Hey, everyone. My name is Megan Lengel, and I hope you've been enjoying the Connections Conference so far. I am 23 years old, and I have a bachelor of science in psychology and sociology. I also have Usher syndrome type 1B.

I use one cochlear implant, which I was given when I was two and a half years old. And I also prefer to use English to speak. But the first language I was ever taught was American Sign Language, though I don't use that as much as I would like.

I have been an Usher ambassador in Virginia for about half a year, alongside with Tim Chambers, the other Usher ambassador in Virginia. And I am the young adult coordinator for the Usher Coalition. And I have been the coordinator for about two months, so I'm fairly new at that position.

And as with the newness of my position, all of the resources I'm going to be talking about today are also relatively new, and are still a work in progress. So keep that in mind as we're going through the presentation. Feel free to pause the video at any time to take notes.

So today, we're going to be first going over the objectives I have for the presentation. Then we're going to be going over some statistics of young adults. Then we'll be going over the resources that currently exist through the Usher Coalition. Then we'll be going through some goals that the Coalition and I, personally, as well as some other organizations, have for improving the resources that already exist or may exist in the future for young adults. Then we'll wrap it all up in the end.

So with this presentation, what I really want to do is to get everybody acquainted with what the Usher Coalition provides for young adults. And I also want to encourage the young adults watching to participate and engage with the Coalition and each other.

So starting with the statistics, with young adults, there really is a huge lack of specific statistics, looking at resources or really any issues particular to young adults with Usher. And as we go farther into this presentation, I want you all to keep in mind that I've come up with this arbitrary number to indicate who I'm thinking of when I'm talking about young adults. And the age group that I've come up with is people between the ages of 18 to 28. As far as I know, that's not an official number that the Coalition has come up with, or really any other researcher, or agency has come up with when speaking particularly about a young adult with Usher. That's just something that I've come up with.

So really, when researchers are looking into issues concerning young adults with Usher or are developing resources for young adults, they usually split young adults into two categories, the first one being children between the ages of birth to 21, and the other being employment age adults between the ages of 18 to 62, so two very, very disparate groups with huge age gaps in between the two of them, with a lot of overlap, four years of overlap.

So when we're just looking at the first group, children ages zero to 21, based on 252,000 congenital deaf and hard of hearing youth, for ages birth to 21 in 2017, it has been determined that around 3% to 10% of deaf and hard of hearing kids have Usher. The conservative estimate for that-- so assuming that only 3% of deaf and hard of hearing kids have Usher-- is 7,560. So that's assuming that there are 7,560 people, ages birth to 21, in the United States with Usher syndrome.

When we look at a liberal estimate of that-- so assuming that 10% of children ages birth to 21 that are deaf and hard of hearing have Usher, the number comes out to be 25,200. So that's assuming that there are around 25,200 people, ages birth to 21, with Usher syndrome, a huge disparity.

Then when we go into the second category of employment age adults, ages 18 to 62, researchers estimate, in general, that there are around 20,000 to 50,000 adults with Usher or people, in general, with Usher in the United States. And then when we narrow that down to employment age adults ages 18 to 62, and we're just assuming that there are only 20,000 people with Usher in the United States, then the number comes out to 11,000 employment age adults in the United States with Usher. That's a conservative estimate.

Then if we look at the liberal estimate-- assuming that there are around 50,000 people with Usher syndrome in the United States-- then that number comes out to somewhere near 27,500 employment age adults with Usher syndrome.

So what does this mean? [CHUCKLES] This means there's a huge disparity in the numbers, in general, for both of these age groups. But also, that younger adults are very hard to find in any of these numbers. It's really, really difficult to be able to find where the young adults are in between 7,560 to 27,500 adults or kids. But how many of those people are people with young adults? There's really no good estimate about that out there.

So for that reason, we really need more young adults to be signing up to the USH Trust Registry so that we can begin tracking those numbers and, hopefully, get a better idea of how many Usher syndrome young adults in the United States there are, and what kinds of resources they need. And this is just in the United States. Also, I should add, this does not include the rest of the world.

