

Echoes

THE CHILDREN'S HEARING INSTITUTE
www.childrens hearing.org



DECEMBER, 2007

Five-Year old Jordan Flowers Receives Prosthetic Ears

Echoes readers were introduced to the story of little *Jordan Flowers* last year, when his mother, Olympic Gold Medalist (Bobsled) *Vonetta Flowers* accepted a "Hearing Hear-o Award" at our Benefit Gala. *Jordan* was born deaf due to an under-developed nerve connecting his ear to his brain. In December 2005, the three-year-old child received an auditory brain stem implant – which is not approved for children in the U.S. – in Italy. *Vonetta* told our Benefit Gala audience that she: "...never imagined that at 30 weeks I would deliver twin boys, who weighed two pounds, nine ounces and three pounds, eight ounces....never imagined that they would have to spend six to seven weeks in the hospital's NICU....never imagined that one of our sons would be born with a profound hearing loss and that we would have to learn sign language in order to communicate with him.... never imagined that we would have to travel half way across the world to find a doctor to operate on him so that he could possibly have a chance to hear....never imagined any of this because we believed that our kids would be normal, just like all of the other kids in the neighborhood, but our life suddenly changed when our sons were born two and a half months prematurely."

Jordan's dad *Johnny Flowers* recently wrote us that in September, *Jordan* received a pair of new prosthetic ears. These were fashioned at the University of Florida from casts of *Jordan's* twin brother's ears. They were attached using magnets that clip to metal posts implanted in *Jordan's* head by surgeon *J. Scott Hill*, of Children's Hospital of Alabama.

The new ears also secure the processor that sends sound to *Jordan's* auditory brain stem implant. Proud dad *Johnny* says: "You will be amazed at how *Jordan* is adapting to his new environment."



We also want to share the news that *Vonetta's* CHI "Hearing Hear-o Award" is currently on display at the Forbes Galleries (Fifth Avenue and 12 Street) in an exhibition called "*Olympic Gold, 1908-2006.*" The award is accompanied by this statement by *Vonetta*: "I am honored to include this award on behalf of all the people who have been affected, like my son, with profound hearing loss and for those who continue to support our cause."



Heroic Young Teacher “Gives Back” Following Surgery for Acoustic Neuroma

Last month, The Children’s Hearing Institute received donations from the family and friends of Amy Meltzer, who wrote us her story of courage:

Last November, I had surgery for an acoustic neuroma and had it removed at NYU Medical Center. My doctors were Dr. Roland and Dr. Golfinos. I absolutely loved them! They put

me on the track to being positive and how I would cope with having “brain surgery”. I had translabrynth surgery and lost all hearing in my left ear because they had to cut through my mastoid bone to get to the benign tumor in my vestibular nerve in my left ear. It is so hard but I have learned to adjust and have gotten myself in excellent physical condition so I regained my balance and feel great. I am just so grateful for



Brian and Amy Meltzer

my doctors and my recovery despite my hearing loss. However, I feel for those children who have hearing loss or are deaf. I struggle daily with hearing loss but I am a grown up and can deal and have learned to cope but children can’t always do the same. I have 2 young daughters, Peri 6 years old and Dani 2 years old, and if they had hearing loss I would want them to have any and every opportunity to get the best care to improve their hearing. I am also a first grade teacher and I spend a lot of time with children and I see how different children are. I see on a daily basis how difficult it is for children with any type of disability or impairment to learn and to be social. I want to see children with hearing loss or deficit have the ability to be mainstreamed in a regular education classroom and also be given the surgery or modalities they need to be successful.

My husband surprised me for my 33rd birthday with a party. It was his way of washing away our difficult year and an opportunity for us to give back. We also decided that we had to start fresh and celebrate life and what we have rather than sulk and dwell on the horrible experience. Every month I read Echoes and continuously tell my husband that I am inspired by the stories about donations and events. I was especially inspired by a young girl who donated Bat-Mitzvah money to your organization. I couldn’t stop reading that story. I had to share it with as many people as I could. I knew if she could do something like that we as adults had to give back and find a way. My husband knew that if he had a party for me, I wouldn’t want gifts because I wouldn’t want people to do that for me. I didn’t need gifts. We all love them but I really felt that we needed to make donations to The Children’s Hearing Institute so he decided this was the perfect way to do so in my honor. He asked people who were attending the party not to bring gifts but to make a donation on my behalf.

