

THE B.I.G. NEWS

BUFFALO IMPLANT GROUP

COMMUNICATING ▶ SHARING ▶ COUNSELING ▶ SUPPORTING



B.I.G. STAFF

Gail Cronin *editor & publisher*
 Margie Fitchlee *writer*
 Sean Cronin *proofreader*

UPCOMING EVENTS

B.I.G. Meeting June 8
 B.I.G. Picnic August 5
 Walk 4 Hearing October 2

INSIDE THIS ISSUE

Wait, Worry, and Wish Page 1
 Gadgets for People
 with Hearing Loss Page 3
 Have You Been Looking
 for Dr. Diaz-Ordaz? Page 3
 Alerting to Sound When
 I Am Alone Page 4
 Auction Baskets Page 4
 Treasurer's Report Page 4
 Meeting Report Page 5
 My New Job! Page 6
 Many Thanks Page 6
 Parents' Corner: Kids in
 the Water Page 8
 REFLECTIONS on:
 Second Chances Page 9
 Our Next B.I.G. Meeting
 and Social Page 11

MEETING NOTICE:

Wednesday, June 8
 6:00 – 8:00 pm
 St. Mary's School for the Deaf
 2253 Main St. - Buffalo

Wait, Worry, and Wish

by Jessica Jurusik

Wait, worry, and wish is what my husband Brian and I have done since the moment we found out that we were going to be parents. For nine months we waited, worried, and wished for the day we would get to hold our baby. The day came, and while I needed a C-section to deliver, I felt great after and Kayleigh was absolutely perfect. It wasn't until the following day that we learned everything was not perfect. There was worry over a very deep sacral dimple, which needed a sedated MRI to confirm all was fine. There was worry of jaundice, but that resolved after a week of sunshine. There was worry about her lingual frenulum, but that was resolved at the ENT office at just a week old. The last hurdle was the newborn hearing screening.

Kayleigh failed hers in the hospital, but we were told it was probably fluid from the C-section or possibly a faulty machine. It wasn't brought up again by our pediatrician until I mentioned it at her three-month appointment. We were then told we should look into seeing an audiologist to rule out any real issue. This was when the real waiting, worrying, and wishing all started.

For the next six to eight months Kayleigh struggled to pass any hearing screening and was referred to the ENT for observation. Everything was written off as fluid in the middle ear because Kayleigh suffered numerous ear infections. We tried bringing up our concerns with our pediatrician's



office. We were told that we were just being overly worried first time parents when we mentioned that she

didn't babble. It became very obvious to us that she wasn't hearing. We finally demanded a repeat auditory brainstem response test, and just before her first birthday a non-sedated test was performed locally.

We felt skeptical about the specialist we were referred to from the moment we walked into his office. At the time, we were living in Broome County and there weren't many options of where to go, so we went on the recommendation of our ENT. The whole appointment was a disaster. The doctor had to troubleshoot the machine upon arriving and once the test began the electrodes had to be replaced several times. There were long periods of crying, and movement throughout the entire test. We knew that no matter what the results were, they weren't going to be accurate. Kayleigh passed the test and we tried to enjoy that moment but knew it wasn't something we could hide behind. There was more waiting, worrying, and wishing before we finally met with our ENT to discuss the results and our concerns. This

continued on page 5

CORNER



Hello! Finally spring has sprung! I am really enjoying listening to the birds chirping outside, especially first thing in the morning. For those of you who have had their cochlear implants recently activated, you might not be able to appreciate these sounds quite yet. But I encourage you to be patient and practice; try to embrace the challenge. Make your listening practice as fun as possible and not stressful. Relax and take in whatever you can. Be sure to wear your devices as long as possible, increasing the time each day if needed. Avoid turning them on and off as your brain needs to re-train itself in all listening environments. Believe me, I know it is not easy; it can be frustrating and annoying. Everyone's experiences and hearing history is different. These days it is all about instant gratification. With technology inching its way into every aspect of our daily lives, we tend to be impatient. Unfortunately it is not going to happen instantly.

I experienced this myself with my first implant and second implant.

Today I am happy with who I am and my hearing capabilities. I am especially thankful for the ongoing support from my audiologist, SLPs, my dear CI users and friends. Please do not hesitate to reach out to someone who utilizes hearing amplification if you find yourself in need. Did you read Karen Ward's cover article from the last newsletter? I am glad that she and I were able to meet up and ask/answer each other's questions. I am always more than willing to share my own personal experiences. Our B.I.G. membership is made up of a variety of individuals with lots of stories to share. You are not alone in this! Think about it. My gmail is suewantuck@gmail.com.

