

Echoes

THE CHILDREN'S HEARING INSTITUTE
www.childrenshearing.org



FEBRUARY, 2007

Dear Friends,

I join with *Drs. Parisier, Hoffman and Madell*, the Cochlear Implant Center staff, the Board of Directors of The Children's Hearing Institute, and CHI Events Director *Melissa Willis*, in wishing you a healthy and happy new year!

We are pleased to announce that your donations to The Children's Hearing Institute Friends Circle are enabling us to expand *Echoes* this year from four issues to six. This expansion provides a broader opportunity to convey empowering information for families facing the challenges of hearing loss, and the professionals who work with them. It also enables us to inspire our individual, foundation and corporate major gift donors with visible results of their philanthropy: the success stories of children who are hearing-impaired as they flourish in mainstream schools.

As we move toward consolidation of The Beth Israel/New York Eye and Ear Cochlear Implant Center, which is expanding this year at its new location at the Ear Institute of The New York Eye and Ear Infirmary, CHI will also be launching a new electronic newsletter. This will be e-mailed with updates on advanced technologies, new services, staff activities, pro-



Carol Bohdan at far left (yellow jacket); Elaine Parisier in front of her (white sweater); Melissa Willis at very front (black sweater). Cochlear Implant Center staff: George Alexiades, MD kneeling at right (wearing glasses); Ronald Hoffman, MD to right; Simon Parisier, MD behind Dr. Hoffman (grey jacket); Jane Madell, PhD next to Dr. Parisier; Susan Cheffo, MS behind Dr. Madell (pink sweater). Photo taken at *A Family Reunion for Children & Adults with Cochlear Implants, 2005*.

grams and events. To join our distribution list, send your name and e-mail address to: cbohdan@nyee.edu.

As always, we welcome your nominations for inspirational "Hearing Hear-oes," and suggestions for improvements to *Echoes* and/or our award-winning website www.childrenshearing.org. We thank you for your commitment to our cause as we strive to provide the gift of hearing to those in need.

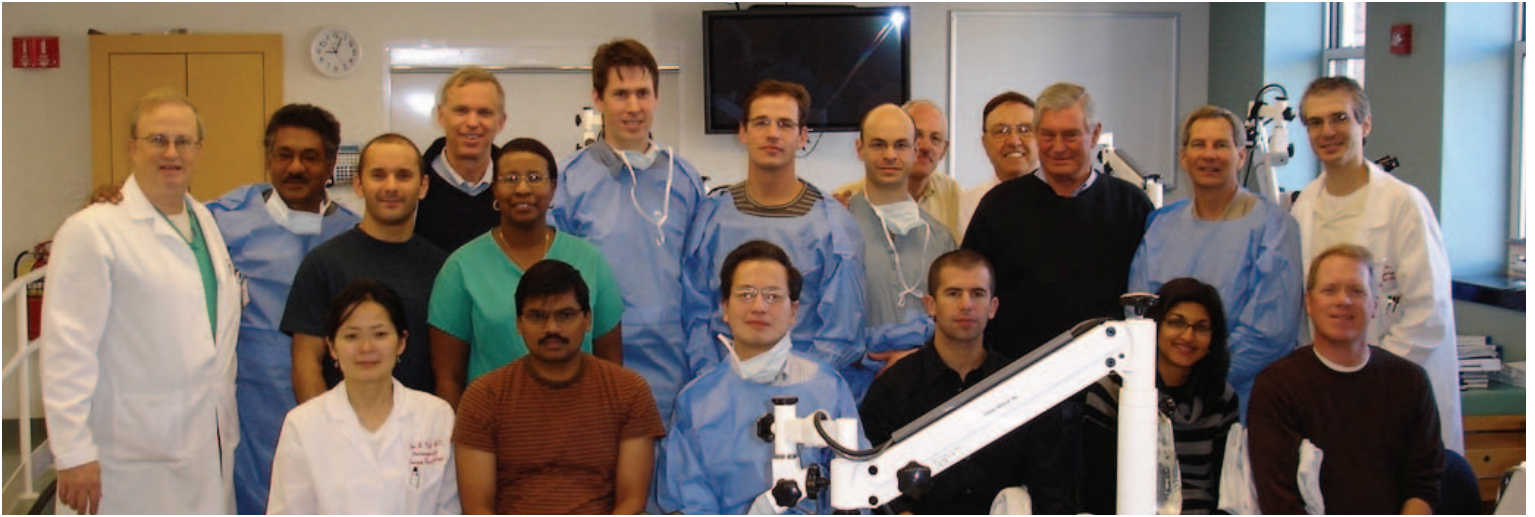
Sincerely,
Carol L. Bohdan
Executive Director

