Congratulations to the 2017 MNH&V High Five Award Recipients

Congratulations to this year’s MNH&V High Five Award recipients, listed in alphabetical order from the metro area: Kathy Anderson, Justin Mathes, Hawley Mathieson (not pictured), and from greater Minnesota: Amy Gibbons, and Laurie MacDonald. The MNH&V High Five Award recipients were nominated by parents or care providers of children who are deaf or hard of hearing (dhh).

Nominations for the 2018 MNH&V High Five Award will be accepted from May 1st to July 1st, 2018. To nominate someone simply write a 200 word or less explanation of 1) what the nominee has done above and beyond what is typical for their role and 2) how this individual has made an impact on a child and/or the community. At least one specific example is very helpful. Email your nomination to mnhv@lifetrack-mn.org and include in the subject line “High Five Award”. Please submit only one nomination per family per year. MNH&V High Five Award submissions information can be found at www.mnhandsandvoices.org.

The MNH&V community would like to thank all of the award nominees and winners for their dedicated service. The MNH&V High Five Award was created as a way for parents to publicly recognize individuals who have gone above and beyond on behalf of children who are dhh. Past recipients represent a diverse group of parents, teachers, students, interpreters, providers, advocates, volunteers, and role models.

Kathy Anderson
Two families submitted nominations for Kathy Anderson for the MNH&V High Five Award. The Philaphon family and the Awend family, both from Intermediate School District 287, wanted to honor Kathy for her invaluable support for their families, in addition to the hundreds of other families she has touched during her career in education. This fall Kathy will be retiring after over 30 years in education of children who are dhh.

“Not only has Kathy been an amazing dhh teacher for my daughter for the last 1.5 years, but she has been irreplaceable to myself as well,” wrote Lanae Philaphon. Lanae went on to say Kathy is always available to answer questions about raising a child who is hard of hearing, has provided countless ASL resources, and so much more.

“Amy has always made me feel like I’m not alone in this unexpected journey of raising a daughter who is hard of hearing,” adds Lanae

Amanda Awend has known Kathy for almost 6 years when their son was just 6 weeks old and first identified as dhh. Kathy was one of the first professionals they met and throughout the years she has been just a text or phone call away.

Recently, when Amanda’s 3 year-old daughter was identified as hard of hearing, Kathy reached out to the family even though she does not work directly with the children any more. “She goes above and beyond for all of her students and makes everyone feel like they are her top priority, Amanda wrote, “I am very grateful to have remained in touch with Kathy, and she has been such an important part of our family’s journey.”

Justin Mathes
Justin Mathes was nominated by his understandably proud parents, Nicole

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MN Hands & Voices Welcomes Elena Miranda
New Spanish-Speaking Community Parent Guide

Elena was born and raised in Mexico. She and her husband have been married for 20 years and together they have three children, ages 12, 6, and 4. They adopted their oldest child who is dhh at age 2.5 years. As new parents they learned as much as they could about raising a child who is dhh in order to make the necessary decisions about his education and to better advocate for him.

Elena and her family moved from Mexico to Texas in 2008. In 2015 her husband’s job relocated to Minnesota.

Elena enjoys going for walks, biking, cooking, and making hand-crafted decorations especially for the Christmas tree. When asked what kind of person she is Elena responded with, “I’m optimistic, positive, sensible and a very good friend.”

Elena focused on raising her family for the past 10 years. Before that she worked in Business Administration. She said she feels she and her family are ready for her to start working outside the home again.

“Thank you MNH&V for this amazing opportunity, I’m excited to work as a Parent Guide for the Spanish-Speaking Community,” added Elena.

You can reach Elena at 651.265.2383 or email at ElenaM@lifetrack-mn.org.

American Heritage Girls Troop MN0408

American Heritage Girls Troop MN0408 donated decorated bags and welcome blankets for MNH&V Parent Guides to bring to families with a child who is newly identified as dhh. As part of an American Sign Language (ASL) badge, girls in grades 4-6 learned about different types of hearing aids, basic ASL, and more. One of the requirements for the ASL badge was to learn and do a service project for a dhh organization. American Heritage Girls is a faith-based leadership program whose mission is to build integrity.

