

Echoes



THE CHILDREN'S HEARING INSTITUTE
www.childrenshearing.org

AUTUMN 2005

The Children's Hearing Institute and The New York Eye & Ear Infirmary Raise Cochlear Implant Awareness Among Hispanic Americans

On September 15, the story "Cuando llega el silencio" ("When silence arrives"), by journalist *Cesar Céspedes*, appeared in *Hora Hispana*. This Spanish-language newspaper is delivered to 200,000 Spanish-speaking New York City households with *The New York Daily News*. The story showcases five-year old *Joenny Marte*, who was born deaf, and *Roberto Pena*, age 53, who suffered progressive hearing loss. Each had his hearing restored with a cochlear implant at The New York Eye & Ear Cochlear Implant Center. The story quotes Center physicians *Simon C. Parisier, MD* (CHI Founder) and *George Alexiades, MD*, on the need to raise awareness about hearing loss and its treatment among Hispanic Americans, who tend to be less aware of this issue and the treatment option of cochlear implants. Approximately 500,000 to 725,000 Americans could benefit from cochlear implants; yet there are only 59,000 recipients worldwide. New York Eye & Ear Cochlear Implant Center audiologist *Lisa Rosenberg* also was quoted on how audiologists work with cochlear implant recipients to help them learn to hear with the new technology. *Mr. Pena* says: "I have recovered 75% of my hearing and because of my follow-up, I keep recovering more and more." To read this entire story in English and/or Spanish, visit our educational website: www.childrenshearing.org.



New York Eye & Ear Cochlear Implant Center physicians *Simon C. Parisier, MD* and *George Alexiades, MD* with *Joenny Marte*.



New York Eye & Ear Cochlear Implant Center Audiologist *Lisa Rosenberg* with *Joenny Marte* and *Roberto Pena*.

CHI Sponsors Workshops to Help Parents and Families

On September 27, CHI sponsored the workshop: "How Parents Can Maintain a Life in Balance," where parents of children with hearing aids and cochlear implants had an opportunity to discuss their personal challenges. The conversation was led by *Dale Atkins, PhD*, a licensed psychologist and media commentator, who appears regularly on the *Today Show* and *Good Morning America*. The author of five books, including *I'm OK, You're My Parents*, Dr. Atkins contributes regularly to *Ladies' Home Journal*, *Cosmopolitan* and *Parents*. For topics and dates of upcoming 2005/06 CHI-sponsored Parent Workshops see *Events Calendar* inside and/or www.childrenshearing.org.



Dale Atkins flanked by *Esther Friedman* (left) and *Cecile Seth* (right).



Donations to CHI Honor Loving Grandfather of Cochlear Implant Recipient

Grace Dallaglio is a beautiful seven-year old girl who received a cochlear implant at 13 months of age by CHI Founder *Simon C. Parisier, MD*.

“We worship Dr. Parisier for enabling our daughter to have a normal life,” says her mother *Lee*.

When *Grace’s* loving grandfather *Jack Dallaglio* passed away recently, *Lee* and her husband *Al Dallaglio*, with encouragement from *Al’s* sisters, asked friends and family to make donations to The Children’s Hearing Institute in

Jack’s memory. He was always very proud of *Grace* for her positive outlook on life and inquisitive nature. *Grace* is a second grade student in a mainstream classroom and is enjoying every minute. *Grace’s* older sister, *Lauren*, has become a significant role model for *Grace*. For her seventh birthday, *Grace* asked for her own personal CD player and walks around the house listening to music, just like her big sister. *Grace* is a very social, fun-loving little girl with a zest for life and everything it has to offer!

Your Cash and Stock Donations Provide Infants and Children with the Gift of Hearing

Consider making a donation by check or stock transfer to The Children’s Hearing Institute for the holidays to help us provide infants and children with the gift of hearing. Your tax-deductible donations help support critical research studies to eradicate deafness. They also support services to ease the process of educational mainstreaming for children and teens with hearing loss. Your gift will also help us fund educational conferences for professionals, workshops for parents, networking events for kids and families, and grants we make to such organizations as *The No Limits Theater Group*, providing creative esteem-building opportunities for children with hearing loss.

