MINNESOTA
HANDS & VOICES™

Supporting families with children who are deaf & hard of hearing

May-June 2019

Focus

SPOTLIGHT: A Series of Articles on Individual Journeys and Personal Choices

Technology Choice Part One: Adults Share Their Experience with Cochlear Implant Surgery

MNH&V is planning a series of articles titled SPOTLIGHT. These articles will ask adults who are deaf or hard of hearing (dhh) to share about their choice in hearing technology and communication preferences. First-hand experiences are all unique, but this insight may be useful to parents of children who are dhh who are contemplating similar choices for their child. SPOTLIGHT articles are not an endorsement of any technology or communication option and not meant to be persuasive. SPOTLIGHT articles are about the experiences of the individuals who were interviewed.

This SPOTLIGHT article is about Cochlear Implant (CI) surgery. We interviewed four adults, which we will refer to as Abby, Beth, Cori, and Debbi (not their real names). We first asked them to tell us a little history about their hearing difference.

Abby said genetics is the reason for her hearing difference. She had typical hearing until her early teens when she noticed a change; every year since then her audiogram has shown a significant decrease.

Beth was born with typical hearing and then, at age 14 months, her hearing changed due to complications of meningitis.

"Rubella Baby", explained Clara, meaning her mother was sick with Rubella during pregnancy resulting in her hearing difference.

Debbi was late identified at the age of 3 years old with a moderate to profound hearing difference. She could only hear low frequencies.

All of the adults used hearing aids for many years before deciding to get a CI.

Debbi benefited from her hearing aids because they converted hard to hear high frequencies to low frequencies within her range. However, the manufacturer stopped making the specific frequency compression hearing aids that worked best for her. Researching her options lead her to consider a CI.

Around age 40, family members and co-workers noticed Clara was not responding even with her high-powered hearing aids, which prompted her interest in looking into getting a CI.

> **"When you see your child react to a sound, tell them or show them where the sound is coming from."**

Beth used hearing aids until hearing aid manufactures switched from an analog design to digital. Digital hearing aids gave her vertigo and headaches so she decided to go without amplification for about 11 years. It wasn't until her first child was born that she was motivated to look into getting a CI. When her son was 16 months old she had the CI surgery.

Abby had used hearing aids until her hearing changed to a point where hearing aids were not beneficial. She researched her options, consulted with her audiologist and, because of genetics, she was able to talk to her grandfather who has been using a CI for over 15 years.

The CI surgery for each of the adults we interviewed was for the most part uneventful and without complications, but recovery varied and was unique to each. Also, technology and surgical techniques improve over time and the time span of the surgeries range from 6 months ago to over 15 years ago.

"It was not hard during the surgery, but the next 3 days were a little uncomfortable," said Abby. "I thought I would have less pain, but it was more than I had expected therefore I rested a lot."

Abby woke up from surgery and her head was covered in a bandage. For

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the first week post-surgery she had strong headaches, bouts of dizziness, poor vision and, for a short time, loss of taste. She continued to take the pain relief medications and slept as much as possible. She found it helped to have extra pillows to prop her head so she did not sleep on the side of the surgery.

Once she was nearly recovered she happened to scratch the area of the incision and she was overwhelmed with dizziness. The surgery site appeared to be mostly healed, but her doctor told her it can take up to a year for the swelling and full healing to happen internally.

> **“I would explain to CI candidates that the sounds will not make sense at first, but to give it some time.”**

For Beth her surgery was many years ago, but she remembers waking up feeling nauseous and vomiting from the anesthesia at first. And for the first week she needed to take pain relief medications and found sleeping on the opposite side of her surgery site to be more comfortable. About three days post-surgery Beth noticed her head bandage was getting pretty tight due to excessive swelling. She was instructed by her doctor to keep it on until her follow up appointment about a week post-surgery. She just couldn’t tolerate the head bandage and pleaded with the doctor to allow her to remove it herself at home. She finally got permission and was shocked by what she saw.

“My ear was in the wrong place!” she exclaimed. On the side of the surgery her ear appeared to be in a different place and significantly lower than before. For a moment she thought the doctor had made a mistake. The doctor assured her once the excessive swelling went down her ear would be where it always has been, and it did. After the first week she was feeling pretty good, but she remembers her incision scab taking about a year to stop itching and for the scab to fully heal.

Recovery post-surgery for Clara took 10 days and she was grateful her mother who had a nursing background was available to help. The pain relief medication she was prescribed made her nauseous, so she slept a lot and found ice packs to be helpful. During the surgery her taste nerve was nicked and everything tasted metallic. The doctors said to give it 2 to 4 days, but it took 6 months for her taste to return to normal. She wore her CI for 3 years, but unfortunately had to stop using it as she had developed vertigo symptoms.