New York Times Publishes Letter from Dr. Jane Madell

On December 12, the following letter from *Jane Madell, PhD, CCC-A/SLP, Cert.AVT*, Co-Director of The Beth Israel/ New York Eye and Ear Cochlear Implant Center, was published in *The New York Times*. The letter was written in response to a story that appeared December 5: "Wanting Babies Like Themselves, Some Parents Choose Genetic Defects." The story highlighted a lesbian and deaf couple from Maryland "who both attended Gallaudet University and set out to have a deaf child by intentionally soliciting a deaf sperm donor."

To the Editor:

I understand deaf parents wanting a deaf child who can share their culture. But they should understand that deaf culture is shrinking. Hearing aids and cochlear implants provide deaf children with the opportunity to learn to speak and to have access to educational, social and employment opportunities. The few deaf parents who are withholding hearing aids and cochlear implants from their deaf children are severely restricting their children's life choices.



Back row (Left- Right) Drs. Christopher Linstrom, Leonard Surage, Rogerio Fernandes, David Barrs, Luna Bailet, Clement McDonald III, Kurt Korver, Eric Bergson, Mr. Arthur Tortorelli, Drs. Joseph Arigo, Michael Hunter, Robert Vallis, George Alexiades. Front Row (Left- Right) Drs. Ana Hae-ok Kim, Ravi Krishnamoorthy, Philip Liu, Roger Crystal, Rena Dhandra Patil, Peter Hillsamer. Not pictured on this day: Drs. Ronald Hoffman and Simon Parisier.

The New York Eye and Ear Infirmary Hosts International Course on Ear Surgery

The New York Eye and Ear Infirmary's Department of Otolaryngology/Head and Neck Surgery held a three-day course in November on "Temporal Bone Techniques" in its new Microsurgical Education Center. During the course, participants practiced bone-anchored hearing aid techniques, cochlear implantation, ossicular reconstruction and the latest stapes prostheses. The conference drew participants not only from the New York tri-state area, but also from Europe, Australia and the Caribbean. *Christopher Linstrom, MD*, served as course director. The faculty included *George Alexiades, MD; Joseph Arigo, MD; Ronald Hoffman, MD; and Simon Parisier, MD*, all specialists in otology and neuro-otology.

CHI's Award-Winning Website Expands Educational Content

The Children's Hearing Institute recently enhanced its award-winning website – www.childrenshearing.org – with a new section highlighting "Frequently Asked Questions" of parents who have children with actual and/or suspected hearing loss. We invite you to visit the site and make any suggestions you may have for further expansion.

Dr. Simon Parisier Helps Judge Graeme Clark Cochlear Scholarships

CHI founder *Simon Parisier, MD*, volunteered his time to help judge the 2006 Graeme Clark Cochlear Scholarships offered by Cochlear Americas. This unique award is open to Cochlear Nucleus Implant recipients around the world, to help them expand their world of opportunities by undertaking university studies. The scholarships consist of financial assistance toward a minimum of a three-year degree at an accredited university, and are paid in installments on the completion of each year of study. They are available to Nucleus recipients who are currently completing their final year of high school, to mature aged students who have been accepted into a univer-

sity course or to current university students. Scholarships are awarded on the basis of academic achievement and a demonstrated commitment to the Cochlear ideals of leadership and humanity. 2006 winners *Abigael Brimhall, Jordan Sack, Kathryn DeVleming, David Duncan, and Rachel Chaikof* will each receive \$2,000 from Cochlear Americas for the next four years or until they graduate. For more about this program, e-mail Recipients@Cochlear.com.

