

the **BIG** news

The Newsletter for the Buffalo Implant Group

Volume 25 • Issue 3 - 2013

B.I.G. staff

Gail Cronin - Editor and Acting
Publisher
Janet McKenna - Assistant Editor
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UPcoming Events

B.I.G. Summer Picnic August 2
BHSC Buffalo Brewfest August 9
BHSC Summer Golf Classic August 26
Deaf Awareness Week September 22-28

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Meeting Notice
Picnic on
August 2, 5-8 pm
Westwood Park,
Lancaster



HOLDEN'S JOURNEY

By Kristin Miller

My name is Kristin Miller, and I am the adoptive mother of my son Holden who has bilateral cochlear implants. When Holden came into our lives he was three years old and in the foster care system. Holden was implanted two months before he moved into our home. He was not a consistent cochlear implant user at this point, and his implants were relatively new to him and us. I knew about implants because of my work experience as a social worker at a deaf school, but dealing with them on a daily basis was much different. My husband and I faced many challenges for a long time.

My husband and I did not have to go through the process of making the decision to have our son implanted or not. This process we did not experience, nor do we have any advice for parents about implanting their child. However we do know the struggles after implantation. We were not able to make decisions for him when it was difficult trying to get Holden to accept his implants; again, he was a foster child and the county workers made those decisions. This was one of our biggest struggles. When we attempted to put Holden's implants on him he would resist them by crying, pushing our hands away, running away and moving his head so that we could not get them on. Once we put them on his head he would cry and hold his head. This was heartbreaking. We felt like we were hurting him.

After a period of crying and having us encouraging him to keep them on, Holden would leave the implants on for a very short time. After a couple of weeks of trying to get his implants on, we brought him to the doctor. The doctor told us everything was fine, and the implants were not hurting the child. Again the crying, pushing our hands away, running away and moving his head so we could not get them on him concerned us, and we went to our mapping agency. They too told us that the implants were not hurting him. It was over two months of Holden resisting his implants as we tried to put them on him each morning. We went through this process of getting them on every day.

During these months, Holden would only wear his implants for a short time. He would be "done hearing" after an hour in the beginning. The wear time increased gradually, but he would be "done hearing" before the day's end. Three months after living with us and fighting every day, we were at a mapping appointment. During this appointment the agency told us that Holden's implants might not work well for him. They were not receiving the results they would expect during this appointment. This was difficult news; we fought every day to put his implants on and they might not work for him. The question that came next was should we continue to force him to wear these implants? Still at this point it was not a decision that my husband and I could make. Holden was still a foster child, and we did not have

~ Continued on page 5

THE PRESIDENT'S CORNER

By Sue Wantuck



Sue Wantuck

Happy Summer, everyone! I love this time of year! I can't wait to enjoy the beautiful sunshine and warm temperatures over summer break! I hope that many of you have exciting summer plans to look forward to, such as traveling, visiting

family and friends, and most importantly relaxing!

Our June B.I.G. meeting had a great turnout. The two Cochlear Americas presenters were very informative. I enjoyed learning about Brittany's experiences growing up as a deaf child and receiving her implant 21 years ago. I think it is wonderful that she is trying to "get the word out" and educate people about candidacy and available technology through her position with the company. Sonya provided a brief overview of the NU5 and the new water accessory bag. I have already placed my order and am eager to try it out! I was shocked and impressed to learn that the internal device is expected to last 70 years. I hope that members in attendance also gained useful knowledge from the information shared. If you were unable to attend feel free to access the B.I.G. website for the minutes.

If you are a unilateral ci user, have you ever considered becoming bilateral? I thought about this for a long time. I did research on my own as well as discussing the option with my audiologists and other B.I.G. members. When I felt that I was ready I made the decision to proceed quietly. At the beginning of June I underwent my second implant surgery and will soon go for initial stimulation and mapping. I am currently feeling a lot of mixed emotions but mostly relieved that my surgery was successful and hopeful for what my new "hearing" experiences will be. I love to challenge my life with the world of sounds.

