

the **BIG** news

The Newsletter for the Buffalo Implant Group

Volume 26 • Issue 2 - 2014

BIGstaff

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UPcoming Events

HLAA Walk4Hearing May 4
B.I.G. Meeting May 21
B.I.G. Picnic August 1

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Meeting Notice
Wednesday, May 21
6:00 – 8:00pm
Buffalo Hearing and Speech Center
50 E. North St., Buffalo

AND THEY SAY LAWYERS DON'T LISTEN

By Jeffrey G. Passafaro



Jeffrey G. Passafaro

(probably not listening to them was more accurate.) However, it became apparent to me that my hearing was deteriorating when, at a trial in Supreme Court, I had real difficulty hearing a soft-spoken, female witness give her testimony. (Light bulb moment!)

At this point the story may become familiar to many of you: ENT appointment; testing; followed by recommendation to try hearing aids; off to audiologist for hearing aid fittings; more

hearing aid fittings and tunings; etc,etc.

Fast-forward a couple of years and it became clear that my hearing was continuing to deteriorate rapidly from age 55 on, like falling off a cliff.

Each degradation in hearing was preceded by an episode of some sort of viral attack. Each attack was treated by a course of steroids. Sometimes, the hearing would stabilize, but it never bounced back.

All during this time I continued to maintain my law practice, but I had to restrict court appearances. Even arguing motions and appeals brought the worry and concern that I might miss something important in the course of the argument.

Office practice was easier because I could control the setting.

I suppose my story begins as a kid when we first discovered that I had a hearing loss in my left ear. My father was a doctor, so off I went to one of his friends to be tested. It revealed a modest hearing loss, only in the left ear, and they all chalked it up to childhood measles and that was that.

Except, my mother was not so easily satisfied. She made an appointment with a specialist in Buffalo. This was in the mid-sixties and his advice after reviewing everything was not to worry about getting me a stereo hi-fi, as I couldn't hear the high notes. End of story as far as I was concerned. And it was, for 35 years anyway.

As I entered my early fifties, my wife and family began to complain that I was not hearing them

~ Continued on page 3

THE PRESIDENT'S CORNER

By Sue Wantuck



Sue Wantuck

The season of spring has finally arrived! I am hoping that we have seen the last of the snow and frozen temperatures and nothing but sunshine and warmer weather is headed our way! Working as a teacher, I did enjoy a few extra days off to catch up on things at home. Unfortunately, Mother Nature

has a mind of her own!

I was very disappointed that the weather impacted our general meeting in March and we were forced to cancel. We attempted to reschedule with the presenter from Advanced Bionics for early April but it did not work out. The plan will be for her to come back in early fall.

I recently received an upgrade on the processor for my newly implanted ear. At this time only the new ear was eligible. So I am using both the NU5 and the NU6. I have noticed that with the NU6 I am able to pick up more information while listening to the radio, conversations, and environmental sounds. I recently started to hear the school bus passing my house in the morning while I was inside.

I can't believe it will be four years this July since my first activation. So much has changed with regards to my listening skills and the overall impact on my daily life and interactions. I have a mapping appointment in May and plan to discuss the possibility of upgrading my left side as well. Of course we all want the newest technology. I am not sure what the requirements are, as well as the insurance process, so hopefully I will learn more when I go.

Next month is "Better Hearing and Speech" month. If you are interested in joining the Buffalo Implant Group team at the HLAA "Walk4Hearing" on Sunday May 4 in Rochester, please let me know ASAP. If you would like to make a contribution to the "Walk4Hearing" under our B.I.G. organization please visit the website http://hlaa.convio.net/site/TR?fr_id=2200&pg=entry

My email is suewantuck@gmail.org or you can text me through my cell phone 716-425-9243. I'm looking forward to seeing everyone at the meeting in May! Take Care and Happy Hearing!

FROM THE EDITOR

By Gail Cronin



Gail Cronin

First I must apologize for all the errors in the last issue of The B.I.G. News. The worst gaffe of all was the grossly incorrect date for the winter meeting on the announcement page. October? Where did I get that from? My heart dropped into my stomach when I saw the typo in print. Sorry about that, folks. I wonder if I jinxed us. After all, the meeting never came to pass. It had to be cancelled due to a March blizzard. It was a one day weather event that cleared up as quickly as it came, but it did shut down Western New York for an entire day! Ironically, the speakers from Advanced Bionics, whom we had scheduled for March, are not available for us again until fall. So, the meeting will likely be in... wait for it... October! O.K. Perhaps my typo wasn't a typo after all. Maybe I was having a psychic premonition. (That is a much more interesting explanation for my error than mere carelessness.)

I am glad to have assistant editor Janet McKenna back as my second set of eyes on this issue. I really rely on her to catch the many typos and continuity errors that get by me. I am also glad to have had some time to get used to my new computer. Editing and organizing is getting a little bit easier as my experience with the new email and other software programs allows me more flexibility.

We have been continually blessed with new submissions from members whom we have not heard from before. Jeffrey Passafaro's cover story is a gem. His title made me laugh out loud and I really enjoyed his anecdotes of the other implant users he has encountered on his journey. I also really enjoyed hearing from St. Mary's senior Shekenya Ward-Brassell. She has overcome so much and is well on her way to a successful future.