CHI Sponsors AG Bell's Electronic Newsletter

The Children's Hearing Institute is proud to partner with The Alexander Graham Bell Association for the Deaf and Hard of Hearing in making a difference in the lives of children and adults with hearing loss. In 2007, CHI is proudly sponsoring multiple editions of the "AG Bell Update." This electronic newsletter is e-mailed every other Thursday to approximately 8,000 recipients nationwide. The "Update" will include a link to CHI's website. To receive this free service, please contact *Gary Yates*: gyates@agbell.org.

New York Historical Society Exhibition Fully Accessible

Janice Schacter, mother of a child with hearing loss, and advocate of listening devices at Manhattan's cultural institutions, tells us that *New York Divided: Slavery and the Civil War*, at The New York Historical Society, is the city's first exhibition to be fully accessible to people with hearing loss. All of the videos have captioning and are hearing aid compatible via an induction loop, which has been available in England and now finally here in New York. Children on school trips can hear all of the video information directly through their hearing aids without having to wear devices around their necks. The exhibition continues through September 27. The technology is also available in Temple Emanu-El's main sanctuary/chapel and classrooms at The Museum of Modern Art (see more on MOMA programs in the Summer 2006 issue of Echoes posted on our website).

Hadley's Story

The following essay was brought to our attention by Josh Aronson, producer of "Sound & Fury." Cochlear implant recipient Hadley Arnold, an architect and teacher living in Los Angeles, graciously allows us to share her personal experience. Age 42, Hadley was diagnosed with a profound sensorineural hearing loss in 1994. Derald E. Brackmann, MD at the House Ear Institute, her doctor for almost 13 years implanted Hadley with a CI September 25, 2006. She says "hook-up," with audiologist Dr. Jane Gay, followed on October 12th and 13th. On Friday October 13th, it rained, and Hadley heard it:

"Hello my dear friends: An update! Hook-up to the external processor of my new cochlear implant was Thursday + Friday. I'm a work in progress who is feeling like writing, so buckle your seatbelts. Partly for my benefit (feel like yakking/recording this) and partly for yours (in case you think I have insta-hearing): Here's how everything is going.

Basically, I'm used to life in an aquarium. I look out, and there is Joe. His mouth is moving. I hear a muffled sound-- eh aa i uh aa. He is pointing to the cat, and I know it's story time and I put things together and he is saying: 'The Cat in the Hat.' This is the dinner party in Greek I have been attending for the last 12 years. Lots of what feel like mental adaptive habits are in place, correlating one muffled sound to Joe's vowels, other muffled sounds to car engine, dog bark, and not that much else. In fact, at this point those habits are not so much behavioral or mental or cognitive habits as they are well-worn neurological paths (nothing mental or psychological or creative or intellectual about it---just a program written by use). 90% visual/contextual + 10% muffled noise = meaning.

So then, I get a magnet on the side of my head and 24 electrodes in my cochlea/auditory nerve. Two weeks in silence (no eh aa i uh aa; very nice in fact). I get the outer piece Thursday, lots of programming in discrete bits-- tell me (mouthed by the audiologist) when you hear this beep; is this tone too loud?-- for 24 frequencies at a range of decibels, each programmed individually, not as a whole processor. Then the audiologist hits the on button. And what I hear is the following:

I am still at the bottom of the aquarium. A deep dull noise registers in the vestige of the left auditory nerve: Joe must be talking so I look. My eyes say it's Joe, and my eyes say deep male voice, and my eyes get: eh aa i uh aa. What I hear on my right is the earpiece piping in a sound track from somewhere up on the surface: a lot of little bubbles, big bubbles,



Left to Right: Josie Arnold, Heather Barring, Hadley Arnold, Front: Liese Neelin.

and a jungle full of parrots. Up on the surface, Laurie Anderson and Brian Eno are sitting in a very large metal warehouse, with deep echoes and sharp acoustic bouncing, and they are whispering and telling jokes while they work. They are listening to what Joe is saying to me through the aquarium, sampling the sounds of matter in motion all around Joe and around me, and they are piping their interpretation of that information to me. The environmental sounds of a very quiet room-- maybe a computer or buzzing light fixture or whatever-- form a thick bubbly background mixed in with a range of different voices that form a composite known as Joe: Darth Vader at the bottom, a couple of adults with marbles and mouthwash in their throat, a chorus of female spirits whispering, R2D2, and a jungle full of the ever-present parrots. Each of these voices emits their unique version of "Cat" at a slightly different moment. So in comes a one-syllable word in multiple layers of frequency, and also staggered in time. You might think it's hard to stagger and stutter one syllable, but each pixilated voice utters each constituent frequency of the syllable - cat takes maybe 5? I'm guessing? Distinct little sounds to make one that we recognize as a one-syllable word. That it is a word is one level of realization, that it is a human voice is another, that it is Joe is another; all of that beyond reach at first.

