

Usher Syndrome Coalition | Parent Potluck Live Session

Hello. I am Krista Vasi. I am the Executive Director of the Usher Syndrome Coalition. I want to welcome you all to our first live session. And I will do my best to speak slowly for everyone's sake. And also, I'm very excited to be kicking off the Parent Potluck presented by Ava's Voice.

I want to make sure, just to go over a little bit of housekeeping, that everyone has access to the accessibility features, captioning being one of them. You should be able to see at the bottom center of your screen to the right a closed caption option. If you have not already turned it on, you can do so by clicking that closed caption option and just say, Show Subtitle.

So we have closed captioning. You should be able to see the ASL interpreter who will be spotlighted throughout this live session. And if you have any questions about accessing and using Zoom, please put them in the chat box, which is the bottom center of your screen to the left.

And then if you have any other questions for the Q&A that we will lead into later, go ahead and put those in the Q&A. We'll try to keep questions organized logistics in chat, actual questions in the Q&A.

So with that, again, welcome. And I'm going to go ahead and start with a video from Ava's Voice. And we will go from there. So I will be sharing my screen. Give me a second. And go ahead and start.

[VIDEO PLAYBACK]

- Hello and welcome to the Potluck session of the 2020 USH Connections Virtual Conference. My name is Carly Fredericks, and I am the founder of Ava's Voice. Ava's Voice is an official partner of the Usher Syndrome Coalition, and we are pleased and honored to be with you here today.

So we thought we'd start off our session this evening with a light cocktail that everyone can enjoy from their home. And we are going to be making an orange crUSH, one of my favorites. So we will be doing a regular and a non-alcoholic version.

So first, you'll need a bucket of ice, glass of your choice, fresh oranges, the main ingredient, and you could pick your favorite either flavored vodka-- I like to use Stoli Ohranj, or you can use a type of white rum. It could be your preference, so you pick your liquor of choice.

For those of you who do not enjoy an alcoholic beverage, you are more than welcome to just start with a flavored club soda. Today we have a pineapple coconut. And we're going to top that off with either a little bit of 7UP, or again with that club soda.

First off, we're going to fill our glass with some ice. You want to fill your glass up to the brim. Leave a little bit of extra room. This is my favorite part. We're going to muddle our fresh oranges. So sometimes it's nice to slice the orange first. And I put this little sliver in here, just so it's easy to take it off the rind. And we just scoop from around. And we're going to put this in our muddler.

For those of you that have any other specialty way to diffuse the oranges, you could use that as well. Feel free to just search around the house and use your favorite tools. Put this in.

And then for tonight, I'm going to be using a Stolichninsk vodka. For those of you that like to use measurements, it's about an ounce and a half of vodka that you can pour into your glass. Typically, I just like to eyeball it. And if you're having a rough day, you can add a little extra in there. We're going to just top this off with some flavored club soda. I'm going to use a pineapple coconut.

And we're going to pour just a little bit in there, because we don't want too much as we shake it up. We're going to take this, pour it into our shaker, put your top on, give it a little shake.

[SHAKING]

I like to wait till the smaller glass gets a little frosty. Pour in it, and then you're going to top the rest off with your club soda. And of course, you can't forget about my favorite part, top it off with a garnish and use your favorite straw. We have our orange crush.

For those of you that would like the non-alcoholic version, I would just encourage you, fill that glass up again. Muddle those oranges. And then we're going to top off our drink with just the regular club soda.

As a parent of a child with Usher syndrome, we know that the diagnosis can be completely overwhelming. Wherever you are on your journey, we hope that you will come to the table and find that this session is a comfortable and safe place to connect, share, and meet other families.

Throughout our session this evening, you're going to have the opportunity to meet other parents of children with Usher syndrome and ask some of those burning questions that may be on your mind. You're also going to get to hear from some of our teens with Usher syndrome, and they're going to share some tips and tricks to self-advocacy. At the end of our session, you'll also be able to ask them questions as well. We are also excited to announce that we may have a special guest that may pop in.

- Is that good? Can I have one?

- Sure. But I know you're ready for college, we're just not there yet.

- OK.

- Here's to crushing it. Enjoy the rest of our session.

[END PLAYBACK]

Well, hello. Welcome.

Welcome to Carly Fredericks. Take it from here, Carly.

Thank you, Krista. Hello, everyone, and thank you for joining us this evening. I wanted to first and foremost start by saying a huge thank you to Krista and the entire Usher Syndrome Coalition Committee. Julia Dunning, Nancy O'Donnell, the Usher Syndrome Society, one of our USH partners, for all the hard work and diligence that you have done just to make this happen.

We know that it was a lot to take on, a first ever for most of us, although now it's feeling like our new normal, being online. But we just really want to thank you. You are at the helm of the community, and it is so much appreciated, more than we can express. So thank you.

So with that said, Pam, are you with me? I guess we'll raise our glasses for everyone that made their orange crushes tonight. Do we have a strawberry crush there, Pam, or did you make an orange crush?

Me too. I'm sorry. I just don't like orange drinks, so I went my own way.

OK. So we have a strawberry crush and an orange crush. So we're going to raise our glasses tonight. We're going to toast to everyone who is joining us now for, let's say, making it through remote learning, joining yet another Zoom meeting, even just making it here tonight. I know everybody had a crazy day, I'm sure, like I did. And I would say just for crushing the parent game. So cheers, everybody.

Cheers. Yum.

Uh, well, I don't know about you, Pam, but I actually have to say, although it's been a lot of planning, I feel like it was a little bit of a blessing being asked to be the facilitator of the Parent Potluck, because I think making that video was the first time I ever got dressed in quarantine.

Yes, I think we can all identify with that. My yoga pants are on sabbatical.

[LAUGH]

I do have a bone to pick with you, though.

With me?

Yes, that documentary video. I know now why you didn't let me watch it until the finished product. I can't believe that I cried.

[LAUGH]

Well, for those of you out there who do not know Pam and I, I am the sensitive one in the relationship. So the fact that we caught Pam on camera being a little bit of emotional-- I couldn't show her the release before it came out live. So sorry about that, Pam. Looks like you're taking over the sensitive part.

Yeah. Well, I'm really glad we took the time to capture those moments, you know? I just can't believe it's been this long. It's been 11 years since the boys were diagnosed. And really, to tell you the truth, there's been a lot more smiles than tears. So I want to thank you all for joining us.

Hi. In case you're not familiar with our organization, I'm Pam Aasen, and this is my compadre, Carly Fredericks. And we proudly represent Ava's Voice established in 2015. I can't believe it's been that long. An organization that's specific to Usher families and youth.

Yes. It feels like yesterday that this dream was kind of just coming into our minds. But for those of you that are not familiar, the mission of Ava's Voice really is to empower youth with Usher syndrome and to educate families and school communities.

So it was built on this exact dream, this opportunity to make connections, to gather together. You know, I see the attendees coming in, and I'm recognizing the names. Many years ago when Pam and I received the diagnosis of our children, Facebook was not thriving the way it is today. There were not private groups. There were not ways to find other families. The diagnosis for many of our older families were just starting to come out. So it hasn't been that long. So for us, having the opportunity to have this platform was so important.

And now that it's been growing and there's been more opportunities to make connections, we're really focused on more of those face-to-face opportunities, how we can gather as a community

beyond the conference that we have yearly. We've been so grateful to be able to attend some of those conferences. But for many, it's not possible. And so having a platform like this really feels like a blessing this year in quarantine.

