

THE B.I.G. NEWS

BUFFALO IMPLANT GROUP

COMMUNICATING ▶ SHARING ▶ COUNSELING ▶ SUPPORTING



UPCOMING EVENTS

B.I.G. Picnic	Aug. 4
Walk4Hearing Kick-Off	Aug. 13
Walk4Hearing	Oct. 8
DAW Kick-Off	Sept. 23

INSIDE THIS ISSUE

The Medical Mystery	Page 1
President's Corner	Page 2
From the Editor	Page 2
The Medical Mystery (cont.)	Page 3
Walk4Hearing	Page 4
Reflections On	Page 4
Meeting Report	Page 5
Our Readers Say	Page 5
Beyond Cochlear Implantation	Page 6
Parents' Corner	Page 7
Summer Camp	
T-shirt Sale	Page 7
Building Skills For	Page 8
Self Advocacy	
Bye-Bye TTY	Page 8
Treasurer's Report	Page 9
Did You Know?	Page 9
Many Thanks	Page 9
It's Picnic Time!	Page 10
Buffalo Implant Group	Page 11
Basket Raffle Donation Form	

MEETING NOTICE:

Sunset Dinner Picnic

Friday, August 4

5:00 – 8:00 pm

Westwood Park, Shelter #5

175 Pavement Road, Lancaster

The Medical Mystery

By Ron Sipos

Once upon a time there was a boy who was blessed with generally good health, which continued into his adulthood. However, when he reached his mid-50s, things changed.

For a few years there were some odd, strange physical quirks and issues which arose, all of unknown cause or reason, but fortunately they ultimately passed. Doctors were consulted, tests were performed, all with negative results, deemed “unremarkable.”

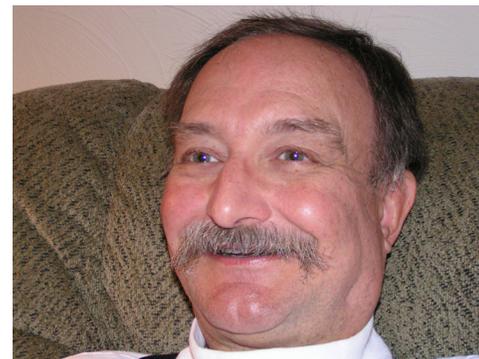
Eventually things came to a head when, over the course of a few weeks, an occurrence of Bell's Palsy began, followed by a loss of balance and equilibrium, general sensory dysfunction, and hearing loss. That's my story, in a nutshell. Life changed, in dramatic ways. I'm a mess!

The onset of my hearing loss was unforeseen. There was a sudden total and complete loss of hearing in the left ear, accompanied by a progressive loss of hearing in the right ear. Medical/health professionals were consulted, and ultimately under the primary care of and coordination by otolaryngologist Steven Buck, M.D., of the Buffalo Medical Group, efforts were taken to forestall further hearing loss in the right ear, and recover hearing in the left ear. Efforts at recovery were unsuccessful, but following a few months of treatment with the dynamic hearing loss in the right ear oscillating weekly from 20% to 80%, the hearing capability in the right ear ultimately stabilized at about 50%.

At that time I also began a relationship with the Buffalo Hearing and Speech Center (BHSC), which provided support and therapy. The staff there, from top to bottom, has been fantastic. Audiologists Alison and Julia, and speech therapist Andrea, have been of particular assistance to me, for which I am extremely grateful.

With the use of a hearing aid via BHSC, I settled into a new life of being a wobbly, dizzy person, who talked funny, with significant hearing loss, and while not finding a ‘comfort zone’ did adapt and accommodate as best as I could and proceeded with my life.

Medical professionals of every specialty (save OB/GYN, for an obvious reason!) were seen, and just about every test imaginable has



been performed, most of them multiple times. I was, and remain, a very bad patient, however, defying diagnosis. Doctors here in Buffalo, and at the Cleveland Clinic, were and are left scratching their heads in dismay trying to determine just what is wrong with my body, and why. Several have mentioned that, at some point, I am likely to be the subject of a very interesting medical journal article. I don't seem to fall into any recognized category of diagnosis, let alone treatment. Medications (some of intense, industrial-strength variety, many of which had some nasty side effects) and courses of treatment have been tried, in hopes of improving my condition, each ineffective and to this point of no avail.

The working theory is that I am suffering from a neurological compromise and deficit of unknown etiology. Primary functional losses are at the base of the brain where the cranial nerves are located, and in areas of the cortex of both the cerebrum and the cerebellum. Best guess is that this is a result of a past infection of some type, viral or bacterial, compromising my auto-immune system, which developed slowly over time before fully manifesting itself. I have been deemed to be non-contagious.

After about half a year of living with reduced hearing, and learning many variations to life with the assistance of my hearing aid, I awoke one morning as usual. Mid-morning one of our cats meowed at me, and it did not sound as it should. I spoke to the cat, and my own voice sounded unusual to me. Turning on both the TV and the radio to QC (quality control) my hearing, I could barely make out what was being said; this limited capacity diminished quickly. By noon I could hear nothing. I entered the world of the bilaterally profoundly deaf.

President's Corner

By Sue Wantuck

Hello! Summer is finally here and hopefully there will be lots of beautiful, warm days to come!

