

Minnesota Connection to Legendary Audiologist Marion Downs

Marion Downs, regarded as the "Mother of Pediatric Audiology", passed away on November 13, 2014 at the age of 100. Marion devoted her professional life to promoting the benefits of early identification of newborns who are deaf or hard of hearing (DHH). Downs pioneered the first infant hearing screening program in the United States in the early 1960s. Today the universal newborn hearing screening program is responsible for checking the hearing of some 4 million newborns in the US each year.

Marion Pfaender, born January 26, 1914, grew up in New Ulm, Minnesota. In 1935, she attended the University of Minnesota (UMN) until her junior year. She then married George Downs the couple moved to Colorado and had three children. As her children enter their school years she found time to finish correspondence courses graduating from the University of Minnesota in 1948 with a major in political science and English. Years later Downs would receive an Outstanding Achievement Award from the UMN.

Marion Downs enrolled in graduate school at the University of Denver (DU) and received a master's degree in audiology in 1951. Marion said she loved her career as an audiologist, but choosing audiology was serendipity. In a 2003 interview with audiologist Douglas Beck, Marion told the story, "It was right after the war and GI's were lined up for a mile in every department. So I looked around and chose the shortest line. That was Speech and Hearing!"

Marion Downs career begins at DU, teaching audiology and directing the audiology clinic until 1959. Then she worked as an audiologist in the ENT clinic at the University of Colorado School of Medicine. It was there that Marion and Doreen Pollack, pathologist and audiologist, initiated the practice of fitting hearing aids on infants as young as six months old. Downs saw a direct relationship between early amplification and improved language development in infants who are DHH.

In 1962, Downs developed a way to test the hearing in newborns and published the report in 1964. In 1995 her research on the need for early hearing screening and intervention was validated by Dr. Christine Yoshinaga-Itano, researcher, audiologist, DHH teacher, and Hands & Voices board member. Soon hearing screening was accepted and adopted in all 50 states. Downs continued to work at the ENT clinic until retiring in 1982. "Being an extremist, I said very young means at birth, and that seems to have stood the test of time," Marion told Douglas Beck.

Throughout her career Marion Downs faced opposition to newborn hearing screening. Most pediatricians and otolaryngologists in those early years did not accept newborn hearing screening. "Marion's career started at a time when her male colleagues didn't believe a baby's hearing could be tested at birth. She was a pioneer," said Dr. Yoshinaga-Itano.

Marion Downs persevered to form the National Joint Committee on Infant Screening, which is responsible for promoting the methodologies of screening and follow-up that are still used today.

Dr. Yoshinaga-Itano adds, "When I came into the profession forty years ago, I met adults that Marion had identified back before the technology we have today. They were going off to become doctors and lawyers because they were early identified. Now I'm identifying their children."

Find Douglas Beck's 2003 interview at: audiologyonline.com/interviews/interview-with-mariondowns-audiologist-1666



Marion Downs

Understanding Families' Needs for Mentors & Role Models

Lifetrack recently contracted Wilder Research to conduct a needs assessment for families with young children (ages 0-6) who are DHH. The goal of the project is to make recommendations to expand the mentor/role model services and programs available to all families with young children who are DHH in Minnesota. Wilder will be conducting focus groups and interviews with adults who are DHH as well as parents of children who are DHH.

Parents:

Please complete this short web survey by March 27 to tell us about your needs and to sign up for a focus group or interview at http://wilderresearch.org/go/lifetrack2015

Adults who are DHH:

If you are interested in participating in an interview or focus group about mentor/ role model programs and services, please contact Sera Kinoglu at sera.kinoglu@ wilder.org or 651-280-2735 (voice).

Deaf Awareness Day

Hosted by Minnesota Association of the Deaf Citizens (MADC) on Saturday, April 25 from 9:00 am to 5:00 pm. Located at White Bear Lake High School, South Campus, 3551 McKnight Rd in White Bear Lake, MN.

Fun for families with supervised children activities, concessions, product demonstrations, coffee chat, and over 40 vendors. Meet people from diverse fields such as education, human services, arts, government, business, health care, religion, interpreting services, and more!

For more information or to sign up for exhibit space contact: DAD@minndeaf.org or online at: http://www.minndeaf. org/2015/01/10/deaf-awareness-day/

MNH&V EMPLOYMENT OPPORTUNITY

MNH&V is looking for a Parent Guide for SE Asian Communities. Candidates should be fluent in both English and Hmong languages and be eager to support other parents like themselves with a child who is deaf or hard of hearing.

