

Family Camp

24 Years of Helping Children with Hearing Loss and Their Families

When a child has a hearing loss, it impacts all members of the family. It is common for both parents and children to feel alone and overwhelmed by the social, financial and emotional challenges that can arise when raising a child who has a hearing loss.

Over the course of its 24-year history, the House Ear Institute's Family Camp has helped to address these challenges by offering a safe social setting for kids and parents to relax and share their experiences and feelings with other families who are dealing with a pediatric hearing loss.

The camp has always encouraged tolerance for different philosophies and embraces all communication and language choices, and no family is ever turned away because of economic hardship. For many, the camp's unique and supportive atmosphere and the opportunities it affords for personal growth are not found anywhere else and are what draw families back each year. Camp has become an annual tradition for more than half of the families who attend and for the counselors who volunteer their time. "In any given year, it is where you can witness the development of life-long friendships over the course of a single weekend," said Marilee Potthoff, director of the Family Camp program.

In 2009, the Family Camp weekend was held June 5 – 7 and brought together a record 186 campers and counselors. It was filled with a mix of activities for the entire family, along with separate age-specific recreational programs for the kids and informational workshops and discussion groups for parents. This year, the parent program included an emotionally-charged teen panel discussion on growing up with hearing loss. The camp also featured workshops on the effects of parent role-modeling, how to encourage a child's assertiveness as well as a group session to discuss family challenges, and relaxation techniques to help parents deal with stress. Each year, children's activities include

hiking, team sports, arts and crafts, nature programs, acting and rhythm workshops, martial arts, first aid safety, and challenging activities such as rock-climbing. All youth programs are designed not only to be fun but to build a child's self confidence, encourage their desire to learn, and develop cooperation and respect for others.

The passionate feedback that the Institute receives from parents and counselors each year reinforces the idea that Family Camp is filling a vital need for families with pediatric hearing loss in powerful and often personal ways.

"There is no other place around like Family Camp where the kids can let down all of their armor and relax and relate to other kids who have hearing loss," said parent Linda Ward. "We value that each year, we learn something new, and that we can share





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– DEBBIE HURTADO, PARENT



The 2009 camp was generously sponsored by Southern California Edison, Delta Zeta Foundation, Employees Community Fund of Boeing California, The Woods-Claeyssens Foundation, Ann Pepper Foundation, Sketch Foundation and the Los Angeles Associates of the House Ear Institute.

and learn new things from other families. It is also a place that gives parents a level of confidence and security that a child’s needs are being met. We really like the way the camp is run and would not change a thing.”

“The biggest benefit that I receive from Family Camp every year is the interaction and networking with other parents of deaf children,” said parent Debbie Hurtado. “Mostly, in day-to-day life, a parent feels isolated. This gives me a chance to be in the ‘in crowd’ since we are all struggling with the many issues of raising a deaf child.”

“We’ve been coming to camp for the last seven years, and we love the tranquil atmosphere and the opportunity the camp brings to communicate with other parents and children,” said parent Cathy Warner. “We like that we can all come as a family, and it is one place where my daughter, who has a hearing loss, can be with her peers and feel like she’s normal, not abnormal. She’s made lifetime friends at the camp and is thrilled to help other children with hearing loss as a counselor this year.”

Camp counselors, such as Phil Pico, also shared what they value most about the Institute’s Family Camp. “I volunteer at the Family Camp because it’s rewarding to me to influence the kids in a positive manner and watch them grow up and make lifelong friendships,” said Pico. “It seems most of them come out pretty well.”

With the program approaching its 25th anniversary in 2010, the need for Family Camp continues to grow. The dates for the 25th anniversary session are June 4 – 6, 2010. If you would like more information on the Family Camp program or would like to become a sponsor, contact the Office of Development at the House Ear Institute, tel. (213) 483-4431. ❖

“I think the peace and tranquility in the game has helped me as I lost my hearing.”

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tranquility in the game has helped me as I lost my hearing. But when I make a bad shot, there really isn’t that much “peace and tranquility!”

Looking back five years to my first surgery, I now see that day as an important detail in shaping who I am, but NF2 does not define who I am, it’s only a small part of me. ❖

“My interest in politics and the economy stems from my grandfather, Ron Paul, and his political message of freedom, liberty, sound money, anti-war and a smaller federal government. But I separate my grandfather from my congressman. I love his message and agree with every word because it makes sense to me

and because it is rooted in the United States Constitution. I voted for my grandfather not because of his kinship to me but because of his message and his promise to uphold the Constitution with every vote he makes in the House of Representatives.”

Mark’s mother Lori is proud of the way Mark is handling having NF2 and says that she receives her strength to deal with it from Mark. She remarks on the shock of the diagnosis: “It just struck us out of the blue. No one else in the family has had NF2.”

Despite his health and hearing problems, Mark is a normal 19-year-old. One thing he misses is being able to use the drive-thru at fast food restaurants. At school his teachers use a voice recognition

system that translates their speech into words on the computer screen for him to read. The family uses email to communicate a lot more now. Instead of calling, they send Mark emails and he responds on his Blackberry. She adds that Mark is currently enjoying temporary hearing improvement through a recently acquired hearing aid, which is allowing him to communicate more easily.

Lori says that Mark is very passionate about politics. “He’s



interested in the economy and pays close attention to what is happening in government. He traveled with his grandfather, Ron Paul, during the campaign of 2008 and attended the presidential debates.”

NF2 EXPLAINED

Neurofibromatosis type II (NF2) is a genetic disease of the nervous system characterized by bilateral, non-cancerous, fibrous tumors (also referred to as vestibular schwannomas or acoustic neuromas) that grow on the vestibular nerves. Growth of these tumors results in pressure on auditory and facial nerves that causes hearing loss and facial paralysis. Untreated, these tumors can result in loss of hearing and balance, and ultimately death. Because of their location, removal of these tumors typically necessitates severing the auditory nerve, causing deafness.

When NF2 is hereditary, it results from a genetic mutation and occurs in approximately one in 25,000 live births in the U.S. People with this condition

are born with one mutated copy of the NF2 gene in each cell. In about half of cases, the altered gene is inherited from an affected parent. The possibility of an affected parent passing the disease to a child is 50/50. The remaining cases result from new mutations in the NF2 gene and occur in people with no history of the disorder in their family.

A cochlear implant cannot be used to treat an individual with NF2 because the auditory nerve is not available to carry sound signals from the cochlea to the cochlear nucleus in the brainstem. Instead, an NF2 patient like Mark may benefit from an auditory brainstem implant (ABI), which places tiny electrodes on the brainstem, bypassing the severed auditory nerve to transmit sound information directly to the

brain. “The ABI is a remarkable device that allows many patients deafened by NF2 surgery to hear again,” said Dr. Derald Brackmann, a House Clinic neurotologist who is treating Mark. “But as wonderful as the ABI is, we won’t be satisfied until we can stop NF2 altogether,” Brackmann continued.

To combat NF2, researchers in the Institute’s Center for Neural Tumor Research are seeking new drug-based therapies that will lead to future human clinical trials. Utilizing a tumor “cell line” developed at HEI, and unique animal models, Dr. Marco Giovannini and his co-workers are screening selected agents for those with the greatest potential for limiting growth or eliminating entirely the tumor cells resulting from NF2.