

Echoes

THE CHILDREN'S HEARING INSTITUTE
www.childrenshearing.org

AUGUST, 2011



Cochlear Implants – A Personal Perspective **by Simon C. Parisier MD**

In May, Simon Parisier, MD was invited to speak at the University of Maryland – School of Medicine (Department of Otolaryngology) Graduation Celebration. In his speech below, Dr. Parisier brings you through the history of deafness and reveals how this journey changed, not only his life, but the lives of so many deaf children and adults.

It is 1976 and I'm a young Otolologist, 10 years out of residency. The pediatricians ask me to consult on a young child being treated for bacterial meningitis. The perfectly healthy child developed a high fever, a headache and has been comatose. She has responded to high dose intravenous antibiotics and is getting better. However, her developing speech is now garbled and incomprehensible. She doesn't seem to respond to sound. Her balance has been affected. The parents say, "Doctor what's happening? Please help her." I explain that the bacterial infection has spread to the child's inner ears and has deafened her. Without hearing, the speech she had developed as a three year old has disappeared. I have to say, "I'm so sorry but your child is profoundly deaf..." I compassionately answer the many unanswerable questions as to what lies in store for their previously perfect child. This experience made me, the young otologist, feel helpless, frustrated and inept.

Historically, what happened to profoundly deaf children?

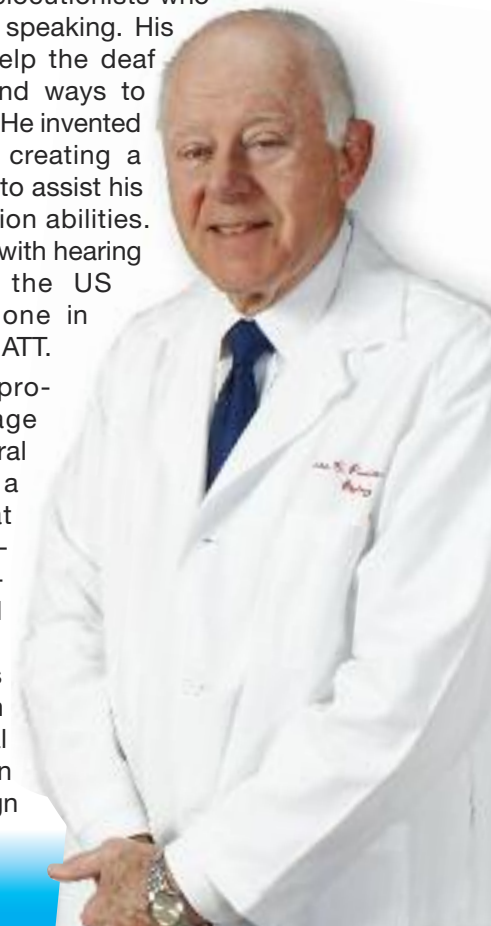
In 1771, Charles Michel L'Abbe de L'Epee, took shelter during a rain storm in a house inhabited by two deaf sisters. In the warmth of the kitchen, he recognized that though they could not talk, they communicated using meaningful gestures. He developed a natural language composed of signs based on the insights he gained from watching deaf subjects and started the first public school for the deaf in Paris. A royalist, his mission was jeopardized by being jailed during the French Revolution but he kept his head and was eventually freed by Napoleon.

Coincidentally, in Connecticut, a physician who had a 7 year old deaf daughter asked his friend and neighbor, The Reverend Thomas Gallaudet, for help in finding a way to educate his child. Traveling in Europe to study methods for teaching deaf students, Reverend Gallaudet visited "L' Institut National de Jeune Sourd de Paris", The French School for the Deaf, and was introduced to Laurent Clerc, a teacher and highly educated student of the L'Abbe. The Reverend studied methods of manual

communication and learned sign language from Clerc. Together, they returned to Connecticut and in 1817 founded "The Hartford Asylum for the Education of the Deaf and Dumb" Four years later it was renamed "The American School for the Deaf". The Doctor's deaf daughter, Mary Coswell, was one of the first students. Interestingly, The Reverend's son, Edward Gallaudet, in 1864, founded the first college for the deaf in Washington DC – Gallaudet University.