Also in this issue we have some contributions from our regulars, as well as technological updates. As technology continues to change, our organization and our offerings will evolve as well. We are working hard to increase our presence on social media. We are also now posting back issues of our newsletter on our website. In order to receive the current issue, however, you still must subscribe. We really do need the financial support of all our members in order to continue with our important work.

If you have sent a check in through the mail since February, you may have noticed a delay in our response and deposit of your funds. The weather has interfered with our general meeting and Board meetings this winter, which also interrupted our regular business. This truly has been a strange winter. I can't recall the last time I have seen so many school and meeting cancellations in one season. And then came that snow over spring break. My children and I were singing, "I'm dreaming of a white Easter." We've never done that before. Fortunately, the winter weather appears to be behind us and we are now seeing more consistent signs of spring.

AND THEY SAY LAWYERS DON'T LISTEN..... Continued from page 1

One on one, face to face became the norm. Unconsciously, I became a very able lip reader. However, the situation could not continue indefinitely. Clients, staff, courts, fellow members of the Bar were all very patient and considerate. But that too has its limits.

Marc Wilcox, a clinical audiologist at the Youngerman Center for Communication Disorders at SUNY Fredonia suggested I might be a candidate for a cochlear implant. A what, I asked? There began my education on cochlear implants and the process. Thank you, Marc. He introduced me to Buffalo Hearing and Speech Center and Buffalo ENT Specialists as the gateway to getting starting on the cochlear implant trail.

Knowing nothing about implants or the process involved, I found it was a steep learning curve. Marc Wilcox and the kind people at BHSC did all the testing in tandem. Since all of you know the process, I'll skip over all those matters involved and just relate one anecdote about that time.

Much to the chagrin and annoyance of my wife, I kept passing the hearing test and was declared not yet a candidate. Living with me day to day, she could not believe that such a thing could be. She was incredulous. As this occurred more than once she remarked, "Flunk the damn test, you idiot, so we can get going!"

I tried to tell her test conditions did not simulate real life in the least. Rather, they were conducted in a sound proof room under ideal acoustic conditions. Needless to say, she was half-joking and we laughed about it afterwards.

I cannot emphasize enough how kind and thoughtful Marc Wilcox was during this period. He endlessly adjusted and fiddled with my hearing aids to try to give me the best chance to continue my usual and normal life, which necessitated some usable hearing.

The same must be said for my doctor, John Stanievich. He and his office were always accommodating and tried to assuage my degrading hearing loss as best they could. Dr. Stanievich also reassured me that I was a good candidate for implantation and would do well.

Eventually, with all the tests, scans, etc. complete and insurance authorization in place, the day came for surgery at Sisters' Hospital with Dr. Stanievich.

So at age 58, I found myself for the first time in my life going under for a surgical procedure. As I'm something of a chicken and a brat to boot, the day was rather more trying for my wife and staff than for me. My last words to the anesthesiologist were, "Make sure you bring me back." He did.

The hardest part of the process is waiting out the four weeks until activation. All the usual fears went through my mind, and all turned out to be groundless.

Immediately upon activation with JoAnn Hammer, I heard recognizable sounds and understood voices. Nothing sounded the same, but they were there and

present in my mind. Most people sounded like Daffy Duck on three martinis. But it got better as JoAnn said it would. And it did, quickly, as the mapping sessions progressed and concluded.

The best exercise was using my implant daily at the office to hear and interact with people. The phone, which previously was a real problem, dramatically improved, and a happy day came when JoAnn programmed in the telecoil button.

In the first weeks I heard sounds I hadn't heard in years: birds singing, dogs barking, turn signals clicking and on and on. I particularly enjoyed hearing the "poof" my gas grill made when I lit it to cook on the deck.

Prior to surgery and deciding upon which device to use, I exchanged e-mails with B.I.G. members and visited an implantee here in my home county of Chautauqua. Thanks to all of you for your very thoughtful comments and ideas.

A particular thank you goes to Sam Spritzer, who assured me that I could resume all sports activities after surgery and implantation. Golf and downhill skiing were a big part of my life, and thankfully they remain so now approaching the fourth anniversary of implantation. (Full disclosure, I now wear a helmet while skiing.)

Beyond being aware that Rush Limbaugh lost his hearing and has a cochlear implant, I didn't know much. Since I'm implanted now, I try to reciprocate and be helpful to anyone who crosses my path and expresses an interest either in it, or in hearing difficulties in general.

Not long ago, at a wedding reception, a young lady sidled up to me and said, "I bet we are the only two people in the room who know you are wearing a cochlear implant." I was a little taken aback and amused by her approach, and also somewhat wistful for my long past youth when I might have replied differently.

This delightful young lady was studying speech pathology/audiology and was curious about my experience. We spent some time together answering all her questions. It struck me what a strange process it is to be treated by doctors, audiologists and the like, who all hear normally, when they can have no personal experience of what the patient is hearing, or is going to experience. I'd like to think that I was helpful to that eager student.

In another vein altogether, I was at dinner with family following a round of golf with my brother-in-law when I felt a tap on my shoulder. I turned to see a rather distinguished-looking and well-dressed gentleman who pointed to my implant and turned his head so that I could then see his. He introduced himself as Arthur Martinson from California. We traded cochlear experiences for the next half hour.

