

July/August 2004

Though she may appear delicate, little Madison Fuchs is made of tough stuff.

Madison and her parents, Dennis and Linda Fuchs of rural St. Cloud, have battled a list of medical challenges in the past five years, starting when Madison was just 3 months old.

Born healthy, Madison became seriously ill at about 3 months with what doctors believe was a virus that affected her heart, leaving her fighting for life. While the Fuchs waited for a heart transplant, tiny Madison was in a coma. Her heart stopped twice. One of her lungs collapsed. Her kidneys shut down. Still, Madison wouldn't give up.

At 5 months old, she received a heart transplant at Fairview University Medical Center. She needed to stay in the hospital another two months,

tubes and wires connected to her small frame.

"She was so sick," Linda said. "She was close to not making it." The doctors and nurses were amazed at Madison's tenacity. Madison went home from the hospital at 7 months weighing 10 pounds — the same she weighed at 2 months.

"She was just a little stick," Linda added.

Madison needed 11 different medicines, given round the clock. Linda and Dennis took shifts to care for their daughter.

"Our first goal was to get her to gain weight so she'd be able to fight off any sickness," Linda explained. Madison couldn't be around anyone who was sick. So the Fuchs kept her home for months. They spent that time on a 24-hour cycle of medicines, feeding, and worrying.

"She was vomiting all the time," Linda explained. "We were trying to get the meds into her, but she had to keep them in for at least an hour so they'd be absorbed into her system. We'd give her meds, wait an hour praying they'd stay down, then try feeding her."

It took about a year for Linda and Dennis to feel they had things under control. Linda, who was "climbing the corporate ladder," had quit her job to care for Madison full-time.

As Madison neared age 2, the Fuchs noticed her speech wasn't progressing. They had her hearing tested, but she passed an otoacoustic emissions test. So, they attributed her speech delay to her illness and let it go. But over the following year as Madison's speech still was delayed, they became concerned. An Auditory Brainstem Response test (see Page 5) showed that Madison had a profound hearing loss.

"That was difficult to hear on top of everything else," Linda said. "It didn't seem right to pile any more on us."

Before Linda left the audiologist's office, she picked up a brochure from the Family Support Connection.

"I called and talked to Candace (Lindow-Davies)," Linda said. "I needed to know what to expect." When she got off the phone, Linda said she felt more hopeful.

Linda and Dennis looked at their options and decided to get a cochlear implant for Madison.

"For us, the only question was how quickly she could

Family deals with medical challenges along with hearing loss



Dennis and Linda Fuchs and their daughter, Madison, live outside of St. Cloud.

Family's challenges ... continued on Page 3

Here's What's Happening

**Saturday,
July 24**

Share with other parents at the Family Support Connection's Coffee Chat from 9:30 to 11:30 a.m. at Como Park Pavilion in St. Paul. See Page 4 for details.

**Saturday,
July 24**

Meet up with other families that cue at Como Park at 10 a.m. at the Como Park Zoo Entrance Gate by the Conservatory. A transliterator will cue the 11 a.m. "Sparky the Sea Lion" show. Bring a picnic lunch. If you have questions, contact Katherine Burns-Christenson at KBC29@aol.com or 952-929-3965.

**Tuesdays,
July 27,
August 3**

Storytimes are ASL-interpreted Tuesdays at 2 p.m. at Merriam Park Library, 1831 Marshall Ave. in St. Paul. July 27 is the Brodini Comedy Magic Show. Crazy Daisy comes Aug. 3. For more information, call the library at 651-642-0385(v), 651-298-4184(tty).

**Fridays,
July 30,
August 6, 20**

The Cued Speech Association of Minnesota (CSAM) sponsors "Play and Cue" events from 10 a.m. to noon for kids who use Cued Speech and their parents. July 30 meet at Rosland Park, 4300 W. 66th St., Edina. Aug. 6 meet at Farquar Park, 13266 Pilot Knob Road in Apple Valley. Aug. 20 meet at Pearl Park, 414 E. Diamond Lake Rd., Minneapolis. If it's raining, events will be moved. Contact Tom Johnston, CSAM Play & Cue Coordinator, at ThomasMJohnston@mn.rr.com for more information.