So I would have to say before we get started, I do want to just go over some additional housekeeping. So for those of you who may be just joining us, you do have the option to add CART services at the bottom of your screen. You can click on the More and just click on Open Subtitles, and that should pop up your captioning. If at any point you do not have access to our interpreter or to those CART services, please leave a note in the chat pod for us so that we can address some of those issues on the side.

As we continue this evening and we share a little bit more, we will be having an open dialogue, so we do want to hear from you. Just pop on. Say hello. Drop us a comment. We want to engage with you. If you do have a specific question-- yep, I see Krista popping on.

Yes, I am popping on because I do believe that quite a few of you are joining directly from Whova and it's only showing the interpreter. So what I have done is I've included the link, the general link which I had put in the Whova agenda, but I'm not sure-- I'll have to check on the issue there. The chat box now has the general link that you should be able to click on from your computer, laptop, desktop. And you'll be able to see a gallery view of everyone else on the screen as well.

So I truly apologize for that issue. And let me know if there's-- throw any more questions in the chat. Let me know if there's anything else I can do to help. But try to open that link from your computer. Thank you.

Great. Thank you.

Thanks, Krista.

Also, I'll just make a note for the captioner. We're going to make sure that we speak slowly so that we catch everything. OK, great. I see that you're able to join us. Hi, Valerie. Welcome.

So as we continue tonight as shared, please drop those comments in. We want to know that you're here. Please engage with us. We will have a Q&A pod. In the Q&A pod, as we are opening our dialogue or as we are playing some videos in the later part of the session, if you have any questions, please drop them there, and we we'll make sure that we address all those questions.

OK. And if you can't find the link for those of you who are on the Whova app, it has been dropped in

the chat pod as well. So you can find the direct link in the chat pod. Great. OK, perfect.

So Pam, let's get back to that documentary a little bit, because I think for many, first and foremost, we appreciate all of the love that everyone has been showing, whether it's been on the Whova app, whether you have stopped by our Facebook page or have shared the documentary and humbly shared your own stories. I have to say, that's huge for us. We know how hard it is to be able to share your experiences. Sometimes just sharing with our own families can be extremely overwhelming.

I know for Pam and I, it's like, there was that breath of fresh air. It was like, oh my god. Am I sitting with another person who just gets it? You know? So we just felt it was so important to show you the full spectrum of what we've experienced on our journeys up until now. We know we have a long way to go. And you'll get to hear from our kids later in the session.

But there is a disconnect that happens, I think, when you have a diagnosis of Usher syndrome. You try to talk to your parents or family members, and they just don't get it, right? They have that love for you, they have that love for your children, and it's hard to be able to openly express the feelings that we're going through, because there's so many feelings as parents that we go through.

So when you have that time to really sit down and talk to someone else, there's just this sense of peace and comfort that comes with that. So we hope tonight as we talk about this topic, wherever you are in your journey with your children, that you know that this is a safe place that you can ask questions.

You know, sometimes people always say me, I'm sorry. I don't know if this is a silly question. There are no silly questions. It's just like being a parent, you know? How many kids ask us so many different questions? Every question is a great question, and it sparks a different topic. So we want to encourage you, just to know that this is a safe place to share, this is a safe place to ask, and we will do the best we can to provide you any information we have for you and your family to make educated decisions for your family.

And Carly, I think I'd like to add that not just Ush families have been sharing the video, but many relatives, friends, friends of friends. We're seeing it go out all over, and that really adds to the awareness.

And most of the comments I see are, you know, I knew your children had Usher syndrome, but I didn't really know what that meant or what everyone's going through at any given time or the difficulties, their experiences. They're often just seeing the successes as well. And so I think that's been really

positive in our community as well. I am monitoring the question and answer box. I'm not seeing anything right now.

So I think one of those real-- I would say most popular questions that we receive, I know for me when I talk to families and I get that first phone call, it's the unknown, right? It's the unknown of this diagnosis that I think paralyzes us, you know? It's debilitating at times. We go to doctors, we go to educational specialists and they say, we don't know what to expect around the corner.

And people will say, well, you know, when? When is that time? Or how do I talk to my child, or how do I share this information with my child? That definitely seems to be more of a common theme across the board. So maybe Pam, you could share a little bit. What time is it appropriate to talk to your child about having Usher syndrome?

Well, you know, that's something certainly that happened a little differently for us, since we didn't learn until they were five and seven, and most families are learning much younger now and dealing with that question at what age. So given the age they were and that we'd been talking regularly to them about their ears being different than others and why they needed special teachers, so we kind of just threw it in there right away and started talking to them about their eyes being different as well.

And since they'd already been talking to their classmates and giving presentations in kindergarten to their classmates, we kind of would put it in there and just talk about what they needed and why they needed it, so they had that understanding. And as they would ask questions, we'd add a little bit more.

I remember distinctly-- and my mother actually called me after she watched the video. And she said she remembers when she told me that she was mad at me for telling the boys. She did not understand why I would tell them something that was so devastating.

And it was not until she went to a conference and listened to an adult talk about their experiences of not finding out until they were much older of what they were going through, and they felt such a sense of relief at that point, understanding why they were having the experiences and the difficulties that they did. So she did change her tune, and she understood. So it it's certainly family to family, and you have to judge what they're ready for. And that's kind of what we did, just brought it in as it was appropriate.

Yes. I would say for us, it really was just following Ava's lead. At times, she would ask questions. We

would always just bring a little bit of attention if she started with the night blindness. And you would tell her, you know, you're seeing a little bit different at night than Mommy or Daddy is seeing. And if she would ask more questions about that, we would continue the conversation.

But sometimes she would ask a really deep question, and she wanted a quick, simple answer, and then she didn't want to continue the conversation. So you know, a lot of times-- and I'm sure Ava will share later in the session-- she probably doesn't remember that distinct moment of the conversation. But along the way, it's like she gradually started having more and more of an understanding about what it meant to have Usher syndrome.

I do want to say hello to Eric in Virginia. I love seeing different states come in. Carolien, hello. Welcome. Jess. Oh, we do have a question from Marcia. So Marcia's question is, hello, everybody. I would like to know if your kids take any supplement, vitamins, or things like that. You want to answer that, Pam?

Sure. Trying to remember. We have done-- I remember early on we did-- and I wish my husband was here with me now, because that was kind of his job. We kind of separated the roles, and I took over the educational aspect and he took over the smoothies and the supplements. So lutein and zinc, and I know at one time we did some vitamin A, but we stopped that after our last visit with the doctor. So we're just kind of trying to sort it out all over again, because things have changed over time as well.

Yeah. So when parents ask those questions, for us, we had seen a nutritional ophthalmologist many years ago who had a particular theory around retinitis pigmentosa. We had saw a retina specialist who also encouraged certain vitamins. However, with Ava being a young woman and going through hormonal changes, we were always very-- again, mindful about what additional supplements we were adding to her diet.

And as a teenager, we can feed them and do all the things when they're young, but we can't prohibit they shove those burritos in their mouths and all of those other goodies. So while we do our best, we do not have a specific regimen that we are on daily. Most of our care, particularly around diet, is just having a balanced diet and protecting our eyes.

There is some great topics that were shared this week during the conference. I know there is a particular topic around diet that I believe was yesterday, Pam. Was Sonia's presentation...?

Yes, it was. Yep. And she provides very good tips on really healthy eating, and that's what we kind of focused on in the beginning as well. We did get a question there of why we stopped vitamin A

supplements. And we did see one doctor who was worried about the amount of the dose that kids would receive. So we just kind of thought, well, we're not getting any-- mind you, this was five years ago-- consistent information, so we focused on the diet. And I should ask my husband to write in the Q&A what we did, and then I can share that.