Our spring general meeting took place on Thursday, April 7 at BHSC. It consisted of a short power point presentation on the most current assistive listening device technology. Afterwards there was a hands-on-opportunity to check out all of the accessories compatible for each brand, Advanced Bionics, Cochlear Americas and MED-EL. It was interesting to see all of the options and think about how

an individual's choice would be based on their lifestyle. Those who enjoy running would want wireless technology, as compared to someone who loves swimming would likely lean more towards the waterproof. The ability to use Bluetooth in the car so a phone conversation could be sent right to your processors, or a parent using the mini microphone to have conversations while driving in the car would be very beneficial. A disadvantage in my particular situation is that I have two different models of cochlear implants, the NU 5 and NU 6. NU 6 currently has the Bluetooth while NU 5 does not. I would prefer to listen with both ears, not just one. However my health insurance will not cover an upgrade at this time. I would have to pay 50% of the cost out of pocket, which is ridiculous. These companies need to realize that these devices are medically necessary to our everyday lives!

I look forward to seeing everyone on Wednesday, June 8 at St. Mary's School for the Deaf. Bruce Goldstein will be our guest presenter. He is an attorney, who focuses his efforts on the rights for those who have a hearing loss.

Happy Hearing!!



Happy belated Mother's Day to all the mothers who celebrated this month! As I pulled together this issue I was struck by the three wonderful contributions we received from moms who shared their experiences with us for the first time. Jessica Jurusik shared her heartwarming story on our cover, and touched on the feelings of fear and hope that all parents can relate to. Mary Jo Savinsky and Jazmine Sanders both shared their experiences with accessories to help their kids

with cochlear implants have freedom in the water. I thank all three of these superhero moms for their fantastic submissions to our newsletter!

Recently, a few members have contacted us with questions about their mailing label. Please note that there is a date that appears next to your name on your label. This date represents the date that your dues are paid through. So, if you have paid your membership dues already this year, the date on your mailing label will read 12/31/16. If you pay your dues in person at a meeting, our treasurer, Lisa Hill Nowicki, will update your

file immediately. It should be noted, however, that if you mail your check to our Post Office box your mailing label might not be updated before you receive your next newsletter. That is because Lisa usually brings me a new set of printed labels at the same time that I bring her the most recent batch of mail from our P.O. Box. As a result, it frequently happens that she updates the mailing list just after giving me a set of labels to use for mailing. So please don't worry if your mailing label isn't correct. It will be updated by the next cycle. And if you have any question about the status of your dues payment, feel free to contact us.

continued on page 11

Gadgets for People with Hearing Loss

by Mike and Karen Ward



There are a large number of assistive devices (or as we like to call them, “gadgets”) on the market for people with hearing loss. Every individual’s needs will be different, but we would like to share the items we have tried and found effective.

ClearSounds powered neck loop (www.clearsounds.com)

- For devices without a direct audio cable or for people who would be more comfortable wearing a neck loop. We have found a power neck loop by ClearSounds along with the T-coil in the device allows for connection to multiple devices like MP3 players, laptops, cell phones, assistive listening devices like what is provided by Shea’s Theater and more. This is an excellent product. We have dealt with customer support and their warranty center and have been very satisfied.

Sonic Alert (www.sonicalert.com) has a large number of useful products:

Sonic Alert alarm clock with telephone signaler and super shaker (SBT425ss) \$69.99

- 113 dB extra-loud alarm (with adjustable tone & volume control)
- SS12VW Super Shaker™ bed vibrating unit
- Built-in flashing alert lights
- Built-in Telephone Signaler
- Plugs in to a regular outlet

- You can choose to be alerted by either the loud alarm tone, the bed shaker or both

- To be alerted to a ringing telephone, there is an additional cord that needs to be plugged into a phone jack.

Sonic Alert Wireless Doorbell and Telephone Signaler \$99.95

- Wirelessly connects to doorbell for easy installation
- Plugs into a standard telephone jack
- Built-in chime for hearing members of the family
- Built-in outlet to flash an attached lamp
- Sends a signal to all Sonic Alert® remote receivers

Sonic Alert Wall Mount Receiver Extra Bright 360° Strobe - BL300 \$54.95

- Plugs into any electrical outlet
- Multiple units can be placed throughout the home

Lifetone HLAC151 smoke alarm sensing alarm clock (www.lifetonesafety.com) \$189.00

- The Lifetone HLAC151 uses patented monitoring technology to actively listen for the high-frequency sound of any smoke alarm.
- Wakes you up and alerts you with 4 different signals
 - o Loud, low-pitched (520 Hz)
 - o Powerful vibrating bed shaker
 - o Instruction in a baritone voice (“Fire! Get out!”)

- o “FIRE” in large text against a flashing orange backlight.

- We talked to an engineer with Lifetone for over an hour prior to purchases and were very impressed with the work they have done on this unit. We have tested this unit by activating a smoke alarm in the basement and the Lifetone unit was able to detect the alarm on the second floor even with the bedroom door closed. To ensure activation, we use the smoke alarms below.

First Alert – One Link smoke alarms

- This is not specifically for the hearing impaired. We use them in conjunction with the Lifetone smoke alarm sensing alarm clock. These smoke alarms communicate with each other therefore if one alarm is triggered, all get triggered. For example, if the alarm in the basement goes off, the units on the first and second floors are activated, therefore ensuring the Lifetone unit will activate.

