Lifetrack Resources

The Family Support Connection

FOCUS

—for families with deaf or hard of hearing kids—

May 2005

A cochlear implant doesn't amplify sound like a hearing aid. Instead, it bypasses the parts of the ear that aren't working and sends sound signals right to the part of the brain that can make sense of them.

A study presented last month at the 10th Symposium of Cochlear Implants in Children showed no difference in outcomes between infants implanted at 6 months and at 12 months. The Food and Drug Administration has approved cochlear implants beginning at 12 months of age.

Advances in technology help cochlear implants deliver better sound quality

Estimates of the number of people worldwide who have a cochlear implant vary, but the number floating around at the 10th Symposium of Cochlear Implants in Children last month was 85,000. Cochlear Corp. has the largest share. 63,260 people have received its Nucleus brand.

Cochlear implants have come a long way since they were first introduced more than 20 years ago.

The first cochlear implant to receive approval from the Food and Drug Administration (FDA) back in 1984 was a single-electrode device from Cochlear Corp. that was manufactured by Minnesota-based 3M. Today implants have many electrodes to provide a better sense of sound.

The three manufacturers that have FDA approval to market their devices are Cochlear Corp. with its Nucleus brand name, Advanced Bionics with its Clarion and Auria products, and Med-El with Combi and Tempo.

A cochlear implant is an electronic device that can provide a sense of sound to a person who is severely to profoundly deaf. How well people "hear" with an implant ranges from an awareness of sound to understanding speech and an improved ability to talk. Research has shown that children who receive an implant at a young age fare better at understanding speech with an implant than children who receive an implant when they are older. The definitive study on the effect of age at implantation is in the May 2004 Archives of Otolaryngology (see archotol.ama-assn.org/cgi/content/abstract/130/5/570).

Today's implants have parts that are worn outside the body and parts that are surgically implanted in the head and inner ear. The external speech processor picks up sound from the environment, converts it to digital signals and transmits those through a headpiece that is attached with a magnet to the receiver, which is implanted on the skull. The implant converts the digital signals to electrical impulses and sends them down tiny wires to an electrode array, another tiny wire that has contact points—electrodes—on it that has been threaded inside the spiral-shaped cochlea inside the ear. These electrodes work like the hair cells in a normally functioning ear to stimulate the hearing nerve, which sends the information to the brain to interpret. Each implant manufacturer's website has diagrams and explanations of how a cochlear implant works. Their websites are listed on Page 4.

Over the years, cochlear implants have become smaller and more convenient to use. The most noticeable change has been in the batteries that run them. Users no longer need to tote extra batteries wherever they go, changing them every few hours when they wear out. Advanced Bionics promises 9- or 17-hour "full-day" batteries that can be recharged overnight. And, Cochlear's new "Freedom" implant, introduced last month, claims batteries that last up to five days. Freedom uses regular AAA batteries in the body-worn processor and hearing aid-type button batteries in its behind-the-ear (BTE) model.

Implants...continued on Page 4

Here's What's Happening

Saturday, May 7 — **Deaf storyteller Estella Bustamante signs stories** for kids ages 3 to 7 at 10:30 a.m., Merriam Park Library, 1831 Marshall Ave., St. Paul, 651-642-0385(v), 651-298-4184(tty).

Tuesday, May 10 — **ASL poetry readings with Cara Barnett and John Lee Clark** begin at 7:30 p.m. at the College Of St. Catherine, Whitby Hall, Room 120 B. Donations accepted. For more information, contact Anna Saindon at 608-628-2699 or alouisesaindon@yahoo.com.

Monday, May 16 — **A workshop on Special Education laws** offered by Wisconsin Families for Hands & Voices runs from 6:30 to 8:30 p.m. in Madison. Contact Molly Martzke at 920-437-7370 or email handsandvoiceswi@yahoo.com.