And again, I don't think I mentioned this, but these statistics-- I'm not going to go into too much detail explaining where I got these-- but you can go on to the Usher Syndrome Coalition website to find some more information about these. But yes, so if you're a young adult and you haven't yet registered in the USH Trust Registry, go to www.usher-registry.org. And there should be a link somewhere on this website for you to go to that. And it's a really quick sign-up. But that really helps us to be able to track young adults and better-- just have some sort of an estimate that isn't somewhere between 7,000 to 27,000 people that could possibly be young adults with Usher.

So moving on to the actual resources that the Coalition has. The first resource we're going to be talking about is the young adult Facebook group, which is called Young Adults Living with Usher Syndrome. And on this page, you can see two screenshots.

On the left, the screenshot at the top says Group by Usher Syndrome Coalition, and has the title of the group. And then it says that it's a private group. And as of me making those screenshots, we had 123 members. But as of now, we have around 130 members in that group.

And on the right is another screenshot. And you can see a post that somebody has made about a movie, *Crip Camp-- A Disability Revolution,* saying that's really good, and people should watch it. And there are five reactions on it with a comment. And it's been seen by 50 people.

And below that, you can see two comments. One of them saying, "I will check it out ASAP," and the other one just talking about their thoughts on the movie. And on the right of that screenshot, you can see the short About section that just has a brief description of what the Young Adults Living with Usher Syndrome Facebook group is. Again, you can see it as private, so only members can see who is in the group and what they post. But it's also visible to anybody that types in Young Adults Living with Usher Syndrome in the Search box on Facebook can find it.

It's a general group, so anybody can talk about anything, basically. It's not a specific group with a specific intent, other than to connect people.

And then below that, you can see some popular topics in the posts, which are USH Conference, Volunteer Opportunities, College and Support Group. Obviously, there are other things that are talked about too, but those are some of the popular topics so far.

So for this young adult Facebook group which I am the moderator of, basically, like I said, the intent is just to keep it as social and informative of an environment as possible. Anybody can post anything they want in this group. And everyone is free to post and chat about whatever they want, really.

There's no limit, other than inappropriate content.

And the goal of this group is to keep young adults with Usher informed about things that are applicable to them, such as college, work, Usher research, internship opportunities that aren't necessarily Coalition affiliated, and so on and so forth. And this group is open to everyone, regardless of language, country of origin, gender, or sexual orientation, anything. This is not a group that's limited to just young adults in the United States. And we have an international group. We have people in Mexico, and in Sweden, and some other places that are in the group right now.

And you just join by going on Facebook and typing in the title. And then you will be presented with a list of membership questions. All of those are technically optional, but we do want to keep this group as insulated as possible, meaning only young adults with Usher, again, that arbitrary age between 18 to 28.

So we really do need at least the questions of, "Do you have Usher syndrome?" and "How old are you?" to be answered. But the other ones are just, what are you doing, and what are your goals, and that kind of stuff. And if you don't respond to those first two questions, then I or somebody else will reach out to you and ask you to give us that information before we accept you to the group. But that's basically it, not a formal application process or anything.

The next resources is the "Just for Young Adults" web page on the Usher Syndrome Coalition's website. On this page are the USH Blogs, which we'll talk about in a minute. And there are also two webinars, "Educational Considerations for Students with Usher Syndrome," and "Starting a National Dialogue on Finding Children with Usher Syndrome."

And this web page is really a work in progress, so we really want people to contribute by filling out this comment box, which you can see on the screen. There are two screenshots. And on the left, at the top, in yellow, it says, "Want to contribute to the young adult page."

And then below that are four empty fill-in boxes. The first one asks for your First Name. The second one asks for your Last Name. And the third one asks for your Email. And those are three required sections to fill out. And then the fourth box asks you to Type your experience here or upload a document below.