Room loop

- Although this is not a commercially purchased unit (it was built from a stereo receiver), it is the most used device in our home. It allows the CI user (or user of any device with a T-coil) to hear the sound directly and adjust the volume of the TV to a level that is comfortable without overpowering the hearing members of the family. If TV viewing is an important part of your life, we would highly recommend looking into this.



Have You Been Looking for Dr. Diaz-Ordaz?

Dr. Ernesto Diaz-Ordaz, neuro-otologist and cochlear implant surgeon, has joined Kaleida Health’s Buffalo General Medical Center. His new office is located at 100 High St. on the sixth floor. For appointments, call his new office at (716) 859-2175. Documents can be faxed to (716) 859-4208.

Alerting to Sound When I Am Alone

by Will Licata



BC400



SB1000



SS12VW

So many things in our lives today rely on sound to get our attention. Whether it is a phone, a smoke detector, a pet, or a child, noise is usually the primary method to try drawing attention. As my hearing loss progressively grew worse I found that I really cannot hear much when I am unaided.

This can be particularly difficult when I am alone. For me, I needed a solution that could wake me up or get my attention when there was sound. Any sound. The sound could be from things such as a phone, house alarm, CO alarm, smoke detector,

etc. Basically I needed something to hear for me when I can't.

After looking at a number of products on the market I discovered there was nothing all inclusive. Some devices can trigger a bed shaker when the phone rings, or when the smoke detector goes off, but they are limited. Also, most of these products were vendor specific, so I would be required to purchase their smoke detectors, or CO alarms.

Eventually I came across a solution that was perfect for me. It consists of three components from SonicAlert.com. The first piece is the SB1000 alarm clock. This alarm clock works with the SS12VW bed shaker. These two components can shake the bed at whatever time you decide to set the alarm for. The SB1000 alarm clock also has an outlet on the back to plug in a table lamp. When the alarm goes off, not only can it shake the bed, but it can also flash the lamp.

The third component is the BC400 Baby Cry Signaler. This is basically a sound detector. Its intended purpose is to listen for the sound of a crying baby. When the BC400 picks up the sound of a child needing his/her mother, it sends a

signal to the SB1000 alarm clock. This triggers the bed shaker and flashes the table lamp. The significant thing to understand is that it detects more than just a crying baby. It can pick up a smartphone ringing, a smoke detector sounding, a doorbell ringing, a dog barking, and so on.

The BC400 just needs to be plugged into a standard electrical wall outlet. There is no wire connecting it to the SB1000 alarm clock. As a matter of fact, it does not even have to be in the same room as the alarm clock. The BC400 has a sensitivity adjustment as well. This allows me to control how loud the sound needs to be before it triggers.

I placed the BC400 next to my nightstand. Now if work calls at 2am I am woken up by the bed shaker and flashing light. It also picks up the house phone ringing, and all my emergency safety devices. I no longer have to find individual or specialized solutions for all the things that want my attention.

These products are all available from SonicAlert.com. The solution runs about \$120. Note: I have no affiliation with Sonic Alert.

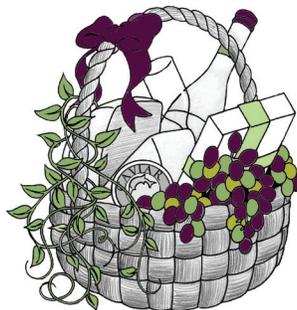
Auction Baskets Needed

In preparation for our summer Sunset Dinner Picnic scheduled for Friday, August 5, we are collecting donations for our ever popular basket raffle! Once again, Sr. Dorothy Feltz is serving as our organizer.

Please consider asking local business people and vendors that you may know to consider donating a basket to our cause, or please put together a themed basket yourself. Remember that all

donations to B.I.G. are fully tax deductible.

You can bring your basket donations to our next B.I.G. meeting on June 8, or bring them directly to the picnic on August 5. Sr. Dorothy will be available at the June 8 meeting to answer any questions you may have.



Treasurer's Report

by Lisa Hill Nowicki

Thank you everyone! Our income, year to date, continues to exceed our expenses. However, with the newsletter being one of our largest expenses, this will change soon. As a reminder, the date next to your name on the label will let you know if you are up to date with your dues. If you are not, please send in your payment of \$20 to our Post Office box or pay in person at our next meeting in June.

was the second time we were told that we were just worried first time parents. Even with these doctors telling us she could hear, we knew something was wrong and could not let this false positive fuel our denial. We were not sure where to go next or who to ask for help because our trust in doctors was fading quickly. Thankfully we were able to get Kayleigh evaluated for early intervention services and she qualified. We were paired with our speech therapist and we finally had someone we could trust. She provided us with so much expertise and guidance in this journey. She pushed us to get answers when doctors were telling us to enjoy our little girl and stop worrying.

Around Kayleigh's first birthday we had a series of difficult events occur. We were exhausted as a family but received uplifting news. We were expecting again! This news gave

us strength and we pushed forward. We insisted on a sedated ABR and traveled to Syracuse in December.