And I also wanted to take a moment to say hi to some participants from Canada. I saw Jen Celebre, or "Ce-le-bray." Jen, I'm sorry. I'm not sure. I've never said your name out loud before.

[LAUGH]

That's OK, Pam. We've known each other for how long, and I still pronounce your last name wrong. I get her [INAUDIBLE] every time.

Yeah. So I just want to say thanks, you guys. So our fellow Canadians are joining us.

Yes. Welcome, everyone. We also have more participants joining on. But something you said before, Pam, really struck with me. The roles. You know, that's something even in preparing for this, we didn't talk about. And that happens so often that parents assume certain roles within this diagnosis.

For those blended families out there, you know, hello. Welcome. We have a blended family in our family. So Ava's father is married with his children and I'm married and have additional children. So Ava is very fortunate to have four siblings now, soon to be five. And we assume roles. Ava's father is very big on learning about research and finding out where advancements are in research for curing the vision aspect of Usher syndrome, where I've always taken on that day-to-day educational component.

So don't overwhelm yourselves. I think there's so many times that we put so much pressure on ourselves as parents to find all the answers. Unfortunately, there are times that we are waiting for more data to come out, very similar to the diet, you know? I remember years ago, I would always stand up and the researchers would be on a panel. That was always one of my favorite parts of attending conference. And I would say, what about diet? You know, is diet a topic? Because they say you are what you eat. Is there a way that we could slow down this progression?

So there are things out there, and I encourage you as a community, this is where we feel having these opportunities to connect as families, you do find out a lot more information than what's published. So if we can continue to share what we learn along the way, this is what builds our community of practice.

And that's really what I value most, is having that community. And we're so fortunate to be so close together because we share. And we don't necessarily go to all the same specialists. We started in different places. But we have now shared Dr.-- oh, gosh. Now I forgot his name. Glasses guy. I'm going to see him tomorrow.

What was that?

Dr. Sewa.

Dr. Sewa.

[LAUGH]

That's funny that I can't remember his name. Dr. Sewa who has built very specific prism lenses for the boys who say that their vision has improved when they have their glasses on, because he's developed a way to direct the light into the healthy part of their retina. So I don't have that ability to say whether it's good or not, but they're happy. And as long as they're happy, I'm happy.

We're going to do a quick interpreter switch, Pam, before we continue.

OK.

Great. Yeah, that's definitely, I would say, another hot topic that parents ask about, what particular vision specialists they should be seeing and when. And as Pam shared, we are very similar in that aspect.

There is a lot of disparity amongst the states as far as what services are available. Here in the state of New Jersey, we do have a Commission for the Blind and Visually Impaired. And under that service, they do provide a low vision exam every few years if you're eligible. So we have always taken advantage of seeing a consistent retinal specialist that is very familiar with Usher syndrome on a consistent basis.

However, in those off years, we prefer to see all different types of low vision doctors. I have to say, there have always been something that I've learned along the way, like Pam shared. You know, we learned about this doctor that had prism lenses. The kids really seemed to enjoy them.

At one point, we were really interested in those protective lenses and how they should be tinted. So we're really focusing on when Ava became very active in sports. You know, what type of shade was better for indoor sports? What was better for outdoor? And it has been for each child a very different

thing. Contrast seems to be one of those areas of their vision loss that is impacted. And so for them, finding that right shade, it could be really beneficial.

Now Carly, we had a question earlier in the app about O&M training to parents. So maybe that's something we can address now, because that's also very different for everyone, at what age they decide to start it. Again, my kids were diagnosed a little later, so they began O&M training pretty quickly at that time. And I then determined that as they got older-- and I'll probably give Gavin a chance to address that when he joins us.

Yes. I think that is a great topic. And we do have a couple of follow-up questions to our previous discussion. So Diane wanted to know, have you found resources for swim goggles with prescription?

[SIGH]

My guys are big swimmers. They have never wanted their prescription for their goggles. So it's not really something that I've gone out and looked for, because every time I ask them, thinking that it might improve or help them see in the next lane, whatever it might do for them, but they're happy in their space when they're swimming, and they want to leave it at that.

Yeah, I have to agree. You know, there's been so many resources that have been shared with us that I would bring to Ava's attention. And she kind of seems to pick and choose what works for her at times.

But swimming in particular, even that, she refuses to wear those cochlear implants even to this day. She is a teenager, and the girls are having discussions around the pool, and she's just happy being comfortable and swimming without those devices. So I would share with many parents that are on the call, as those kids come up on those years, that happens, you know? And our philosophy has always been, let's build our tool box, share all the resources that we know, and it's up to them to kind of pick and choose what works for them in those moments.

[INAUDIBLE]

Sorry. Carly, just goes to show you how different it is from child to child. With Ethan and Gavin, they love wearing their processors in the water with their aqua accessories, and they wear swimming caps. Whether they're at the beach or in the pool, you can always find them because they're in their bright, bright red swimming caps.

And Megan had shared a comment that her son Ezra does not like to wear his sea-eye in the water either. And we do know that, Megan, because Ezra joined our USHthis Summer Youth Camp last

summer. And I have to say, that was one of the best parts about camp, getting all kids together that have devices, that have glasses. They all just decided what worked for them in that moment.

And it was an amazing thing, because they knew. They knew to tap on each other's shoulders when they wanted to talk to each other to make sure they were in their line of vision so that they could read one another's lips. Some kids dabbled in sign language that were never exposed to it before. So it was such just a beautiful moment to see them be able to totally be themselves around each other, and all the kids just got it.

Well, Carly, we have another question. Does your teen go out at night? I worry a lot because she's 16 and she sometimes meets her friends, and it's dark already when she comes back. Do you want to start?

I will start. So funny enough, I will share, Pam has been kind of my mentor in this. There has been opportunities where we get to meet each other, whether it's at amusement parks. And the boys are a little bit older than Ava, and they were already starting to get a little bit of that freedom at night. And I was right where you are, Marcia. I would feel like, oh my god. What if she's not next to me when her vision is gone, and then all of a sudden she has no one to grab on to?

Ava for some reason has always been very comfortable in her own skin. And while I'm so grateful for that, it's also something that totally drives me insane, because there's many times that she'll take off without her cane or she'll be in the pool and it starts to get dark, and she'll wait till that very, very last second. But she's comfortable.

[LAUGH]

So we do have a plan. I think friendships and open discussions around what to do in those scenarios is extremely important. We've always encouraged Ava to pick her friends carefully. We've always found educating her peers about being with our family at night. They know what her needs are. I think for our kids, they really do have to develop trusting relationships to be able to go out into the community and trust the people that they're with.

Someone had just asked, how old is Ava? So Ava is 14. She'll be 15 in the fall, going into high school. And she actually just asked me, there's her first girl/boy party going on tomorrow night for graduation.

And the first question she will tell you that I asked was, is it supervised, and who else is invited?

Because I know the kids too, and there's certain groups of kids that I'm comfortable with. So again, you're going to do what's best for your family. Megan had shared buddy system. I love that. There's always that one buddy that you want. I agree.

I wonder if you remember, Carly, when I first moved to New Jersey and we met, that was certainly a worry that I had about moving, because the boys had their buddies in Canada who helped them at Halloween, who held their hand or let them put their hand on their shoulder. And so I wondered, why would I move them away from their close friends who would be the person for them?

And they did find those people here, and you know, now Ethan is 18 and Gavin is 15. They're out at night a lot. These days, with a high school graduate who likes to go see the sunset on the beach, they're up really early, and it's always dark. And I really have to trust their judgment in finding that friend and knowing that they're going to be with them no matter what. But it doesn't mean I don't have the conversation on a regular basis.