On Thursday morning, my brain could not recognize that chatter, bubbling, shading, echoing and staggering as identifiable sound, let alone a word with meaning. It could not distinguish the bubbles in the aquarium (layers of low-grade

background noise) from the spikes that were apparently the most important thing to hear, Joe's voice. It was purely aesthetic, devoid of even bare meaning. I could see that someone was speaking, and correlate that to a spike in activity in my right ear, but to understand, I just lip read. Or I just looked without effort, stopped trying to read, just closed my eyes, and forgot about meaning for a while, while I tried to get a handle on Laurie and Brian's sound show.

By Thursday evening, this began to change a little. I had homework. Since the only sound I can hear, and know for sure what it is saying and how loud it is saying it, is my own voice (by feel in the throat and chest), I read a loud to Josie. (Mr. Popper's Penguins, in case you are wondering). By starting with my own voice, knowing the word, feeling the approximate decibel level at which I am saying it, and hearing it the old way (dull muffled left ear) and the new way (Brian and Laurie's version in the right), it gave the brain a basic set of information to work with. Oh: that is what the words Drake, polar, and ice box sound like when said at conversational level by the person we know as Hadley. Great, says the brain, that's a lot of information; let's start building a new database.

By keeping it simple, the database expands. I watched Josie read a poem at dinner on Thursday, then listened without eyes. I watched Peter speak, I took my eyes away and had him repeat; Oh, says my brain, those are the sounds we associate with these two people saying these simple words; let's call that set, Peter's voice, the other set Josie's. It's not really like a voice yet, either one, it's more like a tear or an event in the fabric of background noise-- a spike that I can grasp is unique to them and soon will sound like a voice that I come to know as theirs. Strange, because I thought I knew their voices; the mind fills in so much to complete the portrait sketched by minimal sound. Likewise, mufflers squeal like what I would have remembered as a digital pig; a cat seems to be emitting a long synthesized croak that seems something more like a steroidal frog; and at the moment, the dogs quack.

Friday was back to the House Ear Institute for day 2 of more programming-- let's bump this up, reach further in this direction, let's cap and soften that one, then 'on' again. Hi Laurie. Hi Brian. By 2:30 on Friday afternoon I drove to Josie's school and picked her up with two buddies for carpool. I am so accustomed to being the dumb butler/deaf chauffeur-- in other words hearing nothing from the back of the car-- that I just assumed my usual servile driving persona and drove along in my accustomed aquarium. The bubbles and the parrots were chattering away; all the little background noises of engine, traffic, etc. The brain, so accustomed to aggressively sweeping all available info for meaning, keeps trying to pass off meaningless noise as words, so I have even in 48 hours gotten into the habit of ignoring the chorus of whispering voices-- the car, I am quite sure, did not just say 'miscarriage upstairs.'

So between the aquarial state, and the new skepticism that Laurie's and Brian's whispery avant-garde chorus might be

playing tricks on me, I of course did not expect to hear anything from the back seat. And then I get a little tear, a spike, in the background chatter. At first it sounded like a pixie, an elf, and Tickle Me Elmo sitting at the bottom of an empty pool playing cards maybe, but then for a second it sounded like: 'Mrs. Rauch is stricter.' It didn't even occur to me that I just heard my daughter talking, because the brain still thinks that can't be possible; must be the engine. But somehow it sinks in. Then I hear: 'Tricky Tuesdays start next week.' And I am not even looking in the rearview mirror to get this! I almost drove off the road when I realized I am actually overhearing the children's conversation, without visual input. Then I got another spike, or event, indiscernible but new and intriguing: it sounded like bells and chimes, a light tinkling. I looked in the mirror to see if this was the unreliable Brian/Laurie chorus of fairies, or whether it could be related to activity in the back seat. It was the sound of little girls laughing.