Wednesday, May 18 — **"Practice Cue Clutch,"** a directed practice for all levels of Cuers runs from 6:30 to 8 p.m. at Java Jacks in Minneapolis. For details contact KBC29@aol.com.

Friday, May 20 — **A seminar on ADHD in deaf and hard of hearing people** goes from 8:30 a.m. to 4:30 p.m. at the University of Minnesota, St. Paul Campus. Cost is $30. Regions Hospital's Spring Workshop is for professionals, but interested parents can attend. Sponsored in part by Lifetrack Resources Greater Minnesota Assessment Services. For details contact Kristen Swan at 651-254-2742 (v), -1888 (tty) or Kristen.L.Swan@healthpartners.com.

Friday, May 20 — **The 5th and 6th graders in Como Park Elementary's DHH program perform "The Pirate's Folly"** in ASL with voice interpretation at 6:30 p.m. at Thompson Hall Auditorium,1824 Marshall Ave. in St. Paul. Admission is free.

Saturday, May 21 — **Community of Hope's annual Community Carnival** runs from noon to 4 p.m. at Peace Lutheran Church, 7160 S. Robert Trail in Inver Grove Heights (2 miles south of Hwy 494). Activities include face painting, crafts, games, and prizes. For information, contact Laurie A. Johnson at 651-455-0093 (v/tty) or COHDeafOutreach@aol.com.

Saturday, May 21 — **Experience storytelling in ASL** at the Mankato Barnes and Noble from 10 to 11 a.m.

Saturday, May 21 — **"Play & Cue"** from 10 a.m. to noon at Veterans Memorial Community Center in Inver Grove Heights with other kids and parents who use Cued English.

Sunday, June 5 — **"Step into the Past: The Institute's Period Rooms,"** an ASL-interpreted tour at the Minneapolis Institute of Arts, begins at 2 p.m. For details, call 612-870-3131(v), 612-870-3132(tty) or email dhegstro@artsmia.org.

Saturday, June 18 — **CSD hosts Deaf Day at Valleyfair Amusement Park** from 10 a.m. to 4 p.m. Tickets are $23 for adults and $13 for children less than 48" tall, but older than age 3. Tickets can be purchased at Valleyfair's group sales ticket window on Deaf Day or in advance at CSD of Minnesota, 2055 Rice St., St. Paul between 8 a.m. and 5 p.m. weekdays.

ASL-Interpreted Performances

King of Hearts
Thursday, May 12, 8 p.m.
Theatre Latte' Da & Interact Theatre companies at Loring Park Playhouse, 1633 Hennepin Ave., Mpls., 612-343-3390 or www.latteda.org.
In the final days of World War I, a small French village has been taken over by the Germans. They have planted bombs to blow up the village, and so the townspeople flee, leaving the "crazy people" of the nearby St. Anne's asylum to fend for themselves. An American soldier comes to investigate the rumors of bombs before the American forces arrive, only to meet these townspeople who don't seem quite right. Many of the roles in this play are beautifully performed by persons with disabilities.

The Hobbit
Friday, May 20, 7:30 p.m.
Wednesday, May 25, 10:30 a.m.
Reduced tickets: 612-874-0400.
Children's Theatre Co., 2400 3rd Ave. S., Mpls.; www.childrenstheatre.org.

She Loves Me
Fridays, May 27 and June 10, 7:30 p.m.
Guthrie Theater, 725 Vineland, Minneapolis; 612-377-2224(v), 612-377-6626(tty); www.guthrietheater.org.
This romantic comedy is based on the 1936 play "Parfumerie," which inspired the movie"You've Got Mail."

FOCUS is published by the Family Support Connection at Lifetrack Resources. Submissions are welcome and can be sent to the editor via email.

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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.

In Your Corner:

Cochlear implants still 'hot topic'

By Candace Lindow-Davies,
Family Support Coordinator

Cochlear implants have been a hot topic as long as I can remember. Our family first learned about them when our ENT (Ear, Nose and Throat doctor) brought it up after our son was first diagnosed with a profound hearing loss in 1995. I remember being jolted at the thought of performing surgery on such a young child.