**Sundays,
August 1,
September 5**

Free ASL-interpreted tours are offered at the Minneapolis Institute of Arts. Aug. 1 is "Currents of Change: Art and Life Along the Mississippi River, 1850-1861." The Sept. 5 tour is "Shazam! Art and Science." Tours meet in the museum lobby. For details, call 612-870-3131(v), 612-870-3132(tty) or email dhegstro@artsmia.org.

**Wednesday,
August 4**

An ASL Interpreter is on hand for Saint Paul Parks and Rec's FREE Kids Karnival from 6 to 8:30 p.m. at Harriet Island. Activities include a petting zoo, carnival games, Moon Walk, a coloring contest, prizes, and face painting. Dinner is available for \$3 with hotdog, chips and pop. For more information, see www.ci.stpaul.mn.us/depts/parks.

**Thursday,
August 5**

Make reservations for the Family Support Connection's picnic for families with children who are deaf or hard of hearing. See flyer for phone numbers.

**Saturday,
August 7**

CSD hosts Deaf Day at Bunker Hills Wave Pool in Coon Rapids from 11 a.m. to 7 p.m. Cost is \$9, \$6 for those over age 62 or under 4' tall, and free for under age 1. Tube rental is \$2. Parking is \$5. For more information, contact Linda Pressley-Ford, CSD of Minnesota, 651-487-8872 or email lpressleyford@c-s-d.org.

**Friday,
August 13**

Hang with signing friends (7th grade and up) at the ASL Deaf Culture Youth Event from 7 to 11 p.m. at North Central University Gym, 910 Elliot Ave. in Minneapolis. Open gym with basketball, entertainment, and refreshments. RSVP to Emory Dively, eddively@mac.com.



ASL-Interpreted Performances

The Music Man

Friday, July 30, 7:30 p.m.
Tickets: \$5-8
District 622 Community Theater
North High School, 2416 E. 11th Ave.,
North St. Paul

The King and I

Saturday, July 31, 2 p.m.
Ordway Center for the Performing
Arts, 345 Washington, St. Paul;
651-224-4222, TTY 651-282-3100,
www.ordway.org

**You're a Good Man,
Charlie Brown**

Friday, Aug. 6, 9 p.m. FREE
New Hope Outdoor Theatre, 4401
Xylon Ave. N., 763-531-515,
www.ci.new-hope.mn.us

Thoroughly Modern Millie

Saturday, Aug. 28, 2 p.m.
Ordway Center for the Performing
Arts, 345 Washington, St. Paul;
651-224-4222, TTY 651-282-3100,
www.ordway.org.

Mame

Friday, Sept. 10, 7:30 p.m.
Tickets: Reduced to \$17
Bloomington Center for the Arts, 1800
W. Old Shakopee Road;
952-563-8575,
www.bloomingtoncivictheatre.org.

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Please note that information about events, services, or other organizations does not imply endorsement by the Family Support Connection.

The Family Support Connection's mission is to build better lives for children who are deaf and hard of hearing by providing parent-to-parent support to families. Please visit our website at www.familysupportconnection.org.

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Family's challenges ... continued from Page 1

get the implant," Linda said. "We were absolutely sure about it and don't regret it one bit."

Madison's type of hearing loss, auditory neuropathy, often isn't picked up by otoacoustic emissions tests or sound-field testing, Linda explained. Doctors speculate her hearing may have been damaged while waiting for the heart transplant.

"When she was in a coma, she could have suffered nerve damage that showed up later," Linda said. The coma and her early illness also affected Madison's motor skills. She wears glasses to correct a "lazy" eye and a shoe insert for a foot problem. She also has developmental delays — she's not hitting the milestones in language and physical abilities that are typical of a child her age, Linda explained.

Now Madison is almost 5. She still requires medicine to keep her body from rejecting her heart, but she's down to twice-a-day doses, which has freed the Fuchs to focus on Madison's speech and language capabilities.

"Now that's our top priority," Linda said. "We don't have time to worry about rejecting because we're so busy with other stuff."

Some of that stuff includes speech therapy three times a week plus weekly sessions of physical and occupational therapies. She also goes to summer school in St. Cloud three days a week.