I look forward to seeing all our members at the annual B.I.G. Picnic on Friday, August 2 at the Westwood Park in Lancaster. Please be sure to attend this worthwhile event! Bring family and friends. The more the merrier!
Happy Hearing!!!!



FROM THE EDITOR

By Gail Cronin



Gail Cronin

Just when I started working on this issue of The B.I.G. News, I received the news that my new nephew was born prematurely with some serious medical complications. Not long after, I was emailing assistant editor Janet McKenna. I mentioned that my nephew was about to undergo open-heart surgery. Something in her email reply touched me deeply.

Janet said, "How fortunate that he lives in an age when the littlest ones can be helped and go on to a full life." That is so true. We do live in an age, unlike any before, in which medical and technological advancements border on the miraculous. The same can be said about the latest in hearing surgery and technology.

In this issue of The B.I.G. News we see many examples of how the latest technology is improving people's lives, often surpassing our expectations. Kristin Miller shares the story of her son Holden's journey from frustration to progress in communication using the bilateral cochlear implants that he received while still in the foster care system. It took a lot of time and patience, but his family's support has really paid off. Our spring meeting report recounts the personal journey of Brittany Pellegra, as well as the technology update given by Dr. Sonya Reschly. Dr. Reschly shared with us the new waterproof cover for Nucleus devices, which has come to the market in perfect timing to fulfill Holden's need for it.

Our newest Board member, Jessica Holst, Speech-Language Pathologist at St. Mary's School for the Deaf, has agreed to be our liaison to all cochlear implant manufacturers. She will keep us informed of their newest technological advancements. She has included a chart in this issue to help compare device features across companies. Jessica also reports on the recent Rochester Walk4Hearing and the newly formed Hearing Task Force for Erie County Early Intervention. All these resources are designed to improve the lives of people with hearing loss.

Also in this issue, Janet McKenna shares the exciting news that Regal Cinemas has expanded the availability of their Access glasses for closed captioning. Janet introduced us to this new technology in the spring issue. Janet also reports on a recent panel discussion she and another B.I.G. member, Jimmie Sorrento, participated in for the Rochester HLA chapter.

Margie Fitchlee's reflection in this issue is on the subject of time. She reminds us that the present is a great time for those who have hearing loss. Just as my nephew is fortunate to live in an age where surgical procedures for newborns are the difference between life and death, today's hearing technology can be the difference between isolation and the freedom and sense of connection that come with communication. At no other time in history have we had so much opportunity.

I hope that all our readers will take the time to make connections with one another in the coming months. We've enjoyed high attendance at our recent meetings and hope for a good turnout at our summer picnic on August 2. Come and enjoy some delicious food and an evening of fellowship. If you haven't reached out, now is the time!

COCHLEAR IMPLANT COMPANY LIAISON REPORT

By Jessica Holst

B.I.G. has recently adopted a new board position, that of Cochlear Implant Company Liaison. The charge of this position is to provide members with the most recent CI technology updates. This information will be included in our quarterly newsletter. In addition, this position will coordinate rotating presentations from each implant company to best meet the questions and curiosities of B.I.G members. As this is a new position for the group, feel free to email holst.jessicam@gmail.com with any recommendations of how your technology needs can best be met.



Jessica Holst

	Advanced Bionics	Cochlear America	Med-El
Current Implant	HiRes 90K HiRes 90K Advantage	CI24RE CI24R Double Array CI422	CONCERT (titanium) SONATA (titanium) PULSAR (ceramic)
Implant Warranty	10 years	10 years	10 years
Current Sound Processor (wearing options)	Neptune  Harmony 	Nucleus 5 	RONDO  OPUS 2 
Eligibility for Upgrade to the Current Sound Processor	Recipients implanted with a CII or 90K (implanted since April 2001) can upgrade to the Neptune or the next generation speech processor technology under FDA review.	Recipients implanted with the CI22 implant are eligible to upgrade to the Freedom Processor. All other recipients are eligible to upgrade to the Nucleus 5. All implant types will be able to upgrade to the next generation speech processor technology as it will be backwards compatible for all implant models.	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	Neptune: 3 years Harmony: 3 years	Nucleus 5: 5 years	RONDO: 5 years OPUS 2: 5 years
Remote Control		Nucleus 5 Remote Assistant 	FineTuner for use with the RONDO and OPUS 2 
Microphone	Neptune: Located in headpiece; T-mic available with accessory Harmony: T-mic at ear canal entrance, omnidirectional mic at top of ear; Programmable mixing ratios between mics	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	Neptune: Waterproof sound processor & AquaMic configuration Harmony: Water resistant	Nucleus 5 is waterproof with rechargeable batteries in the Aqua accessory	No claims made
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