Since that time, a lot has happened—both for our family and for the technology. A lot more children have been implanted, a lot more research has been done, and the technology has improved dramatically. However, what remains the same is that this is a very personal decision each family must make. I have met families who have made the decision to implant and families who have chosen not to implant. What is right for one family is not necessarily right for another.

The same is true for communication options. This, too, is such a personal decision, and the Family Support Connection has been firmly founded on the belief that with good information, support and parent role models, each family will make the best choice.

The decision to implant a child is huge. The decision to implant a child in both ears (bilaterally) is even more difficult. Back in the '90s, implanting one side was the only option. It was believed that one ear would be left for upgrades in technology. And, since surgery and follow-up were incredibly expensive, there was concern about insurance coverage for even one implant.

Today, there is a growing argument for bilateral implantation. Cochlear implant manufacturers have been doing research on adults for years, and now, the number of children receiving two implants is increasing. In some cases, timing is a huge factor. For the Wanha family, ossification of the cochlea (hardening of the inner ear that may prevent future insertion of a critical part of the device) due to meningitis was a large part of their decision to implant their daughter, Annika, in both ears. Parents, Rebecca and Allen, are convinced that Annika, who is 3 now, is doing so well because she can hear in *both* ears.

"We can't hold the ear for future technology," Rebecca said. "Annika will grow up with her 'two ears' and not remember anything differently." Rebecca also notices Annika's ability to localize sound with two implants.

"Annika doesn't search the room to find out where the sound comes from," Rebecca said. "She can just turn and find the sound."

For the Burgoyne family, their son, Michael, 8, faced a second surgery anyway. His first implant was slowly failing internally. When Julie and Mark Burgoyne knew surgery was needed to replace the device, they decided to take the opportunity to implant both sides.

"Our window of opportunity was open, and we really felt like this was a special gift given to Michael," Julie recalled. "He deserved to hear with the very best technology possible. We had talked to some bilateral users who really enjoyed the 'surround sound' they received with two implants. We were told that Michael would have an easier time hearing in loud environments."

Fast forward, and Michael loves his two implants, his parents say. He understands speech without visual clues. Recently, he told his mom he can hear his twin cousins talking to him at the same time, one on each side of him—through both implants.

As for adult implant users, Cindy Graf reports being very pleased with her two implants.

"I have taken part in studies related to bilateral versus one cochlear implant, and the findings are amazing," Cindy said. "Wearing both implants in a soundproof room, I surprised myself and the researchers at how well I heard the faintest sounds. Having two implants has given me the confidence to work in an elementary school setting with hearing special education students and all hearing staff. Schools are very noisy places even for hearing people!"

Another adult implant user, Kathy Allen, a Consumer Advocate Coordinator for Cochlear Corporation agrees that hearing with one implant feels like something is missing.

"We have two ears for a reason so why not have two implants?" Kathy said. "I spent a lot of time talking to people who have bilateral implants and they all say the same thing—it is like having 'surround sound,' and they would be LOST without their second implant. They also tell me how much better and fuller music sounds with two implants versus one."

Some families are more hesitant to go for the second implant. There is the inherent risk of surgery, the concern about missing future advancements in technology, the need for more research, having two processors to maintain and program, and so on. Parents with children who are very successful with their first implant also argue that they do not want to compromise their child's current progress. The Alexander Graham Bell Association has published several articles in their parent-friendly *Volta Voices* magazine about this issue. (See www.agbell.org to subscribe.)

In any event, it is clear this discussion will continue.More kids and adults are getting implants bilaterally, blazing the trail for others to follow and proving again how much things change.