Giving long-term appreciated stock offers you a two-fold tax savings. First, you avoid paying any capital gains tax on the increase in value of your stock. In addition, you receive a tax deduction for the full fair market value of the stock on the date of the gift. For income tax purposes the value of such gifts may be deducted up to 30% of adjusted gross income, with an additional five-year carry forward. To make a donation or stock transfer, call us at: 212-614-8380, or make a donation online at www.childrenshearing.org. We look forward to welcoming you to our family of supporters.

Help Children Who Are Hearing-Impaired With CHI Note Cards — Gifts That Give Back

Looking for holiday greeting cards or the perfect holiday gift? Consider CHI’s new note cards featuring original artwork by international artist *Shoshannah Brombacher Miller*: “Beethoven – The Spiral of Sound.” These high-quality, glossy finish note cards are packaged in sets of ten, with envelopes, at \$25 per set, including shipping. Your tax-deductible purchase helps transform the lives of children who are profoundly deaf. To learn about the artist’s inspiration and the symbolism behind her dramatic work, visit our website: www.childrenshearing.org. To order note cards – perfect for any occasion, all year round - call the Institute: 212-614-8380.



Any Hearing Loss Requires Immediate Medical Attention

The October 24 issue of *People* magazine reported that 26-year old rapper *Foxy Brown* was recently diagnosed with severe sudden sensorineural hearing loss, a condition that affects 10,000 people without warning. The loss occurs due to damage to the hair cells that turn sound waves into signals for the brain, and happens as a result of viral infection, a tumor, trauma, vascular or autoimmune disease or a side effect of some medication. Most suffer loss in only one ear and, when treated early, the condition can be reversible. Unfortunately, Ms. Brown’s condition is more severe, with loss of hearing in both ears. She may be a candidate for a cochlear implant. People need to know that any loss requires immediate medical attention.

Schapiro Fund Grant Brings Good News for Educational Mainstreaming

The Morris and Alma Schapiro Fund recently renewed for 2006 a \$75,000 grant made in 2005 to The Children’s Hearing Institute toward support of critical educational services for children and teens that are not reimbursable by insurance. This generous grant enhances the ability of The New York Eye & Ear Cochlear Implant Center to assist families in choosing the appropriate educational setting for children with cochlear implants and/or hearing aids, work with schools in providing optimal services, and assist families and professionals in maximizing the learning environment for children and teens with hearing loss through local and regional conferences, seminars and workshops.

“Helping Children Hear” Raises \$900,000 To Benefit Children Who Are Hearing-Impaired

On October 30, The Children’s Hearing Institute held our 22nd Annual Benefit Gala – “Helping Children Hear” – at the Time Warner Center, where 350 friends and supporters joined for a festive evening of dining and music provided by performer *Jon Bon Jovi*. The event honored *Lyor Cohen*, Chairman and CEO of Warner Music Group’s U.S. Recorded Music, with CHI’s *2005 Jule Styne Humanitarian Award*. The Gala raised \$900,000 to support deafness research and programs to assist educational mainstreaming of children with hearing loss. “We thank Mr. Cohen and our guests for raising these funds. They will make a real difference in the lives of children and families struggling with hearing loss,” said *Leonard Boxer*, Chairman of the Board. Supporters included music industry luminaries *Ahmet Ertegun* (who served as Benefit Chair), *Clarissa and Edgar Bronfman, Jr.*, *Madonna*, *Paul Simon*, *Melissa Etheridge*, *Mariah Carey* and *Russell Simmons* as well as Warner Music Group, Cablevision, Atlantic Recording Group, Victory Records, Def Jam, MTV Networks, Tommy Boy Entertainment, Goldman Sachs, Advanced Bionics, Cochlear Corporation, Karsch Capital, XXL Magazine, and Access Industries. *Amy Cohen* inspired guests with her film “Listen To Me,” which portrayed the challenges of the Cohens’ daughter *Bea*, whose hearing was restored with a cochlear implant.