Arthur was implanted years ago in California, first generation with the box and wires running from his belt. He has since been upgraded several times. By

REFLECTIONS ON: LIFE'S PATHS, DETOURS, AND HELP FROM MY DOG!

By Margie Fitchlee

We in the “Cochlear Community” are well aware that life leads us down many paths. Some are straight and forward, some are filled with twists and curves, and others thrust “detours” in our way. Whatever the path you are on right now in your life, rest assured that for many of us there is and was a light at the end of the tunnel. That light to me is known as a “cochlear implant.”

I am still traveling on that journey. After going through the various phases I mentioned above I have finally reached a destination that I am thankful for and comfortable being at. It is by no means a “paradise” where all is perfect but a “plateau” which allows me to live my life comfortably and to look at the future with a much clearer view.

I traveled along quite merrily as many of us do: a husband, a family, a home, a good job, and even a beloved dog. All was going well for me and then “BAM!” came those twists and curves. This was quite a devastating and scary period of my life. I had no idea what the path I was entering onto would challenge me with.

The trip down that twisty path was to be one full of many trips to doctors and audiologists. It was to be one full of countless examinations, hearing tests, fittings for hearing aids, adjustments, equipment failures and yes, even a failure in my faith and strong belief in the power of the human spirit. I was literally at my “wits end.” I am sure many of you have encountered similar experiences as you have traveled down this path.

Somehow I managed to persevere. I went to my job at school each day with the hope that I could just get through that day. One day at a time, I came home and rested, and kept on going. I tried so hard to hang on to the life I was so accustomed to. The severity of my profound hearing loss finally got

the better of me. I graduated to being a “late-deafened” individual who by the Grace of God found a detour, a way off that twisty path and it led straight to the office of Dr. Ernesto Diaz-Ordaz.

The detour I was taken on has helped me regain my life. A life I can now cope with. I also regained my faith and belief in the power of the human spirit. The cochlear implant I received was truly a life saver for me.

As I look back on that period of my life, a period where my world was slipping away from me, I ask myself, “How did you cope? How did you manage to get through all of this?” My family was grown and on their own, my husband worked very long hours at the factory. I was more or less alone trying to cope with the prospect of never hearing any of them or anyone else for that matter again. Luckily, I had my doggie “Maggie Mae” there for me, always waiting, always loving, always listening to my fears and comforting me through my tears.

Doris Day states, “I have found that when you are deeply troubled there are things you get from the silent devoted companionship of a dog that you can get from no other source.” Her statement sums it up perfectly for me. Maggie Mae and I logged many hours together. We also logged many miles together, walking the Erie Canal and the paths around my new development in Florida. She was a constant in my life. I don't know what I would have done without her. She sensed that I was troubled and could almost always be found by my side. I was so lucky to have her for 13 years. My life has a large void in it without her.

My hope for all of you on this journey is that you too can persevere, that you too can forge on and that you too can reach that plateau that I have found. Perhaps



Margie Fitchlee and Maggie Mae

the love of a beloved dog or pet can help you get through those days where hopelessness creeps in. Perhaps a detour off that twisty path will lead you to the office of Dr. Ernesto Diaz-Ordaz. If there is a chance for help he is the man you want on your team.

It has been told that: “God said I need somebody strong enough to pull sleds and find bombs, yet gentle enough to love babies and lead the blind. Somebody who will spend all day on a couch with a resting head and be support with eyes to lift the spirits of a broken heart. So God made a dog.”

That is why God made “Maggie Mae” a part of my life, for she surely lifted the spirit of my broken heart. Think about this: DOG spelled backwards is GOD... and may God Bless all of you.

SHARE YOUR IDEAS!

We are in the process of redesigning our logo. If you have ideas to share, bring them to the next meeting or email a member of our Board.



KEEP ON

By Janet McKenna

On a frigid day in January, my spouse and I moved from the Grand Island house where we'd lived since 1985 to a two bedroom apartment in Brickstone, a "senior" complex near Rochester.

The building is brand new, and there have been many meetings and socials for residents. Too, there are patio homes for more residents. We are all "elders." This means at least a third of us have some hearing loss. Another person in the building uses two cochlear implants as I do. A third lady, profoundly deaf, desperately needs one but hasn't taken the first step yet.

I began nagging about hearing loops, using microphones, and accommodations for hard of hearing people at our first meeting. Probably presentations by Hearing Loss Association will follow. Brickstone has agreed to be a sponsor in the Rochester Walk4Hearing. This is mutually beneficial: they get publicity among a population which might move into their residences while HLAA receives a sponsor.

Even in wonderful Rochester, things are not perfect for cochlear implant wearers. The Unitarian church I attend has a very good hearing loop in its sanctuary, but no one knew that a microphone is necessary to employ the loop in a meeting room. And so it goes. We still must keep on to advocate and educate so we can participate in the larger society, anywhere.

Let's all hope for a warm spring May 4 as we welcome the B.I.G. walkers at the HLAA/Rochester Walk4Hearing! It is NOT ABSOLUTELY NECESSARY that you WALK!! The gathering is really a festival for people who don't hear well, a meeting place for upstaters. We'll meet you on the Erie Canal in Perinton Park.

