

# Echoes

THE CHILDREN'S HEARING INSTITUTE  
www.childrenshearing.org



APRIL, 2007

## Annual Family Fun Day for Children and Adults With Cochlear Implants



Carly Howard, Allison and Kyle Schneider, Kevin Howard

The Almskog Family



The Zwerlig Family



The Winkler Family



On March 31, The Children's Hearing Institute sponsored our Annual Family Fun Day. More than 200 attendees gathered at Madison Square Garden's Play by Play restaurant to enjoy a buffet lunch. Guests were then treated to a free performance of The Ringling Brothers and Barnum & Bailey's Circus...the Greatest Show on Earth. Kids, teens, parents and family members were introduced to one another by our Parents Committee, including: *Carrie and Kris Almskog, Stacey and Jamie Blecher, Brenda Cotsen and Jeffrey Benjamin, Edna and Tom Curley, Elissa and Allen Kestenbaum, Eileen and Brian Riano, and Beth and Vincent Trama.*

"It's so important for families facing the challenges of hearing impairment to share their frustrations as well as their successful coping strategies," says *Jane Madell, PhD, CCC-A/SLP, Cert. AVT*, Co-Director of The Beth Israel/New York Eye and Ear Cochlear Implant Center. "Children and teens with hearing loss are not always able to articulate their needs and feelings. We're gratified we can provide families with support systems for dealing with their challenges."

# Hearing Loss and the Importance of Knowing What the Doctor Is Talking About



Dr. Simon Parisier,  
Founder CHI

The January *New York Times* story "The Importance of Knowing What the Doctor Is Talking About" underscores the need for medical schools, residency programs and physician continuing education programs to include training in clinical communication skills. Often doctors fail to clearly speak with their patients about their medical conditions and how to manage their medications. The consequences, writes *Times* reporter *Jane Brody*, "are poorer health and greater medical costs."

"Misunderstandings can be exacerbated by the fact that doctors and other health care practitioners may not recognize that their older patients may be experiencing hearing loss and are simply unable to hear everything that is being said to them," says *Simon C. Parisier, MD*, co-director of The Beth Israel/New York Eye and Ear Cochlear Implant Center. It is estimated that about 21 million people in the U.S. who could benefit from hearing aids do not use them either because they do not realize they have hearing loss, cannot afford them or do not like to use them. *Dr. Parisier* offers these tips for physicians and other health care practitioners who come into contact with seniors:

- *Recommend a hearing screening to all patients over the age of 65. Hearing loss is the third most prevalent chronic condition among older Americans, after hypertension and arthritis. It can lead to decreased quality of life and depression.*

- *When speaking, always look the patient fully in the face. If you're writing or entering data into a computer and your head is down as you speak, or you are doing a procedure while speaking, your patient may not be hearing you.*

- *Ascertain by his/her feedback if your patient totally understands your explanation of his/her medical condition, your advice and prescription outlines. If the patient has not heard you, in effect, you have not communicated questions, information or instructions.*

- *If while taking a history, an elderly patient appears confused or disoriented it may be that you have not been heard or understood. Ask a family member about his/her hearing. The effects of hearing loss can be mistaken for dementia, or even Alzheimer's.*

- *Provide a written explanation of prescription guidelines and schedules, especially if the patient is taking multiple medications.*

Dr. Parisier also offers these tips for helping patients maximize their experience in the doctor's office:

- *Let your doctors and health care practitioners know you*

*have a hearing problem.*

- *If you wear a hearing aid or listening device, bring it with you.*

- *Ask doctors, nurses and health care professionals to speak slowly and clearly while facing you since lip-reading enhances hearing.*

- *Ask doctors to explain your medical condition in layman's terms.*

- *Come to your appointment prepared. Bring a list of questions, a writing pad and pen.*

- *Two sets of ears are better than one. Bring a family member or friend with you.*

- *Request information in writing, especially if you need to follow a complicated schedule of medications.*