Hours are flexible, 10 hours a week, based out of our St. Paul location.

Provide emotional support, unbiased information, and referral resources to families with children who are deaf, deafblind or hard of hearing throughout Minnesota. Connect parents to other parents and to local community resources. Plan and implement family support activities. Represent MNH&V in the community. Responsible for developing specific programming for the cultural community, investigating, and reporting activities related to these activities.

Come join a dedicated team of parents who share your commitment to providing a full range of opportunities to families so our children reach their potential.

For more information: www.lifetrack-mn.org/about/careers

Email resume: HR@lifetrack-mn.org Apply online: www.lifetrack-mn.org/about/careers

CSAM Annual Meeting

Join Cued Speech Association of Minnesota (CSAM) for their Annual Meeting on March 7, 2015, from 10:00 a.m. to noon.

Edina Library conference room 5280 Grandview Square Edina, MN 55436

Everyone is invited to attend the Annual Meeting to find out more about the CSAM organization, sign up for volunteer opportunities, and to learn about cued speech.

Be a part of the CSAM community!

There are open positions on the board and as board member-at-large, in addition to the positions of CSAM President and co-President. You can improve your own cueing skills while you help support the people of Minnesota who desire to learn more about cued speech and work on developing their skills, too.

If you are interested in the open positions please ask questions or requests for more information by sending an email to: info@cuedspeechminnesota.org.



Noah, one of our newest welcome blanket recipients.

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In Your Corner

Parenting our wonderful (and sometimes complicated) children who are deaf and hard of hearing is no small undertaking. Raising children, whose development is not typical and whose communication is not in common with the majority, is the hardest, most rewarding work we will ever do. Add the need to constantly advocate; explain; mediate; and perhaps educate oneself and learn an entirely new language in the process; the task can be overwhelming.

With time and a community of supporters, this job can become familiar and yes, easier. As the mother of a now young adult, I have found this to be true. Passing much of the responsibility of self-advocacy to my son has been a great relief and a time saver! But my inner control freak roars at times, wishing he would take the better, more logical, and proactive path.

To give you an example, my son has a lot to advocate for as a college freshman. He needs to sign up and pay for classes that fit his schedule and major, order the right books, let disability services know what accommodations he requires, and arrange for transportation to class, as he doesn't drive. Once at class, he needs to talk to his interpreter about his needs, explain his FM technology and need for access to written information to the instructor, jockey for good seating in the class to fit his (once amplified) unilateral hearing, and consistently advocate for his needs as the environment changes. Seems simple enough but it is a bit impressive when you pick it apart. I honestly wonder how I would have done in the same circumstances at the same age.

So, this works well when the planets align and all the pieces of this puzzle come together. But then a piece falls on the floor, then another, then another. What my son has gained in advocacy, he has yet to develop in troubleshooting. For example, on the first day of the new semester; the transportation arrives, the instructor is on board, but interpreter does not show. Desperate text number one. Day two, the transportation arrives, interpreter shows, but the professor does not. Desperate text number two. Day three, the transportation does not show. Desperate text number three. Week two. a different combination. Week three, yet another. Sigh. Can mama catch a break here? More importantly, can my son get reassurance that advocacy works??

Remember, for many of our children, we have built beautiful support scaffolding around our children in special education. And I am grateful for all the help from teachers, educational interpreters, transliterators, etc. But when our children are out there in the world, on their own, that scaffolding needs to come down. And as much as I hurry to jump in and fix things, I have had to let the consequences happen. Simply, he needs to screw up. And I have to watch. And it is painful.

And I have periodically confronted the well-intended kindness of friends and family. While exploring his independence one summer, my son took public transportation to and from work. It took twice as long, but it was part of the grand plan called "transition." Well, on more than one occasion, Luke very happily accepted rides home from neighbors who saw him waiting at the bus stop. Any smart kid would, right? To the point, I had to ask these sweet friends to stop. Sometimes the scaffolding is not something you have even constructed.

