

Newborn Hearing Screening: One Family's Story

By Emily Rezmerski

Olivia was born Dec. 20, 2001, at Immanuel St. Joseph's Hospital in Mankato. On our second night in the hospital, a nurse came in and asked to take Olivia for some routine tests. My husband and I paid no attention to what the tests were since everything appeared to be normal.

Everything seemed fine until we were ready to be discharged from the hospital. Our doctor explained that there may be a problem with Olivia's hearing because her newborn hearing screening came back as "Refer." He also explained that this was probably nothing serious—she could have a slight loss, a frequency loss, or it may just be fluid blocking her hearing. He gave us some information about hearing loss, and we were discharged.



Olivia Rezmerski, 4, poses with her parents, Emily and P.J.

A couple of weeks later, we returned to the hospital, and a nurse performed another hearing screening. This time we were allowed to watch. The results were the same as before. Both ears came back "Refer."

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Newborn hearing screening costs about \$30 per child and takes about 9 minutes to do. Costs are much higher if a hearing loss is not diagnosed until later in life.

— National Center on Birth Defects and Developmental Disabilities

Family Support Connection teams with state agencies to expand services for newborns with hearing loss

The Family Support Connection is teaming up with state agencies that are bringing together local, regional, state and national resources to help families with babies who are identified through newborn hearing screening as having a hearing loss.

Hearing loss is the most frequently occurring birth defect in the US. About one in every 350 babies is born with a hearing loss. Left undetected, hearing loss makes it difficult, if not impossible, for a baby to acquire fundamental language, social, and thinking skills. However, research has shown that when babies who are deaf or hard of hearing get access to language by the age of 6 months, they can achieve age-appropriate language skills by the time they enter kindergarten.

Because of this, the National Institutes of Health's Consensus Development Conference on Early Identification of Hearing Loss that was held in 1993 recommended that infants all across the nation should be screened for hearing loss, preferably prior to hospital discharge. The term for this is Universal Newborn Hearing Screening (UNHS). When this recommendation was made, only 11 hospitals in the country routinely screened newborns. Also before UNHS, the Commission on Education of the Deaf estimated the average age that children with congenital hearing loss were identified was 2½ to 3 years of age, with many children not being identified until age 5 or 6.

Since then, newborn hearing screening has become standard in most

states. Currently 37 states (plus the District of Columbia and Puerto Rico) have statutes related to universal newborn hearing screening. Although Minnesota is not one of those states, all 111 birthing hospitals *voluntarily* screen infants for hearing loss, and many of them screen newborns before discharging them from the hospital. With about 70,000 babies born in Minnesota every year, about 200 may be deaf or hard of hearing.

"Early diagnosis and timely medical and educational interventions can prevent or reduce the delays in speech, language, socialization, and academic development that typically accompany hearing loss when it is identified in older children," said Nicole Brown, Coordinator of the UNHS Program at the Minnesota Department of Health. Intervention may include hearing aids or cochlear implants, and/or teaching the family and baby visual communication skills such as sign language or Cued Speech.

The state has a "1-3-6" goal for its Early Hearing Detection and Intervention (EHDI) program. That means that all newborns in the state should be screened for hearing loss by 1 month of age, and, if they have a loss, be evaluated by an audiologist by 3 months of age and enrolled in an Early Intervention Program by 6 months of age.

To ensure this, agencies including the Minnesota Department of Health, joined together to create the state's EHDI Network. The Network has 16

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What's Happening Around Town