This summer will be very different for me without my beloved dog, Bucky, who passed away this past February. He was one month shy of his 14th birthday. I took his passing hard, as he was such a big part of our family and especially since my boys are now older and more independent. Bucky and I had a very special friendship and relationship. I sorely miss his presence and companionship every day. The grief, sorrow and loneliness I have dealt with after his passing is very similar to that of when I lost my residual hearing seven years ago. Both happened in the month of February. Both situations left me needing to accept what life has dealt and to determine what my next steps would be. When I finally decided to get an implant, Bucky helped me with my rehabilitation. He guided and

led me to different sounds along our daily walks around the neighborhood. He would patiently stop, sit and wait if I heard something I needed to focus on and explore longer, such as airplanes flying above, leaves blowing in the wind, birds chirping in the nest, neighbors doing a variety of outdoor activities. I can remember discovering and hearing "his sounds" for the first time. The way his nails scraped on the concrete sidewalk, the jingle of his name tag around his collar, his panting when he was tired etc. Today, when I venture out for a stroll I carry his paw prints in my pocket and take in all the sounds and think about all of our memories together.

I would like to give you all a friendly reminder that there will be the B.I.G. annual picnic coming up on Friday, August 4 from 5 to 8 pm at the Westwood Park in Lancaster. Please come and join the fun! PLEASE inform Melissa Burroughs that you are coming.

Her email is melissab@smsdk12.org or call/text 716-523-2991 to RSVP

Also the Walk4Hearing is on Sunday, October 8 from 9 am to 1 pm at Delaware Park in Buffalo, NY. Please join our team, enjoy some fresh air, take a nice walk and meet new people!

I hope that everyone has a safe and wonderful summer! Happy Hearing!!!



From the Editor

By Gail Cronin



It has been a busy time for members of B.I.G., with so many things happening. Plans are underway for our annual picnic on August 4. That is our biggest event of year. I do hope that you are planning on coming, and perhaps even bringing a prize basket to donate to our Basket Raffle. Information about the picnic and a Basket Raffle Donation Form can be found in this issue.

Another big event coming up is the HLAA Walk4Hearing on October 8. I'm sure that you've heard by now that the annual walk that is usually held in Rochester is coming to Buffalo this year. If you would like more information about walking in the Walk4Hearing and/or you are interested in helping us volunteer behind the scenes to make this year's event a success, please consider attending

the Walk4Hearing Kick-off event on August 13 at Big Ditch Brewing Company, sponsored by HLAA. More information can be found in Sue's article in this issue.

Also please note that at press time we do not have final details about Deaf Awareness Week, which is held annually in September, but we do anticipate that there will be a DAW Kick-off event held at the Walden Galleria on Saturday, September 23. Buffalo Implant Group usually hosts an information table, along with other groups and agencies that serve people who are Deaf or Hard of Hearing. I mention this now so that you can make a note on your calendars and check our website as the date approaches, since our next issue of The B.I.G. News will not be out until early October.

I would also like to mention that there is an ongoing opportunity for peer support at the Hard of Hearing Peer Support Group sponsored by DAS (Deaf Access Services) on Wednesdays from 10

am – 12 noon at their offices in the Tri-Main Center at 2495 Main St., Suite 446, in Buffalo. After a brief holiday break the group will resume with summer meetings on Wednesday, July 19. There is no charge for this service. For more information you can contact DAS's Community Education and Outreach Manager, Gloria Matthews, at gmatthews@wnydas.org

I hope you enjoyed our cover story by Ron Sipos. I know I did. I love it when a submission can catch me by surprise and make me laugh out loud. I thank Ron for writing such an excellent piece, and sharing so much of his unique story, especially on the short notice we gave him. I would also like to thank two other new writers, Jenna Schwab and Kristen Puglisi, both of whom are professionals who work with people who have hearing loss, for their contributions to this issue. And once again I want to thank all of our Board members for contributing to this newsletter. It really is a group effort.

Attempts at recovery of hearing by my extensive team of treating physicians, including Dr. Buck, were futile. They tried their best.

Deafness is a significant challenge. The ability to interact with the world is greatly diminished. But, interestingly, things aren't silent for those so afflicted. With deafness comes tinnitus, as the brain tries to make up for the loss of reception of outside sounds, to compensate. The brain tries to "fill in" for what's missing. And, it's maddening! Noisy!! And too often with irritating sounds!!! It descended upon me with the loss of hearing in one ear, then with an even greater vengeance upon bilateral hearing loss.

During my time as a non-hearing profoundly deaf person, I began to learn sign language, ASL, mostly self-taught. Fortunately, I seemed to pick it up rather quickly and easily. Not being a member of the 'deaf community' and with minimal contact with other deaf people, I had little opportunity to make practical use of it. Lip reading (also known as speechreading) is much harder to learn, apparently, and that's been much, much more difficult for me. I seem to have no proclivity for it. As even my audiologists conclude, I am a terrible lip reader! Communication suffered. My wife Pauline would typically write lots of little notes to me, so much so that I'd feel bad for her when her hand would be tired and sore.

It was determined by Dr. Buck, along with other otolaryngologists both here in Buffalo and at the Cleveland Clinic, together with the providers at the BHSC, that I was a good candidate for cochlear implants. That process was commenced. Dr. Buck referred me to surgeon Dr. Ernesto Diaz-Ordaz at Buffalo General Medical Center, who after further testing and evaluation performed bilateral implantation surgery in May of 2016, involving Med-El Synchrony Pin Flex 24 CIs. The procedure was successful, and went as anticipated, with no unusual complications or issues. Dr. Diaz-Ordaz is a wonderful, gifted surgeon. The activation of my cochlear implants occurred a month later, in June of 2016, with Alison and Julia of the BHSC attending to that task, who had already been working with me during my time using a hearing aid, and as a non-hearing profoundly deaf person. I've just recently observed my one year anniversaries of both the surgery for and the activation of my cochlear implants. They work!