Some people brought gifts which of course was great but I was thrilled to see how many people donated money to your organization. We have been wanting to be a part of CHI and didn’t know how. I kept saying I wanted to donate and would not want gifts. I needed to do this to help others.

Why walk, when you can skate?



On October 28, The Children’s Hearing Institute co-sponsored *Why walk, when you can skate?* a fundraising event organized by *No Limits Theatre* at Trump’s Wollman’s Ice Skating Rink in Central Park to benefit oral deaf children. *No Limits* tells us the kids as well as the families had a wonderful time ice skating around Wollman Rink and bonding with new friends. Through the support of CHI and other funders, *No Limits* will be able to continue its Educational Outreach Program and add on a few new shows before the end of the year. Their goal is to reach as many elementary school aged children in the tri-state area as possible. This program does not only benefit the children of *No Limits* but it proves that all children, no matter what obstacles they face, can achieve their goals and dreams.

NIH Director: Hearing Loss a Key in Future

Last month, National Institutes of Health (NIH) Director *Elias A. Zerhouni, MD*, said that hearing loss is one of the fastest growing areas of disability, and he advised scientists to focus on developing a new generation to look at the systems of biology, rather than one element at a time. “To achieve the breakthroughs we are looking for, researchers need to broaden their understanding, from the basic elements of the system to understanding how all of those elements interact,” he said. “The only way to do that is to break down the walls between disciplines. If you miss that trend, you miss a great opportunity to develop the technologies and cures of the future.” *Dr. Zerhouni*, the 2007 Neel Distinguished Research Lecturer and the man the American Academy of Otolaryngology President *Richard T. Miyamoto, MD*, called “the most important research figure in the whole world,” talked about the paradigm shift medicine is currently undergoing, and stressed that otolaryngologists - head and neck surgeons are essential to the developing future of research. “The aging population is going to drive the medscape, and those changes are going to directly affect you,” he said. “Over the next 25 years, hearing loss will be one of the top four illnesses.” That role includes helping to convince policy makers that funding research is a good thing for both individual citizens and the economy as a whole.

Cochlear Implant and Hearing Aid Families Join CHI and Radio Disney AM 1560 to Educate the Public about Hearing Loss



DJ Jenn with panel: Ronald Hoffman, MD; Jane Madell, PhD; Simon Parisier, MD; George Alexiades, MD; Ana Kim, MD

More than 100 members of cochlear implant and hearing aid families joined us October 7 at Bridgewater's at South Street Seaport for the taping of a special kids' concern show highlighting the challenges of hearing impairment and how to protect your hearing. The show was hosted by *Radio Disney DJ Jenn*, and featured professional experts from The Beth Israel/New York Eye and Ear Cochlear Implant Center, including co-directors *Drs. Ronald Hoffman, Jane Madell, and Simon Parisier*; and *Drs. Ana Kim and George Alexiades*. Radio Disney AM 1560 aired the show during October's *National Children's Health Month*. The show kicked off a year-long awareness-raising campaign during which Radio Disney will air a CHI-sponsored "Hearing Tip of the Week" every Friday afternoon.



The Rosenzweig Family



Emanuel and Abigail Dyer, Gail Taylor, Sandra and Trevor Dyer



Lisa Vasanth with son Brandon, Sophia Altieri



Marcus Sambar, Liz Davison, Nick Sambar, Samantha and Veronica Miller



Martine Lyons, Emani Simms, Chance Lyons, Isabelle King

Three-year old Bilateral CI User Luca Trama Enters Ivy League's Pre-K Class for 2007-2008 School Year



Beth Trama, proud mother of little Luca, sent us this happy update: "On his first day of school, after his 'breakfast of champions' he told his little brother Noah that his 'engines are ready!' And he was off! Upon arrival, Luca 'raced' into his new classroom and joined his classmates. This will be Luca's 2nd year in the mainstream! He attended Ivy League last year, a school that not only embraced him but our family as well. Ivy League helped us meet whatever Luca's needs were/will be. It's no wonder he is 'reved' up each morning before school! With Beth Israel Cochlear Implant Center acting as our 'pit crew' he is ready & set to win many 'checkered flags' this academic year!! Go Luca! VRRROOOOOOOOOOM!"



CHI Teen Music Workshop A BIG Hit!