REFLECTIONS ON: TIME

The Past, the Present, and the Future

By Margie Fitchlee

Depending on our circumstances some of us on this earth want to stop time, some of us want to speed up time, and some of us simply want to slow it down. How would you describe your feelings about time? We have no control over time, but perhaps we have some control over what we do with our time. Some of us can't help but live in the past, some are always looking ahead to what the future might bring, and some of us simply happily or unhappily go along with the flow that the present provides us with. After just finishing Mitch Albom's book "The Time Keeper" I couldn't help but reflect on this concept we call "TIME" and what it might mean for those of us with profound hearing loss or deafness.

It has been said that "Yesterday is history, tomorrow is a mystery, today is a gift from God, which is why we call it the present." I feel one nice thing about the present is that it affords us the opportunity to look back at the past but also gives us the excitement and the anticipation to look ahead to the future.

For many of us in the cochlear implant community the present is a place where we can now comfortably participate. The technology and the skillful hands of gifted doctors have given us that chance. Today for us is truly a gift from God; a gift I will never take for granted. I will always look at Dr. Ernesto Diaz-Ordaz as the man I feel saved me. I can never thank him enough. It is my hope that down the road he will continue to save many others who take that giant step and decide to go forward with cochlear implant surgery. The present is now a place in which I can function. It may not be perfect, but perfection was not what I was striving for when I made the decision to have the surgery. As I write this article I am sitting on my front porch...listening to the birds chirp, the wind blow, and the cars go by... and reminding myself that

without the use of my cochlear implant none of this would be possible. I am still humbled every time I read other recipients' stories. They leave me with no reason to ever feel sorry for myself. Our journeys all differ, yet we are ever entwined by the circumstances that we have encountered.

The last issue of The B.I.G. News and its lead article written by Gloria Matthews left a huge impact on me. I am so proud of this young lady. I wish I could just give Gloria the biggest hug and take all her challenges away. The poem at the end of the article was written straight from her heart. A valuable lesson is to be taught in those words; a lesson we can all learn from. Writer Ken Keasey feels the same way Gloria does. He states, "See with your ears, and hear with your eyes." I have become very successful at doing just that myself but never realized it until I read Gloria's fantastic poem: THANK YOU Gloria.

Time truly does have a way of healing. I really do believe that. When my hearing loss became unmanageable I often said to my husband that one of my biggest challenges was trying to simply relax. That might seem strange to some, but all of the things I did to relax no longer worked. I could no longer successfully watch television or go to the movies. I could no longer listen to music. I could no longer pick up the telephone and call anyone. The world I knew was closing in on me. I started to withdraw, isolating myself from others, and I did not like my new world. It was a place filled with uncertainty and fear. It was not a comfortable place, not a place where I wanted to stay. Luckily for me help was on the way. My implant surgery brought me back to a place where I can function. Yes, time does fly. It was four years ago in July that I had the surgery.

I find it fascinating that as far back as the 1800's Ludwig van

Beethoven felt much like I did before my surgery. He tells us, "Forgive me when you see me draw back when I would have gladly mingled with you. My misfortune is doubly painful to me because I am bound to be misunderstood. For me there can be no relaxation with my fellow man, no refined conversations, no mutual exchange of ideas. I must live almost alone, like one who has been banished. I can mix with society only as much as true necessity demands. If I approach near to people hot terror seizes upon me, and I fear being exposed to the danger that my condition might be noticed." I too felt overcome by the kind of hot terror he spoke of. I was not afraid that my condition would be exposed, but just that I simply wouldn't be able to understand what those around me were saying. Beethoven truly showed us that the only thing deaf people can't do is hear. The feeling of "hot terror" for me has thankfully subsided. I am however sure that for many out there going through the traumatic profound loss of their hearing, the "hot terror" is very real. I can now approach people, mingle, exchange ideas, and be understood. This is my wish for all of you.