The day came and the test was performed. We were called in to a small consult room to meet with the audiologist. She didn't need to say anything, her face said it all. Kayleigh had severe to profound sensorineural hearing loss in both ears. From that moment on our lives changed, starting minutes later when they wheeled Kayleigh out to us. I tried to comfort her like I had before but things felt different. I knew the words I was saying to calm her were not making a difference and I was flooded with emotion. The tears and questions soon followed, along with more waiting, worrying, and wishing. That night I lay in bed wondering what we would do. Would the hearing aids work? Would she talk? How

would we learn to sign? Would she be happy? And the hardest question, why Kayleigh? Was it something I did or did not do? Could I have prevented it? As the next few months unfolded, all our questions were answered but new ones arose just as quickly.

At the start of the new year, Kayleigh received her hearing aids but we knew almost immediately that they weren't enough. While we were discouraged at first, we knew we had options. She could continue to live in silence and learn sign language to communicate or go for a cochlear implant that would allow her to hear and maybe give her a chance at spoken English. We have no other hearing loss in our family and the cochlear implant seemed like the clear choice but were not sure what the right choice would be for Kayleigh. Would she be accepted into the deaf community

continued on page 7

Meeting Report

by Gail Cronin

Our last B.I.G. meeting took place on Thursday, April 7 at Buffalo Hearing and Speech Center. Following some brief business announcements we welcomed guest speakers discussing "Assistive Listening Devices for Personal Use." Drs. JoAnn Hammer and Alison Ulatowski started off the presentation with a review of the accessories offered by each of the three cochlear implant manufacturers.

Dr. Hammer highlighted several devices offered by Cochlear Americans for their Nucleus devices including the highly versatile implant mini microphone, the wireless TV streamer, and the wireless phone clip. She explained how Bluetooth technology is used for wireless sound transmission in many devices. Dr. Hammer made a point of reminding both cochlear implant candidates and current users who may be upgrading their sound processors in the future, that you choose which accessories you would like when you make your processor purchase. Those that you

do not choose at the time of initial purchase can be purchased later at an additional cost. It is helpful to know what accessories fit your lifestyle before you place your order.

Dr. Ulatowski discussed the accessories available to Advanced Bionics implant users including the Compilot all-in-one remote, the remote mic, and the TV link. She also described how the Compilot works with both AB implants and Phonak hearing aids, and therefore is a great option for candidates who will continue to use one Phonak hearing aid along with a cochlear implant in the other ear. She also discussed the Phonak DECT cordless phone and the Phonak Easy Call cell phones adapter.

Dr. Hammer returned to the podium to discuss accessory options for MED-EL devices. The Clearsounds Quattro 4.0 is recommended, as the MED-EL sound processors are Bluetooth ready. This accessory is available for use with all

Bluetooth devices. She discussed the Waterwear covers currently available and notes that MED-EL expects to release more accessories in the future.

Finally, Will Licata was invited up to the podium to discuss the Sonic Alert devices that he has used in his home as a complete alerting system. Many participants were impressed with his system and he graciously agreed to write an article for this newsletter with all the details. You will find it on page 4.

After the speakers had finished, the audiology staff and students demonstrated the accessories at three separate tables, divided up by manufacturer, so that each CI user in attendance could examine their accessory options directly.

There were 35 people in attendance and we enjoyed pizza and desserts throughout the evening. We sincerely thank Kristen Miller and Vicki DeMarco for providing sign language interpreting services.

My New Job!

by Gloria M. Matthews



Happy Spring! I must first apologize for not being in attendance for B.I.G.'s first general meeting of the year. I was looking forward to learning about all three companies assistive listening devices. I hope that everyone was able to learn more about what kind of assistive listening devices were available to CI users.

In the past five months, I've been busy working for Deaf Access Services as their Community Relations Assistant. I was hired in November, just before the Vera Bradley Bingo Fundraiser, and began December 1, 2015.

My job entails managing social media accounts, writing and publishing the monthly e-newsletter, managing the contents on the website plus the DAS online store. What you may not know is that I was one of the few individuals who helped in finishing up and launching DAS' newest website. After the launch of the new website for DAS, I automatically had to dive into the planning and coordinating of the DAS Spring Gala, which was why I couldn't attend the first meeting of the year. I was caught up in finalizing the details, working on graphics and more. The Spring Gala

was held on Friday, April 15, 2016 at The Grapevine Banquets in Depew. Since I was the Event Coordinator, I am just relying on feedback on how well it went. While I was there, it felt hectic in the beginning but eventually everything smoothed out. I had a few people come up to me to tell me that it was a job well done. What caught me off-guard was I was recognized by DAS' Executive Director, Sharon L. Hanson, and the Board for the hard work that I invested into the Gala that made the event possible. As I type this, I'm still processing that. So in all fairness, it was a learning experience and I learned so much.