For the last year I have been on the journey, in the long process of learning how to hear again. Nothing sounds like it did before, with very few exceptions. Live human voice sounds as if it's coming over a very poor quality speaker system at a fast food restaurant drive-through lane, or like the adults used to sound in the old Peanuts TV programs of my youth.

Many sounds are so, so different to me. The afternoon of my activation, my wife and I returned home and, from our kitchen, I heard a sound that I can best describe as a metal rake being repeatedly dragged across concrete. Curious about such an activity on a warm, clear summer day, I asked her who was out in their driveway raking it. Surprised at my request, she looked outside, and said no one. I told her I heard that sound. She looked out again, listened, and said birds were outside singing. Birds singing! Strange! Imagine that!



I'm learning how to interpret the sounds that I am hearing and translate them into something understandable. It's coming along. My audiologists say that I'm progressing very well; better than expected. My learning curve has approximated a reverse-exponential curve, with significant early gains and, over time, continued gains but at a slower rate. I still can't make out 99% of electronically transmitted sounds yet, though, like TV, radio, telephone, any amplified sound, or the computer speakers. Music is still very messy; it's mostly monotone sounds, like a Gregorian chant. Beat and rhythm are pretty good, but melody remains an issue. Live unamplified music, whether vocal or instrumental, is best for me at this point. This is going to be an ongoing journey, but one that I've willingly and enthusiastically embarked upon.

It's a wonder of modern medicine, science, and technology, all guided by the loving hand of God. It's a miracle! God is great!

The past year has been quite memorable. Surgery. Activation. Hearing the first sounds in a long, long time. Significant reduction in tinnitus. Getting involved with the Buffalo Implant Group. Preparing to take ASL classes at Deaf Access Services in the Tri-Main Building to become proficient in that skill. Making my wife roll her eyes, then smile and laugh, when I told her that "you don't love me anymore; you no longer write lots of little notes to me!" Having my first MRI performed with CIs in place, at and by the Dent Institute. The reason I had the one particular Med-El product implanted was upon the unanimous recommendations

of my doctors, therapists, and other health care providers as I need ongoing brain MRIs to monitor my changing and sometimes worsening condition. Yes, tests of various sorts continue, and I really, really, REALLY want to know what is wrong, what the cause(s) were/are, and how this mess in my life came about.

Regarding my most recent MRI, I must confess that, even with the "right" CIs implanted, and with all appropriate steps and precautions taken beforehand, I was still a bit apprehensive prior to the procedure. There was some mild paranoia that my head would explode from within mid-MRI like the famous John Hurt scene in the movie *Alien* where the creature explodes outward from inside his abdomen. Nope! Head intact, CIs still work, good images obtained.

As bad as deafness is, to me the loss of balance and equilibrium is even more debilitating. There's so much I can't do anymore that was once taken for granted. Every movement takes extra time, and planning. Walking is difficult. I'm a "wobbly" one. When walking, I now use a cane; I have acquired several to choose from on a daily basis. Stairs are brutal, especially descending. I haven't driven in years. I really, really miss driving.

With the multiple neurological deficits I am dealing with now, I've also had physical therapy for my vestibular issues, speech therapy at BHSC, blood clots (DVT in left leg, ankle to groin) and related pulmonary emboli (PE) that required hospitalization and medication, and an inventory of medications of various sorts that each seem to have their own benefits, and often issues, some of them insidious side effects. Eyesight, smell, and taste are all at reduced levels. I twitch, I shake, my eyes tend to roll; I get tics, spasms, and cramps.

My lovely bride has merited sainthood for seeing me through all of this, and for taking such good care of me. I should have asked the Pope to start the canonization process for her when he was last here in the country! This whole episode of the hearing loss, along with my other new limitations, is not fair to her; not fair at all. Nor to the rest of my family. Friends and acquaintances, too.

On a cool crisp day last fall, I was outside very slowly raking leaves in our front yard. I heard the sound of a metal rake being scraped across cement. Looking around, I searched for the birds that I believed to be singing nearby. Not seeing any, I finally noticed a neighbor also raking leaves. He moved them towards the tree lawn adjacent to the street, and as he passed over the sidewalk I'd again hear the birds singing. Or so I thought.

At what the hearing world might consider an irritating, annoying sound, I smiled. As a tear slowly found its way down my cheek. It is such a joy to be able to hear again!

Walk4Hearing

By Sue Wantuck

This is a friendly reminder to join our Buffalo Implant Group (B.I.G) team for the HLAA (Hearing Loss Association of America) "Walk4Hearing." It is 3.1 miles long and not a competition. You can run, walk, push kids in strollers, etc. It is a wonderful opportunity for community members, especially those with hearing loss, to come together, have fun and learn. This is a fundraising event and several participating organization/agencies will get a percentage of the money raised to help cover their own maintenance costs. The 2017 Walk4Hearing will be here in Buffalo at Delaware Park from 10:00 am to approximately 1:00 pm on Sunday, October 8, 2017.