So, I say to parents early in their journey, there is hope. Your children will be launched into the world, and your hard work and that of the cavalry of professionals who walked with you along this path will have paid off. If I have any words of wisdom to share today, it is this. Build your scaffolding carefully. Only erect structures that your child truly needs. And then, take each piece away. From that place, you will see the most amazing, satisfying, emotionally stirring creation your eyes have ever seen. The bumps in the road (even the huge ugly ones) are there for a reason. "Failures, repeated failures, are finger posts on the road to achievement. One fails forward towards success." — C.S. Lewis

And remember, there are many of us here to guide and cheer you on.

Children's Theatre Company invites MNH&V's families to an ASL interpreted performance of Huck Finn on March 27th at 7:00 p.m. Discount tickets are \$5.00 per ticket.

RSVP Now! Availability is Limited! To request tickets call 866-261-0857 (toll free) or email mnhv@lifetrack-mn.org.

Accessible tickets are made possible thanks to a community partnership between Children's Theatre Company and MN Hands & Voices.



Record Busting 2015 MNH&V Family Roller Skating Event: 307 Participants!



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Save the Date MADC 61st Biennial Conference

Minnesota Association of the Deaf Citizens (MADC) invites anyone who is interested to attend their 61st Biennial Conference! The theme this year is, *Expect. Employ. Empower*, which acknowledges the importance of our surrounding communities and their supporters.

The MADC 61st Biennial Conference is a two day event, October 16 and 17 from 8:00 am to 5:00 pm, located at Calvary Community Church in St. Cloud, MN. The conference is an opportunity to network, determine advocacy needs, host an award luncheon, and hold business meetings.

For more information https://madcconference.wordpress.com

For questions contact Sherri Rademacher by email at srademacher@minndeaf.org or Linda Fairbanks by email at lfairbanks@minndeaf.org I am Jean Volkmuth from Faribault, MN. I am really excited to be the new MNH&V Parent Guide for the SouthEast Region. My husband and I have five very busy children. My oldest daughter, Clare, has recently been identified as hard of hearing. We are new to the DHH community but have found so many wonderful people to help us through this new adventure. My family enjoys outdoor activities both in winter and summer, reading and spending time together. I come ready to service families with my years of experience in counseling and Life-Coaching in crisis situations. I have worked with families who have diverse cultural backgrounds and I look forward to getting to know all the families in my area.

MN Resource Libraries

Minnesota Resource Libraries is a statewide resource for all children who are DHH, visually impaired or deaf/blind, and their families and educational service providers. The MN Resource Libraries are located on the campus of the Minnesota State Academy for the Deaf in Faribault, MN.

Books and DVD's are available for loan to the general public. Find a catalog for the MN Resource Library online at: mn-state-academy.follettdestiny.com/ cataloging/servletpresentadvancedsearch redirectorform.do?l2m=Library%20 Search&tm=TopLevelCatalog



Grace, one of our newest welcome blanket recipients.

MNH&V 4th Quarter Report Well Received

An increase in MNH&V regional and culturally specific Parent Guides has had a positive impact on our community. Parents with newborns who are newly identified as DHH receive much needed support sooner. In 2014, 4th quarter alone, 55 families were in contact with a Parent Guide and most of them within one month of their child being identified as DHH. Stories and comments from MNH&V families and Parent Guides included in the MNH&V 4th quarter report made the success rate real and heart-warming.

Nicole Brown, EHDI Coordinator at MN Department of Health, in an email wrote, "While the numbers and statistics are impressive, I get goose bumps reading the stories and comments. In particular, I'm so impressed with the work of the cultural guides and how thankful parents are to have information in their native language. It's also obvious how impactful some of the home visits can be (and so fantastic how many parents are taking you up on your offer!). The story about how the IFSP goals were rewritten after talking it over with the parent quide is fabulous. Being able to bounce something off someone who completely understands is all it takes to question when something doesn't feel right."

Nicole Brown's comment highlights how important it is for parents to have a person to talk to who is knowledgeable, unbiased, and also a parent of a child who is DHH. MNH&V staff credit changes made in the overall system of reporting, faster referrals from MDH's Early Hearing Detection & Intervention program, and improved processes within MNH&V. These changes were necessary to improve a statewide goal to have families contacted by a Parent Guide within the first month their child is identified as DHH. Helping families make informed decisions and find the services they need are priorities for all involved in the MN EHDI system.

Once Upon a Sign Book Series

The first three stories from Once Upon a Sign performed by an all deaf cast in American Sign Language (ASL)! Includes English voice over and subtitles, accessible to all family, friends, and classmates.