What the future will bring is unknown. My faith and my belief in the power of the human spirit tell me it will be a better place. A place where technology and medical miracles will prevail. A place where I hope the struggles and challenges of folks like Gloria Matthews and myself will subside. I look forward to the future...forward to the excitement and the anticipation that comes with it.

The Irish tell us, "The future is not ours to know, and it may never be- so let us live and give our best and give it lavishly!" May God Bless All of You.



Margie Fitchlee

HOLDEN'S JOURNEY..... Continued from page 1

the power to make decisions. The foster care system expected us to continue to use the implants.

We became very relaxed with the implants. If Holden wanted them off, we did not force him to put them on. If he did not want them on we did not fight with him about putting them on. Three months later we went to another mapping appointment. During this appointment he cried every time the agency adjusted his implants. We noticed as well that he responded to his name and the different mappings they were programming. This was shocking to us.

We continued to put Holden's implants on him daily. During the next three months we noticed that he was able to process more information. Holden began to turn when he heard his name. This was truly amazing. Holden was mapped again, and he was not holding his ears the same way he had previously. This was a turn of events for Holden.

Holden still resisted when it came to wearing the implants all the time. During the weekdays his implants were on first thing in the morning before school, but they might come off soon after he was home or well before bedtime. On the weekends we were a bit more relaxed. But if his implants did not go on first thing, Holden would fight us when putting them on. Holden was very comfortable not having them on. These types of fights continued for two years.

During Holden's kindergarten year we noticed a huge change in his use of his implants. He began to use words that were intelligible to us. They might not have been understood by those whom we did not know, but we understood him. His vocabulary continued to build, and his processing began to improve. It was truly amazing. In his kindergarten year he showed so many gains that we decided to try a part-time mainstream school program. Previously Holden was in a deaf school, which used a total communication process. The decision to make the change was tough and scary at the same time. We did not want Holden to get frustrated; we wanted him to gain more.

The mainstream program was for two hours at the end of the day. The teacher was flexible; this was shown by her acceptance of Holden and his interpreter for the last four months of the school year. Holden excelled during this time. His voice quality and his processing improved so much that we asked for the mainstreaming to continue for more hours and more academics.

Holden is now completing his first full year of mainstreaming with excellent progress. We do continue the support from the deaf school; this has been part of Holden's success. He will say words I never would have expected to come out of his mouth. With each and every day we hear more words. The struggles in the beginning were extremely difficult. We had very low expectations. Now our expectations have been met, and new ones continue to enter our minds.

Holden was implanted with a Nucleus Freedom implant. In May he received an upgrade to the Nucleus 5 speech processors. We have been thrilled with the upgrade because they are so much lighter on his ears. Holden does not complain about them hurting his ears any more. He liked his new implants the moment he received them. He really liked the color, the way they sounded, and how they felt. The old implants were very heavy and hurt the top of his ears. Holden now puts his implants on every waking moment and really enjoys the benefits he receives from them.

In fact, he enjoys his new implants so much he wants them on every moment. The other day Holden told me I needed to make him "swimming ears." He insisted that he needs to have his implants on when he is swimming and needs to hear. My response to him was to tell his speech teacher to make them for him. I diverted the question because I did not have "swimming ears" for him. The next day I was talking to a co-worker who told me that Cochlear Americas approved a cover for the NU5 for individuals to wear their implants in water. I was ecstatic! Now I could give Holden "swimming ears."

~ Continued on page 10



REGAL EXPANDS ACCESS GLASSES

By Janet McKenna



Thanks to Regal Entertainment Group for broadening availability of their "Access" captioning glasses.