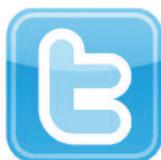
Items for the Next Newsletter Due Monday, June 16

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COCHLEAR AWARENESS NETWORK (CAN) - DIGITAL OUTREACH COMMITTEE

By Gloria M. Matthews

In late November 2013, former Cochlear Americas Northeast Manager Brittany Pellegra notified me that I would take up a place on their Digital Outreach Committee as a Cochlear Awareness Network Volunteer. This is a team of volunteers who would like to help candidates learn more about Cochlear Americas and their technology using social media. The committee's purposes are to help Cochlear stay on top of what candidates are looking for, support recipients, encourage conversation, promote CAN activities and report any complaints to their Network manager. In addition to this, all CAN volunteers get a monthly email from their Network manager giving them talking points to start on social media. The best part is, as a volunteer you can get creative about how you present the topics.

There is now a new Northeast CAN Manager as of late January. His name is Chris Hasson. Brittany Pellegra relocated to Tennessee to take the role of CAN Manager for Tennessee, Kentucky, North and South Carolinas, Virginia, D.C., and Maryland. It was a great pleasure to work with Brittany and I wish her all the best. Chris Hasson, a BAHA recipient and Cochlear employee for the last three years, looks forward to working with and meeting with all Northeast volunteers and non-volunteers.

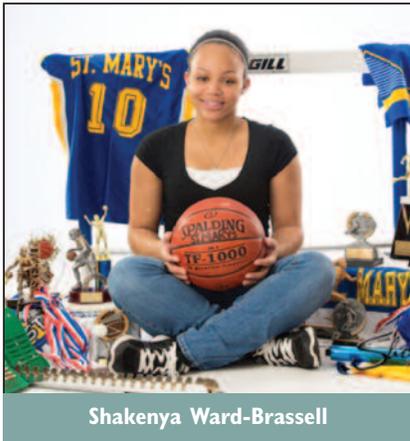
I have not been active in social media since late January due to health issues. However, I will be returning soon with new topics in the two groups I am more active in on Facebook: Cochlear R US and Cochlear Town. I am also active in the Cochlear Community website. I co-manage B.I.G.'s Facebook page with Tina Pilkey, as she holds down the fort on the Twitter account page. So in a way, being able to help out B.I.G. on social media played a role in my becoming active in the various online communities via social media. It is my way to contribute to the hard of hearing, Deaf, and CI communities. I have learned a lot from others in all the communities online and I continue to do so.

For the month of May, we will be spreading awareness of Better Hearing and Speech Month. So if you have a Facebook and/or Twitter account please like us and follow us as we will share valuable information that can be shared with anyone you feel would benefit from learning more about hearing loss and the solutions available for them, or friends or family members.

Please feel free to make suggestions as to what you would like to see on our Facebook page and Twitter feed. Happy Spring!!!

MY JOURNEY TOWARD COLLEGE AND CAREER

By Shakenya Ward-Brassell



Shakenya Ward-Brassell

My name is Shakenya Ward-Brassell. I am 19 years old and a senior in high school at St. Mary's School for the Deaf. I was born two months premature in Highlands, Florida. The doctors felt that they did not have the proper technology or medications to treat me appropriately. As a result I was transferred to Women

and Children's Hospital here in Buffalo, closer to my mom's family.

As a newborn I stayed in the hospital for about four months. During that time, my lungs collapsed and my mom found out that I was deaf. They were unable to provide a cause for either. It is possible that my hearing loss was related to medications or that I was born that way.

My mother told me at first she was so terrified and upset about my deafness to the point that she refused to hold me. My grandma had to force her to do so and remind her that it was her responsibility to take care of me. My mom followed up with the necessary appointments with doctors and audiologists. I received bilateral hearing aids when I was two. Soon after, I started early intervention services though Buffalo Hearing and Speech Center. I didn't learn sign language until I came to St. Mary's School for the Deaf when I was five. I picked up signs easily and was able to communicate successfully with my teachers and peers.

I enjoyed elementary school, my friends, and especially being involved in sports. When I was in fourth grade, I started to get migraines frequently. Not knowing what the underlying cause was, I stopped wearing my right hearing aid because it was too loud and I felt it was the reason for my headaches. For six years I went to many doctors, undergoing a variety of tests and procedures hoping to figure out the cause. During that time I noticed that my hearing was changing. Sometimes it would be lower or totally gone for extended periods of time (one week, three weeks, one month etc.). Finally the doctors determined that I had Enlarged Vestibular Aqueduct Syndrome (EVAS). This is caused by malformations in the inner ear. Ducts and sacs are enlarged, which are believed to cause hearing and balance problems. It is characterized by episodes of vertigo (dizziness) with fluctuating hearing loss caused by head injury, changes in barometric pressure, or after high levels of physical activity. Finally we had some answers. But I was not willing to give up my love for sports because of this. So I continued to deal with the migraines and accept the risks of losing my hearing.