When my son was first implanted in 1999, children passing by us in the store would stare and point at my son's head and ask, "Mommy, what is that thing stuck to his head?" Back then, typically, the mother would hush the child and quietly say, "Don't stare. I have no idea." Today, children may point to the head piece behind his ear, but I'm amazed at the mother's response: "Honey, don't point but that's a cochlear implant, and it helps that little boy hear better." Wow. Times have changed!

Implants...continued from Page 1

The new Freedom offers other conveniences, too. It has the first "splash- and sweat-resistant" processor—a real improvement, since humidity or moisture is the number one cause of device failure.

All three manufacturers have some sort of new technology in the processor that enhances the devices' performance. But none has yet come out with the futuristic implants mentioned in last month's *FOCUS*. These cochlear implants of the future will be fully implanted—no external processors, microphones, headpieces or batteries will be necessary.

One last improvement to the performance of current implants has nothing to do with their size or structure. Researchers are finding that patients have a better understanding of sound when they receive implants for both ears in what's known as "bilateral" implantation. The Medical College of Wisconsin is conducting a five-year study on the effects of bilateral implantation. So far, no results have been posted on the college's website (www.mcw.edu).

Cochlear Implant Websites:

Advanced Bionics
Headquarters in Sylmar, California
www.bionicear.com

Cochlear Corporation (Australia)
U.S. headquarters in Englewood, Colorado
www.cochlearamericas.com

Med-El (Austria)
U.S. headquarters in Durham, N. Carolina
www.medel.com

National Institutes of Health
www.nidcd.nih.gov

Food & Drug Administration (FDA)
www.fda.gov/cdrh/cochlear/index.html

Families in NE Metro invited to pizza party

The Parent/Child Support Group for families in Northeast Metro 916 school districts will hold its last meeting with a pizza party from 6 to 7:30 p.m. Tuesday, May 10 at Capital View Center in Little Canada. $10 per family donation is requested. Make reservations with Barb Young, 651-415-6905 or byoung@nemetro.k12.mn.us.

Auditory-Verbal conference set in Canada

The Biennial Auditory-Verbal Conference takes place July 8-9 in Toronto. The international conference focuses on current research and techniques in teaching deaf or hard of hearing children to listen and speak. It is open to parents and professionals. Registration materials and more information are at www.auditory-verbal.org.

The May 16 deadline for registering for the Parent/Child Institute at Minnesota State Academy for the Deaf (MSAD) in Faribault is just around the corner. The Institute, June 3-5, focuses on families with younger children, with workshops on educational issues and communication strategies plus fun activities for kids. Cost is $30/family. The weekend is sponsored by MSAD, MN Resource Center; Minnesota Department of Education, Early Hearing Detection & Intervention; and, MN Department of Health. To register see www.msad.state.mn.us.

Camps cater to kids with cochlear implants

A couple of camps focusing on kids or adults with cochlear implants are offered this summer.

Heather Whitestone McCallum, Miss America 1995, will give the keynote presentation at the 11th Georgia Peach Cochlear Implant Association Family Retreat, which takes place June 10-12 in Chatsworth, Georgia. Registration forms are available at www.gpc.edu/~btucker/gpcia/index.htm.

Colorado Neurological Institute's Center for Hearing offers a 4-day camp, CNI Cochlear Kids Camp, with recreation and education for children with cochlear implants and their families. This summer's camp is Aug. 18-21 at the YMCA Family Conference Center in the Rocky Mountains near Estes Park. Cost is $250 for a family of 4. For information see www.thecni.org/hearing/kidscamp2005.htm.

Free camp gives girls glimpse of science careers

The deadline for applying to EXITE, the free day camp for girls entering grades 6-9 who who have a disability, has been extended to May 16.

EXITE (EXploring Interests in Technology and Engineering) is sponsored by IBM and PACER. The camp will be held at PACER Center in Bloomington on July 21, 25, 27, 29, Aug. 2, and 4 from 9 a.m. to 4 p.m. Interpreters will be provided. Activities include hands-on work such as building a circuit board, tearing down a computer, and making a polymer. Participants also will meet professionals who have disabilities and tour IBM's Rochester facility to see scientists at work and meet one to be their email mentor for a year.