I joined the Walk4Hearing in Rochester about five years ago to help and support those who have hearing loss, either Deaf or Hard-of-Hearing. I enjoyed going each year and meeting other people, chatting and sharing life experiences. It is my desire to help others and tell them that it is okay if you have a hearing loss and you are not alone. If you need more information and/or help,

please reach out to me at suewantuck@buffalobig.com

There will also be a Walk4Hearing Kick-off Event sponsored by HLAA on Sunday, August 13 from 1:00 to 3:00 pm at Big Ditch Brewing Company at 55 E. Huron Street in Buffalo. If you would like to attend this informational event, RSVP to Ann Rancourt from HLAA at arancourt@hearingloss.org so that she can get an accurate headcount. Come and learn more about walking, raising money, and/or volunteering to assist with logistics on the day of the Walk.

Date: Sunday, October 8, 2017
Schedules: 10 am Walker
Registration/Check-in: 11 am -- Walk begins -- 3.1 miles
Location: Delaware Park
Meadow/Ring Road
84 Parkside Drive
Buffalo, NY

"The Hearing Loss Association of America (HLAA) Walk4Hearing is the largest walk for hearing loss awareness in the country.

Every spring and fall thousands of walkers - children and their families, young adults, young at heart, and everyone in between - form teams and walk in their communities to increase public awareness about hearing loss, help eradicate the stigma associated with it and raise funds for programs and services. HLAA depends on generous volunteers to raise funds, generate enthusiasm and awareness at each of the Walk4Hearing sites."

Feel free to visit the Buffalo Walk4Hearing webpage at http://hlaa.convio.net/site/TR?fr_id=2429&pg=entry, where you can get more information and register to be a member of the Buffalo Implant Group walk team.



Reflections On: Summertime and the Living is Easy

By: Margie Fitchlee

I recently read that "Every summer has a story." The stories for each of us will vary, but will also remain the same, for those of us with profound hearing loss and deafness have a common bond. I call that bond a journey to better hearing.

It is hard for me to believe that almost eight years have passed since I had cochlear implant surgery. It was the summer of 2009; it was a summer I shall never forget. Celia Thaxter summed it up for me when she said, "There shall be eternal summer in the grateful heart." I have often referred to Dr. Ernesto Diaz-Ordaz as the man who saved me! My heart will be forever grateful to this wonderful man for giving me a chance to hear again. The sounds of summer are all around and those of you who are having cochlear implant surgery this summer will experience such a sense of glory when you get to experience them. You too will have a grateful heart.

Summer has always been a special time of year to me. My birthday was always around the last day of school (June 22) so as a child I not only got to celebrate it, I got to look forward to summer vacation and a chance to re-energize. This summer I get a



Photo by Irina Bos courtesy of Talon Bay Homeowners Newsletter

chance to look forward to some more milestones in my life. I'll be celebrating my 47th wedding anniversary and my 50th class reunion. Where did all of those years go?

L.M. Montgomery wrote, "I wonder what it would be like to live in a world where it is always June." In some ways that is the world I live in. I spend the months of December-May at my home in South Florida. I love the Florida birds, the sunshine and the wildlife. I live in Middleport, New York from May-December, where I love being close to family and friends. I guess I am what they call a "snow-bird."

This past winter my Florida community was bursting with wildlife and birds. We had a resident alligator living in our ponds. "Big Al" was about 12 feet long and weighed over 450 lbs. During mating season this year the alligators got quite brave and started visiting the fronts of neighborhood homes. They were quite bold. A trapper was called in and "Big Al" was taken away. Many of us breathed easier once he was gone. Herons, egrets, wood storks, turtles and other wildlife abound in my community. I am blessed to experience all the wonderful creatures that reside with me.

What is it about summer that puts a smile on our faces? Kenny Chesney felt it. He even wrote a song about it. He says, "It's a smile, it's a kiss, it's a sip of wine. It's summertime." For many it's time to take a vacation, go to the drive-in, go on a picnic, take

in a concert, hit the beach, and simply enjoy life! Many with profound hearing loss will find some of these activities a challenge, but they will persevere. We know firsthand what it means when someone says, "where there is a will, there is a way." We look forward to the upcoming summer picnic held by the Buffalo Implant Group. This year's Summer Sunset Dinner & Picnic is taking place on Friday August 4 at Westwood Park in Lancaster. It starts at 5:00 pm at shelter #5. It will include dinner and a Basket Auction. We hope many will join us for this wonderful event. Come for good food, fun and fellowship.

Summertime for the Board of the Buffalo Implant Group is a time for us to gather all in the name of keeping the Buffalo Implant Group going. We will be working on fundraising event ideas, selling our B.I.G. t-shirts and helping organize the Walk4Hearing, which will be held on October 8 at Delaware Park. Yes, we can say "the living is easy," and busy! An unknown author had it right when they said "summer should get a speeding ticket." For we all know it flies by way too fast. Enjoy it! God Bless!



Meeting Report

By Lisa Hill Nowicki

On Wednesday, June 7 the Buffalo Implant Group held our general meeting at St. Mary's School for the Deaf. Even with one of Buffalo's first beautiful days of the season, around 40 people were in attendance.

Sue Wantuck opened the meeting requesting a vote to change our bylaws to add an additional Corresponding Secretary position to our slate of officers. The request passed. This change will go into effect for our next election in the Fall, creating the additional position beginning in 2018. Sue also touched on the tee shirt fundraiser, the B.I.G. picnic in August and the Walk4Hearing taking place in October.

Guest speaker Lori Davidson, AuD, a Clinical Territory Manager from Cochlear, provided a wonderful presentation on the history of Cochlear Americas, important things to know and what is new around the three latest Cochlear Nucleus systems: the Kanso Sound Processor, Nucleus 6 Sound Processor and the Nucleus 6 Sound Processor with Hybrid Hearing.