It has been a very intense first five months on the job. To be honest, I don't think just anyone could've pulled it all off. I think only someone with some knowledge, patience, and background in nonprofits, volunteerism, and event planning would've been able to pull it all off. But as I mentioned earlier, I'm still processing these last five months and playing catch up with my own life. Overall, I've enjoyed the experience and the opportunity given to me to show my work, but I could not have done it without the helpful

advice and tips from my awesome supervisor Petra Saunders and Ms. Sharon L. Hanson because it truly has been a learning experience for me.

I am still doing social media for B.I.G., so have no worries. I may not have been able to post as much because of my time being devoted to the Gala, but now that I am free of planning a major event, I can now have that extra time to get back to my own things - my NORMAL routine! Plus, during this entire process I owe my son some MAJOR mommy-and-me time! I look forward to seeing you all at the next meeting!

Please don't forget that May is Better Hearing and Speech Month! Plan to write to your local newspapers about your hearing loss, the support you have received from us, your audiologists, doctors, friends and even family. Also explain why it's important for the public to be aware of the resources available to them and their loved ones, and how these resources have been of help to you.

Many Thanks

Tracy Balon
Jeanette Berry
Buffalo Hearing and Speech Center
Melissa Burroughs
Craig and Jackie Carpenter
Sharon Carroll
Elsbeth Chidiac
Matt Coleman
Joe Cronin
Sean Cronin
Kathy Danahy
Linda Dorsey
Sr. Dorothy Feltz
Margie Fitchlee
JoAnn Hammer

Lisa Hill Nowicki
Jessica Holst
Jessica Jurusik
Will Licata
Kathy Maroney
Gloria Matthews
Fr. Bob McArtney
Doug McSkimming
Diane Mogavero
Mark Morehouse
Shirley Morehouse
Norma O'Brien
Jean Ras
Kenyon Riches
St. Aloysius Gonzaga R. C. Church

St. Mary's School for the Deaf
Jazmine Sanders
Mary Jo Savinsky
Carol Schillace
Maxine Schwertfager
Sisters of St. Joseph
Mary Ann Slon
Joe Sonnenberg
Sandra Swaciak
Jan Telban
Sue Wantuck
Mike and Karen Ward
Alison Ulatowski
Zenger Group

having the implant? If we did not choose to implant would she resent us? Would she resent us if we did choose to implant? Would we be able to connect with her and communicate? These questions kept us both awake at night, as did her nightly dance parties, but these quickly took our minds off these heavy decisions and reminded us she was a perfectly happy child.

We decided to have genetic testing done. I was not as eager to obtain this information as Brian was. Honestly, I think I was scared. What if it was not genetic and



was something I had caused when pregnant? What if I ate something when I was nursing or was exposed to something in the environment? All these things weighed heavily on me. We moved forward with the testing and just waited, worried, and wished.

We learned Kayleigh has a genetic mutation known as Connexin 26. This knowledge was good to have because people with this mutation often make excellent implant recipients and we knew our chances of having subsequent children with the same mutation was 25%. More waiting, worrying, and wishing about our new baby I was carrying and what this meant for her. The plus side was that I knew I could go home and happily enjoy the Oreos and deli meat I was craving without the worry that I was causing damage to the little ears forming on our new precious baby.

We ultimately decided that the implant would give Kayleigh the best of both worlds. She could hear the birds and sweet sound of her own laughter but could also enjoy

the silence if she so chooses. After making this decision the real work started. We had to choose an implant center, apply to be a candidate for the implant, and then wait, worry, and wish before hearing the team's decision.

My husband is one of the most intelligent and thorough people I have ever met so I left the researching up to him. He researched the implant centers, surgeons, procedure itself, the devices, all of it. He left no stone unturned and I am so grateful for that. It was a mentally exhausting process that I am not sure I would have survived. After our past experiences, we knew we needed to find a team that we could trust. We ultimately chose The Children's Hospital of Philadelphia (CHOP) and begin the process of becoming a candidate. We completed a very lengthy application that required lots of reports from doctors we had seen over the past year and a half. We met with some of the team and submitted our application. The initial meeting seemed very promising but we did not want to get our hopes up. Then we received the letter we had been been waiting, worrying, and wishing for. She was a candidate! We decided to start with just one implant and scheduled the surgery.

Leading up to the surgery was more waiting, worrying, and wishing. Kayleigh's life was about to change and she didn't know it. She didn't know that a skillful surgeon would make an incision behind her ear and put in a device, a piece of technology, a small miracle, that would give her the gift of sound. Brian and I were prepared, at least we hoped, to carry the burden of worry for her. We worried about the procedure, we worried about her recovery, and we worried about the long term outcomes. We hope some day she understands this and thanks us for making this decision for her.

On July 30, 2013 Kayleigh received her first cochlear implant. The surgery was a success, all electrodes fired and her recovery was simple. It didn't slow her down one bit. She was attempting

headstands that night. Most implant recipients wait two weeks for activation but at the time of Kayleigh's surgery I was almost nine months pregnant and Philadelphia was a four-and-a-half-hour drive, so we were able to schedule activation for just nine days later.