“Although I was a little nervous, surgery was easier than I expected,” said Debbi. She used the pain relief medication she was prescribed and avoided strenuous activities that tended to give her a headache. She slept a lot and interestingly found that sleeping on her surgery site relieved the pressure she felt pressing on her skull.

> **“Parents and family should still face the CI user as they speak and be patient with them throughout the process.”**

“Clear” is the word used by all the adults to describe the sounds they heard when the CI was first activated. Compared to hearing aids, which seemed to muffle or distort sound, the CI simply made sound clear. Environmental sounds in particular took an adjustment period, as they were too loud and often continuous. Some adults had to take breaks wearing the CI; the noise was annoying or even gave them headaches. Understanding which sounds were speech took the brain time to sort out.

“It took a long time and lots of appointments for adjustments,” Clara explained. “That was a challenge with a full time job and raising my family.”

We asked the adult CI users if they had any tips or “ah-ha” moments they would like to share:

“Keep an eye on your child regarding body reactions from medicine.”

“I would explain to CI candidates that the sounds will not make sense at first, but to give it some time.”

“Parents and family should still face the CI user as they speak and be patient with them throughout the process.”

“Follow your child’s lead and allow break time from the CI.”

“Try to sound proof as best you can before putting the CI on to ease into the sound.”

“When you see your child react to a sound, tell them or show them where the sound is coming from.”

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709 University Ave. W., St. Paul, MN 55104

MNH&V Welcomes Mee Vang, SE Asian Community Parent Guide

"I look forward to meeting with families from the SE Asian communities and helping them get what they need for their family," said Mee Vang, MNH&V SE Asian Community Parent Guide. Mee joined MNH&V last March to support families in the SE Asian Community who live in the metro area as well as greater Minnesota.

"Whatever comes your way, remember you have a family at MNH&V," said Mee.

Mee and her husband have been married for 27 years and live in a suburb north west of the Twin Cities. They have four children; their 1st child and 3rd child are profoundly deaf and their other two children have typical hearing. They raised their children in a large communal home made up of Mee's immediate family and her in-laws. This way of living was at times a lot of work, but Mee felt it was a wonderful environment for her children to grow up in. Their family communicates daily in several languages; Hmong, English, and American Sign Language.

Mee Vang, MNH&V SE Asian Community Parent Guide

Whenever possible Mee enjoys spending time with her husband, children, and their dog, Max. The family loves to go on walks, cook meals together, and watch movies.

Contact Mee Vang by email at meev@lifetrack-mn.org or call at 651-265-2350.

Welcome to our newest MNH&V welcome blanket recipient from the metro area.

This child who was identified with a hearing difference received a teddy bear with hearing aids from MNH&V

MNH&V Events

ALL MNH&V Family Events are open to ALL Minnesota families who have a child who is dhh. Siblings are always welcome!

Thursday, June 13
Spanish Speaking Community Family Event
5:00 to 8:00 pm
1100 N Hamline Ave., St. Paul

Wednesday, June 19
MNH&V Trivia Night:
A Social Event for the Whole Family
6:00 to 8:00 pm
Lake Monster Brewing
550 Vandalia Street, St. Paul

Thursday, June 20
MNH&V SE Regional Family Picnic
5:00 to 8:00 pm
10 Jefferson Parkway, Northfield

★ **Thursday, August 1** ★
MNH&V Annual Family Picnic-Metro
5:00 to 8:30 pm
Como Park Midway Pavilion
1199 Midway Parkway, St. Paul

Tuesday, August 13
SW Region Annual Family Picnic
5:00 to 7:30 pm
900 Mound Ave, Mankato

Saturday, September 21
Reading on the Farm
10:00 am to 12:30 pm
2820 245th Street East, Hampton

Get the latest MNH&V news and events at www.mnhandsandvoices.org/news-events or send an email to www.mnhandsandvoices.org to sign up for the MNH&V Weekly ***SOURCE***.

★ *Look for these stars to find article topics relating to specific MNH&V Family Events.*

Fostering the Joy— The Unexpected and Totally Amazing Musical Talents of Anna Colbenson

When Anna's parents, Joseph and Nicole, first found out their only child had a severe hearing difference at the age of 3 and would benefit from wearing hearing aids they were blown away, mostly because she had perfect speech. It was stressful in the beginning for Anna's parents, because they didn't know what Anna's future was going to look like and they were scared of the road ahead. They started the way many parents do by learning all they could. A clever idea they tried was to fashion "hearing aids" out of pipe cleaners and pom-poms for them to wear hoping to encourage Anna to wear her hearing aids.

Joseph and Nicole have always been big music fans. They constantly listen to music at home and they have attended music events and concerts with Anna ever since she was a toddler. Anna's hearing difference did not change their love for music.