## Personal Cochlear Implantation Stories on Television:

### PBS Pilot Features Beth Israel Cochlear Implant Recipient

The Spring 2005 edition of *Echoes* featured the book by Beth Israel cochlear implant recipient *Michael Chorost, Ph.D.*: "Rebuilt: How Becoming Part Computer Made Me More Human." Michael and his mother *Susan Chorost* (of the Summit Speech School) were featured January 17 on Public Television's *22nd Century*, a one-hour pilot for a potential new PBS science series. The segment focuses on Mike's losing his residual hearing, having cochlear implant surgery, and his activation. For information, visit: [www.pbs.org/22ndcentury/](http://www.pbs.org/22ndcentury/)

### HBO Documentary Highlights Journey from Silence to Sound

HBO's new documentary "Hear And Now" won the audience trophy for best documentary at January's Sundance Film Festival. In the film, screenwriter *Irene Taylor Brodsky* documents the extraordinary decision by her deaf parents *Paul and Sally Taylor* to undergo cochlear implant surgery at the age of 65. The deeply moving story follows the couple, active and accomplished members of the deaf community, allowing us to share their experience of everyday sounds for the first time. For further information on the 86 minute film, visit [www.festival.sundance.org](http://www.festival.sundance.org).

## Educator Liaison Program Receives \$50,000 and \$10,000 Grants

The Joseph LeRoy and Ann C. Warner Fund and the Charles Henry Leach II Foundation have joined with us to empower children who are hearing-impaired by providing \$50,000 and \$10,000 grants respectively to support the Educator Liaison Program of The Beth Israel/New York Eye and Ear Cochlear Implant/Hearing & Learning Centers. The program's goal is to eliminate "risk" and "disability" factors by working with mainstream teachers to help children who are hearing-impaired to succeed in school; develop hearing, speech and language skills; and reach their full life potential. We currently serve 60 schools, and are experiencing rapid growth as our reputation spreads and more families apply. Since such services are not reimbursable through medical insurance, CHI supports them

## Florence McCahill Memorial Fund Created by CHI Board Member



William C. McCahill Jr. at left, with CHI Board member Gregory Fischbach and Ellen McCahill at CHI's 2006 Benefit Gala "We Listen So Kids Can Hear."

*William C. McCahill Jr.* has been a distinguished member of The Children's Hearing Institute Board of Trustees since 1990 and serves as our Treasurer. When his mother *Florence* recently passed away, *Mr. McCahill* asked family and friends to memorialize her by making gifts to CHI. "My long-term commitment to The Children's Hearing Institute is very meaningful to me and my family, especially my wife *Ellen* and daughter *Teresa*. My mother would have been proud to have this fund established in her name," says *Mr. McCahill*. *Mr. McCahill* joined Apollo Real Estate Advisors in 2006. He has been involved in the campaigns of Lincoln Center's Real Estate and Construction Council and Israel Bonds' Real Estate and Construction Division for two decades. He is also Vice Chairman of the New York City Housing Partnership, Council Member of the Urban Land Institute, Adjunct Professor at NYU's Robert Wagner School of Public Policy, and a former Governor of the Real Estate Board of New York. He has been honored for his philanthropic endeavors by Albert Einstein College of Medicine, Lincoln Center and Israel Bonds.

through fundraising. In addition to these grants, this program also is served by an annual \$75,000 grant from The Morris & Alma Schapiro Fund. Continuing philanthropy will enable us to provide Educator-Audiology services to mainstream schools now wait-listed due to financial constraints.

### May is "National Better Hearing and Speech Month"

Since 1927, Congress has designated May as a time to raise awareness of issues about hearing, and speech and language disorders and recognize hearing and speech professionals for their important work. Organizations around the country team up with the Council for Better Hearing and Speech Month to educate the public and offer free or reduced price hearing tests and assistance in obtaining hearing aids. For information on activities around the country, visit the websites for the American Speech-Language-Hearing Association [www.asha.org](http://www.asha.org) and the National Institute on Deafness and Other Communication Disorders [www.nidcd.nih.gov](http://www.nidcd.nih.gov).