Use "Fun Signs" to sign along with the characters and a recap of important signs used in each story. You don't need to know ASL to enjoy these timeless stories, but you will learn some signs along the way!

Once Upon a Sign is a series of classic children's stories re-created with modern themes. Delight all over again in timeless stories with new twists.

Now available! Little Red Riding Hood, Goldilocks and the Three Bears, and The Magic Mirror

Coming soon! Jack and the Beanstalk (spring 2015), The Stone Soup (fall 2015), Three Little Pigs (fall 2015)

For more information visit www.dawnsignkids.com



Cued English Opportunities

Early May 2015 the National Cued Speech Association (NCSA) will offer classes at the Commons Hotel near the U of M, Twin Cities campus.

FREE Introduction to Cued English May 1 and 2 from 8:30 am to 4:30 pm

The NCSA Deaf Children's Literacy Project invites you to discover how children who are DHH can learn the building blocks of English phonemes and lifelong English literacy through Cued English.

InsCert Basic Instructor Workshop (BIWS)

May 1 and 2 from 8:30 am to 4:30 pm BIWS Cost: \$150

BIWS Certification Exam May 3 from 9:00 am to noon

Cost: \$150

Tools, Techniques, and TLC for Teaching Cued Speech May 2 from 1:30 pm to 4:30 pm Cost: \$60

Educational Interpreting Defined and Skills I by Language Matters, Inc. May 1 and 2 from 9:00 am to 4:00 pm Cost: \$150

TECUnit, Inc. Cued Language Transliterator National Certification Exam

May 2, individual test times and locations will be made available to those who have registered after the April 1, 2015 registration deadline. Cost: \$375

Cues On Tap, Evening Social Event

Come meet the NCSA board members and socialize with fellow cuers. Saturday evening on May 2, 2015 Location: To be announced.

RID CEUs pending approval. A minimum of 10 participants required to run course.

For more information go to: http://www.cuedspeech.org/index.php



Another thankful welcome blanket recipient.

California H&V DHH Family Camp

The 16th Annual California Hands & Voices DHH Family Camp will take place over Memorial Day weekend on May 22 to 24, 2015 at Camp Marston in Julian, California. Registration will close on April 15th or once we are full.

Family camp is open to families raising a child who is DHH. Typically around 125 people attend from all over the US!

Please feel free to contact us at info@cahandsandvoices.org

For complete details http:// cahandsandvoices.org/index.php/ events/23-cahv-events-all-regions/41-2015dhh-family-camp

Rollerskating Fun!

"Thank you all so much for having the skating party tonight! It's so wonderful for our little one to see and be with other

kiddos who are also DHH. Plus, she and her big sister LOVE rollerskating! Thank you for a memorable time!" Maria, Steve, Annalise, and Evie (our DHH daughter)



2015 Summer Camps

Spring Camp Cheerio May 15-17, Family Camp Roaring Gap, NC cuedspeech.org/cue-camps

CA H&V DHH Family Camp

May 22-24, Family Camp Marston, Julian, CA cahandsandvoices.org

Aspen Camp

May 29-June 1, family + KODA (deaf parents, hearing children) June 2-8, KODA ages 8-12 June 9-18, KODA ages 13-17 June 16-29, ages 13-17 July 7-20, ages 10-15 July 21-Aug 3, ages 8-12 Aug 6-10, family (hearing parents, deaf children) Snowmass, CO aspencamp.org/

Camp Sertoma

June 6-10, gr 2-8 East Gull Lake, MN campsertoma.com

AHIHA Hockey Camp

June 6-13, DHH players Woodridge, Illinois ahiha.org

Camp D.O.V.E. (Deaf Outreach through Visual Effects)

June 14-19, ages 8-18 Athens, GA campdove.org/index.html

Summer Camp

June 14-19, ages 12-17 June 21-24, ages 6-11 Sulphur OK osd.k12.ok.us/dhac/

CNI Cochlear Kids Camp

June 18-21, age 3-18 July 30-Aug 2, age 3-18 Estes Park, CO thecni.org/features/by-condition -2/hearing-disorders/cochlearkids-camp/

Runnin' Bison Fundamental Basketball Camp

June 21-25, gr 6+ Fremont, CA June 26-July 2, gr 6+ Frederick, MD msdathletics.org/summercamps/