“Bea is my light – she reminds me of life’s possibilities,” says Mr. Cohen. “Honestly, I feel like the luckiest person on earth. I promised myself that if Bea could ever hear me tell her I loved her, I would do anything and everything in my power to help other parents have the same opportunity. The bonus is that Bea can now say, ‘I love you, Abba,’ back.”



Elaine & Simon Parisier, MD; Penny Glazier
and Amy & Lyor Cohen



Ahmet Ertegun & Barbara Liberman



Ann & Andrew Tisch



Leonard & Enid Boxer and Mr and Mrs Stanley Zabar



Mr and Mrs Scott Fishman



Paul Simon and Jon Bon Jovi

Positive Deafness News From The UK

Deafness is a major health issue in the UK, as well as the U.S. Deafness Research UK (The Hearing Research Trust) reports that nearly 9 million people in the UK – one in seven of the population – are deaf or hard of hearing. The following stories recently emerged from London:

Crucial Gene for Inner Ear Development Revealed

A researcher at Deafness Research UK (The Hearing Research Trust) - UK's only non-profit organization dedicated to helping people who are deaf and hard of hearing through medical research and education - has established one of the genes responsible for the development of the sensory regions in the inner ear, which include the hair cells that detect sound. This discovery could have major implications in hearing research, especially in the use of stem cells to regenerate hair cells – and could ultimately lead to a treatment for deafness. Professor *Karen Steel* worked with scientists at the University of Hong Kong and Nottingham's Medical Research Council in uncovering the significance of the gene Sox2. The study, published in May's *Nature* journal, looked at two sets of mice, one group completely deaf and the other severely hearing impaired. Both had balance problems. Knowing that hair cells detect sounds and their associated supporting cells in the inner ear are paramount to hearing, the team studied these cells within the ears of the two groups of mice. The deaf mice had no hair cells or supporting cells and malformed inner ears, and the hearing impaired mice had very few hair cells and abnormally developed inner ears. They found that this was due to the lack of Sox2 activity in the ear in the deaf mice and reduced Sox2 activity in the hearing impaired mice. "We have identified a gene that controls development of all the cells that detect sound and balance in the inner ear," says Professor Steel. "Manipulation of this gene could allow us to regenerate key parts of the auditory system in people with hearing impairment. If we want to use regeneration as a therapy to treat deafness, then we have to look further than hair cells. Supporting cells will be just as important because they are needed for the hair cells to survive and function. Sox2 is now the best choice of gene we have to test whether we can trigger regeneration of all the cell types needed for normal hearing."

New International Resource for Researching Deafness Funded

In October, UK's Economic and Special Research Council announced the award of funding for a significant new research center – the Deafness, Cognition and Language Research Centre (DCAL). Based at the University College of London, DCAL will receive 4.5 million pounds over the next five years to study deafness, linguistic systems and communication. The goal is to create a world-class hub of excellence connecting these fields of research in a new way, leading international collaborations. Emphasis will be given to neuroscience and how language is processed by the brain.

"Hearwear" Exhibition Celebrates Hearing Devices

"Hearwear- The Future of Hearing" is currently on view at London's Victoria and Albert Museum until March 5, 2006. The results of an innovative project to radically re-think the future of hearing, "Hearwear" displays designs and prototypes of the UK's best designers, including Ross Lovegrove, Priestman Goode, Industrial Facility and IDEO. The display was designed to show fashionably designed "hearwear" can be as desirable and accessible as "eyewear," and to change the way people think about hearing. The exhibition suggests revolutionary new possibilities in hearing products for everyone, not just people who are deaf or hard of hearing, and introduces the possibility of new products to allow everyone to control and enhance the sounds around us. Imagine having a remote control you can use to instantly block out the sounds of sirens or a screaming child; or a product that allows you to hold a clear conversation in a noisy bar. The display includes stylish and attractive designs for hearing products, some almost like jewelry, that people not only need but also will really want to wear. For more information, and visuals, check out the Victoria and Albert Museum website: www.vam.ac.uk.