- Friday, Feb. 10** **The ASL-Interpreted Family Concert Series** begins with Ross Sutter & Friends Scandinavian Music at 7:30 p.m. at St. Matthew's Episcopal Church, 2136 Carter Ave. in St. Paul. Tickets in Advance: \$5; at Door: \$6. TICKETS: 651-645-5699.
- Saturdays, Feb. 18 & Mar. 11** **Minnesota North Star Academy hosts Deaf/Hard of Hearing Teen Night** for kids ages 12- 18. The night includes open gym, games and movies from 6 to 11 p.m. at Gustavus Adolphus Lutheran Church, 1669 N. Arcade St. in St. Paul (use the south entrance with green doors). Cost is \$2.
- Tuesday, Feb. 11** **"Cue Clutch"** meets at Java Jacks, 46th & Bryant in Minneapolis from 6:30 to 8 p.m. for anyone who wants cueing practice. For more information, contact Katherine Burns-Christenson at 952-929-3965 or e-mail kbc29@aol.com.
- Tuesday, Feb. 11** **A Deaf Culture Salon** runs from 7 to 9 p.m. at St. Paul College Auditorium, featuring Trudy Suggs of Community Emergency Preparedness Information Network (CEPIN), a project funded by the Department of Homeland Security that focuses on emergency preparedness for deaf, hard of hearing and deafblind communities. Registration starts at 6:30 p.m. Cost is \$5. American Sign Language (ASL) is the official language of Deaf Culture salons. For more information, contact Mike Cashman at mcashman@c-s-d.org.
- Thursday, Feb. 23- Friday, Feb. 24** **"Cabin Fever Getaway"** for families who live in the state's upper northwest region takes place at Seven Clans Water Park and Casino in Thief River Falls. For registration information, contact Karen Dvergsten, 218-874-8215.
- Saturday, Feb. 25** **"Bullying and the Child who is Deaf or Hard of Hearing" is the topic for a free workshop** presented by PACER in coordination with the Family Support Connection. See Page 6 for details. PACER also will have a workshop on "Communication and Partnership" March 14 from 7 to 9 p.m. at Metro Deaf School. To register, call 651-2224-3995 (v), 651-222-0984 (tty) or e-mail contact.us@metrodeafschoo.org.
- Tuesday, Feb. 28** **"Taking the Maze out of Funding"** offers information on medical funding sources and other resources available to families with children who have special needs. This free workshop runs from 8:15 a.m. to noon at the Minnesota Department of Health, Snelling Office Park, 1645 Energy Park Drive, St. Paul. To register, go to www.health.state.mn.us/mcshn or call 651-215-8956 or 800-728-5420.
- Saturday, March 4** **The St. Paul Public Library presents Deaf Storytime** at 10:30 a.m. at the Merriam Park Branch Library, 1831 Marshall Ave. For details, call 651-642-0385 (v) or 651-298-4184 (tty).
- Sunday, March 5** **The tour "Ruth Duckworth, Modernist Sculptor"** at The Minneapolis Institute of Arts is ASL-interpreted beginning at 2 p.m. at the round bench in the museum lobby. For more information, call Visitor and Member Services at 612-870-3131 (v) or 612-870-3132 (tty).
- Sunday, March 5** The 2 p.m. performance of **"Pure as the Driven Snow; or A Working Girl's Secret"** by the Bloomington Art Center Theater Company is ASL-interpreted. Tickets: \$12 adults, \$10 seniors/students. Reservations: 952- 563-8587. Bloomington Center for the Arts, 1800 W Old Shakopee Road.



ASL-Interpreted Performances

Fiddler on the Roof

Friday-Saturday, Feb. 17-18, 7:30 p.m.
\$12, \$10 students/seniors, \$14 box seats,
Lyric Arts, 420 E. Main St., Anoka;
763-422-1838; www.lyricarts.org.

Beauty and the Beast

Sunday, Feb. 26, 2 p.m.
\$10; \$8 ages 12 and under
Rochester Civic Theatre, 507-282-8481,
www.rochestercivictheatre.org

Pinocchio

Friday, March 3, 7 p.m.
Sunday, March 5, 2 p.m.
Reduced to \$16, students/seniors \$14,
children 4-12 \$11; Reserve by Feb. 24;
Phipps Center for the Arts, Hudson, Wis.;
715-386-2305; www.thehippys.org

Prom

Wednesday, March 8, 10:30 a.m.
Friday, March 10, 8 p.m.
Reduced tickets: 612-874-0400
Children's Theatre Co., 2400 3rd Ave. S.,
Minneapolis; www.childrenstheatre.org.

