It is recommended to parents of a child who is first identified as deaf or hard of hearing (DHH) to have genetic testing done. When MNH&V Parent Guides visit these new families the question often comes up as to why medical professionals make this recommendation. In the midst of so much to do and learn with a new baby and about raising a child who is DHH, why would genetic testing be important? We brought this question to Lisa A. Schimmenti, M.D., a geneticist in the Department of Otorhinolaryngology at the Mayo Clinic to learn more about the ins and outs of genetic testing.

“The best time for genetic testing is as early as possible. So many medical decisions for children who are DHH are made early in life, knowing the cause can be helpful for decision-making,” said Dr. Schimmenti.

Genetic testing for a child who is DHH might provide useful information about the child’s future health and educational needs. It is estimated that genetics play a role in up to 70 percent of children identified as DHH. Of those children identified as DHH due to genetics, 1/3 are associated with a group of signs or symptoms that happen together or a syndrome. Knowing why a child is DHH can help parents and providers make decisions on how to best support them. For example identifying syndromes associated with hearing loss may also indicate other medical conditions such as vision loss, thyroid disease, neurologic conditions, heart rhythm abnormalities, kidney issues, as well as other conditions. Another example a child who is identified as hard of hearing genetic testing can indicate if their hearing loss is expected to progress over time. Information about the nature of a child’s genetic condition can help the child and their family to receive the support and resources they need early on.

“For the children who are identified with a form of hearing loss that is associated with other conditions, a plan to manage that condition is established. For example, for a child with hearing loss associated with heart rhythm abnormalities, a cardiologist with observation, medication or devices can manage that child’s care. For a child who is at risk of losing vision, then discussions regarding language training would occur,” added Dr. Schimmenti.

The first step to genetic testing is to meet with a clinical geneticist and/or genetic counselor. During your first visit you will be asked questions about your child’s medical history, your pregnancy history and your family history. The geneticist will examine your child, possibly order additional tests such as obtaining a blood sample, and schedule a follow-up visit to discuss results. If a blood sample is taken it would be sent to a laboratory where the DNA is isolated and sequenced to look for over 400 genes known to cause hearing loss. Typically it takes 4-6 months for the laboratory to send results back to your provider. The clinical geneticist and/or genetic counselor will then interpret the test results and review the findings with the family at the follow up visit.

Dr. Schimmenti describes the three types of results from genetic testing:

1. Positive result: means a genetic variation was identified to explain an individual’s hearing loss.
2. Negative result: means there were no genetic reason to explain a hearing loss. This does not mean the hearing loss is not genetic, it just means a genetic cause was not identified.
3. Ambiguous result: means a genetic variation was identified, but the evidence to interpret the difference is insufficient. Sometimes the significance of variations is not apparent right away or testing other family members is needed. It’s possible over time new knowledge will emerge to make interpretation possible in the future.

“Our ability to perform genetic testing is always improving, so if someone had genetic testing in the past and it was negative or ambiguous, it is recommended to follow up with genetics as there may be new information or new testing available that can impact medical care,” added Dr. Schimmenti.
The Ins & Outs of Genetic Testing, continued from page 1

Most health insurance companies see genetic testing as the standard of care for children who are DHH, as well as, the Joint Committee on Infant Hearing, the American Academy of Pediatrics and the American College of Medical Genetics. Genetic testing is NOT experimental and has significant benefits in caring for children and adults who are DHH. Health care policies that exclude genetic testing it can be very frustrating for families and providers. The appeal process can be time consuming, but is an important way to educate health care companies and help shape future policy changes. Most health care providers will work closely with families to appeal denied health insurance coverage.

“In my practice, I send a letter to the company explaining the benefits of testing and how testing informs and changes medical management. I also send copies of papers from the Joint Committee on Infant Hearing and the American College of Medical Genetics,” said Dr. Schimmenti. “When I speak with representatives from insurance companies, they have not taken the time to learn about the benefits of genetic testing from a medical standpoint.”

Results from genetic tests are useful for some families to prepare for the medical and educational needs of their child. Genetic testing can be emotional for families because it provides information about other members of the family, and not just the child being tested. Each child receives half of his or her genes from each parent combining in such a way that is unique for the individual child. Genetics are complex and the results of testing do not always explain the mystery of why a child is DHH.

EHDI Family Leadership Award

Nominations for the Early Hearing Detection and Intervention (EHDI) Family Leadership Award will be accepted until January 20, 2017. The award will be presented on February 27, during the opening session of the 2017 National EHDI Meeting in Atlanta, Georgia.