Access glasses have already been introduced to newsletter readers. In issue 2 we noted that the glasses, which display movie captions, then could be borrowed at the Regal Theater complex at Elmwood Center 16 just south of the village of Kenmore.

The theater chain now features Access glasses at their movie theaters throughout Erie and Niagara counties. The Buffalo News "Western New York

Movie Directory" has clarified its listings too. At the top of the listings are symbols for hearing impaired (deaf symbol), open captioning (OC), closed captioning (CC), and descriptive video service (DVS).

Look closely for the symbols in movie listings at these Regal theaters:

ELMWOOD CENTER 16,
2001 Elmwood Avenue
WALDEN GALLERIA STADIUM 16,
1 Walden Galleria Drive

NIAGARA FALLS STADIUM 12,
I-90 at Niagara Falls Blvd.
TRANSIT CENTER STADIUM 18,
Transit Road at Wehrle Drive
QUAKER CROSSING,
3450 Amelia Drive, Orchard Park

Movie goes with hearing loss throughout Western New York can partake of captioned first-run films with their companions at no extra charge at their local Regal complex. Let's hope other chains follow Regal's example.

SPRING MEETING REPORT

By Gail Cronin



Brittany Pellegra and Dr. Sonya Reschly

For the first time, B.I.G. held a meeting at St. Mary's School for the Deaf. It turned out to be a fantastic location with ample parking and a comfortable meeting

space. The staff at St. Mary's was very welcoming and helpful. Approximately fifty people attended to hear Brittany Pellegra and Sonya Reschley from Cochlear Americas. Communication was facilitated by two wonderful volunteer professionals. We appreciate Barbara Meyers, the sign language interpreter, and Chrisann Militello of Western New York Court Reporting Services, who provided CART captioning services as she has done for many years.

space. The staff at St. Mary's was very welcoming and helpful. Approximately fifty people attended to hear Brittany Pellegra and Sonya Reschley from Cochlear Americas.

Brittany Pellegra is a Cochlear Awareness Network Manager and an implant user since the age of four. Her family history of deafness covers multiple generations. She has been upgraded to five different external speech processors. Among her challenges were waiting for insurance approval and going bilateral. She explained her position at Cochlear Americas as providing patient support and information.

Sonya Reschly, Au.D., is a Clinical Applications Specialist. Dr. Reschly gave a brief overview of the history of cochlear implants over the last thirty years. Discussing the company's

intentions for the future, she mentioned the possibility of a cochlear implant that would still allow a recipient to retain use of his or her residual hearing. Dr. Reschly reviewed Cochlear Americas' current sound processors, battery modules, remote control, and other features. She also talked about special options for rare cases, such as optional electrode arrays and auditory brainstem implants. Dr. Reschly really impressed the crowd by showing us the new waterproof cover for Nucleus devices. Participants were able to feel the material and ask questions.

Following the guest speakers, President Sue Wantuck led a short business meeting. At the ensuing social time, Diane Mogavero bought an immensely popular Pecan Pull Apart dessert. There were many requests for the recipe, so we are printing it below. Our next meeting will be the summer picnic on August 2 at Westwood Park.

SECOND QUARTER TREASURER'S REPORT

By Lisa Hill Nowicki

Thank you everyone for your membership and donations. For the second quarter our expenses exceeded our deposits by \$68, with our largest expense around the newsletter. YTD (year to date) we are positive with a \$52 balance, though this newsletter and next month's picnic will have us dipping into our reserves. Your membership status is the date to the right of your name on the newsletter. Please consider supporting B.I.G. by renewing your 2013 membership if you have not done so already.

CORRECTION

The last issue of the B.I.G. News incorrectly stated that the money raised at the picnic basket raffle would be used to offset the costs of the picnic. That was an error. All money raised through the summer picnic basket raffle will go to our scholarship fund. A Scholarship Committee is currently being formed. It will oversee the funds and award an annual scholarship to a deserving student. Information about the new scholarship fund will be covered in future issues as the committee progresses in finalizing the program. All costs for the picnic will be covered through other donations to our operating budget.