The Children's Hearing Institute sponsored a Teen Music Workshop October 18th at the Sheraton in Plainview, Long Island. Teens with hearing loss met with Casey Cheffo, a music major from SUNY Albany. She is currently pursuing her Masters in Special Education, Early Childhood Education at LIU CW Post. Casey has played many instruments throughout her school career, although singing has been her first love and where she has received comprehensive training. In college she played in different ensembles, and sang in choruses and bands. Currently, she works in a second grade special education classroom and has taught various music workshops in school as well as during summer camp.

Although Casey's formal training is not with the hearing impaired, her mother who has bilateral cochlear implants, helped her understand how hearing music with cochlear

implants is very different than with normal ears. Casey encourages kids to discover the different sounds instruments can make, and to understand variations in rhythm. She uses age-appropriate, popular music that kids enjoy to distinguish these pat-



terns. This is achieved with hands-on activities with various types of instruments. She is also helping children recognize lyrics to some of their favorite songs. Our goal is to create comfort and trust, so children feel confident enough to gain knowledge of their favorite types of music. They will also sing together and have the opportunity to sing into a microphone!!

Having fun and interacting with one another is an important goal for the teens. With some meeting for the first time, opening lines of communication and ultimately creating friendships can evolve as the workshops progress. Establishing a rapport with teens and creating a positive climate was one of the most important goals during the first workshop. This is a goal Casey plans to continue as they meet during future workshops where they will have the opportunity to interact and sing! Our next scheduled Teen Music Workshop will be held Thursday, November 29th in Plainview, Long Island. **To register please contact Melissa Willis: 212-979-4523.**

'Holy Grail' Of Hearing: True Identity of Pivotal Hearing Structure is Revealed

Our ability to hear is made possible by way of a Rube Goldberg-style process in which sound vibrations entering the ear shake and jostle a successive chain of structures until, lo and behold, they are converted into electrical signals that can be interpreted by the brain. Exactly how the electrical signal is generated has been the subject of ongoing research interest. In a study published in the September 6 issue of the journal Nature, researchers shed new light on the hearing process by identifying two key proteins that join together at the precise location where energy of motion is turned into electrical impulses. The discovery, described by some scientists as one of the holy grails of the field, was made by researchers at the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Institutes of Health (NIH), and the Scripps Research Institute in La Jolla, CA. "This team has helped solve one of the lingering mysteries of the field," says James F. Battey, Jr., M.D., Ph.D., director of the NIDCD. "The better we understand the pivotal point at which a person is able to discern sound, the closer we are to developing more precise therapies for treating people with hearing loss, a condition that affects roughly 32.5 million people in the United States alone."

When a noise occurs, such as a car honking or a person laughing, sound vibrations entering the ear first bounce against the eardrum, causing it to vibrate. This, in turn, causes three bones in the middle ear to vibrate, amplifying the sound. Vibrations from the middle ear set fluid in the inner ear, or cochlea, into motion and a traveling wave to form along a membrane running down its length. Sensory cells (called hair cells) sitting atop the membrane "ride the wave" and in doing so, bump up against an overlying membrane. When this happens, bristly structures protruding from their tops (called stereocilia) deflect, or tilt to one side. The tilting of the stereocilia cause pore-sized channels to open up, ions to rush in, and an electrical signal to be generated that travels to the brain, a process called mechano-electrical transduction. Most scientists believe that the channel gates are opened and closed by microscopic bridges - called "tip links" - that connect shorter stereocilia to taller ones positioned behind them. If scientists could determine what the tip links are made of, they'd be one step closer to understanding what causes the channel gates to open. This is no easy feat, however, because
(continued on following page, back cover)

Courses, Papers, Presentations

■ **Hoffman RA, Parisier SC, Roland JT, Jr.** *In reference to orbital sequelae of rhinosinusitis after cochlear implantation in children.* Laryngoscope. 2007;117(8):1505-1506.

■ **Linstrom, Christopher MD:** *Incidence and Management of Postoperative Complications with Bone-Anchored Hearing Aids.* The Politzer Society, Cleveland, OH, October 13-16, 2007.

■ **Linstrom, Christopher MD; Linda Vetere:** *“Starting Your Vestibular Therapy Program.”* The American Academy of Otolaryngology-Head and Neck Surgery, AAO-HNS National Conference, Washington, D.C., September 18, 2007.