Yeah. And Carolien has shared, how do you let the search for a cure not affect your emotional well-being? We've had the diagnosis four years ago, and I seem to have less faith in them finding any treatment at this time. Do other parents recognize this?

I will be completely transparent with you. I have never been that person who has just-- I've always had hope for a cure, and I still have hope to this day. However, I want to enjoy our lives now. I want Ava to enjoy her life now and in the future. So we've always focused on the tools. We've focused on the resources. We want Ava to live a happy and independent life with or without her vision.

So it is debilitating, you know? I think we can all identify with the fact that we have our moments. You know, it seems like it's an up and down roller coaster. At times I try to remove myself and let myself have that minute to get it all out. But for the most part, I have to say, this is what drives my passion, being able to get these kids together. You know, showing them the opportunities that it doesn't mean they can't do the things that they want to do. They're just going to do those things a little differently, and that has been the forefront of our work.

These relationships, us sharing. You know Ush mom, you inspire us daily, the fact that you have been putting your story out there since the day Jackson was diagnosed. That's huge for our community. So that's really what supports our emotional well-being on a daily basis.

You know, self-advocacy is so important. And for these kids to be comfortable in their own skin and be proud of who they are-- I don't feel Ava walks around our community, like, hi, I'm Ava with Usher

syndrome. They see Ava and they see an athlete, you know? They see the class president. They see someone who wants to help other people. Yes, Ava will share Usher syndrome as a part of that. That's made her who she is. But it's not what we think about every single day.

And I remember very well in the first few years after the diagnosis and receiving information about studies, and they would say, promising studies. And we got a call once to get information about a study that was going to happen in Philadelphia. This was when we were living in Toronto. That never happened, and it seemed to be we'd be hearing the same thing.

So we kind of switched our focus to, OK. This is what our lives are going to be. You know, again, we have the hope. But we decided as well that we wanted to focus on raising them to be confident, good advocates for themselves and go out in the world and be who they are, no matter what parts that may entail.

And then to come to New Jersey and to be able to continue and further that journey into advocacy and building a community, that really has what-- it's not on the forefront of my mind anymore. I listen to the discussions on 1B, and I was listening, thinking, oh, that's interesting. It sounds like there's things down the pike, but I'm just not willing anymore to get my hopes up.

And that doesn't mean that we don't support it. We 100% are so grateful for the organizations that exist, that have taken the lead on that. And there's been so many that have really stepped up to the plate to really dive in and understand the research.

You know, I'm always in awe of our Usher parents, just as much as I am of our Usher kids. It just seems like we do it all. We become the experts, right? We all go home with these beautiful babies, and we're just learning how to be new parents, and then we become professionals in hearing loss and learning how to provide communication to our kids whether it's sign language or utilizing assistive hearing devices. We're even becoming professionals using Zoom, you know? This is something new for us, Pam. I mean, we've gotten quite savvy over the past couple months.

We really have. And I'm switching over to the chat here, because I see-- I think it's Nilam that asked a question about, what swimming caps do the boys use? And they actually use the swimming caps that we buy from their teams. So they're just regular swim caps. But perhaps we can talk about that at another time, Nilam, and share with you how maybe they put it on or the difference in thickness compared to the regular caps that are out there. So we'll look at that later.

Yeah. So just to continue that conversation, you know, I think it's very important for everyone to

continue to be in the know about what's going on in the research community, and why we are so grateful for the Usher Syndrome Coalition. For those of you who have not signed up for the USH Trust, that is extremely important, and there is going to be a session on that I believe tomorrow morning. Make sure you learn.

Read into it, but don't get stuck there for too long. I always say, there is a balance, and we will continue to financially support what is going on. But in the meantime, we're just raising our kids. And sometimes that involves discussions around Usher syndrome, and sometimes it doesn't.

And Carly, furthering what we've talked about about community and certainly our Ush families, another important part of that that we've been very fortunate with is having Rebecca Alexander close by. But before I move on to a quick story about that meeting, you want to address about our special guest that maybe is not joining us tonight?

Yeah. So we were very hopeful that Rebecca Alexander was going to join us this evening, and she had every intention to. She actually just texted me a few minutes ago. She actually had an ophthalmologist appointment today and is still dilated. So unfortunately, she doesn't know if it's going to wear off in time for her to join on and be able to successfully be part of the webinar.

But yes. Having Rebecca as a mentor for our kids, along with many other individuals with Usher syndrome that have shared their stories, their talents, their successes-- I love that thread and the Whova app where someone said, share your successes. That's huge. It has been huge for us. We know there's a social and emotional component to this for both as parents and our children, but those relationships is really what we attribute the success of our kids to.

Rebecca, we met just a few years ago, and I feel like I've known her forever. For those of you who may remember, we were doing a Usher for Usher Syndrome challenge. And it was going to be this campaign online to really try to bring attention to the Usher syndrome community.

And so she had called me and just said, hey, I saw that you shared the post. And I was so starstruck, because I read her book and I met her dad. And I just felt like I was talking to one of my girlfriends. And we are built of the same mindset.

And when she had heard that we wanted to host a camp for kids with Usher syndrome, she said, I need to be all over this. Number one, she loves camp. I've never met a girl in my life that loves camp more than Rebecca Alexander.

And so she had come, but she's also in the role of our strength coach. And that was great for our kids.

I mean, she was able to have those really heart-to-heart conversations with them throughout camp. And having those relationships and peers, again, has just been something that we find so beneficial. So we hope that providing these opportunities that your kids will start to develop some of these relationships and have those mentors as well.

Certainly. Because as parents, we certainly are trying to do everything we can to provide them the tools that they need to go out in the world. And we have our Usher families. You know, we're spending time together. But that role model part is something that we can't provide.

And I never really knew what Ethan felt until-- I don't know if you know. Ethan is not with us tonight, because he's actually graduating from high school at this very minute if the rain doesn't cancel it. So he actually had planned on being here, but because of COVID, this was postponed, and I'm just happy for him that he gets to have an in-person graduation.

But for his college essays, one of them had to be about a role model. And I found it very interesting what he wrote, because he said he didn't know he was looking for a role model. And when I first introduced him about Rebecca, he was being a little stubborn. You know, stubborn teenager. But as he got to know more about her, he decided he wanted to meet her, because he could see that she was impacting other people with Usher syndrome, and showing the world that she would face every challenge.

And he also wrote that what he valued most was his time with her to share experiences and stories, because the age difference between them doesn't matter. It's the shared experience of having Usher syndrome, which is the one thing us as parents, we can't share that bond that our children have with their friends or adults that also have Usher syndrome. And he wrote, if you don't have it, you can't understand it.

And he ended it with, my parents have given me all the tools I need to be a good advocate for myself, but she has shown me that life is out there, and you just have to live it on your own terms. And that was about-- you know, you learn these things. With an 18-year-old now, you just can be hopeful that you're doing everything right along the way. And we're finding that we have made some good decisions during this time.

Yeah. I have to say, it has been one of those things that is hard to explain. For Ava, she would say to me, you don't get it. And I would say, you're absolutely right. I don't. But you don't get what it's like to be your mom, you know? So we have those connections as parents. But just talking to someone that

really, truly understands where you're coming from really is important.

And I know Rebecca was really hopeful to share tonight about one of the first conferences that she went to at the Foundation for Fighting Blindness. And I won't go into all the details of the story, but she said up until this day, she still has a relationship with the young man that she met there, and they both had the same type of vision loss. And regardless of whether he had Usher syndrome or not, they made that instant connection, and they still keep in touch. So while we know Rebecca and many others are experiencing this even as adults, having those relationships are so important.