When I was a sophomore I decided I wanted to try mainstreaming at Niagara Falls High School. Communication has always been a challenge for me throughout my life and this experience was not an easy transition. With my hearing aid I was able to speech-read and understand a lot of what others were saying within a small and quiet environment. When working in groups or in noisy settings, like the gym and cafeteria, I easily became anxious and frustrated. I felt that I was struggling to keep up with what was going on when I did not have an interpreter consistently in the classroom. Also the bus ride took 45 minutes, and as a result I fell behind on credits needed to graduate on time. I felt that it was in my best interest to return to SMSD full time in order to stay on track towards earning a Regents diploma.

One day last year, during a basketball game, I went up for a rebound and somehow the ball slipped through my hands and hit me hard in the forehead. As a result, I couldn't hear for about three months. That was the longest period of time it has ever lasted. It was horrible; I couldn't stand the silence and was unable to listen to music. I was worried that my hearing might never come back. I started to consider the idea of a cochlear implant. I was curious if getting my right ear implanted (the one I have not worn my hearing aid on since fourth grade) and still using my strong left ear with a hearing aid was a possibility. I went to our school audiologist to ask questions and find out more information.

There was a lot to learn and consider about the entire process: surgery, equipment brand, recovery, rehabilitation, maintenance, appointments, etc. I quickly became overwhelmed and was uncertain if this was something I wanted to and/or was ready to pursue. I felt strongly about wanting my communication skills to improve as I planned to attend Rochester Institute of Technology in the fall to major in psychology. I plan to get my master's degree in Clinical Psychology, and eventually work toward a doctorate degree so I can obtain my dream job as a deaf Clinical Psychologist. I knew that having more access to sound could only benefit me in the future. So I decided to set up the appointments at Buffalo Hearing and Speech Center to start the candidacy process. It was determined that I was eligible.

Even though implanting my dominant ear (left) was the recommendation for best results; I decided to get the implant in my right ear. I was fearful that if for some reason surgery did not go well, it would destroy the residual hearing I was so reliant on and I would become totally deaf for the rest of my life.

I had my surgery on August 2, 2013. I was comforted that when I woke up, I was in the regular room with my family and my boyfriend Jake asking how I felt and if I needed anything. I was sleepy, sick, and weak and felt like I was going to die. After an hour or two, they released me. I went home, took my medications and went to sleep. I was in so much pain that I couldn't sit,

stand, walk, or even talk. Sleep was all I wanted to do just to keep the pain away. For three days straight after they released me, I had been in and out of the hospital because of the massive pain. On the third day, they did some testing which indicated that I had a fluid leaking in my brain and we were told that that they were supposed to keep me overnight on the day I had my surgery due to my EVAS. I stayed for two additional nights for monitoring and then I was released. Overall, the surgical and recovery process was not a good experience for me.

One month later I had my initial stimulation. All I could hear was buzzing and I quickly became upset and hated the sound. I had a hard time wearing the device for more than ten minutes and I was also having problems with the magnet. Between the magnet falling off continuously and the buzzing I was so annoyed that I couldn't tolerate it for a whole day, and I had many headaches. Everyone kept telling me that I needed to get used to it and that it would get better with time. I was not sure I believed them or that they truly understood how awful it sounded. I didn't really see any improvement until after my third or fourth mapping. I also changed the magnet to the highest power (#6) which required medical approval.

Soon the buzzing began to fade away and I could start picking up real sounds, many I have never heard before with just my hearing aids. My first experience was when I scratched my fingernails against the wall. I stopped suddenly and scratched the wall again. I said to myself, "I can hear that! How awesome is that!" I have also noticed birds chirping outside and other people talking from a distance.

At school it was recommended that I receive speech and language services in order to practice my listening skills. At first, the basic activities annoyed me because I felt that everything sounded the same. After doing the same things over time and adding new maps to my processor I began to notice improvement in my ability to detect differences and pick up words.

It has been almost six months and I continue to remind myself to be patient and that it will be a slow process. I love wearing my NU5 processor and I have no regrets about it after all! I am looking forward to getting upgraded to the NU6, hopefully within the next few months. I am impressed with what it has done for me so far and am excited to see what the future holds for my listening abilities.

I hope that my processor will provide me confidence to use my voice again at college when interacting with peers and professors. Ever since I was made fun of at a friend's house when I was 13 years old I have been self-conscious about speaking in public. It had a huge impact on my self-esteem. My family and friends have been supportive in encouraging me to stay focused on reaching my personal goals of graduating from high school and attending RIT. I will be the first person in my family to pursue a college degree. I want to thank those who have helped me through this process.

AND THEY SAY LAWYERS DON'T LISTEN..... *Continued from page 3*

profession he was an aeronautical engineer and took the chance on an early implant to stay employed and engaged. He's done beautifully with the implant and continues to do so into his eighties.

Last May while awaiting US Supreme Court Chief Justice John Roberts' speech at the Jackson Center in Jamestown, I saw that behind me were placed the school children gathered for this historic occasion. One little lad was wearing a cochlear implant. We noticed each other and smiled back and forth.

I struck up a conversation with the boy's aide who told me a little bit about his background. She was assigned by the school district to use sign language with him to make sure he was getting everything in school, and she accompanied him on all school outings for the same purpose. I inquired how well he was doing post-implant as he had learned to sign first. My impression was that he was still working out the kinks. Again, I tried to be helpful and encouraging to both of them.