Thanks to the cochlear implant, Madison can hear well now, although her speech is still "coming along slowly," Linda said. "I realize how fortunate we are that she can hear us and understand what we say." It's possible that Madison's ability to speak clearly was affected by her early illness and it's not due to her deafness, Linda added.

"That's the thing about kids with multiple issues — you can't really peg them in any box, which is both good and bad," she said. While she appreciates that her daughter is a unique individual, it would be helpful if her medical issues followed a standard pattern "so I'd know what to expect," Linda explained. The charts the professionals show her are those for normal growth and development, which only highlight Madison's shortcomings, she added.

"They say 'she's not doing this' or 'not doing that,'" Linda said. "Sometimes it seems like days and days of negatives and it's wearing." To counter that, Linda started writing down anything "new, cool or different" that Madison did each day.

"Then on those days when all I've heard was the negatives about what Madison isn't doing yet, I could look at that and I'd feel better," Linda said. She also learned the value of taking time for herself apart from Madison.

"Kids with multiple issues have incredible needs," she said. "It's overwhelming. You need to take care of yourself so you can take care of your child. That's something Candace told me early on," she explained. "I had to learn how to take care of myself and not feel guilty about it."

The Fuchs are trying the Auditory-Oral approach with Madison. She attended Northern Voices in Roseville this past year, which was over 60 miles away, "but totally worth it," Linda said. In the fall, Madison will continue school in the St. Cloud district.

Madison's health has been good lately. She was in the hospital last December with pneumonia, which scared Dennis and Linda. They caught it quickly, though, and Madison soon recovered. Since she's feeling better, Madison has had the chance to try out behaviors that are common for her age — she likes to throw tantrums.

"I think it's half that she can't express what she wants and half that she's just stubborn," Linda explained. "But, they told us in the hospital that it was her stubbornness that helped her survive, so you have to appreciate it."



A Little Grin

By Linda Werness-Jaroszewski

A mother had signed up her children and their two cousins for a local kids' "Fun Run." As the date grew closer, she began to worry about how her son, who is "Deaf Plus," would do in the race. It wasn't the hearing loss that concerned her, but the fact that he had cerebral palsy. She hated the thought of him struggling to finish or becoming upset that he was not as fast as the other children. But, she couldn't pull him from the race when all the kids were so excited.

So, the week before, she tried to coach him by saying, "It doesn't matter how fast you run. It's that you tried very hard. Not everyone can win. It's about how proud you are of yourself..."

The day of the race, the kids all lined up at the start. Her son watched her interpret the race director's instructions. "BANG" — they were off. His younger sibling and cousins tore off down the course, and he followed. He was doing much better than she expected! At the turnaround, she lost sight of him and signed to her husband, "How's he doing?" Overcome with laughter, her husband finally signed back, "He's running fine. But he's so busy giving everyone 'high-fives' and 'thumbs up' that he can't run fast!"

Then she saw him. He was running with a huge grin on his face, egged on by yells from the crowd. He was among some of the last finishers. As he crossed the finish line, she ran to him. He beamed up at her, "I did my very best, Mom!" Tears came to her eyes, and she hugged him, saying "You sure did!"

In Your Corner

By Candace Lindow-Davies,
Family Support Coordinator

“Deaf Plus” is a term we affectionately coined around here. To be more accurate, it should be “Deaf or Hard of Hearing Plus.”

It is meant to be a positive term, not in any way insensitive to the child who has a hearing loss as well as medical issues. In fact, I see it as an “A+,” meaning the child carries additional positive qualities. At first, the “plus” might not appear positive to parents. But, it is a gift — one that needs to be carefully unwrapped. Time helps you unfold and appreciate the possibilities.

I have a lot of respect and admiration for parents of children who are “Deaf Plus.” As the parent of one such child myself, I have found it very encouraging to talk to other families. The Fuchs family, in our feature article, is one of the many inspirational families I have met.

Before working at this program, I thought my family was among a small minority. Quite the contrary. I learned at the 2004 National Early Hearing and Detection Conference that 40% of children with hearing loss have other medical issues such as autism, low vision, cerebral palsy, organ transplants, cancer, or attention deficit disorder.