The EHDI Family Leadership Award is to honor a parent or family member of a child who is DHH for providing exemplary leadership in their state EHDI system. The recipient will be selected by NCHAM’s Family Advisory Committee. NCHAM will cover the travel and registration costs for the Family Leadership Award recipient to attend the 2017 National EHDI Meeting.

Nominations should be 500 words or less and include a description of:

- How the nominee is involved in their state EHDI system
- What the nominee has done to improve their state EHDI system
- How the nominee is related to a child who is DHH

The selection committee will only review materials submitted in the application and will not be able to conduct their own research to determine the nominee’s background and qualifications.

Send nominations by email to Djenne Morris at dmorris@ncbegin.org. The award recipient and the nominator will receive an email notification by February 1, 2017.

Parent Guide for the Cultural Spanish-Speaking Community

MNH&V is looking for a Parent Guide to continue to serve families in our Spanish-Speaking Community. Candidates should be fluent in Spanish, from the community Latino themselves, and eager to support other parents with a child who is deaf, deafblind or hard of hearing. The program for the Spanish-Speaking Community is established, but in need of an individual to continue to provide emotional support, unbiased information, referral resources, and connect parents to other parents.

The Parent Guide for the MNH&V Spanish-Speaking Community is responsible for organizing events, sustaining, and reporting activities related to these events. This person represents MNH&V in the community and participates in family support activities. The work schedule is flexible and 10 hours a week.

For a full outline of duties and application go to: www.lifetrack-mn.org/about/careers/parent-guide-10-hours-week
Happy New Year 2017

and willing to help us out. I contacted the funeral home who followed up with her and finalized all the arrangements. What a blessing and comfort to have her there, providing interpreting for the informal conversations, doing a fantastic job interpreting the music, the readings, and being with us during military honors at Fort Snelling. I hope you all have people in your life who are as gracious and dedicated to their field. I know there are many.

So, it took me aback when the funeral director pulled me aside after the service to ask how I’d like to handle the interpreter bill. I thought we had covered that detail before. I thanked her for clarifying but said that under the Americans with Disabilities Act (ADA) the funeral home would be required to cover the cost. I also added that I worked in the field. She said, “Sure. We can do that. You have to cover all the other things during his life.” To which I said simply said “yes” but wondered if she even knew the half of it, of what families do, but also what individuals who are DHH have to endure. I let it go, but later wondered if she knew what her responsibility was but wanted to see if I’d cover the charge. I’d like to think she just wasn’t aware. But I sure want to make sure other families and adults are well informed.

And I do want to put a plug in for the upcoming Deaf/Hard of Hearing Lobby Day at the MN State Capitol on March 8th. I would like to encourage our parents to consider taking the morning off to spend some time on the hill, modeling our civic engagement to benefit our children so they are inspired to be active participants in legislative matters. “Bring Your Child to the Capitol” Day! I guarantee it would be worth it and training is provided. Here’s a link to register: http://www.surveygizmo.com/s3/3257526/Registration-for-2017-Deaf-DeafBlind-Hard-of-Hearing-Lobby-Day

Deaf, DeafBlind & Hard of Hearing Lobby Day

Wednesday, March 8, 2017

Rally from 11:00 am to 12:00 pm

The 2017 Lobby Day will be held on Wednesday, March 8, at the MN State Capitol. Lobby Day is held every other year, this year 300 people are expected to attend. Help represent the deaf, deafblind and hard of hearing community and join in the fun.

Lobby Day brings together deaf, deafblind and hard of hearing people, friends, families, allies, and legislators. This is a valuable opportunity to gather as a community and to discuss with legislators issues important to individuals who are DHH and deafblind.

Register early for Lobby Day

Throughout the day legislators will be available to meet with individuals by appointment. Training is also available for those who want help preparing for the appointments (optional). Early registration helps organizers ensure accommodations for the Rally and for appointments with legislators.

Example topics:

• Issues important to you and your family, such as communication access and equal opportunities

• Additional funding for MNCDHH

• Grants for Support Service Providers and Intervenors for children and adults who are deafblind

• More funding Deaf Mentors to help develop communication skills for families with a child who is DHH


Find more details about Lobby Day at http://mn.gov/deaf-commission/get-involved/lobby-day/
Organize Paperwork; Binders are a Wonderful Tool
By Emily Burke, MA, PsyS, and MNH&V Parent Education Guide

Do the papers and handouts you receive for your child overwhelm you? Parents with a child who is DHH can receive a mountain of paperwork for Individual Education Plans (IEP), audiologists, clinics, health insurance documents, ASL classes, cued speech classes, school activities, clubs, events, and the list goes on. Avoid losing track of important dates and keep the most current paperwork accessible when you need them—especially to review language progress, audiograms, evaluation reports, etc.