Recipe for: Pecan Pull Apart

- 1 1/2 stick oleo (margarine or butter)
- 1 1/2 cup sugar
- 2 teaspoons cinnamon
- 1 1/2 cup pecans
- 2 cans 2-8 oz Pillsbury Crescent Rolls



Separate dough from each can into four rectangles. Cut each rectangle into half length-wise. Roll dough strips into ropes 12 inches long. Dip each rope into melted oleo. Roll into combined sugar, cinnamon, and nut mixture. Line a 14-inch pan with foil. Grease the foil. Starting at center of pan, loosely arrange ropes in a spiral fashion. Bake at 375 degrees 20 to 25 minutes or until golden brown. Enjoy.

MEETING MINUTES

Are you looking for the minutes from our last meeting? All Meeting Minutes now are located in the "Minutes" section of our website.

ITEMS FOR NEXT NEWSLETTER DUE MONDAY, SEPTEMBER 16

DEAF ADULT SERVICES EXPANDS CLASSES FOR HARD OF HEARING AND LATE-DEAFENED ADULTS

By Donna Cork



Our first ever Hard of Hearing/ Late-Deafened ASL class was held March 6. In the nine years I've been employed at DAS there has never been a class for this population. DAS has always offered this group of people the opportunity to take ASL classes for

free, yet many of them seem to feel forgotten, lost or even left behind. It was suggested that a class just for this group be developed and be taught by a hard of hearing person such as me.

Eight shy people attended this first class. The evening was spent talking about ourselves, our frustrations and why we were there that Tuesday night. Questions were asked, myths were cleared, and helpful suggestions were made. We shared mishaps with what we thought we heard, sad stories and ways we improved our everyday lives. We learned about hearing aids, cochlear and Baha implants, new technology and apps that help us communicate. At the end of the session all eight students left having gained a sense of belonging while losing their shyness. Commenting on their experiences:

"I think our class was great dealing with late deafened adults because we all heard before losing our hearing. I am always in favor of bridging the hearing world and the deaf world. My biggest challenge is remembering the correct signs but I am still willing to learn. No promise on my progress but just to be able to sign some things. It's a start in the right direction. I am glad St. Mary's is hosting the B.I.G. meeting. To me this is a good thing. Hopefully it can help clear up many misunderstandings on CIs and give opportunity to many about ASL and how it has helped thousands. Bringing two groups together brings a better understanding all the way around. Peace."

- Jimmie Sorrento

"I have taken Beginners I & II classes in ASL. Donna is right when she said that we, the hard of hearing, seem forgotten or lost. With this group there is a real connection. We are all struggling with hearing loss in one way or another. We try to support each other. I became deaf in one ear from Meniere's Disease in 2008. After four different doctors I found one that knew instantly what was wrong with me. From there we tried different treatments, but my deafness quickened and I lost 97% in a matter of months. I have a Baha implant. Like any device it helps, but it is not like your own hearing."

- Bonny Wilson, DAS Volunteer

MANY THANKS

Buffalo Hearing
and Speech Center
Melissa Burroughs
Jon Erwin
Sr. Dorothy Feltz
Margie Fitchlee
JoAnn Hammer
Peter and Jen Hurley
Shirley Jaskier
Nancy Lamb
Kathy Maroney
Gloria Matthews
Paul Meyer
Barbara Meyers
Chrisann Militello
Diane Mogavero
Shirley Moorehouse
Winifred Morrison
Fr. Bob McArtney
Janet McKenna
Lisa Hill Nowicki
Brittany Pellegra
Tina Pilkey

Laura Pufpaff
St. Mary's School
for the Deaf
Sonya Reschly
WNY Court
Reporting Services
Sue Wantuck
Zenger Group

Editor's Note: The B.I.G. News will now include all members who contribute to our organization financially, either through donations or membership dues, in the Many Thanks list. We also include those who have contributed their time in a significant way. If there is someone we should thank who has been missed, please email Gail Cronin at gdcronin@roadrunner.com

EVENT REMINDER

Buffalo Hearing and Speech Center will hold two annual fundraising events this summer.

Community support is greatly appreciated.