Anna grew up playing with toy musical instruments including a mini grand piano and a tiny drum set. In elementary school Anna loved music class and in 4th grade she asked for piano lessons. In 6th grade Anna joined the school orchestra and began playing the violin. It was then that her parents really noticed her musical talents blossom. Songs she had learned to play on the piano she would transfer to play on her violin.

"It seemed like every time we took her to a concert or to see a new musician she would just get fixated on one of the band players," said Joe, Anna's father. "It never failed. On the way home [Anna would ask], 'Dad, can I learn the [instrument]?'" This lead Anna to taking lessons in guitar, banjo, cello, upright bass, and drums, all while still taking piano lessons and playing the violin in the school orchestra. At one point Anna was in two school orchestras, playing the violin in one and upright bass in the other. Recently Anna got first chair in her high school orchestra, which means she is the top violin player in the class.

During summer Anna plays in community orchestras. Paramount Center for the Arts in St. Cloud hosts *School of Rock* where students from all over the area create bands, practice, and perform a concert.

Anna understands that she has to work harder than her peers with typical hearing in school and in music class. She uses an FM system at school with her hearing aids except she removes them when she is playing her drums to preserve her remaining hearing. Anna's father thinks her greatest motivation to play music and excel at school is to show everyone that, just because a person is hard of hearing, doesn't mean they can't do the same things people with typical hearing can do.

Anna has become a huge advocate for other students who are dhh. In high school last year she received permission to take American Sign Language (ASL) on-line as a foreign language credit and recruited other students who are dhh to join her. She takes multiple college level classes and helps educate her peers about the experience of being hard of hearing.

"There is SO SO much that kids with a hearing difference CAN do. Never limit what you dream for your child. Kids have an amazing way of just going for it and succeeding. So dare to dream big for your little ones," Joe and Nicole said to help foster the joy of raising their daughter who is dhh.

Fostering the Joy is a topic taken from Hands & Voices HQ in an effort to encourage more parents and loved ones to share their joyful moments. Please email your story of joy, big or small, at www.mnhandsandvoices.org.

MNH&V Welcomes Kobe Schoeder, DHH Guide

"If your kid(s) is deaf, it doesn't mean the end of the world," said Kobe Schroeder, MNH&V DHH Guide, when asked what he would like to share with MNH&V families. "It's a start of a wonderful journey!"

Kobe joined the MNH&V team in April as a DHH Guide and he brings with him a unique perspective. Not only is he an individual who is deaf, but he also is the big brother of an individual who is deaf. Both Kobe and his younger brother are deaf and their older sister and parents have typical hearing. Kobe's own life experiences along with growing up with a brother who is deaf give him a better understanding of the issues faced by individuals who are deaf. DHH Guides, like Kobe, are available to share their stories, answer questions, and visit with families.

"I am a big fan of sports," Kobe said about what he likes to do in his free time. Kobe was recruited to play football at Gallaudet University next fall where he plans to major in Physical Education. Kobe graduates from Lakeville North High School in June.


Kobe Schroeder, MNH&V DHH Guide

Contact Kobe by text at 952-322-0504 or email at kobes@lifetrack-mn.org

Give a Hand to… North Suburban Saint Paul Kiwanis


Thank you North Suburban Saint Paul Kiwanis for your donation of handmade tie blankets to help welcome our newest MNH&V families.

VOLUNTEER OPPORTUNITY

MNH&V Annual Family Picnic Metro

Minnesota Hands & Voices (MNH&V) is looking for volunteers for this year's Annual Metro Family Picnic on Thursday, August 1, from 5:00 - 8:30 pm. We are looking for volunteers to help in several areas during the picnic, such as welcoming families through registration and helping children with activities and crafts. American Sign Language Interpreters and Cued English Transliterators will be available at the picnic to provide access, but we welcome any parent or student volunteers who have communication skills, too. Volunteers are also needed to arrive early to help set-up and/or stay late to help clean-up. Please let us know what your "super powers" are and what you might want to do to make this event more special for MNH&V families.

> **"Many hands make light work."**
> — *John Heywood*

Over the years we have been fortunate to have an active MNH&V community of volunteers who have made the Annual Metro Family Picnic a success. Please consider joining us this year. Volunteer registration is easy, but takes time to process properly so as soon as you can commit please contact Anne Barlow, MNH&V Events Coordinator, at 651.265.2400 or email at AnneB@lifetrack-mn.org

MNH&V Family Meet-Up Event, Saturday April 27th

MNH&V EMPLOYMENT OPPORTUNITY

MNH&V DHH Guide

MNH&V is looking to fill 4 DHH Guide positions to support families throughout Minnesota, specifically in the Northern, Southern, and Metro areas. The MNH&V DHH Guide positions offer 10 hours a week, which occasionally include evening and weekend hours, and a family friendly work environment. Also, we are in need of an additional DHH Guide to be on-call.