Binders are a wonderful tool
Use a binder for IEP related paperwork with dividers for IEPs, Prior Written Notices (PWN), Evaluation Reports, Progress Reports, 3-Year Evaluations, etc. Being organized for IEP meetings is very important—so it is necessary to have your most recent IEP on the top and easy to find. Use Post-it® notes to tab each IEP and evaluation with a date. Why not include a divider on progress notes, too. For example weekly or daily notes from your child’s DHH teacher/s on vocabulary and skills they practiced, progress notes from speech language specialists or other school specialists, etc. It’s a wonderful way to monitor progress and growth.

Another binder can be used just for school and extra curricular related paperwork. The annual beginning-of-the-school-year paperwork such as the emergency contact card, immunization form and sports physical forms can be included. Information on applying for financial aid and relevant tax documents if needed for your child’s school situation could be included. Make copies or at least take a photo of the completed forms you fill out annually so you don’t have to rely on your memory for essential information.

Another binder for auditory information and documents from the audiologist. Make separate dividers for audiograms, information about equipment such as cochlear implant and hearing aid companies, equipment warranties and insurance, ordering replacement equipment, etc. That way it is easier to keep track of when to upgrade cochlear implants, hearing aids, and/or peripheral equipment. Make sure to include a section for healthcare insurance claims, accepted claims, steps taken for denied coverage appeals and other correspondence. Tape business cards and contact information on the back of the binder of essential professionals.

Using binders to organize your paperwork gives you endless options and binders are portability. Keeping papers and information grouped by different topics can save time planning and preparing for meetings. Figure out a system of categories that makes sense to you and your family situation and give it a try.

Parent-to-Parent Pointers is a NEW column in the MNH&V FOCUS newsletter. The idea for this column was born when Emily Burke shared a list of tips she had been jotting down as ideas came to her from her personal and professional experiences. Her list of tips is so insightful, useful, and thoughtful, but too lengthy to fit in to one newsletter. MNH&V staff all agreed families would benefit from the strength of Emily’s tips and ask her to author the column. We hope this will inspire others to share with MNH&V their own tips as parents and care givers of a child who is DHH.

Emily Burke is uniquely qualified to share her parenting “pearls of wisdom” with our MNH&V families from the perspective of having grown up herself as DHH and now as a parent with two children, one of which is also DHH and the other is a CODA (child of a deaf adult). Her personal credentials alone are impressive, but professionally Emily has a Masters of Arts degree in Developmental Psychology with a post-masters specialist degree in School Psychology, plus she is MNH&V’s Parent Education Guide. The cherry on top for our MNH&V community is her willingness to author this helpful NEW column, Parent-to-Parent Pointers, and share with us her rich ideas and tips she has learned along the way.

Museum of Errors Interactive Story App
Gallaudet University’s latest VL2 Storybook App is inspired by a children’s book author, Gianni Rodari. Museum of Errors brings tongue twisters and language play into a story about a museum exhibiting where things go... perfectly wrong! The Museum of Errors invites readers to an interesting and imaginative world! This App, created by Silvia Palmieri, combines colorful illustration and animations that will delight all ages!


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.
**DCMP Membership for Accessible Videos**

Described and Captioned Media Program (DCMP) provides equal access through described and captioned educational media. They support and improve the academic achievement of students who are blind, visually impaired, deaf, hard of hearing, or deaf-blind.

Free membership to DCMP is offered to parents, teachers and other professionals who work with students who are DHH, blind, visually impaired and DeafBlind. There are no costs associated with any DCMP services.

DCMP makes streaming a wide variety of accessible videos at home or at school convenient. Not all YouTube videos are accessible, for this reason DCMP members can use their DCMP YouTube channel for accessible videos or a 4-minute preview when available. Full accessible videos are available at the DCMP website.

Find membership registration at dcmp.org DCMP Youtube Channel www.youtube.com/user/dcmpnad

**ASL Class Offered by Easy Signing LLC**

In this 6-unit course students will receive a full introduction to American Sign Language and Deaf Culture. Classes start Saturday, January 14, 2017 through Saturday, May 6, 2017, from 11:00 am to 12:30 pm at Boneshaker Books, 2002 23rd Avenue South, Minneapolis, MN.