We do have two questions. So Jess had asked, besides camp, what other opportunities are there for our kids to meet other kids with Usher syndrome? My 12-year-old went to a camp where kids wear hearing devices, and when I picked him up from camp two weeks later, he was more confident, and he didn't really know how beneficial it would be for him to identify with other kids like him. I think it would be beneficial for him to meet other USH kids. So that is a great question, Jess, and thank you for commenting there and sharing that with the group.

So one of the things, and why we call this the USH Hangouts, a part of this initiative is many years ago-- and I want to personally thank Julia Dunning for all her hard work, consistently trying to find activities for the kids to do at the Usher Syndrome Conference every year-- is we had started-- last year was our first year where we had our USH Hangouts where we had a face-to-face opportunity for kids of all ages and children of parents with Usher syndrome to come to our USH Hangouts, really work on some of those activities, learn some of those self-advocacy skills, learn about themselves. So we are hopeful that when we get back face-to-face that you will bring your whole family to conference so that we can continue to make those connections.

As an organization, we are hopeful to have family weekends as well. Not just camp for kids. Unfortunately, this year we were supposed to hold a discUSH Family Weekend Memorial Day weekend that unfortunately had to be canceled due to COVID. But there are going to be more opportunities within the community.

However, one of the things that we talked about as an outcome to this-- and we will share it with this group-- is we are looking to provide a more virtual platform for the kids to make connections. Right now, we find most of our kids from camp have already connected on social media. We love seeing their comments and encouragement on each other's pages. But that was more of an organic way for them to continue those connections.

We are hopeful to share that. We will be providing more opportunities in the future. And if you have

any ideas, we would love to hear them too. So anybody, we encourage all of the feedback.

Well, Carly, I think our final question for this portion will be, do you keep doing any therapy to improve their balance? Many specialists told us that she can improve just to a top. Therefore, with the years, we stopped horseback riding or other things like that.

And this is certainly something I shared in a blog I wrote for the coalition called "Finding Balance," and I also shared it in the community part of the Whova app, because our journey was certainly similar to many others, I think. We went to many different therapists who often try to get them to practice standing on one foot or walking on a balance beam.

And really, as we got to understand the vestibular system a little more, that that's really not something that they're able to do or practice. They need to focus on their core strength and use that to control their body. And so we have focused on swimming in our family. I've heard other families dance, horseback riding, certainly gymnastics. So we kind of considered their swim their therapy.

And over the years as they became stronger, they-- and skiing as well, which also takes a great deal of core strength to be able to do. They've now been able to learn to ride bikes. And last summer, they both even picked up the surfboard on their own without their dad's help and surfed. So we continue to work on it on a daily basis.

And you know, it could just be me, but I had a talk with both of them, because with COVID, swimming stopped. And all of a sudden, I started to notice their gait seemed to get a little wider again. They seemed a little more off balance. And we discussed how important it was going to be for their whole life to maintain a strong core and find those activities that they wanted to do so it didn't become a chore.

So that's kind of what we've done over time. And you know, Ethan's 18. He has to make his own decisions when he goes off to university and is on his own. And the boys are working at getting Ava swimming with them.

Yes, they are. Two things. So I do want to share a comment in the chat pod from the Haga family about horseback riding. Hippotherapy has been something that I know many kids with Usher syndrome really have received much benefit on in encouraging their core strength. So I know that that is something that a lot of parents have shared about. And Linnea is quite the horseback rider, and she enjoys that sport today as well.

Another parent had asked, how can we encourage or thoughts about to help her son who has Usher 1B who's five-year-old, make it easy as possible to come to things, interacting with playing with friends at school and the playgrounds? So I'm just going to go back to that education for their peers.

I just remember a story when I had-- and Ava was very, very young. She was-- I think at the time, she didn't even have her cochlear implant. She was wearing hearing aids. And I remember she was in the carrier, and I was walking in the supermarket. And one little boy said, what's that on her head, or what's that in her ears? And the mom said, shh! Don't say anything.

And I remember saying, no, no. Come see. That's how she hears. She doesn't hear like you and me. And I thought that I would take those opportunities to really educate other kids, other families. Kids are so inquisitive. They just want to know. And you find that they're so willing to help and be supportive of kids when they know what to do.

For many years, especially with Ava playing sports outside, I know that a lot of the kids would yell, heads up, if they saw the ball was coming her way, and they weren't sure if the sun was in her eyes. So that communication and just that education with their peers is so important. So I would definitely encourage that.

And Carly, I'll make a final comment about that, just because we did experience with Ethan when he was five. You know, I would watch him with a group of children and they, blah, blah, blah, blah, blah. And all the children would go off in one direction and Ethan would be left standing there. And it's a difficult conversation for him as a five-year-old to have with the kids.

So I had to try and think of ways of bringing kids to him. So I was always determined to be the mom at the playground with the most sand toys. So I would bring a huge bag of sand toys for many kids and put them all out and then invite children to come play. And I kind of looked at that philosophy for the rest of their lives. What do we have that could bring kids to them?

And much to my husband's chagrin, one of them was a pool. And I said, if you have a pool, kids are going to want to come. And that certainly helped with moving, but it helped them develop friendships and start a conversation with parents so they could talk to their kids. And eventually, the boys would talk to their friends as well.

That's probably a good time to move it to the kids, because as they've grown older, they've become their own strong advocates for themselves, and we no longer have to do much of anything for them. So I will leave you to introduce that, Carly.

Yep. I'm going to give a moment for us to do an interpreter switch if needed, and also to give Krista a moment to bring up our video. In the meantime, there was a comment in the Q&A, and I just want to make sure that we didn't miss it. Roslyn, you had put a comment in the Q&A. I'm going to encourage you to put it in the chat pod now.

And I just want to clarify, she was quite surprised to hear most people say that they don't have hope in treatment considering there are currently at least four clinical trials in progress. And I just want to articulate. It's not that we are losing hope. I think we're always remaining hopeful day to day. But we just want to encourage in the meantime focusing on the here and now and what we could be doing for our kids that will help them be successful in the meantime.

But I just want to say that, and thank you for all the work you and your husband are doing. We really value all of the efforts you have been bringing to the community. So please share that comment in the chat pod as well. OK, Krista. I'm going to leave it to you.

[VIDEO PLAYBACK]

[MUSIC PLAYING]

- Hi. I'm Ava. I am 14 years old.

- Hi. I'm Gavin. I'm 15 years old, and we both have Usher Syndrome type 1.

- We are also both from New Jersey. We spend a lot of our time together--

- A lot of the time.

- Yes.

[LAUGH]

Educating families and school communities about Usher syndrome. Sometimes people don't understand what it's like living with Usher syndrome, so we find it more helpful when we share our stories and experiences.

- We do those by creating these fun activities that we can share with our friends. And today, we're going to show you some helpful tips and tricks with those activities.

- So when I was in second grade, I didn't want my mom or the teacher talking about me, because I

wanted to speak for myself.

- So Ava created a mystery box, and today we're going to teach you what you need to make your own mystery box.

- First, in order to create this activity, there are three main steps. First, you need something to simulate what it's like to have a vision loss. So what we created was these masks. Basically, you just have a Mardi Gras mask. You have wax paper. You tape it on where the eyes are, and you poke holes to simulate low vision.

- Then once you do that, the next step is to have a box. Any type of box. You know, maybe if you had a lot of orders over quarantine from Amazon, you can use that.

- The objective of this activity is for your friends to utilize their other senses besides their vision in order to figure out what's inside the box.

- So we're going to demonstrate as she puts on the mask.

- Based on the description you gave, I'm feeling bumps on each base of the cube, which means numbers, which is just like on a dot.

- Yeah.