Buffalo Brewfest
Friday, August 9, 2013
First Niagara Center

Summer Golf Classic
Monday, August 26, 2013
Orchard Park Country Club

For information call 885-8318 or visit www.askbhsc.org

HEARING TASK FORCE ANNOUNCEMENT

By Jessica Holst

Erie County's Local Early Intervention Coordinating Council (LEICC) is excited to announce the establishment of a task force focused on closing the gaps in early intervention services for families of children diagnosed with hearing loss. Ninety five percent of children who develop hearing loss will do so prior to their third birthday. Ninety percent of these children are born to parents who hear normally. In the absence of any previous experience with hearing loss, parents are faced with numerous obstacles to support the development of their child.

Parents are strongly influenced by the information they receive, especially in the period immediately following the diagnosis of their child's hearing loss. Attitudes of service professional and educational authorities need to be considered. Philosophies, practices, and preferences of both will influence a parent's decision concerning intervention approach. It is critical that information shared with parents is balanced with detailed descriptions on all available options, as well as the invaluable benefit of the family's involvement. Parents need relevant, accurate, unbiased information to choose what communication modality best fits their family.

The question then becomes: how will families be provided this information? Is there a system in place that provides them the opportunity to become informed by professionals experienced in working with the Deaf and Hard of Hearing populations immediately following diagnosis? Does this process ensure that each and every family of a child diagnosed with hearing loss can say, "I was provided with a broad range of relevant information in terms I could understand and remember immediately following my child's diagnosis?" And most importantly, "I was then able to make an informed decision about the most appropriate intervention approach for my family."

The LEICC's hearing task force represents a wide range of community stakeholders committed to better serving families of children with hearing loss in Erie County. We continue to recruit members who resonate with this cause and would like to serve a role in closing service gaps. Please email jessicah@smsdk12.org or tbalon@askbhsc.org if you are interested in joining our team.



IT'S PICNIC TIME!

Our next gathering will be our annual...

Sunset Dinner Picnic

Friday, August 2, 2013

5:00 – 8:00pm

Dinner catered by Desiderio's, served at 6:00pm

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

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

The entrance to Westwood Park is on Pavement Road between Walden Avenue and Broadway. Shelter #5 is on the left side just past the main building in the park. Our location is just steps away from a large children's playground and a short walk from bathroom facilities. Parking is located right in front of the shelter. For a map to the picnic location, please see the events page on our website.

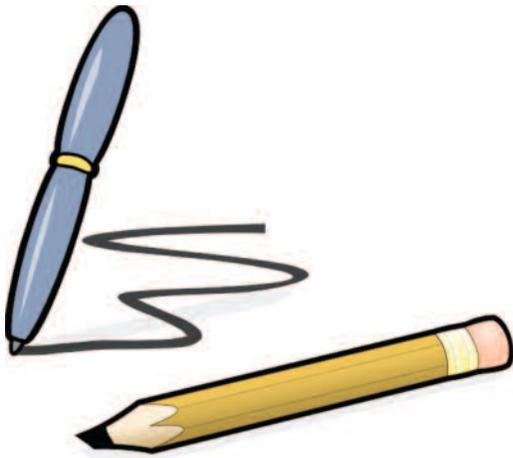
Please plan on participating in our Basket Raffle fundraiser to benefit our upcoming scholarship program. Additional basket donations are appreciated. Baskets can be dropped off to any Board member by prior arrangement, or simply brought to the picnic. The Basket Raffle is being coordinated by Sr. Dorothy Feltz. Tickets will be 2 for \$1 or 20 for \$5.

We need a general idea of how many members will be attending, so RSVP to Secretary Melissa Burroughs at 716-523-2991or bufimpgrp@yahoo.com by July 25 if possible.

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

CALL FOR NOMINATIONS!