Topics evolve around sharing information. Unit 1: Introducing Oneself Unit 2: Exchanging Personal Information Unit 3: Talking about Where You Live Unit 4: Talking about family Unit 5: Talking about everyday activities Unit 6: Storytelling

Find registration information online at http://www.easysigningmn.com/classes-conferences–events.html

**“What the World Gains from Optimism”**

**A Communication Contest for Students who are DHH**

St Cloud Morning Optimist Club is sponsoring a speech contest for students who are DHH. Any student through grade 12 who is DHH can give a 4 to 5 minute speech on the topic, “What the World Gains from Optimism,” in English or American Sign Language (interpreter will be provided). First place winner of the local contest, held in St. Cloud in mid March, will go on to the district competition. Registration for the district contest is by April 15, 2017. The district contest will be April 28-29, 2017. First place winner of the district contest will receive a $2500 scholarship.

Students wishing to participate can receive more information by contacting Ginny Bisek, District Contest Chair, at 320-253-1462 or 320-260-5996 or email at gbisek@charter.net.

**PAHrtners Deaf Services Residential Treatment Facility**

PAHrtners Deaf Services is an out of state residential treatment facility in Philadelphia. PAHrtners Deaf Services is for adolescents who are DHH with emotional, behavioral, developmental and/or psychiatric challenges that make living in their home impossible.

The residential treatment facility is staffed 24-hours a day, seven days a week. All staff are Deaf offering life skills training and community integration. Psychiatric treatment, therapy, and case management are also provided.

For more information email Elena L. Moore at emoore@pahrtners. Call at 215-884-9770 or 267-415-1772 VP www.PAHrtners.com

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**Forest Lake Area DHH Students**

Thank you to the Forest Lake Area students who are DHH for being positive role models by giving back to the community by making Welcome Blankets for our newest MNH&V families.

**Accessible World Travel, Far or Near By, With Wilderness Inquiry!**

All Wilderness Inquiry trips are inclusive and encourage individuals and families from all abilities, backgrounds, and ages to take an adventure. Wilderness Inquiry also works with specific groups, for example last year students from Metro Deaf School volunteered weekly with Wilderness Inquiry. Also, Wilderness Inquiry canoed with groups from Bemidji, Mankato, and the Minnesota State Academies for students who are deaf, deafblind, blind, and hard of hearing.

Find more at www.wildernessinquiry.org.
It’s Time to Think About Kindergarten!

The Minnesota Department of Education recently approved a new public charter school for children entering Kindergarten in September 2017. The Minnesota Academy of Hearing, Speech and Language (MAHSL) will open its doors to all age-eligible children (student must be 5 years old by September 1) with a Kindergarten class in 2017 and expand one grade level per year, up to third grade.

The mission of the MAHSL is to teach students the academic, language and literacy skills to enable them to fully participate in academic and civic life. The program will feature small classroom sizes, a focus on language and literacy, and will encourage a culture of parent and community engagement.

As with all public charter schools, tuition is free, enrollment is open to all students and transportation is provided. MAHSL will be located in Roseville, MN. Enrollment applications for fall of 2017 are due by January 15, 2017 in order to be entered into the February 15 lottery for admissions. For more information or to register for an upcoming Information Session call Erin at 651-633-0913.

Hearing Outcome of Infants Identified as HH & Born with Cytomegalovirus

Congenital cytomegalovirus (cCMV) is the most common non-genetic cause of childhood sensorineural hearing loss. In this study antiviral treatment has proven effective in preventing hearing deterioration in infants identified as hard of hearing (HH) due to cCMV. However, this study focused on infants born HH and on their specific level of hearing after a year, further improvement or deterioration beyond are not included in this study.

The objective of this study was to investigate whether children born HH due to cCMV had any change in hearing after receiving 12 months of antiviral treatment. Data was gathered from all infants with cCMV between 2005 and 2013. Hearing studies were performed only on infants identified as HH and at their followed up 1 year after treatment.

Results from the study showed that infants diagnosed with cCMV 54 (36.2%) and bilateral in 23 (42.6%). After 1 year of antiviral treatment of the 77 affected ears; unilateral in 31 (57.4%) and bilateral in 23 (42.6%). After 1 year of antiviral treatment of the 77 affected ears, 50 (64.9%) had improved, 22 (28.6%) remained unchanged and 5 (6.5%) had deteriorated. Most improved ears (38/50=76%) returned to typical hearing. Improvement was most likely to occur in infants born with mild or moderate hearing loss.

Authors found infants born HH due to cCMV, receiving 12 months of antiviral treatment had significant improvement in hearing. The probability of an improvement was inversely related to the child’s level of hearing at birth.