In the mid nineteenth century, educating deaf children using sign language was controversial. Oralists, who condemned the use of sign language, trained deaf children by having them touch the teacher's face, throat and chest to feel the vibrations of sound. Their goal was to have deaf children develop understandable speech and to acquire lip reading skills. Alexander Graham Bell's mother and wife were deaf. His Grandfather, father and uncle were elocutionists who taught the art of public speaking. His main interest was to help the deaf develop speech and find ways to overcome this handicap. He invented a voice spectrograph, creating a visible record of speech to assist his deaf wife's communication abilities. His further experiments with hearing devices culminated in the US Patent for the Telephone in 1876 and the creation of ATT.

The conflict between the proponents of sign language and the defenders of oral communication came to a head in Milan, Italy, at "The Second International Congress on Education of the Deaf" held on September 6-11, 1880. A declaration was made that oral education was better than manual education and a resolution was passed banning sign



language. The only two countries to oppose the ban were the United States, who was represented by the Gallaudets, both father and son, as well as Great Britain.

We skip forward to post World War Two; the miniaturization of batteries and vacuum tubes resulted in the development of powerful body-worn hearing aids. These aids were the size of a cigarette pack and had wires that connected to ear molds. They were touted as being able to provide sufficient amplification to effectively provide hearing to the deaf, which in turn would enhance their speech, language, and educational achievements and consequently their employment opportunities. Thus, it was assumed that a hearing impaired person of normal intelligence would benefit from this technological breakthrough. Parenthetically, if deaf people did not succeed, it was their problem!

The two opposing philosophies governing the education of deaf children were the proponents of American Sign Language on one side by – for example–The Maryland School for the Deaf and Gallaudet University, and on the other side by prestigious oral institutions such as The Clarke School for the Deaf and The John Tracy Clinic. These warring factions remained polarized through the years. In 1967, David Denton at The Maryland School for the Deaf tried to find a middle ground between the two by formulating “Total Communication”. This approach to deaf education makes use of a number of modes of communications such as sign, oral, auditory, written and visual aids depending on the particular needs and abilities of the child.

So, how did the profoundly deaf do educationally and economically? Unable to hear, the speech development of these children was severely affected and they experienced serious language delays. Indeed, the average graduate of a deaf high school had a third grade reading ability and a fourth grade computation skill. Shockingly, only forty percent graduated high school. The profoundly deaf individual earned the lowest income compared to all other disabled individuals.

The development of the cochlear implant began in the early 1950's when a French Neurophysiologist, Andre Djournou, convinced an otologist, Charles Eyries, to insert a gold electrode with an induction system into the inner ear of a totally deaf patient with a facial paralysis who was having revision cholesteatoma surgery. When electrically stimulated, the patient heard! They followed up with similar experiments in several additional patients with short-lived successes. Their relationship ended on a somewhat bitter note over a disagreement as whether to partner with industry in order to obtain necessary funding that could be

used to develop a more sophisticated, reliable device... academia should not be tainted by commercialization!

It is of interest that the development of cochlear implant technology has benefited from joint ventures between University and Industry. 3-M manufactured and marketed the House single channel implant. Advanced Bionics' Alfred Mann developed the multi-channel Clarion Implant jointly with the University of California, San Francisco. Ingebord and Irwin Hochmair worked cooperatively with the University of Salzburg to develop the Med-El cochlear implant. Graeme Clark working with the University of Melbourne in Australia developed the Nucleus cochlear implant (Cochlear Corporation). Perhaps, if the French team, in the 1950s, had the vision to work in concert with industry they might have achieved better results.

A patient brought Dr. William House a published report from a French Journal describing Djournou and Eyres experiences. Over the next 10 years, Dr. House in collaboration with Jack Urban, an engineer, developed a single channel, wearable cochlear implant. At the same time, Dr. Robin Michelson working with Michael Merzenich, a neuroscientist, developed a multi-channel cochlear implant at the University of California, San

Francisco. However, in 1972, at the “First International Conference on Stimulation of the Acoustic Nerve” there was serious scientific intellectual opposition. The neurophysiologist's dogma, based on animal experiments, was that when an inner ear hair cell died, retrograde degeneration of the affected auditory nerve fibers ensued. This meant that it would be impossible to electrically stimulate a degenerated nerve. These scientists surmised that the implanted patients were receiving vibro-tactile stimulation rather than hearing. They concluded that cochlear implants would not work.

