -- if you have ever gotten a cochlear implant, do you remember the first thing you heard? Or the first time you were able to hear your grandchildren with your hearing aids. Those things are great to remember.

What kind of information would you want to include in this documentation?

Audiograms: we've talked about this pretty much at length. I not only include my aided levels in the booth -- meaning, when you raise your hand when they hear the noise with your hearing aid or implant -- but I also be sure to include my speech scores. Say the word "ball," "say the word "at," different tests like that because even though your audiogram, the Xs and the Os, or the Cs, or whatever, might be in the same place, if your speech scores change, then that might be another clue that might want to get checked out by your audiologist, maybe consider new hearing aids, maybe getting a new map on your cochlear implant. And so having all of that information is very helpful to kind of see if you're stable, getting better, if you're getting worse.

AUDIENCE MEMBER: When I to go my doctor and he has my audiogram made, it includes not only the sounds but on the bottom, it include word discrimination scores.

TINA CHILDRESS: Mine does that, too. But there are some audiologists, depending on their form -- the speech scores may be on another sheet of paper, or on the backside of your audiogram. And you may not see it together. You know, they might just -- they give you a copy of your audiogram, they might only copy that front side that has the Xs and the Os.

AUDIENCE MEMBER: That's new to me. I didn't know that. I thought all audiograms are similar.

TINA CHILDRESS: No, every place has their own form that they use or that they created. The other thing I like to also keep in my journal is phone numbers for my surgeon, my ear doctor, and my audiologist. When I was doing auditory therapy, I kept that person's number and e-mail. So it was just a really quick way that if I was experiencing a problem, that I could contact them right away by calling them or by e-mailing them.

That's also the place where I would keep a record of my appointments. I wouldn't necessarily say what happened at the appointment. But I could look at my book and say, "wow, when my hearing loss was getting, pretty bad, in 1999, I was at the audiologist office a lot as they were testing my hearing. And then I noticed in 2004, okay, maybe I was only going twice or three times a year. But it's nice to know, how often you're going and to just quick snapshot of that.

Another thing that might be helpful is to get a general release of information. Hospitals now are very restricted in the kind of information that they can share with other people. And so, for instance, if you were to go from one doctor at one hospital to another doctor at another hospital, there's a lot of hoops that you might have to jump through to get your record from one place to another.

One way that you could avoid that is to have a copy of your own records; you have every right to take your records that you have in your possession to another doctor. It's yours. It's you. If you have, any other kind of complicating factors, it's nice to have that information in your own possession.

AUDIENCE MEMBER: You mentioned you contacted your doctor by phone or e-mail. Mine won't give any e-mails out. They say it creates too many problems for them.

TINA CHILDRESS: You can kind of see why. I think e-mail has kind of been a blessing and a curse for some professionals. I think for people that are deaf or hard of hearing, they tend to find professionals that are pretty responsive to e-mails. But there are some people that won't do e-mails because it's not billable. And there are some people that they e-mail their doctor all the time. It's like getting free advice in a way without having to make an appointment. So from the doctor's perspective, I'm sure at some point they need to say, okay, either I'm going to answer just this one e-mail, or some doctors say I'm not going to answer any e-mails. They need to come see me, make an appointment.

Also, doctors can't always answer your questions unless they physically have you in your office. And so that might be another reason that, you know, they should say -- you know, write back and say, "Please come to my office. I can't answer this," in an e-mail, rather than just completely ignoring you. Every person is very different.

AUDIENCE MEMBER: Some hospitals have web sites, secure e-mail system, and you can get in touch with your doctor that way.

AUDIENCE MEMBER: Two issues with e-mail. I have a medical-legal background. I worked in the medical field for 26 years. Number one is regarding confidential information. No matter how good your antivirus program is or firewall, next thing you know, every Tom, Dick, and Harry in the world has your confidential information. Secondly, it becomes a liability issue. Once they put something down in black and white, it can always come back later to haunt them to be used against them in a medical malpractice.

TINA CHILDRESS: Right.