The Mayo Clinic and Students, Anna Krauss and Jes Pinkney

Mayo Clinic is committed to supporting a diverse and inclusive workforce. The Summer Undergraduate Research Fellowship (SURF) program within the Mayo Graduate School is 10-weeks where students are immersed in research and participate in real-world projects alongside top researchers in state-of-the-art labs. The program draws 130 of the top students in the country each year to Mayo Clinic.

Mayo Clinic, Department of Otorhinolaryngology, last summer worked with students, Anna Krauss and Jes Pinkney. They are the first students who are DHH to participate in the SURF program.

Jes Pinkney began losing her hearing in 2014. She went to Brown University planning to study international relations. This plan changed to neuroscience when she became fascinated reading the research on the subject. Pinkney spent last summer working on spinal cord regeneration in zebrafish.

Anna Krauss became deaf at the age of nine. Now a senior at the Rochester Institute of Technology in New York, she is studying biotechnology and molecular bioscience. Krauss spent last summer characterizing zebrafish models of human deafness at Mayo Clinic.

In the future Jes Pinkney hopes to pursue an M.D. and Ph.D. in neurosurgery. She wants to continue research, while having both the scientific and physician perspectives.

Anna Krauss eventually hopes to become a science professor for students who are DHH. She says her experience in the SURF program have reshaped her future and pushed her to excel.

“The here at Mayo, I got the right interpreters that were the right fit for me,” said Krauss. “When I get all the information. I pick things up so quickly and I start coming up with my own ideas. There aren’t challenges when I have full access to information.”

Full article http://discoverysedge.mayo.edu/2016/08/30/accommodating-the-brightest-minds/
The listening bubble of a person depends on their level of hearing and environmental sounds. Individuals with typical hearing can hear beyond 3 feet, but to perceive the sounds of speech like s, f, t, p (as in cat, cap, calf) the listening bubble is generally within 3 feet. The listening bubble for children who are DHH using cochlear implants or hearing aids is diminished by the limitations of their hearing equipment and background noise. Amplification equipment, such as FM systems and loops, are useful for students who are DHH when properly used. In a typical classroom setting children who are DHH often do not have full access to class communication, especially class discussions, ultimately impacting educational performance.

Students who are DHH must work harder to listen and process information they receive in the classroom. How language skills are used to ‘fill in the blanks’, their motivation and interest to understand, and the level of fatigue from extended listening can all contribute to how a student comprehends what was said.

**‘Soft Speech’ versus ‘Teacher Speech’**

Audibility refers to how much sound, especially speech sounds, can be heard. Examples of soft speech include comments from peers spoken 6 or more feet away (class discussion) and conversations during social situations. Group learning when competing conversations are occurring also reduces audibility significantly. A student with hearing levels in the range of 25-30 dB will experience 81% audibility of the teacher’s voice and only 25% audibility of soft speech. This hearing level is not uncommon for children wearing hearing aids.

Decreased audibility is different from child to child based on their hearing and how well their hearing aids fit. In general, a child who is DHH can have problems accessing higher pitched consonant sounds (s, f, th, p, k, t, etc.) and brief words and word endings are easily missed, unless speech is presented within the child’s listening bubble. The missed sounds of speech create ‘peaks and valleys’ that cause islands of hearing.


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### The Starkey Hearing Foundation

MNH&V, Deaf Mentor Family Program, and Adult Role Model Program want to thank Starkey Hearing Foundation for their generous donation of 325 Build-A-Bear teddy bears to help us welcome new families to our community.

### SignIt ASL, FREE Sample Lessons

Try SignIt ASL, Unit 1, 9 selected chapters. Learn American Sign Language (ASL) vocabulary, sentences, and fingerspelling. Test your knowledge with quizzes and use the ASL Dictionary to learn new signs. Additional segments available ONLY in purchased SignIt Units:

- Lesson Intro Video (What is ASL gloss?)
- Vocabulary Video + Quiz
- Fingerspelling Video + Quiz
- Sentences Video + Quiz
- Moving On Video
- ASL Interview Video
- ASL Dictionary (see top menu)

Learn more at [https://go.platformpurple.com/?e=signitasl](https://go.platformpurple.com/?e=signitasl)
Family Event

MNH&V Annual Metro Roller Skating Family Event  

Date: Sunday, January 29, 2017
Time: 5:00 to 7:00 pm
Where: Roller Garden, 5622 W. Lake Street, St. Louis Park

FREE!
Plus, receive a coupon for a free hotdog, bag of chips & a pop!

The Roller Garden will be closed to the general public so this is a great way to test your skating skills, socialize, and meet new friends!

For more information visit our website at www.mnhandsandvoices.org