MNH&V DHH Guides must be an individual who grew up deaf or hard of hearing (dhh) and are now active and involved adults willing to share their personal stories with others. Sharing their personal experiences, challenges, and joys as an adult who is dhh offers an invaluable perspective for parents who are raising a child who is dhh.

DHH Guides receive specific training and are responsible to make connections with families. DHH Guides work closely with the MNH&V team to collaborate on family events, represent MNH&V in the community, and participate in family support activities.

To find out more or to apply and send a resume, please visit Lifetrack at https://recruiting.paylocity.com/Recruiting/Jobs/List/1442

MNH&V Community Engagement

EHDI Conference in Chicago, March 3-5

Lobby Day at the Minnesota State Capital, March 6

Deaf Awareness Day, April 27

Public Health Nurses EHDI Conference,

All Families can Nominate an Exceptional Individual for a High Five Award

The High Five Award is an opportunity for parents to publicly thank those who do more than expected on behalf of children who are dhh. Parents are invited to nominate another parent, teacher, interpreter, medical provider, community advocate, role model, or anyone who inspires your family!

Now through July 1st, MNH&V is accepting one nomination per family from parents.

Email your nomination, subject line "High Five Award", to mnhv@lifetrack-mn.org

Winners will be announced at the MNH&V Metro Family Picnic on Thursday, August 1st. Recognition for winners will also take place at the picnic or, for greater Minnesota recipients, in a community convenient for them and the nominating family.

Give a Hand to…

Marion Anderson

Thank you Marion Anderson for the beautiful handmade quilts to welcome new MNH&V families. Marion learned about MNH&V at a community involvement night at her parish St. Joan of Arc Catholic Church in Minneapolis.

New YouTube Videos to Introduce MNH&V DHH Guide Program

Learn more about the new MNH&V Deaf and Hard of Hearing Guides. The DHH Guides are available to support your child and family. Serving ages birth to 21. Go to https://www.youtube.com/watch?v=LGs48dUF_Xc&t=2s&utm_

Thanks for your contribution!

We rely on your generous support to build better lives for children who are deaf or hard of hearing.

Make a tax-deductible donation today.

DONATE

Parent to Parent POINTERS

Making an Inclusive Doll

A MNH&V mother added behind-the-ear hearing aids to her daughter's doll with puffy paint. It is important for children to develop self-identity through play and peer relations, which contribute to strengthening their emotional, social and cognitive development.

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709 University Ave. W.
St. Paul, MN 55104

FOCUS
NEWSLETTER

FAMILY PICNIC

★ 2019 Annual ★ Minnesota Hands & Voices ★ Metro ★

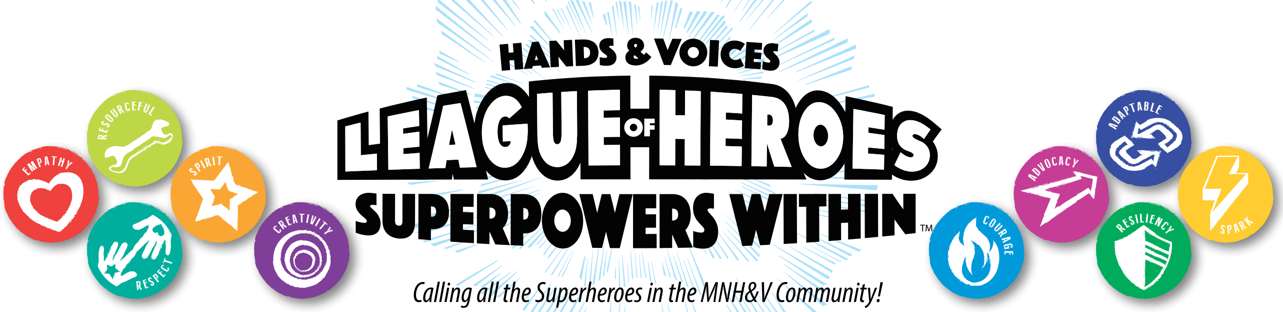
Date: Thursday, August 1st

Time: 5:00-8:30 pm (rain or shine)

Where: Como Park Midway Pavilion
1199 Midway Pkwy, St Paul, MN

Free for Families:
- ★ Dinner
- ★ Fun Games
- ★ Entertainment
- ★ Face Painting
- ★ Door Prizes!

Dilly Bars graciously provided by DQ



Calling all the Superheroes in the MNH&V Community!
Dust off your superhero costume or come as you are to join our Hands & Voices' League of Heroes!

Find more details online at www.mnhandsandvoices.org/news-events/current-news-events.aspx