Those of us who have children who fall into one of these categories may not share similarities day-to-day, but we do share a lot. With each diagnosis, it can become increasingly difficult to figure out how all the issues will affect one another and on which issue to focus first. Parents, understandably, can get overwhelmed. The professionals working with us might each focus on a particular medical issue. But as a parent, we see the whole picture and are constantly trying to balance various needs. In Barbara Gill’s book, “Changed by a Child,” one parent described the experience as “knitting on a dozen different needles.”

So, are we looking for sympathy because our child has medical concerns *and* hearing loss? Absolutely not. But, we might ask for your patience. We might not make decisions quickly because we have so many factors to consider. We may sometimes feel as though our situation doesn’t “fit the mold.”

Still, we want our children treated like any other child — keep the bar set high. This isn’t denial. We’re hanging on to the dreams we’ve always had for our children. It may take our child longer to accomplish a goal, but, as one mother of an older child reminded me, “When he’s 30, it won’t matter that he was 3 when he walked, or even that he walks. Period.”

‘Chat’ features speech pathologist

The Family Support Connection will host a “Coffee Chat” Saturday, July 24th from 9:30 to 11:30 a.m. at the Como Park Pavilion. The featured guest will be Linda Lacher Goddard, a Speech Language Pathologist from Children’s Therapy Center in Eagan. Linda has extensive background working with children who have hearing loss. She is skilled in both sign language and Cued Speech.

All parents are welcome even though this event has been for parents of newly diagnosed children in the past. Childcare will not be provided. For directions see www.blackbearcrossings.com/docs/map_pav.html. The next Coffee Chat will be Oct. 23.

Event celebrates disabled people’s rights

Minnesota disability advocacy groups will celebrate the 14th anniversary of the signing of the Americans with Disabilities Act Monday, July 26 from 11 a.m. to 1:30 p.m. at the Public Health Office Building, 1645 Energy Park Drive, in St. Paul. Humorist Kevin Kling will be speak at 11:30 a.m. Facts about the ADA will be available. For directions, see www.disability.state.mn.us.

Camp caters to kids with cochlear implants

The Colorado Neurological Institute’s Center for Hearing offers a camp Sept. 9-12 for families that have children with cochlear implants to gather, have fun, learn and celebrate success.

The Cochlear Kids Camp is in Estes Park near Rocky Mountain National Park in Colorado. Fees include private lodging and all meals, recreational activities and workshops for parents on topics such as insurance reimbursement, alternative therapy, education and family issues.

Registration deadline is Aug. 1. For information, see www.thecni.org/hearing/kidscamp2004.

Renaissance Festival offers signed shows

Shows at the Minnesota Renaissance Festival will be ASL-interpreted on Saturday, Sept. 11. The festival goes from 9 a.m. to 7 p.m. in Shakopee. For information about the festival, see www.renaissancefest.com.

Conference looks at oral education

The 3rd Annual Oral Education Conference will take place Thursday, Oct. 14, at the Earle Brown Continuing Education Center on the University of Minnesota’s St. Paul campus. See www.mnagbell.org/events.html for more information when it becomes available.

Online CI support group offered to parents

CI Kids is a new online resource for support and exchange of information among families with children that are cochlear implant candidates or recipients, and local professionals. The website is groups.yahoo.com/group/cikids.

Tests help identify hearing loss

To help determine if an infant has a hearing loss, doctors rely on either an otoacoustic emissions (OAE) test or Auditory Brainstem Response (ABR) or both.

Auditory brainstem responses are measured by placing three electrodes on the baby's head or on the head and upper body. Sound is introduced to the baby's ears through tiny earphones while the child sleeps. The electrodes then measure if the brain is detecting the sounds. The test is painless and takes approximately five minutes to administer to a quiet, cooperative baby. An older child needs to be sedated for this procedure since movement interferes with the results.

Otoacoustic emissions are faint sounds that are produced by most normal inner ears. These sounds are so faint, they are not heard by individuals but can be detected by very sensitive microphones placed in the ear canal. During otoacoustic emissions testing a tiny flexible plug is inserted into the baby's ear. Sound is then projected into the ear through the plug. A microphone inside the plug records the otoacoustic emissions that the normal ear produces in response to the incoming sound. The emissions usually are not detected in an infant who cannot hear. Like ABR testing, this test is painless, takes only minutes to administer and is conducted while the baby sleeps.