### Noisy Toys Can Damage Young Ears

"From traditional noisemakers such as whistles, toy guns and musical instruments to talking dolls and animated stuffed animals, many toys are loud enough to cause permanent hearing damage," says *Paul R. Kileny, Ph.D., Director of audiology and electrophysiology at the University of Michigan's Health System's Department of Otolaryngology*. There is as much as a 20-decibel difference between adult and infant ears; thus, infant ears can be damaged more easily. In addition, children hold toys or games closer to their

ears because of the short reach of their arms. "When you make a judgment about whether to buy a toy or game, hold it close to your ear," Dr. Kileny says. "If a toy sounds loud to an adult, it'll sound much louder to a child." The decibel output of toy musical instruments, dolls, and CD players can exceed the 80-85 level at which it is safe for children to be exposed for extended periods. An MP3 player marketed to toddlers measured at a peak of 120 decibels. Computer games often exceed 110 decibels. Musical instruments can peak at those levels as well. "If your child doesn't hear as well as other children, or doesn't hear as well as six months ago," Dr. Kileny advises, "bring this to your physician's attention and request referral to a licensed audiologist to determine the hearing status." For more information, visit "Hearing Health/Preserving Hearing" at [www.childrenshearing.org](http://www.childrenshearing.org) and these other websites:

- UMHS Health Topics A-Z: Childhood hearing loss <http://www.med.umich.edu/1libr/pa/pahearinghgh.html>
- National Institute on Deafness and Other Communicable Disorders: Noise-induced hearing loss <http://www.nidcd.nih.gov/health/hearing/noise.asp>
- American Academy of Family Physicians: How to prevent noise-induced hearing loss <http://www.aafp.org/afp/20000501/2759ph.html>
- KidsHealth: Choosing safe toys <http://www.kidshealth.org/parent/growth/learning/safetoys.html>
- American Speech-Language-Hearing Association: Noisy toys, dangerous play [http://www.asha.org/public/hearing/disorders/noisy\\_toys.html](http://www.asha.org/public/hearing/disorders/noisy_toys.html)

## ***Kudos to "Hearing Hear-oes" Jackie Toscano and James Youngelson.***

We love to publish stories like these. If you know a special someone who has gone above and beyond to help a child, teen or adult who has hearing loss, contact: *Carol Bohdan*, The Children's Hearing Institute, 310 East 14 Street, New York, NY 10003; fax: 212-614-8259; e-mail: [cbohdan@nyee.edu](mailto:cbohdan@nyee.edu).

### ***Jackie Toscano***

This 'Hearing Hear-o Award' nomination comes to us from *Laurie Mirman, MS, CCC* and *Elaine Guardo, MS, CCC*, Auditory/Oral Classes, P36@PS192 in Brooklyn: "With the changing face of technology, children who were once limited in their communication styles to Total Communication or ASL now had a new viable choice: auditory/oral learning. With access to better hearing came access to more speech and the need for auditory only classes for deaf and hard of hearing children in the public schools. It was this need that *Jackie Toscano* saw and with fierce diligence worked to fill. After years of hard work and persistence Jackie's vision of auditory classes for DHH kids became reality. Now the NYC DOE has its auditory/oral program, classes of deaf/hard of hearing children who are learning through auditory means only. With the generous assistance of the Alexander Graham Bell Association Ms. Toscano has brought highly skilled professional development to the family of teachers, speech pathologists and paraprofessionals who are lucky enough to work within this small cocoon of auditory learning. Ms. Toscano's resolve and determination in affecting this change should be applauded. It is for this reason that we nominate her for a 'Hearing Hear-o Award'. She already is OUR Hearing Hero."