Nearly 50 girls have participated in prior summers and called the experience "one of the best camps ever attended." Their comments are at www.pacer.org (click on Simon Technology Center, then click on EXITE camp). The website also has registration forms. For more information, call PACER at 952-838-9000.

New video telephone shows more lifelike image

A new video phone promises callers "true-to-life" visual communication and may well be the wave of the future for signers.

Motorola Ojo™ Personal Video Phone uses highspeed Internet lines to send images zooming between phones in a sixth of a second, cleaning up the jerky images that plague most video phones. If you've seen the TV show "24" you've seen Ojo in use. The phone has a cordless handset that works like a regular cordless phone, plus a video screen "dock." The screen sits upright to capture your face while you view the caller's face. Both parties need to have Ojo for the video to work. Judging by Ojo's online demo, conversations happen pretty much the way they do when people are face to face. The online demo plus pre-order forms are at www.motorola.com/ojo.

Ojo isn't available yet, but is expected later this Spring. The manufacturer's suggested price is $799. Unlimited monthly service will run about $14.95.

AG Bell launches teen website, biweekly e-newsletter

An updated website designed for teens who have a hearing loss is packed with the kinds of things that interest teenagers: movie clips, a message board and chat room, plus games to download.

The site, www.hearourvoices.org, is maintained by the Alexander Graham Bell Association for the Deaf and Hard of Hearing. Along with the "fun" stuff, there's information about internships and camps, the latest on gadgets to make communicating easier, health tips, and inspiring interviews with professional athletes who are deaf. The site also has "IDEA 101" and "ADA 101" to help teens understand the laws that affect them.

AG Bell also has started a biweekly e-newsletter, *AG Bell Update.*For details, see www.agbell.org and click on the scrolling notice. Or, send your name, address and e-mail to webmaster@agbell.org.

A new edition of "The Tactile Mind," a quarterly journal featuring the art and literature of the signing community, comes out this month. After this edition, the journal will be published annually. For details, see www.thetactilemind.com.

A Little Grin

By Candace Lindow-Davies

As required, my son's school has periodic fire drills. This had been an issue since he received his cochlear implant five years ago, as the alarm is painfully loud—especially for someone getting used to random sounds appearing from seemingly nowhere. Over the years, he has graduated from ripping the headpiece off his head to turning the volume down.

A few years ago, a teacher observed him as he filed out of the room with the other children. This time, he had one finger in the ear canal of the unimplanted ear. The other finger was covering the microphone of the headpiece up behind his implanted ear. I guess this is another sign of his acceptance of the implant—he can control what he hears!

Share your 'Grins' by emailing fsc@lifetrackresources.org.

A new technology called "Signlinks" makes it possible for websites to be presented in American Sign Language (ASL). Application developers in Canada created the software to help native signers understand web content that typically is written in English. Using Quicktime 6.5, Signlinks shows a person signing the information on a website. Signlinking currently is used on two websites: aslpah.com and the website of the Canadian Hearing Society (www.chs.ca).

Device captions Broadway plays

A new device is making it possible for people who have a hearing loss to enjoy Broadway shows.

I-Caption® provides text displays on a portable device that's about the size of a hand-held PDA or computer. The computer contains a timed PowerPoint presentation of the show's song lyrics and dialogue. Each slide shows itself for a specified amount of time, then moves to the next one. The slides are linked to the theater's lighting system so they keep pace with the performance.

I-Caption was created by Sound Associates, Inc. in New York City. It was first used in the Broadway production of "Big River." Currently, the system is available for the Broadway show "Wicked."

For more information see www.soundassociates.com.

Students invent vibrating fire alarm

A group of students from Roosevelt High School in Minneapolis have invented a body-worn fire alarm for people who are deaf. The device vibrates when triggered by a smoke detector. The students will get help fine-tuning their invention this summer at MIT in Boston.