■ **Linstrom, Christopher MD:** *“Cochlear Implantation: 25 Years of Hearing Restoration,”* McGill University Faculty of Medicine, Montreal, October 19, 2007.

■ **Linstrom, Christopher MD:** *“The Bionic Ear: Update on the Cochlear Implant.”* McGill University Faculty of Medicine Alumni Update, October 18, 2007, Montreal, as part of the 25th Anniversary of Graduation of the Class of 1982.

■ **Madell, Jane PhD:** *“Auditory neuropathy/dysynchrony”* presented at Grand Rounds, Long Island College Hospital ENT department, September 27, 2007.

■ **Madell, Jane PhD:** *“Managing children with multiple disabilities”* presented at Grand Rounds, Long Island College

(‘Holy Grail’ continued from prior page)

stereocilia are extremely small, scarce, and difficult to handle. Several proteins had been reported to occur at the tip link in earlier studies, but results have been conflicting to this point. Using three lines of evidence, scientists have now demonstrated that two proteins associated with hearing loss - cadherin 23 (CDH23) and protocadherin 15 (PCDH15) - unite and adhere to one another to form the tip link. “Cadherin 23 and protocadherin 15 have been implicated in a variety of forms of late- and early-onset deafness, and a whole range of mutations can produce different outcomes,” says *Dr. Kachar*, a co-investigator on the study. “Now that we understand what the tip link is made of and what conditions are required to assemble it,” he says, “we can study what it might take to rejoin tip links as a possible method for restoring hearing in people with some forms of hearing loss that may have resulted from disruption of the tip link.”

Cochlear Implant Patients Still Enjoy Music after Implantation

Cochlear implants, which restore hearing in profoundly deaf patients, also allow many recipients to hear and enjoy music, significantly increasing their quality of life (QOL), according to a new study. The findings, presented at the American Academy of Otolaryngology-Head and Neck Surgery Foundation’s Annual Meeting & OTO EXPO in Washington, DC, indicate that while cochlear implant recipients experience a significant decrease in their listening habits, about half still enjoy music. In the results of a questionnaire administered to 52 cochlear implant recipients, researchers discovered 38 percent of respondents listened to music more than two hours a week, with 52 percent saying they still enjoyed music post-implantation. Implant recipients who indicated



CHI 2007-2008 Events Calendar

For further information about these events, please call
Melissa Willis at: 212-979-4523

Educational Conferences for Professionals at Beth Israel Medical Center

December 12

*Auditory Neuropathy/Dys-synchrony:
What School Providers Need to Know*
Controversial Issues in Pediatric Audiology:
The Graduate Center, New York City

February 28

Auditory Verbal Day

February 29

Audiology Day

International Temporal Bone Course

November 29 -December 1

The New York Eye & Ear Infirmary

Family Workshops

November 11

Parent Workshop: Early Intervention
Beth Israel Medical Center, 3:00-5:30 PM

November 29

Parent/Teen Workshop, Part II
Four Points Sheraton, Plainview, 6:30-9:00 PM

Newcomers are Welcome!!!

New Topics will be discussed. Parents will meet with
psychologist *Dale Van Dyke*, and teens will meet to
discuss “*Teens & Music.*”

the quality of sound through their implant was better also had higher results in the quality-of-life questionnaire. It remains unclear whether spending more time listening to music makes the experience more pleasant. The authors believe these findings will lead to a greater emphasis on improving the quality of sound that cochlear implants allow, and therefore the quality of life in implant recipients.

CART Services for the Hearing-Impaired

The Children’s Hearing Institute funded a very successful seminar: *“A Practical Introduction to Auditory-Verbal Therapy”* which took place September 30 – October 2 at the Four Points by Sheraton in Plainview, Long Island. This course was given by *Pamela Talbot*, a certified Auditory Verbal Therapist. The conference was well attended and participants were provided with an overview of the philosophy and an introduction to the strategies used to enhance auditory function in children with hearing aids and cochlear implants. To address the needs of the hearing impaired in the audience, CART Services were provided by Realtime Reporting, Inc. **For more information on providing captioning services for the hearing impaired, please call 516-938-4000 or visit www.realtimereporting.com.**



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Visit our educational website: www.childrenshearing.org



The Beth Israel/New York Eye and Ear Cochlear Implant Center and Hearing & Learning Center

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- New York Eye & Ear Center Coordinator:

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212-844-8778

Director: Simon C. Parisier, MD,

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