One last encounter, and a humorous one at that, to end this article. Part of my law practice involves real estate closings. At one recent closing, the buyers, whom I represented, brought with them their young grandson. He took one look at me and turned to his grandmother and said, "Look, Grandma, he's got ears!" Well, I broke out laughing at this astute remark from a five year old, who had bilateral implants. We shared a good chuckle, as has everyone to whom I have related this story.

Yes, I have ears. Well, one ear anyway, and functional hearing. I am grateful and indebted to all those who assisted me along the way. Thanks again, Marc Wilcox, Dr. John Stanievich, and JoAnn Hammer.

As I approach the fourth anniversary of my cochlear implant, I am so grateful that this device and the process perform so well. So well in fact, that at times I find myself taking it for granted, and forget that I even have it on.

I speedily remind myself that is just so wrong. A lot of hard work, study, trial and error, over many years, by many people, went into both the device and the process. NEVER TAKE THAT FOR GRANTED. Be thankful you are still able to practice law, since without the cochlear implant I would not be able to do so. Be thankful you can hear and communicate with family and friends; I remain a part of their world and they are in mine.

So, I resolve to be helpful to all who might ask about the cochlear implant, be thoughtful to those who continue to have hearing problems, and be thankful for the wonderful results that I've experienced.

Jeff Passafaro is a partner in the law firm of Foley, Foley & Passafaro, with offices in Dunkirk, NY. He can be reached by email at ffp@netsync.net.

COCHLEAR IMPLANT LIAISON REPORT

By Jessica Holst

Happy Spring membership! I would first like to mention that due to our unseasonably cold, snowy weather we were unable to host Advanced Bionics' regional representative Katie Skipper at our March meeting. Your Board is working to coordinate a visit from Advanced Bionics at our fall meeting to provide members with the most recent technology advancements and user accessories.

We would also like to thank B.I.G. member Sam Spritzer for pointing out a neglected citation in our previous newsletter. The Cochlear Implant Comparison Chart included in past publications represents a compilation of contact with CI company representatives as well as the comparison chart distributed on www.cochlearimplanthelp.com. The information included on www.cochlearimplanthelp.com is invaluable for CI users and professionals working with this population alike. We are also fortunate enough that Sam Spritzer is a contributing author for this website. Thank you Sam for drawing our attention to this error.

There is exciting news on the Cochlear Implant front. Advanced Bionics and Phonak merged together for their newest implant system, the Naida CI Q70 (Naida CI). Advanced Bionics and Phonak began working together in 2009 to combine cochlear implant and hearing instrument technologies.

Cochlear Americas had some exciting news to share on March 20. The U.S. Food and Drug Administration approved the first implantable device for people 18 and older with severe or profound sensorineural hearing loss of high-frequency sounds in both ears, but who can

still hear low-frequency sounds with or without a hearing aid. The Nucleus Hybrid L24 Cochlear Implant System may help those with this specific kind of hearing loss who do not benefit from conventional hearing aids.

The Nucleus Hybrid L24 Cochlear Implant System combines the functions of a cochlear implant and a hearing aid. This electronic device consists of an external microphone and speech processor that picks up sounds from the environment and converts them into electrical impulses. The impulses are transmitted to the cochlea through a small bundle of implanted electrodes, creating a sense of sound that the user learns to associate with the mid- and high-frequency sounds they remember. The hearing aid portion of the device is inserted into the outer ear canal like a conventional hearing aid, and can amplify sounds in the low-frequency range.

On April 1, Google and MED-EL announced that Google plans to acquire MED-EL. The purchase price is approximately \$1.47 billion dollars. The most fascinating comment in the press release announcing Google and MED-EL's merger is a casual announcement of 'Google Ear' that will start out as a hybrid between a smart phone and a cochlear implant processor.

As always, feel free to email holst.jessicam@gmail.com with any recommendations of how your technology needs can best be met.

	Advanced Bionics	Cochlear America	Med-El
Current Implant	HiRes 90K HiRes 90K Advantage	CI24RE CI24R Double Array CI422	CONCERT (titanium) SONATA (titanium) PULSAR (ceramic)
Electrodes	16	22	24
Implant Warranty	10 years	10 years	10 years
Current Sound Processor (wearing options)	Naida CI Q70  Neptune 	Nucleus 6 CP910 & CP920 	RONDO  OPUS 2 
Eligibility for Upgrade to the Current Sound Processor	Recipients implanted with a CI or 90K (implanted since April 2001) can upgrade to the Neptune or Naida speech processor system.	Recipients implanted with the CI22 implant are eligible to upgrade to the Freedom Processor. All other recipients are eligible to upgrade to the Nucleus 6.	All implant types are able to upgrade to the next generation speech processor technology as all are backwards compatible. OPUS 2 users can purchase the RONDO as an alternative wearing option.
Processor Warranty	Naida: 3 years	Nucleus 6: 5 years	RONDO: 5 years