Off The Shelf

By Robin Coninx, FSC Specialist

If you want to learn more about cochlear implants, take a look at the resources available in the Family Support Connection library. While our library doesn't contain all the information there is regarding cochlear implants, we do try to provide a range of resources from various perspectives.

In the book section, we have "Cochlear Implants in Children: Ethics and Choices." This book provides information from a survey of parents whose children had been implanted for a year. Another book on our shelves is "The Bridge to Sound with a 'Bionic' Ear." This book describes the jouney people go through when they receive a cochlear implant. The book has personal points of view from people in every age group. It was compiled by a woman who lives in Minnesota.

On the video shelf we have "Sounds and Silence." The Discovery Channel produced this 52-minute documentary which includes discussions with people who are deaf concerning the cochlear implant. The documentary also explains how a cochlear implant works and how it is surgically implanted. Another video is: "Cecilia's Story." It follows a girl from infancy thru her 8th birthday, showing both the challenges and the joys she experiences growing up with a cochlear implant.

These are just a few of the resources we have about cochlear implants. For a complete list go to our website at www.familysupportconnection.org. Materials also can be requested by phone at 651-265-2435 (v), -2379 (tty) or outstate: 1-866-DHOHKID. Or, you can email your request to fsc@lifetrackresources.org.

Researchers learn more about auditory hair cells

The quest for restoring auditory hair cells is spanning the globe. Last month, researchers in Britain and Hong Kong announced they have isolated the gene responsible for sensory development in the inner ear. It is called SOX2.

"A number of genes have been found that are required to make functional hair cells, the cells that detect sound or movement and balance in the inner ear, but we didn't find genes that initiate development of the sensory system, which comprises both the hair cells and their supporting cells," one researcher explained. "So the discovery that the Sox2 gene does this is a significant step forward. To develop treatments for deafness in the future, it is now necessary to look at whether this gene can play a part in bringing damaged sensory hair cells back to life or in triggering new sensory cells to grow for use in potential stem cell therapy."

Researchers at the University of Michigan are already using gene therapy to restore hearing in guinea pigs. (See the March edition of *FOCUS*.) And, scientists at Harvard have identified the gene that blocks hair cell growth. (See the February edition of *FOCUS*.)

For more information on this latest discovery, see www.mrc.ac.uk and click on "SOX2" under "News Centre."

Stem cells grow into hearing nerves

New research is showing that stem cells taken from bone marrow could be coaxed into becoming sensory nerve cells, potentially creating hearing in deaf patients.

The cover story of the March 29 edition of the Proceedings of the National Academy of Sciences describes how researchers at Indiana University School of Medicine induced stem cells taken from adult bone marrow to become cells with the characteristics of the sensory nerve cells found in the ear. They used marrow stromal cells which normally produce fat, bone and cartilage.

First the researchers cultivated mouse marrow stromal cells with chemicals known to encourage the development of primitive neurons. Then they exposed the cells to molecules found in the ear during embryonic development. These molecules (called "Sonic hedgehog" and "retinoic acid") caused the marrow stromal cells to further develop into cells with many of the characteristics of auditory neurons, such as the presence of specific genes and proteins.

Scientists have found that the aging brain, not hair cell loss in the ear, is most often the cause of diminished hearing among seniors. Connections in the brain can deteriorate with age, making it more difficult to process sound, the researchers said.

Cool off at Cascade Bay Water Park Social Day for the Deaf and Hard of Hearing Community Saturdays June 11, July 9, and August 13 from 1 to 8:30 p.m. at Cascade Bay, 3830 Pilot Knob Road in Eagan. Contact Linda Pressley-Ford at 651-487-8872 (tty) or lpressleyford@c-s-d.org, or Mary Livingston at St. Paul Parks and Recreation, 651-266-6366 (v), 651-266-6377 (tty) , or mary.livingston@ci.stpaul.mn.us.