The Adventures of Hanuman, King of the Monkeys

Sunday, March 12, 2 p.m.
\$9; 651-225-9265; Weyerhaeuser Auditorium,
Landmark Center, St. Paul;
www.steppingstonetheatre.org

Annie

Sunday, March 26, 1 p.m. \$23-68; Request
ASL: 612-373-5639 Historic Orpheum
Theatre, 910 Hennepin Ave. S., Mpls.; www.hennepintheatredistrict.com/servicesd.asp.

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Our mission is to build better lives for children who are deaf or hard of hearing by providing parent-to-parent support.

Newsletter Editor: Audrey Alwell

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In Your Corner

By Candace Lindow-Davies, Family Support Coordinator

Newborn Hearing Screening has clearly had one of the most important influences on improving the lives of our children who are deaf or hard of hearing. As research has shown, children who are simply identified and provided with appropriate intervention by six months of age, have language development that shadows that of their hearing peers. This is an amazing change over the past. The next step is to ensure that every child born can benefit.

What does this mean for those of us who have older children who perhaps never had access to newborn hearing screening? It means that we harness some of our passion for our own children to help the next generation. We can support legislation that would mandate that all Minnesota babies are screened at birth. We can push for improved reporting by hospitals to the Minnesota Department of Health so no child slips through the cracks, and every family has a cavalry of support through their journey. We can gently remind all of our expectant friends and family to make sure their newborns are screened, and follow-up appointments are kept. We can be aware of any situations where newborn hearing screening is not promoted in a positive way, and correct any misunderstandings about the accuracy of the tests. We can educate ourselves on the issues—attend the MN Summit April 4—and be active and vocal.

For those of us who have had children who *have* benefited from newborn hearing screening, we can let our hospitals know how their efforts have changed our children's lives. We can thank our child's doctor for their support and knowledge. And, we can be grateful for the opportunity for our children to have intervention earlier than ever before.

It has taken a great number of individuals to make universal newborn hearing screening happen, and it will take many more to continue to support the effort and improve the process. But, as parents, we know that every child is so worth it.

Having just returned from our national Early Hearing Detection and Intervention conference in Washington D.C., I certainly feel inspired to continue this work. Listening to presenters, such as Lawrence Siegel and Katherine Jankowski, stoked the fire to push for full communication and language access for our children with hearing loss in the educational setting. Carol Flexer's presentation about brain development prodded us to view early diagnosis of hearing loss as a "medical emergency" since the newborn brain is wired and waiting for input immediately.

With these speakers and many connections with state leaders, all sharing the work they are doing, I feel confident that Minnesota is on the right path to effect change. However, there's still more work to do for our children. But like I said, it is all so worth it.

Conference promotes early intervention

The Minnesota Summit: A Multi-Disciplinary Early Hearing Detection and Intervention Conference April 3 and 4 at the Minneapolis Convention Center offers a wealth of information about hearing loss, genetics, early interventions, new technology and newborn screening.

While the conference is geared for professionals in the field, parents are encouraged to attend. Scholarships for parents are available. Contact Molly Crawford at 651-215-1315 or by e-mail at MNSummit@health.state.mn.us.

The summit is presented by the Minnesota Department of Health with partial funding through a Public Health Conference Grant from the Centers for Disease Control and Prevention. The goal of the Minnesota Summit is to create an organized and systematic approach to move early hearing detection and intervention beyond screening and into intervening.

Registration fees are \$20 for Monday evening's reception only or \$75 for the reception and conference. A special rate of \$25 is available for students.

For registration forms and details about the summit see www.health.state.mn.us/divs/fh/mch/unhs/summit.

Study seeks kids with hearing loss

Participants are needed for a national study on the development of children with hearing loss.

The Early Development of Childrn with Hearing Loss project is studying children born anytime between August 2002 and June 2004 who have a hearing loss. Participants receive \$50 for 2-hour test sessions done every six months until age 4½. The nearest test sites are in Minneapolis and Rochester. The study's results will help improve early intervention programs. To join the study, see www.speechdevelopment.org/support.html.



Paige Christenson, 6, makes her way around the rink during the Family Support Connection's annual roller skating party last month. We had the largest turnout ever, with 225 guests. Hope you can join us next year!