Pass lets families see National Parks free

If you're planning a trip to a National Park, monument or campground this summer, consider applying for a Golden Access Passport for free or reduced-rate admission.

The Federal Government offers the passports to citizens or permanent residents of the United States who are blind or permanently disabled — deafness qualifies. The Golden Access Passport is a lifetime entrance pass to national parks, providing admission to the pass-holder and everyone else in the vehicle if a park has a per-vehicle entrance fee. There are no age restrictions to apply for the card.

The Golden Access Passport also provides a 50% discount on federal use fees charged for facilities and services such as camping, swimming, parking, boat launching, and tours. In addition to national parks, the passport also works for sites managed by the U.S. Fish and Wildlife Service, the U.S. Forest Service, the Bureau of Land Management, and the Army Corps of Engineers.

The only restriction is that the card must be obtained in person with proof of a medically determined permanent disability (an audiogram is sufficient). The passports can be obtained at most federal areas where an entrance fee is charged. You might want to call ahead to a National Park to inquire about pass availability and the required documentation before you leave for your vacation. To find contact information for a specific National Park, see www.nps.gov/parks.html.



Ask a Professional

By Sally Prouty
MN DB Project

Question: In addition to a hearing loss, my son has some vision problems, but can see pretty well. What should I do?

Answer: Children who are deaf or hard of hearing rely mostly on their eyesight for learning. Depending on your son's vision loss, he might misunderstand what he's seeing or completely miss the information he needs so he can learn.

Remember, your son doesn't know what normal vision is, so he cannot tell you if he has problems. Don't wait for major issues to appear! Have your son's vision checked by a pediatric ophthalmologist, and ask for a report. Share the report with your district's educational team.

The team can check the state criteria for a combined vision and hearing loss (deafblind) at: www.revisor.leg.state.mn.us/arule/3525/1327.html. Your son may qualify for increased services to help him learn.

Question: Does deafblind mean there is no usable hearing or vision?

Answer: Absolutely not! Most children who meet state criteria for deafblind have some useful hearing and/or vision. Even "mild" losses affect how a child learns and communicates. Less than 6% of the children who qualify as deafblind are totally deaf and totally blind.

Common causes of deafblind include: CHARGE, Usher, Goldenhar, Cornelia de Lange, Stickler, and Marshall syndromes. Also, premature birth, chemotherapy and brain tumors can cause combined vision and hearing loss.

If you have more questions, contact me at the Minnesota DeafBlind Project. Our team provides free parent and teacher support. 612-638-1525(v), 612-706-0808(tty), 800-848-4905, mndb@skypoint.com or see our web page at dbproject@mn.org.

If you have a question you'd like answered by a professional through this column, call 651-265-2435 (v), 651-265-2379 (tty) or e-mail fsc@lifetrackresources.org.



Off The Shelf

By Robin Coninx, FSC Specialist

This edition of *FOCUS* shines its light on “Deaf Plus” kids — those who are deaf and have other issues. For me, this hits close to home because my daughter was born with many medical issues and is deaf. It reminds me of Emily Perl Kingsley’s aptly written “Welcome To Holland” essay. She writes that having a baby with special needs is a lot like planning an exciting trip to Paris only to find that you’ve landed in Holland — a destination you didn’t expect, but one that has its own merits along with its own challenges.

Rhonda DeBough-Insook experienced this unexpected journey herself with her own special needs child. She has created “A Very Special Baby Book” to help other parents record their babies’ unique milestones. You can check out this book from our library to see how this journal looks.

We also have two other books that should appeal to parents of Deaf Plus kids. The first one is “The Silent Garden” by Paul W. Ogden, who is a professor of Deaf Studies and Deaf himself. Paul gives chapter 12 the title of “Boot Camp for Parents of Deaf Children of Special Needs.” The second book, “Changed by a Child,” is written by Barbara Gill, who has a son with Down syndrome. Her book features stories of faith, courage, fear, and forgiveness. I recommend this book to be at your bedside. It has helped pass late night hours for me.