- If you want to make this activity even more fun, you can challenge your friends to write what objects they think are inside the box on a piece of paper while wearing the mask.

- Then after you're done with the activity, you can ask them how they were feeling and what their experience was like. Maybe once they've thought about it and reflected on their experience, they will realize what it's like to be in our shoes on a daily basis.

[MUSIC PLAYING]

- Hi. I'm Ethan. I am 18, and I have Usher syndrome type 1B. And I am here to show you guys the second tip we have for our DIY session here. So a question I get a lot from families is, when should I introduce my kids to Braille? And we always say that it's always a family decision. However, we think it's important to raise tactile awareness early. This is a fun activity you can do with your kids, and it only requires two materials, ping-pong and egg cartons.

So what you're going to do is you're going to take an egg carton, and then you're going to cut it in

half and use the bottom part as your Braille cells and then the top part to store your ping-pong balls. As you can see here, you can print out the Braille alphabet in order for your kids to translate, and you'll use the ping-pong balls as the black markers there, the dark portions.

So I'm going to show you guys an example. You can take the balls and put them into your egg cartons. And F-U-N. Fun. So this is a great way for you to practice with your family, but also to educate others. And always remember, keep it fun.

- So these were only just two examples of the activities you can do.

- We will provide you a list of some more things that might interest you.

- And most importantly--

- Just be you.

- And as we believe, dream it.

- Believe it.

- crUSH it.

[MUSIC PLAYING]

[END PLAYBACK]

Hey. Have our special guests arrived yet? I see one. And there's two. Hi, guys. How are you? Welcome.

I'm good. And I see Gavin hasn't gotten his quarantine haircut yet. Yikes.

[LAUGH]

I see Ava with all the shenanigans once again. But I was hoping you'd hide your pigtail braids from the documentary.

Well, whatever. That was a very long time ago. We've come far since then, OK?

Well, enough about us. Well, hello, everyone. And I'm so glad you were able to join us. And well, any questions?

[LAUGH]

Well, hey, guys. We're so glad that you were able to join in. We know our parents are going to have lots of questions. So at this time, we are going to encourage all of our parents, please don't write the questions in the chat pod. If you could write them in the Q&A pod, there is a button at the bottom that's green that says Q&A. If you click on that, that is going to be our running list of questions for our teen panel.

Well, we thought we'd start out with, since this was a common theme in a lot of the apps and some of the questions, can you guys talk a little bit about orientation and mobility, also known as O&M instruction, and what that looks like for you? Ava, would you like to start?

Yes, I'll start. So initially, when I was three years old, I started my O&M instruction. I wasn't introduced to the cane yet, but I started with being able to navigate the household using my hands as bumpers. And also, I had a very tiny dolphin that I used to use and trail the walls in my house to get from point A to point B.

And then I was introduced to the cane at eight years old. And at the time, I wasn't really dependent on it. But now as I'm getting older and my vision is starting to change, I'm becoming more reliant on that. And although I really don't want to pull it out sometimes, I always try to make sure I have it on me, because if there is a situation where I really do need it, I'm able to pull that out and I know how to navigate using it.

And then for me, I started in first grade with my mobility instructors. I had an instructor come in and they taught me how to use my cane. And we were like-- they took me out of class for a little bit, and we went on a 15-minute little trip either in the school or outside on the playground. And they taught me how to use the cane, and that went on until fourth grade.

And then when we moved here into the United States, instead of doing it in school, we did it at home. The mobility instructor came home and we did it outside on the streets, and we went even to the downtown near our place. And then we did that all through middle school. And then through high school, we stopped with that.

And I use my cane-- I don't use it that often, but one scenario is I need it, like, we're going in the city at night or something. I'd be using my cane for any other areas that I think I might need it for.

Great. We have a question from Eric. Have you two ever ridden bikes? My daughter was good at it, but

stopped when she broke her leg. Ouch.

Yes. I do know how to ride a bike. It's actually an interesting story. I tried my whole life with my mom and my brother. We tried and tried and tried. And we could never figure it out, so we always just stopped with training wheels.

But then when we moved here and I began swimming, I got my core a lot stronger and I was able to balance a lot better, and my walking skills got a lot better. So then I actually ended up trying to ride a bike again because my friends all then rode bikes. And it took a little while, but it was this one time. I was just like, yeah, I'm going to try again. I hopped on my cousin's bike, and I learned.

And I wasn't the greatest, but I learned. And ever since, I've been learning slowly. And actually, since quarantine, because of quarantine, I've been riding my bike a lot more. And I've been on it almost every week, like twice a week since then, and it's really fun. So yeah, I can ride a bike.

And I must interrupt to say one thing. We had our very first family bike ride during quarantine, so that was a positive moment for us.

Awesome. So at first, I was very hesitant about riding a bike. I've always stuck with training wheels. I usually hated riding a bike because I always struggled so much with it.

But then one distinct memory I have about the first time I've hopped on a bike and actually rode it, I was down in Cape May at my grandparents' shore house. And my grandpa brought out this really awesome purple bike. And I was like, yes. I want to ride this.

So basically, I was in the street, and my grandpa held onto the back. I think I was 10 years old at the time. And he just pushed me. I was like, oh my gosh. Why'd you do that? And then all of a sudden, I just started riding. I was like, wow. And my mom wasn't even there to see me ride the first time. But it was really awesome, and it was such an exhilarating feeling being able to ride a bike.

And now sometimes I do hate it when we're on busy streets and stuff, but it's a really good thing to kind of have, because all my friends love riding bikes. So I just try my best and hope it goes well. But sometimes there are times that I ride up someone's lawn, you know? But oh well. It happens.

[LAUGH]

And I just wanted to add one more thing for parents with younger children. When they're younger, I wouldn't focus on trying. Like, if they want to learn how to ride a bike, I don't want to focus on trying

the absolute hardest right then. Yes, you can try to learn how to ride a bike.

But with my experience, we had different things that we would use to have fun instead of biking. For example, when we were younger, I had this thing called a green machine. It was like a tricycle. It had three wheels, basically. And you could still pedal and you could still turn and all that, but it didn't require balance because it had three wheels. And me and my brother, you know, being boys, we loved going fast and drifting, so it was good for that.

So yeah. If your child is struggling right then, don't worry, because they can still possibly learn in the future. And I would definitely try different options to see what they would like and have fun with. Like for example, my green machine.

Yeah. To add on to what Gavin was saying, my grandpa also has these big three wheelers. They have two wheels, really big ones in the back and then one in the front. And I always found that was a fun way to ride when I couldn't ride my bike or I was too tired to try and balance. So there are many other options, but sometimes you've just got to let your kid go and try for themselves, because that's how sometimes I try to figure out myself.

Well, we have another question here, guys. One mother shared that her daughter hates using the cane. She will use it with her teacher since she is a pleaser, but how do I encourage her to practice and become more comfortable with it?

And I think I could identify with you there, because Ava was very much in the same boat. She would do what she needed to do. I always tease her and say she's a therapy kid, because she wants that session to be over, so she will do it perfectly and then won't look back. So it took some time. You want to share your experience, Ava?

Yes. So I mean, sometimes there are moments now that I realize I don't want to use my cane, and I try to push through it. But the cane is a really beneficial resource when navigating. I know one thing I used to do was I would decorate my cane really cool and kind of match my outfit or put tape on it and stuff. Make it a little awesome thing.

Sometimes it takes time. You can't really expect to use the cane right away, because I know it took me a very long time. And my mom used to tell me, you've got to use it. It'll help you. It'll help you. And over the years, I've come to realize that is a very helpful resource, and that I should start using it much more.