It was nine long days of waiting, worrying, and wishing. We had watched plenty of activation videos online and heard many stories from families, so we felt prepared for a range of reactions. Kayleigh's was not quite the YouTube-ready reaction we had hoped for. Instead, it was a mere glance up and then off with the processor so she could enjoy her M&M's in silence. We were ecstatic all the same. This was just half the fun that day.

We started back home thinking we would have the next week or so to work on getting Kayleigh oriented with the processor. All I could think about was how she finally had the opportunity to hear. Maybe I thought about it a little too much and ignored the signals my extremely pregnant body was sending me. It was a long night with no sleep and in the early morning hours I went into labor!

Claire was born the next night at 6:12 p.m. She looked just like her big sister, absolutely perfect. We waited, worried, and wished as she was taken for her hearing screening. I was not sure what I really wished for at that time. Part of me wanted Claire to be deaf so that they had each other but we were so new to it all we didn't really know what it all meant for our family. Regardless of what we wished for, the results came back and she could hear. Both our girls heard for the very first time just hours apart.

The timing of Claire's birth was perfect because it allowed me to use my maternity leave to be home with our girls and focus on getting Kayleigh caught up. I put in for a year leave and set out to tackle this new challenge. Things were progressing much slower than we had expected but we moved forward with getting

continued on page 7

Parents' Corner: Kids in the Water

The Cochlear Nucleus Aqua+ Water Accessory

By Mary Jo Savinsky



This is our 8 yr old son, Parker. Parker was diagnosed later than most children (a story for another time) and had his bilateral implants activated at 35 months old. He currently wears N6's from Cochlear Americas.

After activation, he attended the Buffalo Hearing and Speech Oral Deaf Education Program for four years. He thrived in the program, and thanks to all the amazing teachers and skilled therapists, he is now mainstreamed and in first grade in our local school district.

We were always told that his processors were water resistant, even without a cover. Although somewhat hesitant, we felt comfortable enough to have Parker start swim lessons wearing his processors. He may not have always "listened," but having the ability to hear the instructor definitely helped Parker learn the basics of

swimming and gain confidence to go under water without fear.

In 2013, Cochlear Americas introduced the Nucleus Aqua Accessory, a water proof bag in the shape of the processor, with an attached coil and cable. We decided to try them and felt better about the processors being enclosed in something instead of exposed, especially at the beach. Although they appeared to be a little bulky and slightly uncomfortable for Parker to wear, we were thankful to have him able to hear us at the beach during our family vacation on Cape Cod.

When the Aqua+ became available in 2014, we were very excited! The design, with a softer, sleeker sleeve that covers the processor and battery, was a definite improvement. The Aqua+ is waterproof in up to 10 feet of water for 2 hours and can be submerged in chlorinated pools, the salty ocean, soapy baths, you name it! The Aqua+ allows the processor's remote assistant to still work. It also comes with a safety line that connects to a swim shirt so if the

processor comes off during swimming, it will stay attached to the shirt. Because, let's face it, nothing makes us sicker than fearing we've lost a processor, especially in the ocean!

The Aqua+ kit was \$249 and came with 2 sleeves, 1 coil, 1 magnet, 2 safety lines, 4 mic lock stirrups and 1 waterproof case. The price may seem high to some, but the value of having Parker able to hear us while swimming, playing at the beach, even taking baths, and not having to worry about the possibility of replacing a damaged processor, justified the cost to us.

We were so happy with the performance of the Aqua+, we recently decided to purchase a second kit so Parker could wear both his processors and have them protected during water activities. This made a difference during a recent trip to an indoor water park with the noise of water splashing, music playing, and kids yelling. Parker could definitely hear us. He didn't always "listen" to us, but at least he heard us! Even the Aqua+ can't help with that!

Advanced Bionics AquaCase Accessory

By Jazmine Sanders



Elliana's first cochlear implant surgery was on May 20, 2014 on her left ear. It was very scary at first, until we saw the look of joy on her face. Her implant was activated on June 18. Then we knew that we had made the right choice.

The implant by Advanced Bionics came with lots of different

attachments, which was a lot to take on for the first time. But once we got into a routine with everything, it was like clockwork. We loved that Elliana was able to hear us and understand us. A year later we were told that it would be best if we did the cochlear implant surgery on her right ear also, because her hearing in that ear was declining. We wanted to do what was best for her, so on August 7, 2015 she had another cochlear implant surgery on her right hear. Again, all went well. Four weeks later we went to Buffalo Hearing and Speech Center for her

activation with Dr. Michelle Dubé. That was the day we got to see Elliana hear with both implants. It was unforgettable. We scheduled her next appointment for about 3 weeks later.