### ***James Youngelson***



**Warren Bryant**

This story comes to us from *Warren Bryant*, who 11 years ago at age 74, was implanted with a cochlear device by *Dr. Simon C. Parisier*. Warren and his wife Elaine have been married for 62 years, and have two children. Warren says: "I am a member of a local Rotary Club for 61 years with perfect attendance every week for 51 years. I am also a volunteer firefighter in the Wharton Fire Department for almost 25 years and am a member of the Exempt Fireman's Association. Having

served in the U.S. Navy in the Southwest Pacific during World War II for three and a half years, I am also a member of my local American Legion Post. Recently for a hobby, I painted many pictures as a self-taught artist using oils and water colors. Golf is one of my favorite sports and I play

quite often during the season. I would like to nominate *James Youngelson*, for a 'Hearing Hear-o Award'. Mr. Youngelson is a prominent and busy attorney who took many hours from his practice to take me into New York for my cochlear implant in 1996, and he stood by me through all phases of the procedure. I'm hearing well now after being profoundly deaf, thanks to his tireless efforts."

## ***CHI Co-Sponsors AG Bell Conference at Mercy College***

On March 11, The Children's Hearing Institute joined with the New York Chapter of The Alexander Graham Bell Association to co-sponsor a conference on social issues for teens with hearing loss. While teens who are hearing-impaired are being educated alongside their hearing peers, many may feel left out of social situations as they endeavor to "fit in." This conference addressed these feelings and provided coping strategies to teens, their parents and professionals who work with them. The event took place at Mercy College in Dobbs Ferry, featuring speakers *John F. Anderson, Jr., LMHC* of The Mainstream Center, *Clarke School for the Deaf* (author of *My Hearing Loss and Me, We Get Along Most of the Time*) and *Kate E. Salvatore, MD* of Princeton Psychiatry, who specializes in child and adolescent psychiatry. *Dr. Salvatore* was born with combined severe-to-profound sensorineural hearing loss in both ears and has a cochlear implant.

## ***Fire Safety for the Deaf or Hard of Hearing***

MedicineNet.com provides important information on fire safety for those who cannot depend on the sound of the alarm to alert them to a fire. There are now smoke alarms on the market that combine sound and light to alert those with limited hearing that there is a fire in the home.

### **Facts & Figures**

- 15 of every 16 homes (94%) in the U.S. have at least one smoke alarm.
- One-half of home fire deaths occur in the 6% of homes with no smoke alarms.
- Half of all fatal fires start at night when people are asleep.

### **Safety Tips**

- Remember to factor in residents' hearing limitations when developing and practicing your home fire escape plan.
- Consider installing a smoke alarm that uses a flashing light, vibration and/or sound to alert people to a fire emergency. The majority of fatal fires occur when people are sleeping, and because smoke can put people into a deeper sleep, it is important to have the necessary early warning of a fire to ensure that they wake up.
- Consider installing a smoke alarm with an extra loud horn. Some alarms now feature horns that sound an 85-decibel alarm.
- Be sure that the smoke alarm you buy carries the label of an independent testing laboratory.
- Keep a communications device nearby. If you use a TTY/TTD device, place it close to the bed so that communication with emergency personnel is possible should fire or smoke trap you in your room.