So Marcia said she has tons of questions. And in addition to that, so how do you feel at night when

you go places out with your friends or new places with or without your cane?

For me, whenever I'm with my friends and all that, I always just make sure. Like, with my friends I can trust, I know my friends who I can trust the most, and I know my friends who I can trust, but maybe not the best. You know what I mean? So I would definitely say going out in places is definitely have someone you can trust, someone you can hold on to, someone who can guide you. And that's the main way I go around at night.

I get close-- one of my close friends to either hold onto their shoulder or elbow or forearm, something like that. Then I just kind of stay two steps behind them and just follow them. And then they speak and say directions of-- let's say there's a curb coming up, something like that. But then also one thing is I would always make sure I have a flashlight, whether it's my phone flashlight or just a flashlight, because that also really helps.

Yeah.

So do you have any advice for a middle schooler who is trying to make new friends in a new school? Maybe you guys could share where you go to school, if it's a specialty school or not, and any advice you have.

So I've just graduated from middle school. I went to a public mainstream middle school in Manchester Township. So when I transitioned from-- I used to live in Old Bridge during my years in elementary school, and then I moved to Manchester about four years ago, entering fifth grade.

I was very nervous, because the school was much bigger. The elementary school had two floors and there was a lot of navigating. But I learned that sometimes there are people who aren't going to understand who you are, but you've just got to be who you are and tell them the struggles you may face. And that's how you'll find who the people you can really trust are.

Well, to add on that, I go to Scotch Plains-Fanwood High School. I just finished sophomore year. And so I also have a similar story to Ava where I was in Canada from when I was born up until fourth grade, and then I moved to the US in New Jersey from fifth grade onward.

But the biggest thing I would have to say is obviously to be you, like Ava said. But then also another thing is you just have to embrace it. If you're out there and you're shy-- which I know is really hard to overcome, and all that. But if you do and if you can encourage your kids to try to overcome that shyness and really expose themselves and let them be vulnerable, that's how I really connected and

had friends.

Because if you're shy and all that, it's not going to work out, because if you're shy, people are going to be like, oh, I don't want to talk to you. If you're just yourself and you open up, people will be like, oh, I want to be with him because he's out and about. He's talking. He's having fun. So that's the biggest thing. Just don't be shy. Be you. And just throw yourself out there.

Yes. Confidence makes such a difference, you know? And you just can't be afraid to get out of that shell.

So have either of you been bullied? How did you deal with that, and how can parents help? Does and doesn't, if you don't mind sharing.

I actually don't think there was an instance where I was bullied. But sometimes you've got to let your kids kind of handle the situation themselves if they're older. But if they're younger, yes, parents, you can step in. But sometimes if they're older, kids have to learn how to deal with people throughout their life, because there are definitely going to be people who you run into, and most definitely aren't going to understand what your situation is. But if the situation with the bully keeps continuing, becomes a bigger issue, then definitely, parents should step in.

Ava, before Gavin speaks, I just want to say that Ethan and Gavin have both said what you just said. I don't think I've ever been bullied. And we've actually had that conversation, because they've come home and explained instances to us that they didn't recognize were bullying, but they were bullying.

And we've talked about this now that they're older, that they didn't recognize it as bullying because they had the confidence to say, well, this is who I am. If you don't like it, too bad. Or go to a different friend group. And sorry to interject, but I wanted to share that, because when you said that, I heard the same thing from Ethan and Gavin. Gavin, go ahead.

I mean, I was really going to say the same thing you said. I was just going to say, yes. I have really been-- me and my brother both have been bullied. But for me, it's never really been the case where it affected me, because I just didn't really care. I could care less, really.

Like, someone said, oh, what are-- I remember this example. It was gym or whatever. I think it was gym, we were playing this game called knockout with basketballs and whatever. And someone said something about me or whatever, and how I was really sweating and I was being really try hard, and all that in gym. And first of all, well, I like to have fun and I like to exercise, so yes, maybe I was trying. But I was having fun, so I don't really care.

But then again, they don't know that because of our balance and because of our vision, we have to work extra hard for just normal activities. So yes, I would sweat maybe more than a normal person, but I really didn't care. Like, I just kept on going. And he doesn't know who I am. I just didn't care. I just went off in my day, didn't talk to him, didn't say anything about it, and just walked away. I just didn't let it affect me, because I don't really care because, like Ava said, the confidence factor in there. You've got to have that confidence.

So did you ever have a "why me" moment? If yes, what helps you get through those moments?

Gavin, do you want to start, or do you want me to start?

I'll start. Yes, I have had those moments where I've been like, why me? Why do I have to have this? And all that. But then the way I just think about it is the way my family has gone through this, with all the experiences we've done, with all the therapy and experiences and accommodations that my mom and dad have done for me is that at the end of the day, I think about it. I'm like, my life after all is not bad. Not one bit. I'm enjoying life.

I've overcome the Usher syndrome thing, which is the biggest part. Once you can overcome the fact that you have it, you can start just living life and just not think about it. And you can just live life, like-- I don't know. Just live life, I guess. And that's just the way I've dealt with it.

And I've just thought, well, I've had so many different experiences that not everyone has experienced. For example, I'm a Paralympic swimmer right now. And if I didn't have Usher syndrome, I would have never been able to do that. And I've traveled to Colorado, to Cincinnati, and all these different places which I would never have been able to do if I didn't have Usher syndrome. So I just try to think of the positives which in my opinion definitely outweigh the negatives.

Mm-hmm. Yeah, sometimes there are moments where I just stop and just think, why is this happening to me? This is so unfair. But then I realize, I was given this opportunity to share my story and help others be able to share their feelings and their experiences with their friends, their family.

And I feel like I most definitely wouldn't be who I am right now without Usher syndrome. Like, I'm class president in my school. I've been given so many amazing opportunities. I'm so overwhelmed with all the experiences I've had. But sometimes most definitely, there are moments. But you've just got to think, there are so many more positives that outweigh the negatives, like Gavin said.

And then just to add one more thing, it may be cringey or it may be something that's said a lot, but

you only live once, so what's the point of being, oh, why me? It's your life. You have it. Whatever. Just, you have it. You only live once. Live life.

Mm-hmm.

OK, guys. Something else to think about. We have a question here. 17-year-old has 10 degrees of vision, central vision left in both eyes. However, he will not use his cane. He refuses, but he chooses to not go out at night with friends. He probably doesn't trust someone. He uses the flashlight if we were at football games at night or a community event. He has changed school three times and needs to have that "be you" confidence.

So before you guys make a comment on that, we're going to do an interpreter switch.

OK. All right.

So we're going to just kind of piggyback those two questions. So there is another question that is at, what age did you know that you had Usher syndrome? So maybe if you can comment on that and how you got to this point of being a little bit more confident as you have lost more vision.

OK. I'll start. So I don't think it's been directly told that I have Usher syndrome. But over the years, I've learned bits and pieces of information. Sometimes like my mom was saying earlier, sometimes I would have conversations and we would talk for hours about what I was dealing with. And then sometimes I would just ask questions. I would just want the direct answer and not go on.

But I think I really experienced the night blindness with my vision and stuff at a younger age because I realized we would be walking-- me and my mom, we would take night walks sometimes. I'd be walking down the street. I'm like, oh my gosh. I didn't even see that there. And she's like, it's OK, honey. You know, I saw that. I was like, you saw that? How? Do you have supervision or something? And I never really understood that, but as I got older and as I learned more information from my mom telling me, then I really understood that I had Usher syndrome.

For me, I was diagnosed at nine. No, wait. No, no, Not nine. What was it? That's my brother. Five. I don't know why I said nine. It's because I got diagnosed in 2009, so I just said nine.