AUDIENCE MEMBER: Those are the two biggest reasons why doctors and hospitals don't want to receive and respond to e-mails.

TINA CHILDRESS: Thank you for bringing that up. I wonder if audiologists tend to do that more because they know that people that have hearing loss would prefer to use that medium versus the phone or what have you. But I can definitely see the confidentiality and the liability things as being two big reasons that a doctor may not respond to an e-mail.

Another thing to keep in your documentation would be warranty information. How many of you

know when the warranty on your hearing device runs out, and you need to either get an extension, or that you know, I should send it for cleaning before this warrant period expires? That is very helpful information to have. Things like the serial number on your device, especially for people that have two hearing aids that look the same or two cochlear implants that look the same. If they get mixed up for whatever reason, then it's nice to know which is supposed to go with which.

Items like trouble-shooting guides so if something were to happen you would be prepared. For instance, with Advanced Bionics, we have a carrying kit that's also a drying kit. You know, like the little crystals that you put your hearing aid in to kind of dry it out. Well, there are directions on how to take the crystals and put it in the oven to kind of dry out the crystals before you can use it with your hearing aid again.

But if you only use it once or twice a year, you are not going to necessarily remember you need to put it in the oven at 200 degrees for an hour and a half to two hours. You may not remember all of that. And so if you have all of your user guides and troubleshooting manuals in one place you know where to go. For some people with cochlear implants (and I think you heard of this with hearing aids, too) your program might get scrambled for whatever reason: static electricity, maybe your hearing aid got zapped by something. And if you lose your program, then you're going to have to start from scratch, and if you're away from home, it would be nice to have that with you as well.

AUDIENCE MEMBER: I was wondering, you see so often, places you can't have cell phones or you can't have wireless connections because it interferes with something. Have you heard of someone who has issues with their hearing aid because of wireless interference?

TINA CHILDRESS: I have not heard of that with hearing aids. I have heard you shouldn't be talking on your cell phone while pumping gas because of some kind of electrostatic discharge. The big thing with implants, especially for kids, would be things like plastic slides that could wipe out a map on your cochlear implant. It's important to have some kind of a backup.

The other thing, a lot of you that have programmable hearing aids or a cochlear implant, you have different settings for each program, like program number one would be your normal setting, whatever normal is for you. Number two might be your setting for listening to music. So maybe your audiologist somehow tweaked your map so that music sounded better. Program three might be for noisy situations. So what happens if you can't remember which program goes with what? You can carry little cards with p-1, program one, p-2, program two and what your programs are.

The other thing you can do is if you have a phone like a Treo, every time you go to the audiologist' office, put it in your phone it has a calendar. Then also write down what your different programs are, so that you have that with you and you can remember, this is the program that I use with my F.M. system. It's nice to have that memory, too. Remember, you forget 40% to 80% of what happens in your doctor's office.

We talked about electronic copies. You know, that could be on, perhaps, that USB drive that we talked about. Some people like to carry (especially if they've got some kind of progressive condition), electronic copies of things like CAT scans or some of the objective measures. Objective-meaning things you don't respond to, but something that's just measured on you and you don't have to respond. Medications and dosages those are great things to have all in one place.

The journal is a great place to keep your information like the support groups that are in your area. Have the web sites all in one place and your favorite Internet links. Web sites like where you like to buy your products, like neck loops, etc. Have that all in one place. If you have certain videos or DVDs that have helped you with your hearing loss, add those. A lot of places now, companies, will have your user manual actually on a DVD like a movie showing you how to connect the different parts. And so that could also be all in one place.

Include your story. What was it like the first time that you got your hearing aid or your cochlear implant? Include pictures of you after surgery. New sounds that you heard. What kind of changes did you see in your programming and how did that help you or how is it not good? It's good to document things that are not good, too, because when you have that information you can take it and give it to the audiologist. This is really important for the hearing aid users, too.

If you find that you're not happy with your program, keep something with you that you can write in. So let's say you're at work, and you have to walk, down the street to get to your office. There's a lot of traffic. If one week the traffic doesn't bother you but then the next week all of a sudden, the traffic is too loud or something is really bothering you, write that down, because that change within a week tell your audiologist, okay, I need to tweak this or that.