In 1975, the National Institute of Health sponsored an independent evaluation of the efficacy of cochlear implants that was conducted by RC Bilger, PhD at the Pittsburgh Eye and Ear Hospital. The hearing of the 13 patients that Drs. House and Michelson had implanted was methodically studied. The report confirmed that these patients were hearing electrically produced sounds. Cochlear implants were legitimized and a new era was born!

One would think that the deaf would welcome this remarkable development that could restore hearing. This was not the case. Remember the story I mentioned: the powerful hearing aids that were the size of a cigarette box, which were developed after World War II that would make deaf people hear? Well, now the

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same otologists and audiologists were spinning the same story and saying that deafness could be cured by a new technology called the cochlear implant. The early cochlear implants were also the size of a cigarette box worn on the body with wires that went to transmitting coils worn behind the ears, closely resembling the earlier hearing aids which had failed to benefit them. They considered new implants to be even worse since they required mutilating surgery. As Abraham Lincoln said, 'Fool me once, shame on you. Fool me twice, shame on me'.

The Deaf Culture was outraged! They have their own language – American Sign Language – and they adhere to the politics of Deafness. Meaning...They do not consider themselves as being broken or disabled and do not need to be fixed. They feel that the hearing world has ostracized them as “deaf and dumb” – because they are different, they are excluded. In addition, deaf children born to hearing parents who have no familiarity with deafness should allow their children to be enculturated and embraced by the deaf culture in a deaf environment. Finally, they say that rather than face the painful, damaging rejection of the hearing world, deaf children should be made a part of the more accepting deaf world where they naturally belong.

Over the next 20 years there was a great conflict between proponents of cochlear implants who considered deafness to be a disability and members of the deaf culture who viewed themselves as an endangered alternative society. International Cochlear Implant Meetings were picketed and disrupted. Accusations were made that by forcibly enculturating defenseless deaf children into the hearing world – genocide of the deaf culture was being carried out.

At present, the efficacy of Cochlear implants has been proven and is no longer controversial. Grudgingly at first, the deaf culture has accepted these advances. Most schools for the deaf have incorporated cochlear implant programs into their early intervention programs. Bilingualism has been accepted. A deaf child born to deaf parents who has hearing restored by a cochlear implant can develop fluent English language skills and be educationally mainstreamed while simultaneously using American Sign Language skills to communicate with profoundly deaf parents, grandparents and other member of the deaf culture.

Today, much like the Salk vaccine led to the eradication of Polio, Cochlear Implants is eliminating profound deafness. The passage of a Federal Law requiring Universal Newborn Hearing Screening has proven to be highly effective for the early detection of a hearing loss. When a significant hearing loss is detected, the infant is fitted with hearing aids. If the child does not hear even with the most powerful aids, a cochlear implant can be performed at 6 to 12 months of age. The auditory input provided by a cochlear implant stimulates the development of the brain's auditory centers. Additionally, in conjunction with the cochlear implant, deaf children who are provided with the necessary supportive environment develop normal language and speech capabilities. They are able to succeed in the mainstream and to achieve equally to their hearing peers.

Now, when I see a profoundly deaf infant, I no longer cringe at the bleak outlook that this child faces. With conviction, I can promise the parents that this problem can be overcome and that their child will be able to develop and achieve a normal and successful life, both academically and socially.



Rare View Hosts The Children's Hearing Institute Young Professionals Event

On an early evening in June, with the majestic New York City skyline as a backdrop, friends of The Children's Hearing Institute gathered atop the Hilton Fashion District Hotel at RARE View for our Young Professionals Annual Rooftop Event. The atmosphere was exhilarating as guests mingled amongst friendly faces, both new and old, to show their support of children with hearing loss. Patrons rushed to purchase raffle tickets hoping to win one of our spectacular grand raffle prizes that included items such as: Yankees Legend Suite Tickets, NY Mets tickets, Loews Miami Beach and W South Beach Hotel packages – all donated by generous sponsors.