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We went from there to the Mankato Clinic for Olivia's 2-week checkup. We met with a nurse practitioner who also had a daughter with a hearing loss. She explained to us that Olivia would need an ABR (Auditory Brainstem Response) Test.

About 2 weeks later, we were back at the clinic doing the ABR test. She was also checked for fluid in her ears. There was none.

A couple of days later, we received a call from her pediatrician who told us that the test showed Olivia was profoundly deaf. She was about 1 month old.

Later that week, we brought her to an ENT specialist. He gave her a thorough exam and found everything structurally seemed to be alright. She was diagnosed at that time with a severe to profound bilateral, sensorineural hearing loss. The doctor told us about our options, including cochlear implants.

We contacted our local early intervention office and were set up with the services Olivia needed. By the time Olivia was 3 months old, we had begun learning ASL and using sign with her.

Olivia underwent surgery at Mayo Clinic when she was 11 months old to receive a cochlear implant. The implant was turned on shortly after her first birthday.

Olivia is now 4 years old and speech is her main form of communication. We continue to use ASL with her as well—we find it very helpful at bath time as well as at the swimming pool. Olivia also wears a behind-the-ear aid on her non-implanted ear to keep the nerve stimulated for a bilateral implant in the future.

We were at Mayo Clinic just a couple of weeks ago for her yearly evaluation. Her test scores were awesome! For the first time ever, the words “within age-appropriate range” were used to describe our daughter's language skills! Thanks to newborn hearing screening we were able to research her options and make informed decisions (that were right for our family) without losing a lot of critical learning time.

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regional teams that include an early childhood special educator, an audiologist, and a teacher of the deaf and hard of hearing.

Soon, the Network teams will expand to include the Regional Parent Mentors that are being hired by the Family Support Connection and other community partners. The Network's goal is to build capacity in local areas to offer a full array of early intervention services to meet the unique needs of infants who are deaf and hard of hearing and their families. The EHDI Network also offers advanced training for professionals in each region, and provides technical assistance to local providers.

“This coordination/cooperation among agencies ensures that no child goes without appropriate services,” Nicole said. “It also means better follow-up care for our youth who are deaf and hard of hearing.”

Resources for Early Hearing Detection and Intervention:

Minnesota Early Detection and Intervention
www.health.state.mn.us/divs/fh/mch/unhs
 651-281-9952
 800-728-5420

National Center for Hearing Assessment and Management
www.infanthearing.org

National Institute on Deafness and Other Communication Disorders
www.babyhearing.org
 This site is geared to parents and has a short video of a newborn having its hearing screened.

Centers for Disease Control and Prevention — National Center on Birth Defects and Developmental Disabilities
www.cdc.gov/ncbddd/ehdi/

Fund-raiser features personalized books for children

Personalized children's books can be ordered as a fund-raiser for Northern Voices, an oral school in Roseville for kids who are deaf or hard of hearing.

The stories are personalized to include a child's name, age, hometown, and friends' names. A list of more than a dozen hardcover titles can be personalized.

To request a brochure/order form, contact Cathy Krier at 612-845-7824.

Cochlear implants with positioners linked to meningitis risk

Children who have an Advanced Bionics cochlear implant that was put in place with a “positioner” face an increased risk of bacterial meningitis, according to a warning put out last week by the Food and Drug Administration (FDA).

The positioner is a rubber wedge that originally was used to help doctors position the implants during surgery. Advanced Bionics Corp. was the only manufacturer to sell implants with positioners. None has been implanted since July 2002.

The FDA recommended long-term monitoring of these implant patients for signs of the sometimes fatal infection of the fluid surrounding the brain and spinal cord. Symptoms include high fever and a stiff neck. The FDA also recommended vaccinations for this at-risk group.

An original study found 26 of 4,264 children with the implants developed meningitis during the first two years following surgery, with those with positioners at greater risk. Now, a new study that followed the same children for an additional two years found another six — all with positioners — developed meningitis. The results appear in this month's issue of the journal *Pediatrics*.