History:

Dr. Graeme Clark, whose dad was profoundly deaf, started the Cochlear concept when he was on the beach with a blade of grass and a shell.

Important Things to Know:

The Nucleus 5 has been on the market almost 9 years and on June 30, 2018 the item will no longer be supported.

Three Latest Cochlear Nucleus systems:

The Nucleus sound processors all feature the Dual Omnidirectional microphone with SmartSound 2 Technology (scanning ability) and is compatible with True Wireless accessories via a remote. The scanning ability is designed to adjust to situations around how much speech

versus background noise you hear. This feature can be turned on manually or could be set to automatically change based on the environment. The wireless accessories have been a huge hit and are not compatible with the Nucleus 5. Bluetooth capability is not in the processor, but in the phone clip where you can use the device to answer the phone without needing to reach for the phone directly. It can also be paired with multiple processors. The Sound Processor also has the ability to data log. This will track your sound processor use and can be used as a helpful counseling tool with your audiologist to programs can be altered to ensure an optimal hearing experience. With the Cochlear Nucleus Aqua+ accessory, these systems tout they are the most water-resistant behind-the-ear sound processor. All major components have a 5 year warranty.

Kanso Sound Processor - Though part of the BTE family, it is an off-the-ear processor, it is the smallest and lightest sound processor available that gives you a bit more discretion around hiding your processor. It does not have the ability to plug in an FM receiver directly.

Nucleus 6 Sound Processor - This is the traditional BTE processor that can use rechargeable batteries.

Nucleus 6 Sound Processor with Hybrid Hearing - This processor is designed for those who currently wear a hearing aid, but struggle with high frequencies. Currently you must be 18 years of age or older to be implanted with this device.

Bone Anchored Hearing Aid:

Baha 5 - this device has three power levels and is approved for surgery for those five years of age and over. The Baha 5 can directly pair to iPhone but cannot plug directly into an FM receiver.

Lori concluded her presentation by sharing resources available from Cochlear Family, a service for all those with devices from Cochlear Americas. The program tells you about your device and its warranties and promotions and the Communication Corner, which has age-based programs and a talking-on-the-phone option where you can call in and practice your phone listening skills.

The meeting was followed by a question and answer session. A member of the audience asked about dental x-rays. Lori stated, if you know you are going to have a procedure give us a call to verify the protocol. At the least, it is always good to turn your processor off for an environmental/medical procedure.

Thank you everyone who attended.



Photos courtesy of Will Licata.



Our Readers Say...

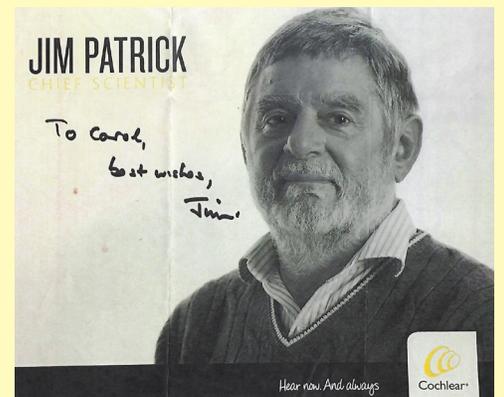
Dear Buffalo Implant Group,

In February I went to my first Cochlear Celebration in Orlando, Florida. It was very exciting to meet the other people who also have the implant. It was interesting to hear the speakers tell us of the different ways you can lose hearing. My husband Jack and I met the inventor of the device I use, Jim Patrick. He was the chief inventor and talked about why he wanted to do this experiment with hearing. We also talked to a man who said he was one of the first few implant users when the original one came out

35 years ago. It's truly amazing how much has changed in technology. It was quite an experience that I will always remember. We will be looking forward to going to the next one in two years. Thank you Jim Patrick. I love being part of the Cochlear Family.

Carol Wesley
Buffalo, NY

Editor's Note: The Cochlear Celebration is a biannual convention sponsored by Cochlear Americas for all users of their devices.



Beyond Cochlear Implantation

By Kristen Puglisi, M.A., CCC-SLP, Licensed Speech-Language Pathologist

So you're a recent cochlear implant (CI) recipient and your implant processor has been activated and programmed - what next? According to the FDA, "The patient's willingness to experience new acoustic sounds and cooperate in an auditory training program are critical to the degree of success with the implant."

In the process of undergoing cochlear implant surgery, between 12 and 22 electrodes replace 20 thousand hair cells in the cochlea of the inner ear. The electrodes then bypass damaged hair cells to stimulate the auditory nerve directly. Why is this important? The brain is ultimately responsible for hearing and interpreting environmental sounds and spoken language. Thus, your brain requires time, and plenty of dedication through practice, to accurately interpret auditory input through the CI electrodes. In the same way you wouldn't expect to perform like a concert pianist without taking piano lessons, you cannot expect to hear successfully without participating in an auditory training program.

Alison Ulatowski, an audiologist at Buffalo Hearing and Speech Center, sheds light on the importance of auditory training services, also known as aural rehabilitation therapy, "Continuous aural rehabilitation therapy with a speech-language pathologist is so, so huge. From the moment patients first come in for their cochlear implant evaluation, we stress the importance of aural rehabilitation to take them to maximal benefit."