And then on the right, the other screenshot shows a box. And at the top, it says Upload File. And it's asking you to Click or drag here to add files. So basically, what this is asking for is for either you to type in a blog or an idea or something that you have put in a picture, a video, anything that you have come up with that you want to put on the young adult page, any directions to resources, anything like that. This "Just for Young Adults" page is really up to interpretation at this point.

So you can contribute by filling out the comment box at the bottom of the page. You just scroll down, all the way to the bottom of the "Just for Young Adults" page on the Usher Coalition website. And that's where you'll find it.

So the USH Blogs are also in that "Just for Young Adults" web page. The USH Blogs are a general addition to the website, but there is a specific section just for young adults. And it is open to all young adults to post as guest bloggers about any topic applicable to living with Usher, such as dating with Usher, how to tell friends about Usher, how or if to tell jobs about the Usher syndrome, and anything like that.

It's similar to the comment box. This is also open to interpretation, though, clearly, these are blogs and not just anything willy-nilly to put up there. But it's really-- anybody can post anything they want, any kind of blog post about any sort of topic [CHUCKLES] you can come up with.

So on the page right now, you can see two screenshots. In the first screenshot, at the top, in yellow, it says, "Young Adult Blog." And below that in white, it says, "View all posts from young adults living with USH." And below that, it has the post date of the first blog, which is October 1, 2019.

And they have the title of the blog, which is at the top of the second screenshot, at the bottom of this page. And it says, in yellow, "Seeing is Believing-- My College Experience with Usher 1B." So this is my post. [CHUCKLES] And so far, my post is the only one in the Young Adult section. So we definitely want more people to be posting in this blog section so it's not just me.

But in the screenshot, underneath that title, it has a basic blurb about who I am. And then it has my name, I guess, my byline. And then below that, it just has the beginning of my blog post.

So if you want to make a blog about anything you want, you can email info@usher-syndrome.org. And most likely, it'll come back around to me to look over the blog that you come up with, or the idea that you come up with. And then I'll probably reach out to you to talk about edits, about developing your idea, and then eventually just post it on the blog.

So moving on, the other resource that the Coalition has are the USH Talks. And these are also on the Usher Syndrome Coalition's website. And the USH Talks are their own web page on the website. And they are a hub of informational videos, community stories, and research updates on Usher syndrome.

And there are ASL translations of some of the videos, as well as one research video that has been given in Spanish. And that's about genetic testing. And all of the videos have been captioned in English.

And there is also an USH Talks video podcast on iTunes, which is pretty cool. And you can see the full catalog of everything that's in the USH Talks on Panopto. And I believe the link to that is on that USH Talks web page. And all of these resources that I talked about can be found on usher-syndrome.com. So if you're interested, just go look at that.

So moving on to talking about some future additions and developments and the goals that the Coalition and I, personally, have to expand resources for young adults with Usher syndrome. First, there is the Virtual Support Group. That is essentially a branch-off of what the Facebook Young Adults Support Group is. It's a monthly support group.

And so far, we've only had one support group in May, which was super successful, and really, really fun. And we do want to-- or I, since I'm the moderator of the group, do want to make this a monthly thing so that it's consistent, and everybody has a chance to be able to get in the support group and talk to other people that have-- that are sharing similar experiences.

And I also want to eventually expand this monthly support group into a series of smaller, more specific support groups that can help give people with Usher syndrome, that also have other needs, a chance to talk to other people that have similar experiences. So by that, I mean people that-- like getting men into one group, getting women into another group, having specific groups for each Usher type, language, anything like that, just to make sure that everybody has that chance to really, really talk about what their needs are.

So moving on to the other goals that we have. We have the Facebook group, which I talked about before. And I'm currently developing ideas to encourage more active engagement with this Facebook group to get more people actively interacting on posts and making their own posts on Facebook, so it's not just the administrators making posts.

So some of the ideas that I have floating around are having guest members post questions or prompts in the Facebook group, posting more fun content, or different kinds of content, having regularly scheduled posts about advocacy, research, deafblind media representation, and other things that are of interest to young adults with Usher. And I am just basically open to ideas. I'm asking young adults for ideas on what we can do to make this Facebook group more fun and more interactive. So that's just an idea for an expansion of the Facebook group.