It remains unclear how the positioner increases the risk, the FDA said. Nor does the agency have enough information to recommend surgically removing the devices, given the risk of postoperative infection.

For complete details, see www.fda.gov/cdrh/cochlear/.

FOCUS is adding advertising space — call us for rates/details!

Workshop to boost understanding of cochlear implants

Advanced Bionics, the only American manufacturer of cochlear implants, will host a two-day seminar in Minneapolis April 20 and 21.

“SuperSize your Cochlear Implant Knowledge and Skills” has sessions for parents, educators, SLPs, and other school and health care professionals. On Day 1, Advanced Bionics staff and clinicians will present on how CIs work, how they are programmed, how to troubleshoot equipment and how to enhance success with assistive technology. Day 2 features four professionals who are experienced with rehabilitation techniques for CI patients. This day is geared for rehabilitation specialists who work with school-aged children. Continuing Education Credits are available.

The workshop will be at Embassy Suites Hotel near the airport in Bloomington. Both days begin with registration at 7:30 a.m. followed by lectures from 8 a.m. to 4 p.m. Lunch is included. The fee for both days is \$139, or \$49 for Day 1 and \$99 for Day 2. To register online see www.bionicear.com/professionals/events.asp. By phone, contact Shreen White at 800-678-2575, ext. 1593. The registration deadline is April 6.

Church adds weekly ASL-interpreted service

King of Kings Lutheran Church, 1583 Radio Drive in Woodbury, offers an ASL-interpreted service at 9:15 a.m. every Sunday. For more information about the church, see its website at www.kingofkingswdby.org, or call 651-738-3110.

Hey students: have your work published! Submit your news articles, stories or art to *FOCUS*, and more than 600 readers will see it. Ask your teacher—you might get extra credit for being published!



A Little Grin

By Patty Lex

Shortly after learning of our infant’s hearing loss (mild to moderate bilaterally), we were at our older son’s hockey game when the father of another player decided to perform his own hearing test on our baby. He clapped his hands and snapped his fingers and made strange noises to get my little one’s attention. Of course it worked — nearly everyone around was looking at him. Then he pronounced that my baby is not deaf, but can hear. I tried really, really hard not to roll my eyes and drop on the floor laughing at his antics.

I then politely explained that my son can hear, but he cannot hear enough to understand speech. I gave him a couple of examples of what it may sound like to a hearing person (music from another room at low volume level, the teacher from Peanuts talking...).

His response was, “OH, well, he *still* is not deaf!”

Oh well, you can’t teach them all, can you?!

If you have a story about your child who has a hearing loss that makes you smile, please share it with us. E-mail fsc@lifetrackresources.org.

Website hosts discussion on bilateral cochlear implants

“Plain Talk About Bilateral Cochlear Implants” is the topic of a live “e-seminar” at noon Feb. 16 on the Internet at www.agbell.org.

AG Bell hosts the seminar, which is sponsored by Cochlear Americas (the maker of Nucleus CIs). The seminar will explore the rationale for bilateral implants and the growing body of data on outcomes.

Did you know? You can find past issues of *FOCUS* at www.familysupportconnection.org. You’ll find other helpful articles, too. Check it out!

Program promotes captions for literacy

In coordination with the annual school-based “Read Across America” event in March, the Captioned Media Program is promoting “Read Captions Across America™.”

Read Across America, sponsored by the National Education Association, focuses on motivating children to read in addition to helping them master basic skills. Read *Captions* Across America is the first national reading event that emphasizes the importance of captions on television, DVDs, videos and computers as a reading tool for children with or without a hearing loss.

The Captioned Media Program website (www.captionedmedia.org) has materials to help schools and libraries plan activities for the reading event. The site also has promotional flyers and posters plus certificates for students who participate.

The Captioned Media Program is a free-loan library established in 1958 to provide equal access to people who are deaf or hard of hearing through captioned materials. The program is funded by the US Department of Education and run by the National Association of the Deaf. To use the service, at least one person viewing the materials must need the captioning. This means that teachers who have a student who is deaf in their class, parents of children who are deaf or hard of hearing, interpreters and those who are deaf or hard of hearing can request library materials from the program.

