>> Hi. I'm Amanda Campbell from South

Carolina. This is a picture of my

family, my husband Morgan, hi oldest

son Ian, mica in the cowboy boots and

little Mia. Mica and Mia both have

usher syndrome which is the most common

genetic cause of combined deafness and

blind necessary: I impacts three major

senses, vision hearing and balance.

What does support look like for the

family of a child that is deaf blind?

And a hope that you'll see as I share

our story how everyone can contribute.

When becoming a parent you want to be

the best that you can be for your child,

navigate parenthood has

its own channels but butted in in an

additional diagnosis your insecurities

about becoming a parent magnify at least

that's what mine did. By the time mica

was six we had gone through the initial

process and learned that mica had

moderate to severe bilateral sensory

hearing loss. I don't remember much of

the information given to me that day by

the audiologist. In humid sight I wish

that I had known to ask for a follow up

appointment, so or I winter that she had

been aware that I needed time to process

before I could absorb any new

information. I personally needed to

work through a deeply rooted fear that I

would be deeped an unfit mother by all

the professionals entering our home and

doing evaluations. I was dealing with

postpartum depression, but I was also

grieving this new reality for my child

and for our family. I was overwhelmed,

jugging work and his feeding therapy,

speech and language therapies,

occupational and physical therapies.

Since I had seen a councilor before I

knew that I needed that support again

and it was here I processed my grief and

began to equip myself with strategies

to build my confidence. This picture of

mica is him as an infant on the first

day he wore his hearing aids. He's in

his pajamas and wearing his new blue ear

molds.

Looking at this picture brings bang the

memory of that overwhelming feeling I

had that morning, I had not yet finch

you had out to incorporate his hearing

aid care into you are oidialy Fiorina

and I had to go to the daycare on all

the same morning -- that same morning

about his hearing needles even while I

was not.

>> We had the change daycares because

someone said his hearing aids were

a choking hazard to other children.

The more confidentiality I became this

becoming his advocate and taking the

lead for his care I left my job as an

engineer and despite all of the progress

that he had made he was still falling

farther and farther behind this language.

And we knew it was clear that we would

not juggle everything effectively, so as

a family we had the try to figure out

how to navigate this added attention

that mica needed and the needs of our

older son Ian, who was jealous at the

extra time having to be spent with his

younger brother and what I was 11ing was

mica did lead me to seek the support

that we needed for. This

is a picture of mica at two years old

refusing to wear his hearing aids and

he has a grim mass on his face. His

speech therapist and audiologist

brainstormed ideas for hearing aid

retention but I also learned from other

parents who had children with hearing

loss and looking back on this I can see

that community of support that was being

built around us. We had a new milestone

at aim three tran sixing from

early intervention to school services.

We partnered with beginnings South

Carolina and they ited me on the IEP

prods and attends those meetings with us

as an additional advocate. They amazing

team of therapists joined me

and assisted in setting new goals with

the school district. They went above

and beyond their job

discriminations and monitored me. Our

family was in a different place at this

point than where we were his first year

of life and it felt like we would

breathe again and we were past the days

of refusing to wear hairing aids.

Mica's baby sister Mia was born after he

turned three and at one day old the

newborn hearing screening we had the

opportunity to educate the technician

about our family history and that informed

her that her attempt at reassurance

about fluted in the ears was not helpful.

At eight days old it was confirmed that

Mia also had bilateral hearing loss.

Things a picture of Mia getting her

first ear mold impressions and she's

wearing the pink pajamas. I felt

confidentiality in raising another

child with hearing loss and even though

I felt sadness and grief at the news I

also knew that I had done this before, I

could do it again, I could do it

bitterly I said to myself this time.

Later on we received testing and I had

come to a place of septages and even

embraces the children's deafness, I had

grown in confidence about advocating

for their milds and learn of usher

syndrome was an entirely different story.

It's one that your children will

eventually go blind is an experience

that I'll never forget. To say I was

devastated would be an understatement.

I knew what to do about hearing loss, I

knew nothing about vision loss. I knew

the medical terms, the inevitable

[indiscernible], counseling again to

help process all this new information.

My husband and I also went to a marriage

courage to work on strengthening our

communication with each other because we

just processed this differently. This

is a picture of mica kiss Mia's cheek as

they sit in a rocking chair and it

reminds me of the moment

that I realized that they have each

other. They have this unique bond, the

greater degenerative disease and an

understanding between them that I can

never fully comprehend.

There was more work to do and I knew

that.

The pediatrician called one evening

after we received the kid's yessing

neck results and she first asked how I

was doing, and then she said, are you

ready to get to work now? And we started

all the referrals that were needed, our

teacher to have deaf referred us

to the South Carolina deaf blind project

after she learned the diagnosis, they ited

me on deaf blindness and resources for

those with usher syndrome. The parents

that I we connected with that had

children with hearing loss could no longer

relate as we processed deaf blind

necessary so the further educate

ourselves we attended the usher

conference and met other families and

other children and adult with usher

Anderson can suddenly to see mica

walking made more sense. The difficulty

that we have had in is it teaching the

children to learn to ride a bike made

more sense. Connecting with other

families with children with deaf

blinderness gave us ideas on how to

navigate dark due to poor night vision.

We learned more strategies and how to

demand our home so they can navigate it

more effectively we moved

mica's bed downstairs and our

audiologist give us tips on what to do

about the fear of falling asleep without

his hearing aids on. Usher syndrome

community was difficult because we had

the face all the potential realities of

their futures as adults, but it was also

a place where I found hope. It was

different than hope for a medical cure

which doesn't exist, but hope that

propelled us forward. I realized how I

needed to empower them and teach them

how to keep going even when it's hard.

This is a picture of mica and Ian,

they're both wearing Katie uniforms and

I would shows how far their bond has

come and strengthened. The jealousy is

Liz and Ian is learning how to mentor

mica.

The karate has been great for mica's

balance and having a tough older brother

has given the two of them somebody to

bond about. They also have their

community and I know now I can't just

teach independence, I have to teach

interdependence and how to built that

community around them for their futures.

Meme learning opportunities arrive

frequently. This picture of mica and me

and it shows mica wear glasses. Had had

had to get glasses and he learned that

his visual field has narrowed more.

Typically a student who

deaf or hard of hearing sittings in the

front of of the class but a child who is

deaf blind needs to sit farther back so

they have a wider view. This is one

example of the unique examples of deaf

blind necessary education. As the

disease progresses the combinations will

need to change. How do you convince

someone is that it is worth the

investment to be proactive with a

degenerative disease rather than reactive?

How do you tell them that you cannot

wait to teach braille skills and mobility

skills before they lose functional

vision in delay need that for continue

success. How do I explain to my

eight-year-old son that he's going blind?

I can't comprehend it let alone an

eight-year-old boy. I don't have all

the answers but I don't have to.

Throughout our story there are people

that have been an integral part of learning

how to lead the charge for our family.

[indiscernible]. I don't know the

words providers, and advocates,

even mentors. Mica and Mia are more

than usher syndrome. They are more than

their accommodations. Every single life

in every community has value. Every

single life in the community is

intertwined just like people are

intertwined the needs of a child are

intertwined with their need for

friendship, the parent's need for a

state of the union relationship; the

need for strong sibling relationships

and the need for a community that

supports.

>>> really pot but we do not have enough

time time for questions because there's

another session that's about the start.

Thanks, everyone for coming.