At that follow-up appointment, Dr. Dubé explained to us about a waterproof attachment called the AquaCase, which could be used with Elliana's Advanced Bionics cochlear implants. We knew that this would really come in handy with Elliana. I was very excited to learn about this attachment because

continued on page 9

by this time I knew from experience how rough the summer could be with a hearing impaired child. Whenever Elliana wanted to get wet with the water hose or swim with her friends, or even go to the beach, it was very scary because we would have to take her cochlear implant off. This meant that she wouldn't be able to hear us if we needed to warn her of anything, and she was also not able to hear conversations other kids were having, which made her feel lonely.

Another consideration was bathing at home, when Elliana constantly screamed for someone to be with her because she was afraid of being alone and unable to hear. This waterproof accessory could help with bath time too. So when we were informed of the waterproof accessories, we were very excited!

Dr. Dubé explained how everything worked and how she was putting a separate program into Elliana's speech processors for when she was using her waterproof accessories. Everything was pretty simple to understand, so that night at bedtime we decided to give it a try. It was much simpler than it looks. As soon as we put it on I asked Elliana if it was working and she replied, "Yes." She stepped into the shower and I noticed that she was very quiet. When I asked her why she was so quiet she said it was because she could hear the water in the shower. She was just listening, which of course made us both smile and I teared up a little just seeing how happy she was.

We are really looking forward to this summer with Elliana's new waterproof accessories. This summer will be special for all of us, but

especially for Elliana since she won't have to feel left out and alone. She's very special and deserves to be happy.

To all the families who are looking for information on the AquaCase, I hope that this helps. I highly recommend it. It's very effective and works well.

Editor's Note: The AquaCase is an accessory for use with the older models of Advanced Bionics devices used by many of our readers. The latest Advanced Bionics sound processor, the Neptune, is fully waterproof without additional accessories. This new device is available for new users and those who are upgrading to the latest sound processor technology. The AquaCase remains available for use with older advanced Bionics sound processors.

REFLECTIONS on: *Second Chances*

by Margie Fitchlee

Winter has passed and the hope of spring lingers within my mind. There is something special about spring, something unexplainable, and something simply wonderful!

"Winter passes and one remembers one's perseverance." Those are the words of Yoko Ono. The long, cold, dark season is gone and for many the struggles associated with it are lessened too.

Spring has sprung! Hurray! L M Montgomery sums it up when she says, "That is one good thing about this world. There are always sure to be more springs."

Spring here in South Florida is very different from that which I grew up experiencing in Western New York. It is much more like our summers back home. One thing, however, remains the same to me. That one thing is how spring always makes me feel excited. I am excited that better days are ahead, excited that change is in the air, and excited

that hope abounds. Toni Sorenson describes spring in such a beautiful manner. She says, "Spring is painted in daffodil yellows, robin egg blues, new grass greens and the brightness of hope for a better life." She also says that, "Spring gives us hope that God believes in second chances."

Many of us in the Buffalo Implant Group know firsthand about second chances. Many of us know that being graced with cochlear implant surgery has given us the second chance we so desperately needed. It has given us the chance to hear and understand speech again. This is something I will always be thankful for. The struggles may still exist, but they are lessened. Perseverance has prevailed and life goes on.

The Buffalo Implant Group cares. We care about all of our members and we care about those of you who are considering cochlear implant surgery. We are here to support, educate and welcome you into our

family. We encourage you to do your homework, research what is available to you, and contact any of us with your questions or concerns.

The late Nancy Regan had some very good advice for all of us when she said, "Don't ever lose hope. Even when life seems bleak and hopeless, know that you are not alone." The members of the Buffalo Implant Group want you to know that you don't have to face your hearing loss alone. We are here for you and we care.

If available to you, take that "second chance." You will be amazed at what lies ahead for you. Enjoy what spring has to offer and look forward to what lies ahead for you. God Bless!



her second implant in January of 2014. The next several months were a struggle. We struggled to get Kayleigh to wear her processors, we struggled to communicate with her, we struggled to get her to participate in therapy, and we struggled with her behavior. There would be small glimmers of hope like when she started wearing her processors for longer periods of time, when she would imitate a sound, or the first time she turned to her name. We would be thrilled for a moment but knew there were mountains to climb. We felt like we were constantly reevaluating our goals for Kayleigh and trying to figure out what was realistic. We were getting the best therapy we could in our area, we were traveling to CHOP for audiology and therapy appointments, but we weren't seeing progress. As that first year went on we knew things weren't going like we had expected so I extended my leave another year and hoped for the best. It was difficult to know if the behaviors were because of the language delay or if there was something other than her hearing loss that was preventing the language from progressing. Kayleigh started three-year-old preschool in September of 2014 and at first it seemed like we were turning a corner but it was short lived. We felt that while our speech therapist was amazing, she was not a long term solution. We had already lost her direct services when Kayleigh aged out of early intervention and we would eventually lose her services altogether when Kayleigh reached school age. Cochlear implants allow a person to hear but that is their only job. It is in therapy that you learn to listen, understand, and speak so we needed to find a place that could offer this therapy. It was in November of 2014 that we began thinking about relocating. It was also then that we met with our team at CHOP to discuss Kayleigh's behavioral issues and were referred to a developmental pediatrician.