Borrowers must register first by logging onto www.captionedmedia.org/register.asp or by calling 800-237-6213 (v), 800-237-6819 (tty), or 800-538-5636 (fax). Captioned materials are listed online and in a printed catalog. The program also offers a monthly “e-zine” that highlights captioned materials around a specific theme, such as Black History Month.



Off the Shelf

By Robin Coninx, FSC Specialist

As we focus this month on Universal Newborn Hearing Screening, I want to recommend a booklet published by the Minnesota Department of Health called “Minnesota Guidelines of Care for Families with Children Who Have a Hearing Loss.” These guidelines offer information on various topics including:

- Connecting with other families of children with hearing loss
- Understanding clinical procedures and roles of various health care providers
- Choosing communication methods Finding support systems and programs

Much more is covered in this booklet. If you would like to receive a copy, please call the Family Support Connection, and we will mail you this booklet. Or, you can review it online at www.health.state.mn.us/divs/fh/mch/unhs/resources/guidelines/index.html. This will put you into the introduction and table of contents.

Remember for your other library needs, go to our website at www.familysupportconnection.org to view the contents of our library or call 651-265-2373 (local) or 866-DHOHKID (toll free).

Website deals with bullying

PACER has a new website to teach children how to deal with bullies.

The Kids Against Bullying website, aimed at kids in second through sixth grades, includes various videos plus games, contests, stories, artwork, poems, information, and much more. Children with disabilities are integrated throughout the site. Go to www.pacerkidsagainstabullying.org.

Researchers use technology to study sign language

San Diego State University has a new lab for studying how the human mind processes languages, especially sign language.

The new Laboratory for Language and Cognitive Neuroscience is taking the most comprehensive approach in the nation to researching languages. The lab is funded by four multiple-year grants from the National Institutes of Health and National Science Foundation totaling more than \$4.5 million.

One of the areas the researchers are studying is whether or not signing enhances a person’s spatial skills. They are also looking for differences between the brains of deaf signers and hearing speakers. Many of the researchers are deaf, and everyone in the lab is fluent in American Sign Language.

To study sign language, the researchers are using some impressive technology. They have 3-D computer motion tracking technology like that used to bring characters such as King Kong and Gollum (from “Lord of the Rings”) to life on the silver screen. They also use Magnetic Resonance Imaging (MRI) to record images of the brain, and an eye-tracking system for measuring and recording eye movements during sign perception and production. The lab also includes digital editing suites and a film studio. For more information about the research being conducted at the lab, see emmoreylab.sdsu.edu.

Retreat planned for families with deaf/hard of hearing autistic kids

A retreat for parents who are deaf or hard of hearing and their autistic children who are also deaf or hard of hearing will take place April 7-9 at Camp Lakodia near Madison, South Dakota. Cost is \$150 per person. Registration deadline is March 1. For more information, contact Deb Skjeveland at dskjeveland@camplakodia.org.

Bullying and the Child Who is Deaf or Hard of Hearing



Saturday, February 25 from 10 a.m. to noon
Lifetrack Resources, 709 University Ave. W., St. Paul

No matter where your child goes to school, chances are he or she has experienced bullying.

- What is bullying?
- What can parents do?
- Could my child be the bully?
- What is the school’s responsibility?

Carolyn Anderson, Parent Advocate at PACER Center and parent of an adult deaf son, will lead the workshop. This free workshop is open to all parents of children who are deaf or hard of hearing. Funding is provided by a Minnesota Department of Education Parent and Family Training Grant.

Please pre-register for the workshop with Family Support Connection, Lifetrack Resources, 651-265-2435 V, 866-346-4543 V Toll-Free, 651-265-2379 TTY, or 866-857-2379 TTY Toll-Free; or E-mail: fsc@lifetrackresources.org.

Child care is provided, but space is limited. Communication facilitators (interpreters or transliterators) also are available on request. Please request child care or interpreters by Wednesday, Feb. 22.

The next PACER workshop, “Working towards a Noble Prize: Effective Parent and Professional Communication and Partnership,” will be March 14, , 7 – 9 p.m. at Metro Deaf School.