Or things like "I was able to hear my husband in the car before. Why can't I do that now?" It may not seem that descriptive to you or it may not seem that significant, but to an audiologist, that can mean a very specific pitch range that they might want to adjust, and knowing that it's changed is a big thing as well. Some people have never heard certain sounds. That's fine. It's when you deviate from the norm that it's important to tell your audiologist.

Some people like to keep records of conferences that they've gone to. They might want to keep their notes from the conferences. They say, "Oh, I remember she talked about journaling. But that was a couple of years ago. Let me look up what she said." So having one place to go is good. Keep the business cards you receive. Everyone here in the exhibit area will be happy to give you their business card. So if you have it, you could say, "Okay, I think I'm ready for an F.M. system now. I'm going to go contact them."

Of course we talked about product information, like user manuals, things like that.

So what will work for you? Everybody here has different skill set and different abilities. What are some

different ways that you can keep this information? Use an organization style that works for you. My husband is one of those people that likes to keep things in piles, but he knows exactly what's in those piles. Anybody know someone like that? They keep piles -- but you know what's in your pile and you don't mess with your pile, right?

You know, I'm someone that has vertical file folders for different things that I have to keep track of things. And, you know, I don't like it when one gets kind of mixed up. I can't do piles of paper. So you have to work with what works for you.

If that means for you, having the banker boxes or even a crate, but you have all of your papers in there, you know, okay, you may need to do some big digging, but that works for you. Some people have the label makers and they label all of the different things, and that works for them. Some people can get really fancy and do things like use the Internet. This woman has a real fancy kind of way of describing her daughter and the things that she was able to hear and not hear. That's great if you have time to do that.

Some people are lucky if they remember to write down in a notebook or a napkin or a scrap of paper, what they're hearing or not hearing. But it is important to record, your C.I. moments and frustrations. That's very important for the audiologist.

For those of you that have cochlear implants, too, there is a web site called <http://www.geocities.com/Heartland/Meadows/4602/mapping.html>. If you hear a sound but you're not sure how to describe it, perhaps you'll find the perfect descriptor word here! It's important because audiologists like to know the quality and kind of sound you're hearing.

For instance, I remember when I first got hooked up with my implant, I said, "everybody sounds like they're gurgling," or someone might describe it as gravelly. This is useful for those who have tinnitus, the ringing in the ears. People describe tinnitus in a million different ways -- chirpy, squealing, or roaring. I heard one woman; she called it "circus music." That kind of information can be very helpful, too.

For instance, someone that has Meniere's disease, and let's say it's undiagnosed, they might describe it as, "I feel like I'm in a waterfall. It's roaring tinnitus." That's very different than high-pitched tinnitus. So hearing roaring tinnitus would kind of clue in the doctor, oh, do you also have dizziness? Oh, is your hearing fluctuating? So it's important to be descriptive in the way that you describe what you hear and what you don't hear.

And, you have to be a little bit disciplined if you want to do this all the time. You might want to keep a small book in your purse or your backpack to write down these different things.

I'm going to be talking a little bit now about some ways to do stuff on the Internet, and I understand that

everybody is not tech savvy, or may not even have access to a fast connection on the Internet, and so you may or may or may not be able to benefit from this.

But some people like to create, their story on a web page for other people to see. If I went to Google, which is a search engine on the Internet, and I just typed, "cochlear implant story", boom, I'm going to get a whole list of people that have web pages.

Facebook, and things like Myspace. They call them like social centers. All of these people go, and invite friends, and then friends find other friends, and then all get kind of connected, but you can also have groups.

So, for instance this is a group that one of our recipients started. It's called "Bionic ears." So people all go to Facebook, and all of the friends that are on there have a cochlear implant, Advanced Bionics device. We talk about things that work and don't work, how to do this, how to do that. But it's one place that you can do it.

AUDIENCE MEMBER: I tried to get information about cochlear implant sites, and a friend of mine told me that most of the sites are restricted to the name brand of cochlear that you have. And there are a few general ones as well. I was trying to get in and I had some problems.