Newlyweds Direct Wedding Gifts to The Children's Hearing Institute

Last June, when CHI supporter *Stephen J. Paluszek* married his wife *Violeta*, the couple and *Mr. Paluszek's* seven-year old daughter *Olivia*, asked wedding guests to send donations to The Children's Hearing Institute in lieu of wedding gifts.

"*Olivia, Violeta* and I thought it would be a wonderful gift on our wedding day to remember The Children's Hearing Institute and try in our small way to enlighten others about its special mission," *Mr. Paluszek* says.

"Having directly experienced hearing loss when I suffered from otosclerosis [an often hereditary disorder of the stapes, or innermost bone of the middle ear, causing progressive deafness], I have a keener awareness than most of how important hearing is in our everyday activities and how much we take this precious gift for granted. When Dr. Ronald Hoffman restored hearing to both my ears by stapedectomys [an operation in which the stapes is replaced with an artificial substitute], we were proud to become supporters of the work he shares with Dr. Parisier and Dr. Madell to address both the therapeutic and educational needs of children with hearing loss."

National Institute on Aging Funds Hearing Studies

Researchers at the University of Michigan Health System say they are launching three federally funded studies into the causes of age-related hearing loss and ways to reduce or prevent that loss. Approximately 44 percent of people suffer from significant hearing loss by age 69, 66 percent by age 79 and 90 percent after age 80, the researchers note. The three studies - paid for by a nearly \$6.9 million grant from the National Institute on Aging - will investigate dietary antioxidants and their potential effects on the aging inner ear, the role of stress pathways in hearing loss, and the genetic, cellular and hormonal factors affecting hearing as we age. The three studies should expand our understanding of the mechanism behind the decline in hearing over the life span, says co-principal investigator *Dr. Richard Miller*.

2005/2006 CHI Events Calendar

For information on these events, call The Children's Hearing Institute: 212-614-8380 or visit our website: www.childrenshearing.org. All Parents Workshops and Educators Conferences take place at Beth Israel's Phillips Ambulatory Care Center, 10 Union Square East, 14-15th Streets.

December 6	Educators Conference, <i>Putting the Pieces Together: The CI Child with Multiple Challenges</i>
December 10	Teen-Mentored Photography/Scrapbooking Workshop To enroll, call Susan Kornfeld: 914-557-3053
January 3	Parents Workshop, <i>FM Systems – What you need to know</i>
February 7	Parents Workshop, <i>Language: The Listening & Speaking Connection</i>
February 2/3	Educators Conference, <i>Controversial Issues in Pediatric Audiology</i>
March 7	Parents Workshop, <i>Transitioning to the Mainstream</i>
March 24	<i>Call to Action: Early Intervention for Infants and Children with Hearing Loss</i> , A Continuing Education Program for Neonatologists, Pediatricians, Pediatric Physician Assistants and Pediatric Nurse Practitioners. Co-sponsored by The Children's Hearing Institute and The New York Eye & Ear Infirmary. To take place at Roosevelt Hospital Conference Center.
April 4	Parents Workshop, <i>Cochlear Implants: Newest Technology; Ask The Doctors</i>
May 2	Parents Workshop, <i>Literacy: Ways to Encourage the Love of Reading</i>
June 6	Parents Workshop, <i>Social Skills: Problems and Interventions</i>

Recent Courses, Presentations and Publications

Parisier, Simon MD; Hoffman, R. MD; J. Madell, PhD, CCC-A/SLP, Cert. AVT: American Academy of Otolaryngology /Head and Neck Surgery Annual Meeting, September 25.
Parisier, Simon, post-graduate courses: Management of Cholesteatoma, Cellular Biology of Cholesteatoma, Cochlear Implant Surgery.