Yet, another spectacular success, this year's event was filled with dedicated, young, enthusiastic New Yorkers who serve as ambassadors of The Children's Hearing Institute, building awareness of CHI's mission among friends, coworkers, and professional and social acquaintances.

Since 1990, the YP committee has been raising funds to support clinical research and educational programs for children with hearing loss. The funds raised at this event will benefit the Hearing Aid Dispensary Program at the Ear Institute of The New York Eye & Ear Infirmary. Hearing loss is America's number one birth defect and leading disability. A startling 28 million Americans of all ages have some degree of hearing loss, from mild to severe, and the number is expected to soar in the coming years reaching an astounding 78 million by 2030! With hearing loss increasingly recognized as a public-health crisis, we count on your support more than ever to enhance our research capabilities, expand our educational outreach, and further our innovative treatments for children.

The committee is extremely grateful to the Individual and Corporate Sponsors for their support in making the evening a tremendous success: Rare Bar & Grill, Avion Tequila, Absolut, Empire Merchants, NBC Universal, The Feil Family Foundation, Weinberg Properties, Melissa and Michael Boxer, Dr. and Mrs. Simon Parisier, Dr. and Mrs. Ronald Hoffman, Lord & Taylor, Mr. and Mrs. Kenneth Iscol, Empire Search Partners, Newbrook Capital, Phonak, Dr. Ana Kim, Dr. and Mrs. Joseph Bernstein, Dr. George Alexiades, RFR Holdings, Legacy Builders, Loews Corporation, Fischer Development, The Wilpon Family, The Shubert Organization, Flywheel NY, The Glazier Group, and the Monkey Bar.

The Children's Hearing Institute is continually seeking new members from the professional community throughout the Greater New York area to serve on the Young Professionals Committee. If you are interested in joining please contact Melissa Willis at 646-438-7858 or via email at mwillis@nyee.edu.

Event Co-Chairs,
Jason Boxer and
Lisa Weinberg

The Children's Hearing Institute

ROOFTOP EVENT

Lisa Weinberg,
Robert Boucai,
Natasha Graham



Jason Boxer and Adam Miller



Stacey and Jon Ross,
Douglas Boxer





**NBC Universal:
Katherine Rieger,
Alyssa Sands,
Jane Mashburn,
Patricia
Gournardes**

**Jonathan
Schindler
and John
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**Lauren Emden,
Andrew Weinberg,
Daniel Wrublin,
Jenna Weinberg**



**Mary Ellen Maddalone,
Christi Loftus, Steven
Indelicato, Kristen D'Adamo**



**Brittany Wunsch, Jon
Bennardo, Jeff Fells, Paul
Milunec, Marlene Wohl,
Michael Liss and
Jordan Mandel**



**Founders of The Children's Hearing Institute, Elaine and
Dr. Simon Parisier, Chairman of CHI Board, Leonard Boxer**

Obtaining Collegiate Success: One Student's Experience

by John Fazzolari



John was a hearing aid user for 15 years before receiving a cochlear implant in the summer of 2010. He is a 2008 graduate from Villanova University where he received a Bachelor's Degree in Finance. He is currently employed in the financial industry in New York City.

College represents a transition period for students and a time of change. It is both difficult and exciting for high school seniors to move on to the next chapter of their lives. The challenge and adversity of a hearing loss further adds to this intrigue. Many students feel it is crucial that they are not labeled as “disabled” or placed in a different classroom than their peers. It is even more complex for students with a hearing disability to thrive in a rigorous undergraduate educational environment. As such, it is important that students reach out and request whatever academic supports they might need in order to avoid any additional difficulties they may encounter in the classroom.