I am staying a bit cocooned as I ramp up; simplifying the input seems to improve the rate and quality of processing going on though I do have to deal with classrooms and meetings beginning Monday and wonder how all that will go. For now, I see that this is a process, working outward in concentric circles, home at the center. They told me a million times that it would be a multi-month process, but I really did not get it until Thursday morning when they hit the on switch. They are not joking that the brain needs to re-wire itself, establish some new paths, as it integrates acoustic and electrical information, sight and memory, and comes up with a richer database for meaning and one hopes beauty. It really is quite a privilege to be witnessing this; it's not just that I feel grateful for sound (as you know, I am also grateful for quiet); I feel grateful to be able to encounter and observe this miracle called the human brain, doing its thing-- adapting, adapting, adapting-- with little or no input from me.

As for spirits: you can only imagine the sensation of gratitude and communion brought on by last night's rain. It's the thing I have been most looking forward to, and that it occurred on my particular October day could not help but feel like a gift, sent specifically to me. We realized it was raining as the three of us sat at dinner in the candlelight. We turned off all the lights so I could get as much visual cueing on the glass as possible, without reflections. Ah, says the brain, that event, that spike, correlated to those tiny spatters: I think we are hearing rain. So I had to go outside for a while, sat down and put my head close to the brick and held one hand out and leaned so close I was getting spattered up from bouncing drops as well as dripped down upon from above, and Josie came out and climbed into my soggy lap and we listened. She fell asleep and Peter took her in and I stayed out a while longer. And, yes, I couldn't just feel and see the rain, I could hear it.

And those are my first two days. Happy to be able to tell you that. And in case I haven't mentioned it yet, Peter has been a saint. (And my buddy Josie is very articulate!). Thank you for all your great thoughts, good cheer, and loving support. Love you tons." XOXO

Courses, Presentations and Publications

George Alexiades, MD; Joseph Arigo, MD; Ronald Hoffman, MD; Christopher Linstrom, MD; Simon Parisier, MD. Temporal Bone Techniques, The New York Eye and Ear Infirmary, November 30 – December 2, 2006.

Ronald A. Hoffman, MD; Simon C. Parisier, MD. Combined Otolaryngology Spring Meetings (COSM), San Diego, April 26-29.

Simon C. Parisier, MD. Triological Society Combined Sections Meeting, Marco Island, Florida: "Challenges in Middle Ear Reconstruction", Panelist, February 16 "Icons of the 20th Century", Panelist, February 17.

Simon C. Parisier, MD. 11th International Conference on Cochlear Implants in Children, Guest of Honor: "Elimination of Profound Deafness – Challenges Faced by Cochlear Implant Technology." University of North Carolina, Chapel Hill, April 11-14.

Implant Recipient Continues to Flourish

Dr. Parisier and his wife Elaine received a holiday greeting card from Barbara and Jeff Michaels, updating us on the progress of their son Jeremy, an 8th grade student at Queens Lutheran School, who was showcased in our Winter 2006 edition. Thanking Dr. Parisier for "non-stop miracles" since Jeremy's cochlear implantation 11 years ago, they enclosed Jeremy's report card highlighting his exceptional 98% cumulative average. Congratulations on your great success, Jeremy!



Jeremy Michaels with his sister Jennifer and their dog King.

Let Them Hear Foundation Expands Insurance Advocacy Program

Receiving insurance approval for cochlear implant candidates and recipients can often be troublesome. In January, the Let Them Hear Foundation's Insurance Advocacy program expanded nationwide. Due to the Foundation's efforts, several insurers have changed their policies from excluding bilateral cochlear implants. Every individual who receives an insurance denial related to hearing impairment qualifies for the Foundation's help. For further information on this program, visit www.letthemhear.org.

Guest of Honor Dr. Simon Parisier Kicks Off Cochlear Implant Conference

Simon C. Parisier, MD will be featured as guest of honor and keynote speaker at the 11th International Conference on Cochlear Implants in Children hosted by the University of North Carolina at Chapel Hill, Charlotte, North Carolina, April 11 to 14. Dr. Parisier will begin the symposium with a perspective on the history and future of cochlear implants in the very young. The symposium has been organized by Harold Pillsbury, MD and Craig Buchman, MD of the University's Department of Otolaryngology-Head and Neck Surgery. A wide range of nearly 1,000 healthcare professionals will learn how their teams can recognize promising opportunities and harness the power of new tools and techniques to deliver successful solutions to hearing disorders in children. For further information, visit www.ci2007usa.com.