TINA CHILDRESS: Right, right. I see what you mean. It's either the manufacturer's site, but there are not a lot of sites that talk about cochlear implants in general. Is that what you're saying? I find that sites like that are actually found more on hospital or cochlear implant center pages. That's where they're not necessarily brand specific, and they talk about the different benefits from cochlear implant.

So you may want to check out different cochlear implant center sites to find information that is more general.

AUDIENCE MEMBER: The reason I'm interested is I'm told by the various doctors that I'm not a cochlear candidate because I hear too well with one hearing aid, but I'm deaf on the other ear. And that doesn't make any sense to me, but the insurance companies won't pay for it if I try to get one.

TINA CHILDRESS: These resources might be very helpful for you. They're called blogs, and it's kind of a concise way of saying "web logs." People will journal, actually, on the computer, and people blog about everything under the earth that you can think of.

They talk about their cochlear implants. They talk about their foot. They talk about what's happening with their daughter at school. But sometimes reading these personal stories can be very helpful to see how people in real life are functioning with their hearing device.

There is a web site, I think, pretty important, it's called www.wikiHow.com/start-a-blog. They have a pretty good description of what a blog is and gave good examples of where to go and the features of the different things.

So everybody does it in their own way. Now I'm going to show you some examples. You know, some people do it very kind of fancy. They put pictures. They might put, you know, upload pictures from their mapping. That's what I did, or they might scan pictures, or they may draw pictures.

It's a way for them to express themselves, too. So they may not be a writer on paper. I sometimes can't write stuff on paper and I'll just go to my blog and just blog. It's very kind of free-flowing. I don't care about typos. I don't care about all of that stuff. I just want to get it out. Blogging is a great way to talk about things that you are experiencing in a day-to-day format.

We talked about files a little bit. You can do it notebook style. You can do it pile-of-paper style, you can do it electronic style. Everyone has their way they like to keep records.

Scrapbooks: You know, if you like to scrapbook, that's a way that people have recorded their hearing history.

A photo book: That little green book is mine. I have many digital pictures that I've taken over the years. They were just sitting in a file on my computer, and I like to do regular scrap booking, but I was just running out of time, and I felt like I didn't have time to devote to do a good scrapbook. So I went on Walgreens.com. All you have to do is up upload the pictures, and you can label it, you can write a story -- whatever you want and then you pick a cover -- I mean that book cost \$20, and it looks so professional. That might be a way you would want to document your journey.

I got the idea for that, actually, from my sister who went on a physical journey -- she went to Japan, and when she was in Japan, she showed all of the different places that she went, the things she ate, the sites that she saw, she went with my parents, and so she made this book, and she kept one for herself, and gave one to my parents. That's a really easy way. If you have pictures sitting in your computer, to document what's going on.

Lastly, I'm going to talk about some of the resources that we have at Advanced Bionics that can help you kind of journal and give you some results. The first thing they have is hearingjourney.com. It is a web-based community and a place to exchange information.

You might write down, "oh, you know what, I heard from Jennifer that a really great way to keep my

cochlear implant on was..." you know. Or "oh, I found out that I didn't realize that the tubing on my ear mold was not supposed to be hard and yellow." Anyone, if you're a new hearing aid user, you may not know that once your little tubing gets kind of hard and it's not flexible any more, that you need to go see your audiologist. And you may forget that. So by documenting it, it's kind of a reminder to you.

The other thing that I'm going to talk about is something called "The Listening Room," it's a web site that has a bunch of auditory therapy kind of questions. And the way that you can use this is you can say, "Hey, I went to The Listening Room today, and I was able to pass level four," or "I learned that these sounds are kind of hard for me to hear. Maybe I should tell my audiologist about that."

So, that is hearingjourney.com. We have over 1600 users on this web site right now. You will get opinions and experiences from potentially many different people and sometimes that's what you need to hear.

You don't want to just hear it from me, someone who works for the company. You might want to hear it from a fellow recipient or candidate.