During the spring of 2004 upon being accepted and choosing to attend Villanova University, I met with both the Office of Disability Services and the Office of Learning Support Services. This included a basic introduction and filling out some simple forms indicating what my disability was and the type of accommodations I required. All information shared with each office is kept confidential and not provided to anyone other than a student's professors. After learning what the school could offer me I developed relationships with people in both offices. Due to my hearing loss I was concerned with numerous obstacles such as large classrooms, teachers with accents or soft, high pitched voices and taking notes without the presence of a note taker. Furthermore, I didn't want to be conspicuous in the classroom and as such, I asked if I could have a friend register with me so he could take my notes. Some students may want a professional note taker, however having a friend sit next to me and keep me in the loop during classes made me feel more comfortable.

Throughout much of my freshman year I had been apprehensive about receiving “special” accommodations, however after my first year it was a much smoother process. A few weeks prior to the start of a semester, I visited both offices to let them know how everything was going and informed them of the classes I needed in order to fulfill my major and minor requirements. This included my preference for certain teachers who I had heard great things about either through word of mouth or online. By my senior year I would simply e-mail the Office of Learning Support Services and the Office of Disability Services with a list of the teachers whose classes I wanted to take and pick up my letters. The letters informed the teacher that I had a hearing disability and explained that if I missed something, it wasn't necessarily because I wasn't paying attention. The school gave me the option of handing the letters to my professors at the

first class of every semester or they would mail the letters. Personally, I preferred to hand each teacher the letter, introduce myself, explain that I had a hearing loss and let them know that I didn't need any special treatment but would appreciate it if I could be facing them in order to read lips as much as possible. All of my professors were very receptive and told me that I should contact them for any reason whatsoever.

Something I found to be helpful to me during my college years was checking out various websites of schools and their message boards. These sites offer tips for teachers who have a student with a disability in the classroom. Tips include suggestions such as: professors should recognize that some students can read lips and others cannot, and that they can improve the academic situation for students who are deaf or hearing impaired by using visual aids, or writing assignments on the board and including due dates whenever possible. School websites also often have tips for conversation etiquette with a person who has a hearing disability such as keeping your hands away from your mouth when you are speaking and understanding that shouting will not help and sometimes makes it more difficult for a person to hear through assistive listening devices. Every student has different needs and it is critical that each student speak with his or her teachers and the university so that everyone involved is aware of what must be done to ensure academic success.

I chose Villanova University because their Office of Disability Services mission was in agreement with the type of educational environment I wanted to be in. Their mission is to have equal access to educational opportunities at Villanova by eliminating physical and educational barriers. My academic experience has taught me that I should not be afraid to ask for what I need. At every turn someone was willing to offer their help. Remember there are many factors that go into the decision of where to attend college. However, students with a hearing loss should ensure that the school of their choice will allow them to receive support services, accommodations and equal access to all University programs. I found a support team that helped me achieve my academic potential and I wholeheartedly believe that was the key to my success.

The Children's Hearing Institute grants \$250,000 to The New York Eye & Ear Infirmary



Dr. Simon Parisier and Dr. Ronald Hoffman presented D. McWilliams Kessler, President and CEO of the New York Eye & Ear Infirmary with a \$250,000 grant in support of the Ear Institute's pediatric services. This gift represents The Children's Hearing

Institute's ongoing commitment to support a "whole child" approach in achieving the best possible outcome for hearing impaired children. Our diversified programs focus on three main areas: addressing a child's medical and clinical needs; educating the professionals that work with the child on an academic level; and providing their parents with the pertinent information needed for the child's in-home success.

A state-of-the-art facility, the Ear Institute brings together a comprehensive, multi-disciplinary approach to diagnosis and treatments of ear disorders. Our diverse group of outstanding specialists are pioneers in cochlear implantation, medical and surgical otology and neurotology, speech therapy, audiology, hearing and balance disorders in adults and children as well as clinical and basic science research.

To learn more about the services, clinical staff and physicians at the Ear Institute please visit their website at <http://www.nyee.edu/ear-institute.html>.

The Susan Cheffo Memorial Scholarship awarded to Corina Lupo



Congratulations to Corina Lupo of Long Island, recipient of the 1st Susan Cheffo Memorial Scholarship. In 1994, before her 1st birthday, Corina was diagnosed with profound hearing loss and was fitted with hearing aids. At age 3, she was implanted by Dr. Simon Parisier at Manhattan Eye, Ear & Throat Hospital. For 18 years Corina strived to overcome the difficulties of her disability and has matured into an honors student, an athlete, and a selfless volunteer in her community and abroad.