You can request library books at fsc@lifetrackresources.org.

Parents can relax at resort during Fall Retreat

The Family Support Connection will hold a Parent Retreat Sept. 17-19 at Ruttger’s Bay Lake Lodge in the Brainerd lakes area.

The weekend’s theme is “Trusting Your Instincts...Following Your Child’s Lead.” Along with playing free 9-hole golf and tennis, eating delicious food, chatting around the fire, swimming and soaking, parents will have time to share their experiences raising a deaf or hard of hearing child and get energized from listening to great speakers.

Dr. Ron Lybarger is the keynote speaker with his presentation of “Empowering Children: Parenting that Fosters Independence.” Dr. Lybarger is a licensed psychologist who holds degrees in interpreting, Addiction Studies, and Counseling Psychology. His interactive discussion focuses on teaching children independent thinking skills, problem-solving strategies, and personal responsibility.

Registration information will be sent to *FOCUS* readers later this summer.

Artificial Intelligence helps hearing aid process speech

A new hearing aid uses Artificial Intelligence to mimic the brain’s natural ability to focus in on speech while filtering distracting sounds.

The Oticon Syncro reacts much like the brain when adjusting to each listening situation. It automatically adapts to changing conditions, always ensuring that voices come through clearly. This new technology is called Voice Priority Processing. For a demonstration, see www.oticon.com and click on “NEW! Experience the Syncro difference!” under the “Hearing Aid Users” category.

Groups organize bike rides at local trails

CSD of Minnesota has teamed with Saint Paul Parks and Recreation to offer a series of bicycle rides for families that have deaf members.

The rides begin at 7 p.m. and range from 10 to 25 miles. If it’s raining, the ride is canceled. A 25-mile ride along the Downtown Riverfront in Minneapolis will happen on July 29. The Luce Line State Trail, a 20-mile ride, is Aug. 5. The last ride is Aug. 12 for 12 miles along Minnehaha Creek Bikeway Trail.

CSD and Saint Paul Parks also will offer swim nights beginning Sept. 10 at Oxford Pool at Lexington Parkway and Iglehart. Watch for information in the next issue of *FOCUS*.

For bike ride meeting place or maps, please contact Linda M. Pressley-Ford, CSD Recreation Program Coordinator, 651-487-8872(tty), lpressleyford@C-S-D.org, or Mary Livingston at St. Paul Parks and Recreation, 651-266-6366 (v), 651-266-6378(tty), or mary.livingston@ci.stpaul.mn.us.

Free fellowships offered

Deaf or hard-of-hearing college graduates may apply for a FREE master’s degree fellowship at the National Technical Institute for the Deaf (NTID), a college of Rochester Institute of Technology (RIT). Recipients receive free tuition and housing plus a \$15,000 annual stipend for a career-related, part-time job. Applications are due by Feb. 15, 2005, for admission the following fall. For more information, contact NTID Office of Outreach and Transition Services, 585-475-2087 (v/tty) or ambnes@rit.edu.

Captioned movie shown

“Harry Potter and the Prisoner of Azkaban” shows with open captions Aug. 23 and 24 at the Kerasotes Showplace in Coon



Rapids, 612-757-6608, Aug. 25 and 26 in Inver Grove Heights, 651-453-1016, and at the CEC in Faribault Sept. 15 and 16.

Make friends at the Family Support Connection's

FAMILY PICNIC!

for families with children who are deaf or hard of hearing.

***THURSDAY,
AUGUST 5TH***

5 to 9 pm!

Rain or shine!



FREE FOR THE FAMILY:

- Dinner at 5:30
Catered by Kentucky Fried Chicken
- Face Painting!
- Temporary Tattoos!

at Como Park Picnic Area

Hamline Ave & Midway Pkwy
St. Paul (See attached map)

Conveniently located near a playground, miniature golf, midway rides, carousel, Como Zoo and Conservatory.



Lifetrack
Resources

Family Support Connection • 651-265-2435 (voice) • 651-265-2379 (TTY)
1-866-DHOHKID (toll-free) • 1-866-857-2379 (toll-free TTY)
www.familysupportconnection.org

Como Park Picnic Area

Hamline Ave & Midway Pkwy
St. Paul