## Courses, Presentations and Publications

- Linstrom, Christopher, Cosetti M, Amrhein T., *"Perioperative Management of Intracranial Aneurysms and Otologic Disease."* Laryngoscope 117:2007, 35-39. Presented at the Eastern Section of the Triological Society, Toronto, ON Canada in January, 2006.
- Linstrom CJ, Silverman CA. *"Short-term and long-term efficacy of the BAHA for single sided deafness."* Poster presentation, Combined Otolaryngologic Spring Meeting (COSM), San Diego, CA April 26-29, 2007.
- Linstrom CJ, Cosetti M, *"Treatment of Glomus Tumors in the Elderly."* Oral presentation, Combined Otolaryngologic Spring Meeting (COSM), San Diego, CA April 26-29, 2007.
- Madell, Jane R. *"Auditory Processing Disorders,"* Casa Colina's Sixth Annual Trends in Autism Conference, Claremont, CA March 10-11.
- Parisier, Simon C., Guest of Honor and Keynote Speaker. *"Elimination of Profound Deafness – Challenges Faced by Cochlear Implant Technology."* Hoffman, Ronald; Christopher Linstrom, Jane Madell, XI International Conference on Cochlear Implants in Children, Charlotte, NC, April 11-13, 2007.
- Parisier, Simon: Triological Society 2007 Combined Section Meeting, Marco Island, Florida, Feb. 15-18, 2007: *Challenges in Middle Ear Reconstruction, Otology Icons of the 20th Century: Addressing Unresolved Issues.*
- Parisier, Simon: Grand Rounds- SUNY Downstate Medical Center: *"Pediatric Cholesteatoma: An Individualized Single Stage Approach,"* February 22.

## April 25 is "International Noise Awareness Day"

"It is time to address the threat that noise poses to hearing, health, learning and behavior," says *Amy Boyle, Director of Public Education at the League for the Hard of Hearing.* This year the League is once again spearheading an effort to educate the public about the necessity of creating a quiet home, school and recreational environment. Continuous exposure to noise above 85 decibels can be harmful to hearing and research shows that noise does not have to be that loud to lead to stress-related disorders, including physiological changes in blood pressure, sleep, and digestion. Noise can also negatively affect children's learning and behavior. Among the activities planned during International Noise Awareness Day, the League will ask the public to observe the "Quiet Diet" - one minute of quiet, regardless of their location, from 2:15 PM to 2:16 PM. For further information visit [www.lhh.org](http://www.lhh.org)

## EuroHear – Bringing The Genetic Basis Of Deafness To Light

The April medical conference: **The Structure and Operation of the Hair Bundle** will be held at the College de France in Paris, highlighting hearing loss as a critical health issue in Europe. Forty million individuals (more than 10 % of the population) suffer from hearing impairment with two million pro-

foundly deaf. The total financial cost, estimated at 100 billion Euros - including special education, speech therapy, hearing aids, and physician and specialists' fees - is more than the combined economic cost of epilepsy, multiple sclerosis, spinal injury, stroke and Parkinson's disease. The conference is sponsored by EuroHear - Bringing the Genetic Basis of Deafness to Light, a multidisciplinary project comprised of 25 research teams throughout Europe. Launched in 2004, this five-year initiative of the European Commission seeks to provide fundamental knowledge about the function of the inner ear - i.e. how sound waves in the inner ear are transformed into electrical signals and sent to the brain - and to identify molecular defects underlying hereditary hearing impairments. Progress will depend on interaction among human geneticists who seek to identify the susceptibility genes for hearing impairment, animal geneticists who will test the function of these genes in animal models, and physiologists, who will dissect the functions of the genes in vitro. Knowledge gained from this project will contribute to the development of better diagnostic tools for the genetic factors causing hearing loss and open new avenues for future therapies.



## CHI Events Calendar

For further information, please call CHI at: 212-614-8380.

### April 25

*Teen and Parent Workshop*  
Cleary School for the Deaf  
REGISTRATION IS FREE

### May 2

*Workshop for Families:  
It's a Family Affair*  
REGISTRATION IS FREE

*Educational Conference for Professionals:  
Beyond Preferential Seating–  
Creating Real Access in Schools*

### June 3

*Workshop for Parents and Families:  
Transitioning to College and Career Choices*  
REGISTRATION IS FREE

### June 21

*CHI Young Professionals Martini Night Under the Stars*

## Event Sponsorships:

### May 5

Hearing Loss Association of America Walk4Hearing

### October 8

2nd Annual No Limits Walkathon