In aural rehabilitation therapy, which generally begins within four to six months of your initial stimulation date, a licensed speech-language pathologist will guide you through a program designed specifically for your needs. The speech-language pathologist collaborates regularly with the audiologist to fine tune patient goals, familiarize the patient with CI technology, and adjust the technology as needed. "A collaborative relationship between the audiologist and speech-language pathologist makes all the difference in the world," says Ulatowski. "Going back and forth helps us to brainstorm and provide the patient with the best services."

Aural rehabilitation therapy is not only centered around improving the patient's auditory perceptual skills, but also educating and training the family member, or primary communication partner, who accompanies them. A family member's

support and participation in therapy is crucial to patient improvement. The FDA states that, "A family member should be included in the training program whenever possible to provide assistance."

During training sessions, the speech-language pathologist presents the CI patient with listening exercises in which they must rely on audition only. Training exercises are almost always presented through the use of an acoustic hoop (i.e., typically an embroidery hoop covered in loud speaker fabric), which is designed to impede lip reading while transferring spoken language with no loss of dB or sound quality. Therapy will target a variety of auditory perceptual skills, ranging anywhere from speech sound discrimination to listening in noise.

Auditory training exercises provided during therapy sessions should then be carried over in the patient's home environment with the support of their family member. These exercises should be completed so that the patient cannot see their family member's face, which can be accomplished through the use of an acoustic hoop, or by sitting next to or behind the patient. "Doing the homework and doing the lessons at home and reviewing them when I come for the next visit... shows how things are progressing or what needs more work," says Carol Wesley, who underwent cochlear implant surgery in December 2015 and has received auditory training therapy at Buffalo Hearing and Speech Center since July 2016. "It's not something that's going to come immediately; it takes some time to see progress because it's a normal thing for your brain to get adjusted to the speech and to the different tones."

Self-advocacy strategies learned during aural rehabilitation sessions, such as requesting for repetition or clarification, or requesting the topic of conversation in a group setting, should be practiced at home during carry-over activities and in every day conversational speech. Family members must also learn to utilize communication strategies in these same environments. Helpful tips for family members to increase successful communicative interactions with the CI user include but are not limited to the following: gain the CI patient's attention first, talk at a slightly slower rate, move closer to the patient, speak clearly, do not obscure your mouth, rephrase (rather than repeat) the message, speak up without shouting, move away from background noise, stand in

good light, and ask the CI patient what can be done to make communication easier. (Wayer, D.S., Ph.D., Abrahamson, J.E., M.A. (1998)

Patients and family members who focus on the positive aspects of cochlear implant listening while maintaining realistic expectations will experience greater levels of motivation and success. Each therapy session should include patient counseling to troubleshoot issues, as well as discussion and documentation of "what's going well" with the implant. Jerry Webster*, who underwent cochlear implant surgery in the winter of 2016 and has received aural rehabilitation



therapy since the summer of 2016, reported during recent therapy sessions that he was able to hear a clock ticking from 16 feet away. Like many patients, though, he continues to experience challenge with understanding spoken language in noisy environments. "I think it's important that people don't get their aspirations ahead of reality, and reality is different for everyone," says Jerry, "Not to be discouraged, (but) don't set your expectations too high. It takes a while. You have to be 'all in' in order to achieve the maximum benefit."

Aural rehabilitation therapy services are essential to the listening success of CI recipients, but for patients who are not able to access therapy in the clinic setting, there are alternative options. "We certainly encourage any sort of therapy you can receive from manufacturer resources and complete at home," says Ulatowski. Educational materials and informational articles are attainable through each of the CI manufacturers, including Cochlear Americas, Med-El, Advanced Bionics, as well as your audiologist.

*Respondent's name has been changed to protect his privacy.

Parents' Corner: Summer Camp

By Lisa Hill Nowicki

It's not too late to sign your kids up for summer camp. There are many summer camps for Deaf and Hard of Hearing Children and Teens. Gallaudet has a wonderful webpage that identifies camps by state through the following link:

<https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKewjLIYPricPUAhXIRyYKHcx2DB4QFghLMAA&url=http%3A%2F%2Fwww3.gallaudet.edu%2Fclerc-center%2Finfo-to-go%2Fnational-resources-and-directories%2Fsummer-camps.html&usg=AFQjCNFCG9wYf36hYtOrrhItZUfOwe2WaQ>

In the Western NY area, Rochester Institute of Technology's NTID (National Technical Institute for the Deaf) division offers a variety of camps for deaf or hard-of-hearing kids. There is a TECHGIRLZ/BOYZ camp for girls and boys entering grades 7, 8 and 9 who are interested in science, technology, engineering and math. As of June 16 there were still some openings for the camp which will take place July 22 - 27, 2017.

Outside of Western NY, the AG Bell Association has a summer program called LOFT - Leadership Opportunities For Teens. This program is dedicated to shaping and transforming the lives of deaf and hard of hearing teens by teaching them valuable skills. Among these skills are self-advocacy, self-confidence, leadership, and communication. It looks like this 5 day camp rotates to different cities every summer. This summer it is in Washington D.C.