Corina will attend Adelphi University in the Fall of 2011 where she has been accepted into the Levermore Global Scholars (LGS) Program. Levermore Global Scholars develop active and informed global citizens who are compassionate about other people, educated in the interdependence of global and local issues, knowledgeable about other societies and nations and skilled in advocating for change and leading civic and global causes. LGS recognize and internalize the importance of social responsibility and justice, civic participation, community engagement, global awareness and global activism.

This Scholarship will provide Corina with additional support as she anxiously awaits the start of her college experience, determined to overcome the challenges of her disability, and undoubtedly accepting all life has to offer – much the same way Susan supported each and every one of her students.

The Susan Cheffo Memorial Scholarship was created in recognition of Susan's commitment to help deaf and hard of hearing children persevere and conquer the challenges they face in their every day lives. She was an extraordinary woman who, despite her own hearing loss, remained positive, focused, and dedicated to helping children succeed both academically and socially. Susan's personal experience and knowledge of hearing loss empowered, not only her students, but her friends, family and colleagues.

Sign Up Today!

Join The Children's Hearing Institute Walk Team



Date:

Sunday, October 2, 2011

Location:

Riverside Park
(West 83rd Street – Riverside Drive)

Time:

9:00am Registration*
Walk Begins: 10:00am (3.1 Miles)

We invite children and adults of all ages to join the CHI Walk Team and Step It Up For Hearing Loss. All Team members will receive a CHI hat and t-shirt and enjoy a day of fun!

Interested:

To join our team, please contact Myrna Farrell at 646-438-7819; mf Farrell@nyee.edu for an instruction sheet or join online at:

www.walk4hearing.org

and click on NYC Walk. Find our team by typing: **The Children's Hearing Institute.**

With your support we can help children move from "a world of silence to a world of sound!"



NY Eye & Ear Infirmary



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The Children's Hearing Institute Educational Outreach Program

UPCOMING CONFERENCES – FALL/WINTER 2011

Cochlear Implants 101 – Hands On Workshops

(CEU Course)

Basic Cochlear Implant Course for Speech Therapists, Auditory Verbal Therapists, Audiologists, TODs & Administrators
Registration limited to 12 Participants. This Hands On Training Course will be held every quarter in 2011

Course Location: The Ear Institute, 380 Second Ave – 9th Fl.

- Friday, September 23, 2011
- Friday, December 9, 2011

Optimizing Auditory Skill Development Through Partnership:

(CEU Course)

Parents, Teachers & Peers – A Three Day Course Intensive – Hands on Therapy Techniques – Only 10 Participants Accepted: Register Early
A course to facilitate a level of understanding and competency in designing and implementing functional listening activities across the age-levels.

Friday, October 14, 2011, Friday, November 4, 2011 & Friday, December 2, 2011

Ear Institute, New York Eye & Ear Infirmary – NYC (380 Second Avenue – 9th Fl)

Register before September 23, 2011: Fee: \$350.00 – After September 23rd – Fee: \$450.00

An Educational Seminar on Hearing Loss

(CEU Course)

(Course CE Sponsor: The Children's Hearing Institute)
For Professionals & Parents: Speaker - Jane Madell, PhD
Topics include: maximizing a child's auditory access to instruction, the key role of parents as advocates, and the best practices for managing hearing loss in a classroom setting.

Session 1 - Managing Hearing Loss in the Classroom

Session 2 - Succeeding with Hearing Loss

Location: Greenwich High School – CT

Wednesday September 28, 2011

Registration Fee: \$10.00/session

Hearing Aid Dispenser CE Course – FALL

Professional Ethics & NYS Law and Infection Control Course
Required by New York State - Dept. of Education,
Division of Licensing

Thursday, October 20, 2011 - Registration Fee: \$85.00

Beth Israel Medical Center – PACC

For more information and to view full course brochures, please visit our website at

www.childrenshearing.org

or contact: Melissa Willis, Executive Director at

646-438-7819 or via email at

mwillis@nyee.edu