Literacy Camp

June 21-26, ages 12-18 Annandale, MN truefriends.org/camp/

William W. Summer Camps June 21-27, ages 6-16

Spartanburg, SC scsdb.org/site/default. aspx?PageID=1

Cue Camp New England June 24-28, Family Camp Lyman, MA

cuedspeech.org/cue-camps

Deaf Teen Leadership Camp June 27-July 2, gr 9-12 Cispus Learning, Randle, WA wsad.org/dtl

Listening & Spoken

Language Camp June 28-July 3, ages 8-18 Martinsville, IN hearindiana.org/index.php?/ Camp

Children's Deaf Camp

June 28-July 3, ages 4-16 Camp Alexander Mack Milford, IN indeafcamps.org

Kentucky Lions Youth Camp

June 28–July 3, ages 6-15 Lions Camp Crescendo Lebanon Junction, KY lccky.org/index.htm

Camp Isola Bella

June 28-July 11, ages 8-12 July 19-Aug 1, ages 13-17 Salisbury, CT asd-1817.org/page.cfm?p=478

Wisconsin Lions Camp

July 5-10, ages 6-17 July 12-17, ages 6-17 Rosholt, WI wisconsinlionscamp.com

Girls Volleyball

Fundamental Camp July 6-10, girls ages 10-18 Pittsburgh, PA gallaudetathletics.com/camps/ index

Immerse into ASL! July 9-17, gr 9-11 Gallaudet University, WA gallaudet.edu

Discover Your Future July 9-17, gr 9-11 Gallaudet University, WA gallaudet.edu

Explore Your Future

July 11-16 & 18-23, gr 12 NTI for the Deaf, Rochester, NY ntid.rit.edu/camps/eyf

Sertoma of St. Joseph July 12-17, ages 7-14 Camp Marvin Hillyard Easton, MO sertomadeafcamp.org

Camp Teresita Pines July 12-18, ages 7-15 Lions Wilderness Camp, CA lionswildcamp.org/schedule/

MSAD Summer Program July 12-24, gr K-7, 8-12 MSAD, Faribault, MN msad.state.mn.us

TechGirlz & TechBoyz July 25-30, gr 7-9 NTI for the Deaf, Rochester, NY ntid.rit.edu/outreach

Health Care Careers Exploration Camp

July 26-31, gr 10-12 Rochester, NY ntid.rit.edu/camps/healthcareers/

Camp Taloali

July 26-Aug 1, Aug 2-8, Aug 16-22, ages 6-18 Stayton, OR taloali.org

Camp Pacifica July 26-Aug 1, ages 7-15

Aug 2-8, ages 7-15 CA Lions Camp, Ahwahnee, CA camppacifica.org

Deaf Film Camp

July 26-Aug 7, ages 13-16 Camp Mark 7, Old Forge, NY campmark7.org

Camp HERO at Camp Victory

Aug 2-7, <mark>ages 6-17</mark> Bloomsb<mark>urg, PA</mark> campher<mark>odeafhh.org</mark>

EX.I.T.E. Camp

July 30, Aug 3, 5, 7, 11, 13, girls gr 6-9 PACER Center, Bloomington, MN pacer.org/stc/exite/Camp.asp

Camp Ross Relles

Aug 2-8, ages 7-15 Aug 29-31, family Lions Wilderness Camp, CA lionswildcamp.org/schedule/

Deaf Children Camp

Aug 9-21, ages 8-12 Camp Mark 7, Old Forge, NY campmark7.org Lifetrack 709 University Ave. W. St. Paul, MN 55104-4804



supporting families with children who are deaf and hard of hearing

Minnesota Hands & Voices is a program of Lifetrack

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Twitter https://twitter.com/MNHandV



Sign up for our weekly mass emails http://www.mnhandsandvoices.org/ news-events/newsletter-signup.aspx The Commission for Deaf, DeafBlind and Hard of Hearing Minnesotans presents

2015 Collaborative Experience A Symposium 🝻 Professionals & Parents



Professionals • April 16-18 **Parents** • April 17-19

Location: Breezy Point Resort 9252 Breezy Point Drive, Breezy Point, MN 56472

Scholarships for parents may be available, ask your MNH&V Parent Guide for information. Symposium sessions accepted for RID CEUs.

For more information visit www.mncdhh.org/symposium/ Registration is Now Open! www.metroecsu.org/registration