Madell, Jane, PhD, CCC-A/SLP, Cert. AVT: "How to Evaluate Speech Perception," International Center for Hearing and Speech, Warsaw Poland, October 2005.

Madell, J. PhD, CCC-A/SLP, Cert. AVT: "Maximizing Speech Perception for Patients with Cochlear Implants," Electro-Acoustic Stimulation Conference, Warsaw, Poland, October 2005.

We Take the Lead on iPod Warnings

Do you listen to loud music while you exercise? Do your teens have the volume turned up on their iPods? Researchers at Boston's Children's Hospital determined that listening to a portable music player with headphones set at more than 60 percent of its potential volume can permanently damage the tiny hairs inside each ear that allow sounds to be heard.

On September 14, The New York Daily News ran the story: "Docs ring warning bells on earbuds." *Dr. Christopher Linstrom*, Director of Otolaryngology and Neurotology at The New York Eye and Ear Infirmary, was quoted: "Certainly the risk of hearing damage is very real, particularly among people who use these types of snug-fitting earphones where there's ambient noise, such as in subways." In October, CHI Founder *Dr. Simon C. Parisier* was quoted on 1010 WINS Radio on the dangers of iPods, noting "loud music is an assault on the ears, that when added to other assaults, such as screeching subways and power tools, can lead to hearing loss by the time you reach your 30s and 40s." In October, *Dr. Parisier* was also featured in a story on the national television show Inside Edition, where he again advised teens and their parents:

"Don't take hearing for granted by exposure to very loud music. The hearing loss it causes is permanent."

Protect Your Hearing At Concerts

Whether your taste is hard rock or pop, you risk damaging your hearing at concerts, says *Dr. David A. Opperman*, of the University of Minnesota's department of otolaryngology. In a study presented at September's Annual Meeting of the American Academy of Otolaryngology/Head and Neck Surgery, *Dr. Opperman* and his colleagues assigned 29 men and women, ages 17 to 59, to sit in a variety of seats at concerts featuring heavy metal, pop or rockabilly music. Two people were placed in each location: front row, stage left, stage right, or far from the stage. One person in each location wore earplugs while the other did not. Before the concerts, the study participants all had normal or near-normal hearing "thresholds," (the softest sounds they could hear) based on the results of a hearing test called an audiogram. After the concerts, when audiograms were given again, 64 percent of those not wearing earplugs had significant hearing thresholds shift, in which they couldn't hear a sound as soft as they could before the concert, compared to 27 percent of those wearing earplugs. "A threshold shift is a decrease in the ability to hear as represented on an audiogram," *Dr. Opperman* said. "The ability to hear before the show was better than the ability afterwards. The shifts occurred regardless of seat location or type of music. The genre of music doesn't seem to matter. The misconception that heavy metal is worse than pop puts the people at the pop concert at more risk."

Dr. Opperman said his study proves that earplugs work, though they are not perfect, as shown by the finding that even some of those wearing the devices had threshold shifts. "The earplugs may not have fit properly." When buying earplugs, which are available over-the-counter, choose those that reduce noise by 21 decibels. Another option is custom-made earplugs, available from an audiologist, which can fit better and provide better protection.

Online Hearing Loss Resources

Did you know that *Medline Plus* is a trusted online resource offering up-to-date news about deafness and hearing loss? This service of the U.S. National Library of Medicine and the National Institutes of Health is located at: www.nlm.nih.gov/medlineplus. For other resources, visit CHI's educational website. Our "Patient and Family Resource Guide" provides a comprehensive listing of resources especially useful for residents of the New York tri-state area: www.childrenshearing.org

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

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- New York Eye & Ear Center Coordinator: *Yvette Sarante*, 212-614-8370

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