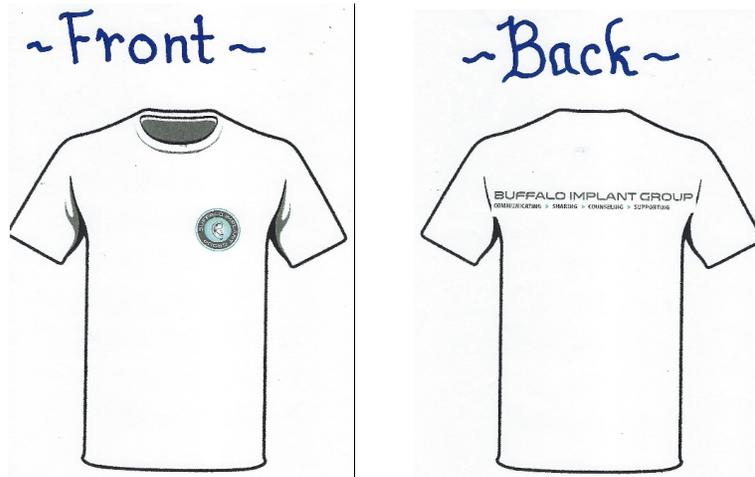
There is also Camp Mark Seven in the Adirondacks that has a variety of different programs for deaf kids and one for hearing children of deaf parents.

If you or your child has recently attended a camp for deaf and hard of hearing children and teens, please let us know, as I would love to hear about it and share it with our B.I.G. family. My email is lhill@rich.com.



T-shirt Sale

We currently have newly designed B.I.G. t-shirts on order, which will be available for sale at the picnic on August 4. All shirts are grey with our logo on the front left side and our mission on the back. Below you can see an approximate artist's rendering. They will be available on a first-come-first-served basis in sizes small, medium, large, and extra-large. If you are unable to attend the picnic, but would like to pre-order your shirts to ensure that you can reserve your preferred size(s), fill out the form below and mail it to us along with your check made out to Buffalo Implant Group. All shirts are \$20 each, with profits from this sale going to support B.I.G. Shirts that are paid for will be held for you until the next meeting unless other arrangements are made.



T-shirt Fundraiser Pre-Order Form
\$20 each – Grey – S, M, L, XL

Name: _____

Sizes(s): _____

Quantity: _____ Total Funds Enclosed: \$ _____

Buffalo Implant Group, P.O. Box 350, Clarence Center, NY 14032-0350

Building Skills for Self-Advocacy

Jenna Schwab, M.S. Teacher of the Deaf

The old proverb, “it takes a village to raise a child” also rings true when applied to self-advocacy with students who are deaf or hard of hearing. Many students will be faced with situations throughout their lives, in which knowledge and confidence will empower them to self-advocate as they see fit. It can be easy for a student to use these skills in a 1:1 setting, especially with a familiar adult; however it may be intimidating for a child to do the same in a situation with someone less familiar to him/her. Therefore, the collective effort of the “village” can foster and nurture the confidence necessary for a child to learn these skills.

The foundation for this skillset begins with education of those around the student, including families, teachers, staff, and peers. At the beginning of each school year, it is essential to provide an in-service to educate the staff with regards to the student’s specific modifications, accommodations, strategies, equipment, and troubleshooting. This in-service allows the staff to ask questions, voice concerns, and build rapport with the Teacher of the Deaf, fostering a team better equipped to support the student.

Education does not end with the adults working with the student. It is vital for peers of the student to also be informed and educated regarding hearing loss

and the equipment necessary. This can be done in a variety of ways, including presentations by the Teacher of the Deaf, the classroom teacher, parent, and/or an older student with a hearing loss. Videos that are provided by implant/hearing aid companies are also a great teaching tool that engage young students and help to address any questions they may have. In my professional experience, a combination of these techniques has proven most effective. For example, this school year an older student talked to a kindergarten class about his experiences, showed them his equipment, and allowed them to ask questions. Following this, a video was shown, and again questions that arose were encouraged and answered by the classroom teacher and Teacher of the Deaf. A better-informed group of peers creates a more welcoming environment for the student, and as such confidence and self-esteem can only grow stronger.

Building confidence begins at home as well as in the 1:1 setting, and can later be carried over to a more natural environment. Students must be confident before they can advocate for themselves. At home, it is important for parents/family members to work with their child on confidence building activities, such as setting small goals, praising the achievement, and talking about the child’s hearing loss. This should also be reinforced in school by both

the Teacher of the Deaf and the classroom teacher. Again, education is crucial for the student’s success. The student should be able to talk about their hearing loss in an age appropriate manner, including what their hearing loss is, what equipment is necessary, and what accommodations and modifications they may need in the school setting. The 1:1 session is a great opportunity to work on practicing these skills. Once the student is comfortable with explaining their hearing loss to a familiar adult, a next step may be to have other adults, such as other teachers or staff members, ask the child questions regarding their hearing loss. This will better prepare the student for un-staged questions that may arise in the future.

Using the techniques mentioned above, the knowledge and confidence gained will help to prepare the student to self-advocate in future situations. During the child’s education, they may encounter curious new peers, substitute teachers, unfamiliar staff, or other adults who may have little to no experience with a hearing loss. When these situations occur, the child will be better prepared to self-advocate for their needs and answer questions independently. Therefore, the collective effort of the “village” is essential to help empower the student to advocate on their own.

Bye-Bye TTY

By Gail Cronin

Because technology is evolving, the TTY (teletypewriter) devices that so many people with hearing loss have relied on for communication could be replaced by more commonplace computers and smartphones. The technology for Real-Time Text (RTT) is now more accessible than ever.

Most of us who use text messaging do not currently use Real-Time Text. We type our message, sometimes edit it, and then hit the “send” button. In Real-Time Text, users send characters as they are typed, in real-time, without any delay or need to hit “send.” Some people might prefer standard texting so that they can edit their messages, but for many people Real-Time Text is a time saver, and in some cases a life saver. Real-Time Text allows 911 operators to communicate with

users without any delay. It is also used in real-time CART and live captioning, among other services and systems.