I think deep down we saw it coming but were surprised how

quickly it was diagnosed. Just one visit with this doctor and we were told Kayleigh was presenting with a high functioning spectrum disorder. In this same visit we were told to rethink our plan to relocate for a program that could offer more appropriate services related to hearing loss and look into an autism program. In one visit, with one doctor, we were told to reevaluate our entire plan that we had been working toward for two years. After much thought, we felt that we needed to focus on the hearing loss to start.

In December 2014 we began looking into programs, and that January we made our first visit to St. Mary's School for the Deaf (SMSD). The research we had done on SMSD was very promising but we were cautious. We went for a tour



and visited the available preschool options. It was all wonderful but when we explored the listening and spoken language program, EARS, it truly was love at first sight. This program meant we didn't have to abandon our original plan of using spoken English as her first language but in the event that this was not a good fit, Kayleigh could almost seamlessly transition into a total communication classroom. We knew that was where we needed to be. We emailed them two days later to tell them we had started completing paperwork to enroll Kayleigh and we wanted her to start as soon as possible. The next four months were full of phone calls, paperwork, and packing. I resigned from my teaching position and Brian began getting our house ready to sell and updating his resume for the job hunt. Reality sunk in that

June when the girls and I moved into an apartment, in a new city, without Brian. For a brief moment, panic set in that maybe we had moved, literally, too fast. Those feelings did not last long because we instantly saw a change. Kayleigh started school on a Wednesday and by Friday had her first spoken words, plural. That fall our house sold, Brian secured a job and was finally able to rejoin us. The next ten months were some of our happiest and Kayleigh's world became so much greater than it was.

In February of 2016 we met with our team at SMSD to discuss her progress. We knew she had been doing great but were nervous. These types of meetings usually went the same way. We would hear how wonderful and kind Kayleigh was but then we would have to discuss her progress and it was always minimal and concerning. We would leave the meetings devastated and like we had no real plan. This meeting was different.

The gains she has made are outstanding. Her behavioral concerns are no more and she is progressing with both her receptive and expressive language. For a child that really didn't have a working form of communication in place for the first two years of her life, it's absolutely a testament to the work she has put in. It feels like a miracle but it isn't. It took blood, sweat, and tears. Kayleigh has worked extremely hard to get where she is and we are so proud. We had no idea how difficult this road would be and there were plenty of times we wanted to abandon our hopes and dreams and start over. We made many sacrifices and fought to get what we needed but we would do it all over again. We still wait, worry, and wish but we know she is on her way and loving her new found world of hearing and communicating. We are forever grateful to those who believed in us, supported us, and helped us reach this point, especially our dream team at SMSD. We cannot wait to see what the next chapter of this story holds for Kayleigh.



Quarterly Newsletter

Subscription/Membership Form

\$20.00
per Year

Name _____

Address _____

City _____ State _____ Zip + 4 _____

Phone (day) _____ Email _____

Implant User Parent Child's Name _____

Device Name _____ Age Implanted _____

Professional, What field _____ School _____

Other _____

**Please make your check payable to Buffalo Implant Group and send the Subscription/Membership Form and/or donation to:
Buffalo Implant Group, P.O. Box 350, Clarence Center, NY 14032-0350**

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

Hearing Loss, the Legal System, and You

The Buffalo Implant Group is excited to welcome renowned attorney Bruce A. Goldstein, senior partner with the law firm of Goldstein, Ackerhalt & Pletcher, LLP, and nationally recognized expert in disability law.

The meeting will be held in the St. Mary's School Assembly Hall. Free parking is available in the lot behind the building. Enter on Main St. In the driveway marked "Main Entrance." Sign Language interpretation will be provided.

Pizza, pop and water will be served. Please consider bringing a snack or dessert to share if possible. But most importantly, we need YOU. Friends and family are welcome. Social time will follow the meeting and speaker.

**Please Join Us
Wednesday, June 8, 2016
6:00 – 8:00 pm
St. Mary's School for the Deaf
2253 Main St. Buffalo 14214**



From the Editor...

cont. from page 2

A few members have also observed that the Walk 4 Hearing held each year in Fairport did not happen this spring. That is because the Walk 4 Hearing has been moved to autumn. This year's Walk 4 Hearing will be held on October 2, 2016. Details will be shared in future issues of The B.I.G. News.

If anyone is interesting in volunteering some additional time to our organization, please speak to one of our Board members at the next meeting. We now wear name tags to identify us, thanks to the efforts of Will Licata. We hope that this new practice makes us a bit more accessible to you, especially our new members. If you are unable to attend the meeting, but would like to volunteer for something, make a suggestion, or share your story for an upcoming issue of The B.I.G. News, please email me at gdcronin@roadrunner.com. I look forward to hearing from you!



BUFFALO IMPLANT GROUP

P.O. BOX 350

CLARENCE CENTER, NEW YORK 14032-0350

www.buffaloimplantgroup.com

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