And the other goal that we have, or the Coalition has, that may or may not happen, but it's a cool idea, somebody in Ava's Voice suggested having a Google classroom for not just young adults with Usher, but for the Coalition and USH Partners to be able to have a place to collect resources across multiple organizations. And it gives us an opportunity to collect resources specific to young adults and get it into its own, quote unquote, "classroom" so that there can be a development of ideas and brainstorming that can happen in one place that is outside of the more informal environment of the Facebook group, the broader environment of the website, which is an odd place to brainstorm anyway.

And it also helps us to shave down ideas and more specifically target our efforts into encouraging active engagement, creating new programs for young adults, giving tips and ways to learn how to be a better advocate for yourself and other people with Usher. And it just gives us an opportunity to perfect ideas for the Coalition, and encourage collaboration and sharing ideas more organically. And it's just another place to put content, again, that is accessible for more people.

So moving on to the last development, the National Center on Deaf-Blindness, or NCDB, is currently conducting an Usher-specific literature review of existing materials, figuring out what works, what doesn't, and what resources need to be developed. And they are currently conducting a small number of interviews of constituents and staff within NCDB which will eventually lead to a survey and possible focus groups containing people with Usher syndrome.

And the goals of this literature review in the study are to increase "child find" of kids with Usher, birth to 21; identify and/or create more materials; and identify or create trainings for all state Deaf/Blind project staff. So this gives us an opportunity to further develop the resources that we have in general. But especially with the focus groups and future surveys that are going to be conducted, it may also give young adults an opportunity to tell and NCDB what their needs are and give them ideas for what resources can be developed for people between the ages of birth to 21, and other young adults with Usher.

And the last goal that the Coalition itself has is to develop a breakout session at the next in-person conference. We were planning on doing a Young Adult breakout session this year, but obviously, that didn't happen. [CHUCKLES] And when that happens, we will be asking for input, mainly from young adults in the Facebook group, but also from other young adults that may not be on the Facebook group. And the goal with the breakout session would be to put faces to the names of young adults with Usher, and give us an opportunity to see, face to face, people that share many of the same experiences that we do.

So that's the end. I hope that with this presentation, you were able to get acquainted with what the Usher Coalition provides for young adults. And I hope I was able to encourage young adults to participate and engage with the Coalition and each other. There are so many opportunities for development and exercising that creative muscle. And I really hope that young adults take up this opportunity. And we also discussed some goals for expansion of the resources that we have and any future resources that may be developed.

And here's my contact information. My email is ambassador.va1@usher-syndrome.org. And again, that's ambassador, a-m-b-a-s-s-a-d-o-r.v-a then the number 1, @usher-syndrome.org. And my Facebook profile is just my name, Megan, M-E-G-A-N, Lengel, L-E-N-G-E-L. So just search my name on Facebook, and you can find me there. And I have other social medias, but they're irrelevant.

And I also want to give everyone a reminder that later on in this week, we are going to have a Young Adult live meet-up. And it is going to be on Friday, July 10th, from 5:00 to 6:00 PM Eastern Standard Time in the United States. And this is really an opportunity for people with Usher syndrome that are young adults that haven't been to the last support group meeting to test out this environment and see if it's something that they want to potentially join later on.

And it's more a teaser from what you can expect from future chats. It's not going to be as informal an environment as typical support group meetings, because it will be recorded for future use. So it's going to be a little bit more of a formal setting, though it's not going to be super straight-laced. It's just maybe going to have more prompts and less personal topics and free-flowing discussion, and certainly less of me ranting about the state of the world, or whatever is bothering me at that point.

And it's really a time for you to bring questions that you may have, either about this presentation or for the young adults in the live meet-up. So bring any questions that you may have, and I hope to see you there.

So that's my presentation. The ultimate goal of the Usher Syndrome Coalition is to connect all young adults and give us people to talk to and ask questions so we can feel more connected and more secure in the knowledge that we are not alone in our experiences. Thank you for watching.