Thanks to a petition from cell phone carrier AT&T, the Federal Communications Commission (FCC) has recently updated its regulations to include Real-Time Text as an option to fulfill accessibility standards. Prior to December, FCC regulations required phone companies and IP (internet protocol) networks to provide only TTY services. Now, newer technologies such as Real-Time Text can satisfy those regulatory requirements. This change will encourage more access, and will eliminate the need for individuals and groups to maintain outdated equipment. Software and phone apps that enable Real-Time

Text can be made available to anyone who owns a computer, tablet, or smartphone.



The new FCC regulations protect those who choose to use TTY’s by requiring that new systems and apps be compatible with TTY’s. However, it is inevitable that eventually the TTY will become extinct as Real-Time Text and other platforms yet to be developed become standard.

Treasurer's Report

By Lisa Hill Nowicki

Hello everyone. Thank you to those that continue to pay their dues. We really do appreciate it. So far about 60% of our readers have paid for the 2017 year. If you are wondering where you stand, please check the date next to your name on the address label. Financially, we are entering our busy time with the picnic. It is an event that we



love to host, which is made possible with part of your membership and donations. Please make sure that you are up to date.

Did You Know?

Repeated and prolonged exposure to loud sounds can cause hearing loss or worsen an existing hearing loss. Scientists recommend that you should not be exposed to sounds over 100 dB for more than 15 minutes per day. Unfortunately, people are exposed to loud sounds daily in their work, on the street, in concerts, at fitness classes, and many more venues. If you are concerned about the volume of the sound that you are exposed to, you can measure it yourself. Did you know that there are dozens of apps that can measure the sound around you? Check your app store and search for "Sound Meter." Read the reviews and choose the one that is right for you. Many of them can be downloaded onto your tablet or smartphone for free!

Many Thanks

Tracy Balon
Buffalo Hearing and Speech
Center
Irina Bos
Christine Burdzy
Melissa Burroughs
Craig and Jackie Carpenter
Darlene Carpenter
Joe Cronin
Sean Cronin
Deaf Access Services
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Sr. Dorothy Feltz
Margie Fitchlee
JoAnn Hammer

Jimmie Harrod
Lisa Hill Nowicki
Paul Hogg
Jessica Holst
Maureen Kennedy
Will Licata
Kathy Maroney
Gloria Matthews
Fr. Bob McCartney
Janet McKenna
Dianne Mogavero
Gloria Plawinski
Jane Ploetz
Kristen Puglisi
Jean Ras

Janet Richter
St. Aloysius Gonzaga R. C.
Church
St. Mary's School for the Deaf
Jenna Schwab
Ron Sipos
Joe Sonnenberg
Talon Bay Homeowners
Newsletter
Mary Thorpe
Sue Wantuck
Karen Ward
Carol Wesley
Zenger Group
Michael Zogaria

It's Picnic Time!

Our next gathering will be our annual...

Sunset Dinner Picnic

Friday, August 4, 2017

5:00 – 8:00 pm

Once again, dinner will be catered by Bobby J's Italian American Grille, served at 6:00 pm

Water and pop will be provided. Please bring an appetizer or dessert to share

Westwood Park, Shelter #5 - 175 Pavement Road - Lancaster, NY 14086

The entrance to Westwood Park is on Pavement Road between Walden Avenue and Broadway. Shelter #5 is just past the enclosed pavilion (where restrooms are located) on the left side, with parking right in front. The children's playground is a short walk away.

The picnic is FREE to all who want to come. We do encourage you to participate in our fundraisers if you can.

Our Basket Raffle fundraiser which will help provide seed money for our future scholarship fund. Additional basket donations are appreciated. Baskets can be dropped off to any Board member by prior arrangement, or simply brought to the picnic. A basket donation form can be found in this newsletter. Please fill one out for each basket you are donating in order for us to have a description of the contents of your basket. Baskets that appeal to men and children are always needed. The Basket Raffle is once again being coordinated by Sr. Dorothy Feltz.

A 50/50 raffle will also be held to help us with our regular operating funds. This year we will also be having a t-shirt sale as well. A portion of the price of our t-shirts will support our chapter.

We need a general idea of how many members will be attending, so RSVP to Secretary Melissa Burroughs at 716-523-2991 (voice or text) or email melissab@smsdk12.org by July 28 (one week prior to the picnic) if possible.

Friends and family are welcome! We look forward to seeing you there!



Quarterly Newsletter

Subscription/Membership Form

\$20.00
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Name _____

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Device Name _____ Age Implanted _____

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Other _____

Please make your check payable to Buffalo Implant Group and send the Subscription/Membership Form and/or donation to:
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Without your support, there can be no B.I.G. News. It is our belief that the B.I.G. News is of great value to our readers and to those who would like to learn more about us. We strive to provide you with current, useful information, inspiring stories and valuable resources for cochlear implant users and the people who care for them. Please show us your support by joining B.I.G. now!

Buffalo Implant Group Basket Raffle Donation Form

Basket Theme/Name: _____

Contents of Basket:

Expiration Date (of any gift certificates or coupons contained): _____

Total Estimated Value of Basket: _____

Donated By: _____





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Awards our Newsletter has Received:

Best National Chapter Newsletter by CIAI

Service to the Hearing Impaired by Kenmore Lions Club

Judy Weiner Award for Service to the Hearing Impaired by Western New York Academy of Audiology