CHI Sponsors Sold-Out Educators Conference

The December 12 **Educators Conference: Social and Emotional Aspects of Hearing Loss**, sponsored by CHI and The Susan Klein Family Center for Educational Outreach, was another sold-out event. More than 100 attendees from the tri-state area, as well as Florida, Maine, Missouri, North Carolina, Pennsylvania and Vermont, participated. The conference featured presentations by David Luterman, D.Ed and Debbie Lang, PhD, as well as Dr. Jane Madell, and staff members of The Beth Israel/New York Eye and Ear Cochlear Implant Center: Susan Cheffo, MS; Nicole Sislian, MA; Rebecca Kooper, Au.D; Meredith Berger, MS; and Elizabeth Ying, MA, CCC-SLP. Michelle Bornfeld, Speech Supervisor at the Strivright/Auditory/Oral School in Brooklyn, told us she was inspired with new strategies to support families while they work through their grief and emotions in relating to a deaf child. We were pleased the post-event evaluation forms included these positive comments:

- "Program was beautifully organized and facilitated."
- "Great conference-came away with some very practical information."
- "Helped to validate some things I am already doing."
- "Bring David Luterman back soon!"
- "Really enjoyed the second presentation from the various support services from here. Nice Job!"



CHI Events Calendar

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

February 1 & 2

Educational Workshop for Professionals:
Controversial Issues in Pediatric Audiology

8:00 AM – 4:30 PM

Thursday – Auditory Verbal Day;

Friday – Audiology Day

REGISTRATION FEE \$95 per/day

Parents Workshops:

REGISTRATION IS FREE

The 2007 schedule will soon be posted on our website.

March 31

Annual Family Fun Day

Want to Receive Our E-Mail Updates?

If you are interested in receiving updates by e-mail pertaining to our conferences for professionals, family workshops, and other events and news, please let us know. E-mail Melissa Willis:

mwillis@nyee.edu



The Children's Hearing Institute
310 East 14th Street
New York, NY 10003

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Contact Us
If you have questions or would like to share a personal story with us, contact:
Carol L. Bohdan, Executive Director, The Children's Hearing Institute
212-614-8261, cbohdan@nyee.edu
Visit our educational website: www.childrenshearing.org



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

- Beth Israel Center Coordinator:
- New York Eye & Ear Center Coordinator:

Surgeons

Director: Ronald A. Hoffman, MD
212-844-8778
Director: Simon C. Parisier, MD,
212-979-4542

George Alexiades, MD
Paul Hammerschlag, MD
Darius Kohan, MD

Christopher Linstrom, MD
Neil Sperling, MD

Educators/

Educational Audiology
212-844-6351
Coordinator: Susan Chetto, MS
Meredith Berger, MS
Lois Heymann, MA, CCC-SLP
Rebecca Kooper, Aud

Social Work
Stacy Purro, MSW

Speech-Language-Auditory Therapy

Michelle Bogaty-Blend, MA, CCC-SLP
Maranna Davila, MS, CCC-SLP
Karen Slotnick, MA, CCC-SLP
Elizabeth Ying, MA, CCC-SLP

Research

Richard Schwartz, PhD

Audiology

Director: Jane R. Madell, PhD, CCC-A/SLP, Cert. AVT,
212-844-8792
Supervisor: Sandra Delapenha, MA, CCC-A

Supervisor Cochlear Implants: Nicole Sisman, MA, CCC-A
Supervisor Hearing Aid Center: Michele DiStefano, MS, CCC-A

Sabrina Alterman, MS, CCC-A
Ariela Bindel, MA, CCC/A

Miriam De La Asuncion, Aud
Nancy Gilston, MA, CCC-A

Megan Kuhlmey, MS, CCC-A
Lori Markoff, MS, CCC-A

Shelly Ozdamar, MS, CCC-A
Lisa Rosenberg, MS, CCC-A

212-844-6351