	Neptune: 3 years		OPUS 2: 5 years (includes rechargeable batteries)
Remote Control	Naida CI Q70 MyPilot 	Nucleus 6 Remote Assistant CR230 & CR220 	FineTuner for use with the RONDO and OPUS 2 
Microphone	Naida: T-mic 2 (three sizes) at ear canal entrance, omnidirectional mic at top and one on headpiece Neptune: Located in headpiece; T-mic available with accessory	Two omnidirectional microphones at top of ear programmable with SmartSound and Autosensitivity for different listening environments	RONDO: One omnidirectional mic OPUS 2: One omnidirectional mic at top of ear
Waterproof	Naida IP57: water resistant for 30 minutes in up to 1 meter of water Neptune IP68: Waterproof sound processor & AquaMic configuration	Nucleus 6 with rechargeable battery module IP57: water resistant for 30 minutes in up to 1 meter of water Nucleus 6 with disposable battery model IP44: resistant to water splashing for up to five minutes Aqua accessory with rechargeable batteries IP68: waterproof	No claims made
User Forum/Community	Hearing Journey	Cochlear Community	HearPeers
Manufacturer Sponsored online Rehabilitation Materials	The Listening Room Musical Atmospheres	Rehabilitation Resources HOPE (Re)Habilitation Resources Listening Tools	SoundScape Interactive Listening Activities Bridge to Better Communication Bridge Downloads

MEETING THE NEEDS OF FAMILIES: A COMMUNITY EDUCATIONAL OFFERING ON CHILDHOOD HEARING LOSS

By Jessica Holst

On April 10, Erie County's Local Early Intervention Coordinating Council (LEICC) Hearing Taskforce hosted an evening focused on answering hearing loss questions for families of children recently diagnosed with hearing loss. The program was titled "Your Child Has a Hearing Loss - What Happens Next?" Families were provided with information on parent resource centers, the basics of hearing loss and amplification options for their child, developmental implications of hearing loss, "take home" strategies for communication success as well as a list of helpful tips developed by parents for parents of a child with hearing loss.

The LEICC's Hearing Taskforce is a new collaborative initiative that represents a wide range of community stakeholders committed to better serving

families of children with hearing loss in Erie County. Representatives from the Erie County Early Intervention Program, area pediatric audiologists, Buffalo Hearing and Speech Center's Oral Education Program, St. Mary's School for the Deaf's Early Education Program, Early Childhood Direction Center, the Parent Network of WNY, Parent to Parent, as well as families of children with a hearing loss were available to answer questions.

It is the hope of the LEICC Hearing Taskforce that this offering be the first of an annual program for families of children with hearing loss. If you would like to become involved in the efforts of this group please email holst.jessicam@gmail.com for more information.

TREASURER'S REPORT

By Lisa Hill Nowicki

The 2014 membership drive remains open. There still are quite a few members receiving the newsletter who have not submitted their 2014 dues payment of \$15. Please remember that your dues expiration date is to the right of your name on your newsletter mailer. If you cannot attend the May 21 meeting, please consider sending your dues to us via mail. For the first quarter of 2014 we continue to trail in the red with expenses (newsletter print charges) exceeding income by \$184.22. We look forward to each of you helping us return to the black next quarter.

CORRECTIONS

In the Winter 2014 issue (Volume 26, Issue 1) the 2014 Cochlear Implant Comparison Chart incorrectly stated that the MED-EL OPUS 2 processor comes with a 3 year warranty. We thank Jeanne Fredriksen, Sr. Consumer Outreach Manager of MED-EL Corporation, for providing us with corrected information that the OPUS 2 in fact comes with the 5 year warranty, just as the RONDO processor does. In addition, both include rechargeable batteries.



The Buffalo Implant Group would also like to credit Sam Spritzer for providing information used in the 2014 Cochlear Implant Comparison Chart. Sam maintains a far more in-depth and detailed comparison chart of available cochlear implant devices at CochlearImplantHELP.com. The Buffalo Implant Group would like to thank Sam and encourages our readers to make us of the comprehensive information and many resources provided at the CochlearImplantHELP.com website.

The winter meeting date posted in the last issue was incorrect. We apologize for any confusion this may have caused. In the event that a date is printed in error, a correction notice will be sent out via email whenever possible. Please be sure that we have an accurate email address on file for you, in order to reach you. In addition, updated information about meetings can be found at BuffaloImplantGroup.com



MANY THANKS



Amy Bamrick
Carm Bauer
Buffalo Hearing and Speech
Center
Melissa Burroughs
Margaret Campbell
Craig and Jackie Carpenter
Elsbeth Chidiac
Joe Cronin
Deaf Adult Services
Jennifer DiLauro
Margie Fitchlee
Jeanne Fredriksen
Jessica Holst
Karen Hornung
Joe Kolis
Kathleen Maroney
Gloria Matthews
Joanne Mayers

Fr. Bob McArtney
Janet McKenna
Douglas McSkimming
Chrisann Militello
Diane Mogavero
Lisa Hill Nowicki
Jeffrey G. Passafaro
Tina Pilkey
Norine Rinker
St. Mary's School for the Deaf
Joseph Sonnenberg
Sam Spritzer
Dolores Tramont
WNY Court Reporting
Services
Sue Wantuck
Shakenya Ward-Brassell
Zenger Group

LOOKING AHEAD TO THE B.I.G. PICNIC

By Gail Cronin

Have you ever been to our B.I.G. annual summer picnic? If not, then you don't know what you are missing. It is always a hit that brings back regulars year after year. Some people even drive great distances to come. At our picnic you will often find cochlear implant users, family members, cochlear implant candidates, people who think they might someday be cochlear implant candidates, professionals in the hearing and education fields, and children of all ages.