Parents are Precious Too

Raising a child who is dhh is often stressful for parents. Children can sense the stress and tension around them raising concerns about stability. So it is important to take care of YOURSELF first, then your relationships with loved ones can flourish. In general, maintaining a healthy positive environment can allow the whole family to function smoothly.

Find a balance in life that works for you. Before feeling overwhelmed look for the support you might need. Network with other parents who share your experiences—they will understand how you feel better than most people would. Professionals, friends, and family can also be supportive.

It’s OK to grieve a change in what you had envisioned for your child, but make sure you do it in a healthy way. Your child needs you! Accept and honor your precious child, and remember you are precious too.

Parent-to-Parent POINTERS

Emily Burke

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and Joseph. They wanted Justin, a young adult who is dhh, to be recognized for his many achievements despite adversity at an early age.

Justin was not identified until age three as dhh. Justin had to work hard to catch up to his peers all throughout elementary school. Now Justin has not only caught up to his peers academically, but has gone on to achieve high honors in an accelerated program in addition to other notable successes. He juggles many commitments such as the National Honor Society, high school wrestling team, tutoring others, and Boy Scouts. Justin completed the requirements and is waiting for his Eagle Scout recognition.

“Justin is a one-of-a-kind kid that was on an IEP since preschool, yet was determined to letter academically at Blaine High School four years in a row in the very difficult Center For Engineering, Mathematics & Science Program,” write his parents.

This fall Justin is attending the University of St. Thomas in St. Paul, Minnesota.

“We are beyond proud of him and want to personally thank all of his wonderful family, teachers, friends and community members who were the “village” that helped us raise an amazing young adult,” add Justin’s parents.

**Hawley Mathieson** (not pictured)
The Christopherson family nominated Hawley Mathieson to acknowledge her dedication to her students and parents alike. As IEP manager for their daughter, Hawley leads IEP team meetings and goes above and beyond to organize teleconferences, attend classroom parent-teacher conferences, and recently she partnered with the school audiologist to troubleshoot equipment challenges.

“Every single interaction and communication with Hawley has exceeded our expectations and we can say with certainty that she has made the difference not just in the course of our daughter’s educational path but also in the social and emotional complexities that come with being a child who is deaf,” wrote the Christopherson family.

One way Hawley has had a positive effect on the family was by introducing the book, *El Deafo*. The storyline helps give language to feelings their daughter may be experiencing. As a result, Hawley has opened up an important line of communication for the family.

“Her energy, positivity and communication techniques have engaged our daughter in owning her hearing loss and building her confidence in a way we couldn’t have imagined,” added the parents quoting Hawley’s mantra, “Be the Boss of Your Hearing Loss!”

**Amy Gibbons**
Amy Gibbons, dhh educator from Moorhead, was nominated by the Kitch family. They are grateful to Amy and other educators in the Moorhead Public School system for their part in supporting the successes of their two children. Their son is a high school sophomore and their daughter is a 4th grader; both have been enrolled in Moorhead’s Public School since they were first identified as dhh. Thanks to Amy and the educational environment both children have grown and become strong advocates for themselves.

Amy has helped guide, teach, and nurture the children with the same support a parent would give. As a result they have confidence to ask any question and be themselves. They are continually challenged in their respective classrooms to learn with the high, yet reasonable, expectations that are set for them. Amy and the team are always looking for new experiences and ways to share community resources with the family.

“Amy has taught both of our kids—she’s been a part of our family for about 14 years! We often joke that she will be going to college with our daughter,” wrote the Kitch family.

**Laurie MacDonald**
Loretta Ronding nominated Laurie MacDonald for her exceptional work as an interpreter for her granddaughter.

“We wished she could always be the interpreter for my granddaughter,” Laurie wrote.