So I can't exactly remember exactly what my mom said or anything, because I was five. But I'm pretty sure it was similar to Ava's story. She knew bits and pieces, and all that. And so I just-- you know, what Ava said I'm pretty sure was what happened. Right, Mom?

Yeah.

Slowly--

Yeah. Slowly.

And then to add to the 17-year-old I think it was, right?

Yes.

The biggest thing I would have to say to that would just be like, is one time, whether it's with your mom-- him and his mom or whatever, just force him to bring the cane out once. Go for a walk at night just once. If he doesn't do it, I don't know. Just do it once.

Go to a bumpy area or something and hold onto him, but make sure he has the cane so he can really experience what information he's really missing without it. Because I feel like that's the only way with what you said that he might really learn why, is if he experiences what information he's losing.

And to add on to Gavin's saying about the making friends part, I find when I have friends-- I feel like there's a group of friends. Like, there's friends I can really trust. Like, I know I can trust them with everything. And there's friends that I know have got my back, but I really can't trust trust them. I feel like you've just got to find those one or two solid friends, and then more friends will start slowly coming. Because when you go out, you can have those one or two friends that you can rely on, you can trust them.

We have another question here. Have you ever had a teacher that just insisted you didn't pay attention or you couldn't focus? And if so, how did you shift their perception? So whether it's attention or just a teacher maybe not believing you couldn't really hear, both of you kind of our surprising sometimes. And we always say that sometimes having Usher syndrome is an invisible disability. How do you cope with working with teachers that may not fully understand your hearing and vision loss?

You want me to start, Gavin?

Sure.

OK. So with my regular mainstream teachers, I really haven't found an issue, because I feel like sometimes you've just got to advocate your needs and make them aware of your situation before school. Usually, my mom does-- I usually go into the school, kind of walk around, meet some of the teachers, kind of talk to them and stuff.

The usual main issue I deal with is substitute teachers, like, all the time. So I leave my classes three minutes early to make sure that I don't get run over in the hallways, because the kids at my school go really fast in the hallways sometimes. So when I talk to a substitute teacher, sometimes they don't understand. They're like, wait, what? You have vision loss and you're deaf? No way.

So sometimes I usually have to explain to them more in depth. I show them my cochlear implants. And then all of the kids in class started chirping, yeah, yeah. She's allowed to leave early. And the whole class just goes, yeah, she can go.

Because I remember one time, I think we were in Spanish class. The one teacher was like, no. You can't go. There's nothing written on the piece of paper here. And all the kids are like, she can go. She's allowed to go. So sometimes you've just got to-- your friends will have your back. And then you've just got to make them aware of your situation.

We have about a minute left, so I'm going to alternate the question so we get to everything. Gavin, is there anything you think parents should avoid doing or saying to their child with Usher syndrome? And I'm going to give you about a minute to answer this, so think fast.

Oh, gosh. Putting me on the spot. Hmm.

[LAUGH]

Something we shouldn't say to you.

Oh, gosh.

[INAUDIBLE]

Ava, I might need a little help on this one.

[LAUGH]

OK. Maybe--

Sorry, Gavin, I can give you a little hint about what you think about when people do things that they think you need in general.

OK. OK. Well, just one thing I wouldn't do is just telling me exactly what I need, I would say. If you come up to me and say something that you think I need maybe, or even if it's a teacher and they

come up and they think, oh, you don't need this, or you need this or you need this, and I don't really need that, that's one thing you shouldn't really say, because you shouldn't try to say anything to me that I need, because I know what I need. If you're older, you know what you need. And I would definitely, instead-- I'm struggling here. I would definitely ask them instead of telling them. That's my biggest thing.

Yeah. That's a great suggestion, asking what your needs are rather than telling you what you should be doing. I like that.

And you have to find that transition time. When they're young, you're telling them a lot what they need. And then as they get older, they're able to articulate themselves. And I don't know what they need anymore.

And the biggest thing there with my mom saying that is when the kids are younger-- and I'm just saying. Like, let's say you're dealing with teachers. The biggest thing was the parents would be the ones saying what they need. Then as they get older, like my mom said, you would transition, and then the kids can say what they need. You never want to let the teacher say what you need.

Mm-hmm. Advocate yourself.

Yeah. And I think the biggest thing-- and to kind of wrap this all together is that you're going to receive a lot of information in the community. At least, we hope you do, you know? Our goal is to create resources as a community. We're really calling out to parents to share their stories, share their experiences, because it is very different whether it's state to state, town to town, country to country. Our goal is to kind of gather these resources and share so everybody can figure out what works for them.

I'm going to go back to that comment in regards to teachers and staff. We do have some resources. We do want to redirect everybody back to our virtual landing page for the conference. So if you do go to www.ushtis.org/virtual2020. Pam, I'm going to ask you to drop that in the chat pod. We do have some educational resources there.

One of the things that Ava shared was every year, whether she was transitioning to a new school or a new building, we would always do a professional development for the entire staff. So whether she was interacting with a lunch mother, a bus driver, an aide, or a teacher, everybody in the building knew Ava's story and knew to just ask her, do you need any support? Do you need any help? This is the thing. It's all about that education, awareness. And that just sparks an open dialogue and makes

people more comfortable.

A lot of the times we find we reach a lot of these barriers just because you don't know what you don't know. And even for our kids, you know, we say to them, we have a resource. You don't know what you're missing. So we want to bring your attention to that, and you decide if and when this works for you.

Build the tool box up.

Build the tool box. So Pam, do you want to talk about some of our opportunities to continue to connect with us throughout the year?

Yeah. And I can just add to that. And the boys own who they are, and they developed a presentation that they gave to their high school teachers once they got to high school. And they did it together, and it was called Two DeafBlind Guys. And they put it right out there and they said, this is what they need. And they did it for the whole staff. So they transitioned from their classmates and individual classrooms to the whole school situation when you're moving for so many different teachers once they're in high school.

So we will be sending a DIY self-advocacy tip sheet by the end of this week. Any resources and updates will be added to that conference page that I just put in the chat. I also want to invite you to maybe be a part of our family-to-family community phone calls. We've been holding them for a couple of years now. They happen from September to May or June.

And it's this kind of setting, or it can be just a phone call. But everybody has a chance to talk to each other. We have guest speakers, adults with Usher syndrome, teen panels, nutrition. But we talk together as a group and decide what kind of things we want to have on those phone calls.

So there will be more information coming out about that, so you can certainly contact us. There is a brochure. And we'll continue to add updates to the website, so please make sure to sign up for those updates.

We also wanted to remind you, for those of you being a little disappointed we didn't get to see Rebecca tonight does not mean you're not going to be able to connect with her. Tomorrow is the Ask the Therapist session. So please join in at 1 o'clock where you can Rebecca those direct questions that you may have for her.

One of the biggest things, though, is we want to see you. We want to connect with you. We want to

learn all of your names of your entire family members, you know? We don't want to forget our children of parents with Usher syndrome and our siblings. We have opportunities for our kids, our siblings to make connections as well.

So please, please be sure to stop by our website. If you scroll down to the USH Hangouts portion, there is a place there that you could submit a video by the end of the week. And all we want you to do is make a quick video where you introduce your family, say your names, maybe where you're from, and just wave hello. We will be compiling all these videos together so that we can introduce our entire USH family.

So please be sure to do that. And remember, no matter how many bumps there are in the road, we just encourage you to keep climbing. And as our kids would say-- Ava, Gavin?

Dream it.

Believe it.

crUSH it.

crUSH it.

[LAUGH]

Thank you so much for joining us tonight, guys, and we hope to see you soon.

Good seeing you all.

Bye.

Bye.