One child I know thinks the B.I.G. Picnic is the highlight of the summer. That would be my eight-year-old daughter Maeve, who has been coming to the picnic every year since she was a baby. I'm not sure what she enjoys the most. It could be the happy, friendly faces. It could be the amazing playground. She certainly loves all the food, especially the desserts. But I think it might also be the basket raffle. She has so much fun putting her tickets in the jars, and she gets a kick out of watching the excitement of the many winners.

The other day as my daughter and I were driving down Niagara Falls Blvd., we felt a strange and very strong vibration in our car. It was startling, and we didn't know what was happening. Then it stopped. Then it started up again, and we both realized that it was actually being caused by the sound waves coming from the car in front of us. The driver had a "super bass" speaker system in his car, and several window decals advertising it. His music was so incredibly loud that it was shaking not only his car, it was shaking our car!

My daughter and I talked about how loud it must be inside his car, and she commented on her own that this was very dangerous and that he was damaging his ears. She then rolled down her window and yelled to the driver (who could not hear her), "Hey! You should turn it down! You will lose your hearing!" Then, after

a moment of pause, in which she was clearly thinking about the ramifications of that, she yelled something else. She said, "But if you lose your hearing, don't worry. You can get an 'earplant'! Then you can come to the Buffalo earplant group festival with us! It's so awesome!"

I could not stop laughing. I thought it was so sweet of her to invite a complete stranger to the B.I.G. Picnic. I also thought her invention of the word "earplant" was pretty funny. And she elevated our picnic to the status of "festival!" I think that says a lot about how much fun it is.

As it has been for the past few years, our picnic will once again be held on a Friday night in mid-summer at Westwood Park in Lancaster. This centrally located facility really has a lot to offer. There are playgrounds, grassy areas, fishing, and restrooms. This year, however, we are going to try something a little different and instead of our usual shelter we have reserved the indoor room. This will offer some added protection in case of rain, bees, or wind, all of which we have encountered in the last few years. This location shares a parking lot with our previous location, so the directions will remain the same. And once again we will have dinner catered by Desiderio's, which is always a hit. Participants are asked to bring an appetizer or dessert to share. We will also hold our annual basket raffle, which serves as a fundraiser for our upcoming scholarship program. Look for details in our next issue of The B.I.G. News.

A slideshow of photos from last year's picnic is available on our website. We hope to see all our members this summer at the picnic, so mark your calendars now with the date:

B.I.G. Picnic Friday, August 1, 2014

IT DOESN'T HURT TO ASK

By Lisa (mom to Sienna, bilateral Auditory Neuropathy)

This past fall my daughter Sienna was having trouble with her hearing aids (Starkey)/FM system connection. We had recently introduced a Bluetooth device (Starkey SurfLink) that allows her hearing aids to connect to the iPad. Ever since that sync, her hearing aids were transmitting a terrible static sound when the school FM boots were put on. After both Buffalo Hearing and Speech Center and Erie 1 BOCES trouble shooting could not correct the situation, it was determined we would have to return her hearing aids, SurfLink and FM system to Starkey for their expertise. I was excited that we could do this over Christmas break. Sienna was heartbroken. Her comment was, "Mommy, now I will not be able to hear my cousins when they come to visit." After I picked up my broken heart, I called audiologist Michelle Dubé at BHSC to see if they had any loaner aids that Sienna could use. They did! Though Sienna stated that her "loaner aids" sounded a little different, she quickly adjusted and had a great Christmas break with her cousins.

Buffalo Implant Group



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Implant User

Parent Child's Name _____

Device Name _____ Age Implanted _____

Professional, What field _____ School _____

Other _____

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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!

OUR NEXT B.I.G. MEETING AND SOCIAL

BHSC's Cochlear Implant Team: What's new in service delivery and access?

The Cochlear Implant Team from Buffalo Hearing and Speech Center offers a "Meet the Team" panel at the May 21 B.I.G. meeting. Key staff from Audiology, Speech-Language Pathology, the Oral Deaf School and clinic administration will discuss new developments in CI technology and delivery of services for all ages, as well as providing information regarding accessing services, insurance questions, and equipment order processing. The panel welcomes questions from the group and will solicit feedback on community needs.

Wednesday, May 21

6:00 – 8:00 pm

**Buffalo Hearing and Speech Center
50 E. North St. Buffalo 14203**

Free parking is available in the lot behind the building, on a first come, first served basis.
Enter at E. North St. and press the button to lift the gate.
Meetings are held in the lower level conference room.

For refreshments we'll have pizza, pop, and water.

Please consider bringing a snack or dessert to share if possible.

A 50/50 raffle fundraiser will take place and the treasurer will be available to accept 2014 dues payments.
Sign Language interpretation and CART transcription will be provided.



BUFFALO IMPLANT GROUP

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Awards our Newsletter has Received:

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