Loretta’s essay goes on tell how Laurie was a wonderful advocate for her granddaughter. Along with interpreting for her granddaughter, Laurie went above and beyond to encourage all of her granddaughter’s classmates to learn how to sign and become more comfortable using sign language.

“We never had to worry about any problems when Mrs. Mac was with my granddaughter,” wrote Loretta. “We were so happy with the job that she did. She was almost like family.”
The Niska Family

We asked Corinne to share her family’s ongoing journey to find the right fit of services to best help her daughter, Anna, reach her fullest potential. The Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education, and ensures special education and related services to eligible children with disabilities. Corinne’s story tells us their ongoing experience with IDEA and what it does and does not mean. Below is a version of her story edited to fit into our FOCUS Newsletter format. Corinne’s full story, in her own words, can be found online at mnhandsandvoices.org.

Corinne and Matthias Niska both grew up in Minnesota. For a few years they lived in Maryland where their daughter, Anna, was born 8 weeks early. Anna spent her first 2 months of life in the neonatal intensive care unit (NICU) at a pediatric hospital. Corinne and Matthias truly see Anna as their miracle baby for pulling through the various complications of her premature birth.

Anna, who is now 4 years old, has a unique combination of diagnoses that make it challenging for her to learn and communicate: autism, global developmental delays, and auditory neuropathy. Anna’s parents have struggled to find the right mix of services, often feeling isolated, even from those closest to the family. They find that very few people understand Anna the way they do.

“My advice to other parents would be to acquire as much knowledge as you can, reach out to every resource you find, and believe that you know your child’s needs better than any teacher or doctor,” commented Corinne.

Anna was first identified as dhh when she was 2.5 months old. She failed her newborn hearing screen, but dealing with life-threatening issues was the priority and the NICU staff forgot to inform them. While in the NICU Corinne and Matthias calmed Anna by singing and it seemed to work. When Anna failed the 2nd hearing screen she was then referred to an audiologist who confirmed Anna was dhh.

Anna received early intervention services such as physical, occupational, and speech therapy as a newborn. Although difficult to diagnose, around age 18 months it appeared Anna had autism. Autism combined with her hearing loss created a problem for Anna to develop language. After a trial with hearing aids, Anna received bilateral cochlear implants at ages 21 and 27 months.

The family moved back to Minnesota in 2015 and Anna continued with early intervention services until age 3. The family became frustrated with how IDEA is applied in practice. Corinne spent hours researching services for her daughter’s diverse needs. Even though public schools are required to provide a free and appropriate education for kids with disabilities, they felt Anna’s IEP was insufficient to help her reach her real potential. Administrators at their school district seemed to want to do more but their budget was limited and, by law, IDEA only offers an “appropriate education”. To them that meant accepting bare minimum progress and lower standards in education than they knew Anna would need. Realizing their public school district could not adequately accommodate their daughters needs, and no time to waste, they had to figure out a better education situation for Anna.

They found out a quality education for their daughter has a price and they had to rely on generous financial help from relatives and friends. Mathias and Corrine were able to advocate for a successful combination of a specialized private dhh school for Anna’s communication needs and the local public dhh school primarily for physical and occupational therapies. Anna made amazing progress with this combined effort. Then in 2016, Anna received a formal autism diagnosis. A year later a spot became available at a provider of autism services and Anna started splitting her days between the private dhh school and autism services.

“Quality early education that helps kids make REAL progress and become independent, productive members of society should be available to everyone, not just a lucky few who can afford it,” expressed Corinne.

Everything changed again this past spring at parent-teacher conferences. Even though Anna had made significant strides her teachers recommended that Anna be enrolled full-day for autism services. Unfortunately, full-day day treatment was not available at their current facility. Once again they are researching available options and looking into insurance coverage and finances. Applications are extensive for full-day autism services and the waiting lists can be over a year, sometimes longer.