The Listening Room, right now, we have it separated into two parts. We have the kids' section and we have a teens and adult section. Now, the kids' section has been around for a while, but the teens' and adult section is going to be coming out very, very soon.

So I encourage you to go to www.hearingjourney.com. There's a link that will send you to The Listening Room. From there you will find out things like, okay, this is the hierarchy of hearing loss. These are effective communication strategies. "Oh, here's an activity that I can do on the computer with my family," or "here's an activity I can do on my own." It gives you resources like that, and you can document that in your journal.

You can get a journal by going to hear@advancedbionics.com.

AUDIENCE MEMBER: Could we get that journal even if we don't have an Advanced Bionics Implant?

TINA CHILDRESS: Absolutely. I think the information that's in there are very helpful tips that can apply to hearing aid users as well as cochlear implant recipients. Absolutely!

AUDIENCE MEMBER: Do you have a group that can go online and share their questions, their experiences?

TINA CHILDRESS: That's exactly what hearingjourney.com is. You can go to hearingjourney.com and go to the web site and read the different posts. That's one way. A second way is every time someone sends an e-mail, you get an individual e-mail. That can be a little overwhelming because there are a lot

of people. The third way is you get a digest, so for that day you see the different topics and all the different responses.

So all of that is possible, as well, with hearingjourney.com. And we have people that have hearing aids. We have people that have devices from other manufacturers, that get on this web site. We have parents, they like to go to our web site and all talk with other parents. So there is a bunch of different ways that you can get that information.

AUDIENCE MEMBER: I like your suggestions about different things that we can document in the journal, a lot of the ideas I never would have thought about. I'm going to have to do my research and find out if there are any C.I. implant centers in my area.

TINA CHILDRESS: Actually, that would be very easy to do. All of the implant companies also have what they call a "find it clinic" application. On our web site, it's at the top of the page, and you click on it and you say what state you live in, and then it will show all of the different implant centers in your state.

Here on the east coast, you could live in Connecticut, and since you have so many cochlear implant centers in the surrounding states that you can choose to go somewhere else. So you just find out which one works for you and what works with your insurance. The sites have the doctors' names, the audiologists' names, a map to the cochlear implant center. You can say, "That's way on the other side of the state. That's not going to work." Or "choose downtown Manhattan. I don't want to go there." So you have those possibilities as well.

AUDIENCE MEMBER: My audiologist, when she's asking me how something sounds, she always wants me to distinguish whether it needs to be louder or whether it needs to be clearer, and I don't always remember to write that down for her. But that seems to be an important point when she's trying to correct my program.

TINA CHILDRESS: Right, right. The other thing, you know, I found that's helpful for going to appointments when you're getting your hearing aid or implant tweaked, let's say you have a piece of music you really enjoy, carry that piece of music with you to the audiologist's office, and play it so if they tweaked your hearing aid or implant, you can say, "oh, that sounds better than before." Or "oh, that sounds better," but that's the one thing that sounds the same.

The audiologist office is not real life. You're in the quiet booth, you have the fake noise that comes in, and you do the testing. What about when you walk out of your audiologist's office into the parking garage and you can't understand a darn thing? So by bringing something from the outside with you is a helpful thing.

I used to actually carry a recording of my daughter's voice. She would be telling me a story, and I would listen to this again and again and again, and if I couldn't hear certain sounds that she said or things sounded better, that was a good clue for my audiologist.

AUDIENCE MEMBER: I was just thinking that's what I love about my audiologist, when we're done programming, she takes me out to the hall and walks down the hall with her back to me and talks. We go into elevator and she talks. We go out into the parking lot with the traffic noise and talks and she asks me, "Does it need to be louder? Does it need to be clearer?" And she goes back and programs it again. A lot of people I talk to don't have that.

TINA CHILDRESS: I was going to say you are very, very fortunate. That is not common at all. Definitely not common!

Tina Childress is an audiologist and Consumer Services Specialist with the Bionic a Association at Advanced Bionics. She is also a late-deafened adult and bilateral cochlear implant user.