“We have advocated so hard for Anna because we believe she has great potential and a great mind, and that she just needs the right support system to help her learn how to share her thoughts and gifts,” adds Corinne.
Meet Lifetrack’s DHH Role Model Shawn Madden

Shawn Madden is a role model for Lifetrack DHH Role Model Program. Shawn grew up and still lives in Delano, MN. He graduated last spring from Kaleidoscope Charter School, Ostego, MN, where he was Co-President of the Student Council and involved in other extracurricular activities. Shawn plans to attend college to major in Psychology eventually becoming a counselor specializing in the unique needs of individuals who are dhh.

At 2 years old, Shawn was identified as hard of hearing and immediately fitted with hearing aids. He communicates by listening and speaking, relying on facial expressions, body language, and lip-reading to gain access. In small group settings he uses the Phonak Roger Pen and a Compilot. He understands communication best with Communication Access Realtime Translation (CART), which he hopes will become more prevalent through advocacy and awareness. For that matter, Shawn hopes any communication modality people chose will someday be more readily accessible.

“Being a Role Model is extremely important to me, because I longed for someone to relate to in my younger years,” said Shawn. “Even though I was and still am thankful for all the wonderful supporters in my life, a whole new world opens when meeting with someone who is dhh when you are dhh yourself.”

Shawn enjoys working with children who are dhh and their families. When he was young his role models were famous celebrities who were dhh, which is very different then someone in-person who genuinely understands your experience. A side benefit of this work is gaining a wider circle of friends who understand the importance of access, making his job and experience in the hearing world not as challenging.

“Never be afraid to ask for help,” is Shawn’s advice to children who are dhh, which personally has helped him to advocate in a variety of situations. “This is easier said than done. If you feel you need help with something, always ask, because that is the only way to improve!”

Shawn’s favorite quote in from Maya Angelou, “I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”

Read more role model biographies and find information about Lifetrack’s DHH Role Model Program at www.lifetrack-mn.org/rolemodel

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Thanks for your contribution!

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MN Hands & Voices Welcomes Suzanne Iwainat
New Central Minnesota Parent Guide

Suzanne and her husband, Josh, have two children who are deaf or hard of hearing (dhh). Their daughter, age 11, was identified as dhh at 4 months old and fitted with hearing aids shortly thereafter. Their son, age 5, was identified as dhh and wearing hearing aids by the time he was only 6 weeks old. Through genetic counseling after their daughter was identified, the couple found they both carry the gene GJB2, which means their children have a high probability of being dhh. They are both hearing and neither has a family history of deafness, so raising children who are dhh is a first for both sides of their families.

“To me MNH&V means connection, they connect with you on all levels and connect you with other families,” said Suzanne. “This is what parents need the most and that is what makes MNH&V so unique and special.”

Suzanne has been home to raise her young family for the past 11 years and, for the last 5 years, she has been on the Special Education Advisory Council for her children’s school district. Suzanne now is a full-time student at St. Cloud Technical and Community College and will be graduating in the Spring of 2018 with a Child, Adult Care and Education/Paraprofessional AAS Degree.

“I feel truly honored that I am able to take part in MNH&V as a parent guide,” Suzanne added. “I want to help families and be that support that they can count on, the same support that was given to me, I want to return that to others.”

You can reach Suzanne by email at SuzanneI@lifetrack-mn.org.

July 25th the 3rd Annual MNH&V Ice Cream Social for families living in the MNH&V regions of Upper Northwest and Northwest Minnesota was held at Gooseberry Mound Park in Moorhead, MN. Joining families to discuss the topic of Educational Advocacy and “Leaping Hurdles” was Lori Vigesa from Therapeutic Services Agency and Jeanne Kolo-Johnson from the Minnesota Department of Human Services-Deaf & Hard of Hearing Services.
2017 Minnesota Hands & Voices Metro Family Picnic Photo Highlights
3rd Annual Conference for Parents & Professionals who Serve Children who are Deaf, DeafBlind, and Hard of Hearing

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