According to the Buffalo Implant Group bylaws, elections must be held each year at the Fall meeting. In order to accommodate elections in the Fall, nominations for officers must take place prior to the Fall meeting. Therefore, nominations for the four offices of the organization can be made at the summer picnic on August 2 or at any time during the month of August. Please speak to Sue Wantuck or Gail Cronin at the picnic if you would like to nominate a candidate. You may nominate yourself. If you are unable to attend the picnic, you can email Sue at suewantuck@gmail.com or Gail at gdcronin@roadrunner.com in order to nominate a candidate. At the right you will find a description of each officer's duties, as it appears in our bylaws.



Article VII – Duties of Officers

Section 1: The President shall 1) represent B.I.G. to the public and other organizations, 2) promote cochlear implants in the media and serve as media contact person, 3) arrange quarterly meeting locations, 4) set all meeting agendas and lead the meetings.

Section 2: The Vice-President shall 1) support and assist the President, 2) act in the President's absence at B.I.G. events, 3) organize committees for development and special events (speakers, social activities, etc.)

Section 3: The Secretary shall 1) handle all official correspondence and 2) maintain minutes of all meetings.

Section 4: The Treasurer shall 1) handle all finances and 2) maintain an accurate accounting of all finances.

More detailed descriptions of the officers' duties can be found on the "Board" page of our website. If you have any questions or would simply like more information, please feel free to contact any of the current officers. Contact information can be found on our website.

B.I.G. MEMBERS TELL THEIR STORIES IN ROCHESTER

By Janet McKenna

Eight ears. Six cochlear implants. Two hearing aids. Four individuals related their cochlear implant stories in a panel on "Living and Hearing with Cochlear Implants" at the May 7 Hearing Loss Association of America/Rochester chapter daytime meeting.

Janet McKenna and Jimmie Sorrento, B.I.G. members who also belong to HLAA/Rochester, joined Al Suffredini from Canandaigua and Ginger Graham from Webster as panelists. Each person's ten-minute tale differed.

Janet emphasized the many changes that have taken place between her first Advanced Bionics implant in 1998 and her second in 2012. She stressed the great broadening of candidacy criteria and less drastic surgery.

Al is a pioneer Cochlear Americas user whose first implant was done in Syracuse twenty years ago. He mentioned difficulties in obtaining insurance coverage for that implant and his newer one in 2012. Al also discussed balance issues. His old implant's electrodes have been fading out, impelling him to implant his other ear.

Jimmie, another Advanced Bionics user, offsets it with a hearing aid. He was elated to be able to converse

with his three year old granddaughter, previously impossible because of her high-pitched voice.

Ginger has had a favorable cochlear implant experience with her Cochlear Americas device. Sometimes she uses a hearing aid with it. Luckily she has avoided balance problems and is a "happy camper."

Repeating the panel at another meeting in the fall is being considered.



Shown at the Hearing Loss Association daytime meeting in Rochester are, left to right, Panelists Janet McKenna, Jimmie Sorrento, Al Suffredini, and Ginger Graham.

B.I.G. MEMBERS JOIN THE WALK4HEARING

By Jessica Holst

On May 5, members of B.I.G. traveled to Rochester to participate in this year's Walk4Hearing. It was a beautiful day to walk along the Erie Canal in support of this worthy cause.

Walk4Hearing events are fundraising 5K (3.1 miles) walks held across the United States. Since its formation in 2006, Walk4Hearing has raised over five million dollars for programs and services for people with hearing loss, and has grown into the largest awareness and fundraising event for the Hearing Loss Association of America (HLAA).

Walk4Hearing educates the general public about hearing loss while easing the associated stigma. Striving to make hearing loss a public health issue, thousands of people of all ages, races, and backgrounds have come together to display their compassion for the cause and to make hearing loss an issue of national concern.

The Rochester Walk4Hearing had 450 walkers present and collected over \$44,000.00. Thanks to all involved members!



Back row: Sue Wantuck, Melissa Burroughs, Patty Milot, Jessica Holst, Danny Wantuck.
Front row babies: Brenden Burroughs, Liam Holst



Sam Spitzer, Jimmie Sorrento, and Sue Wantuck



HOLDEN'S JOURNEY..... Continued from page 5

Our expectations in the beginning were so low for Holden to have any success with his implants. Now it is so hard to think of anything he may not be able to achieve. He truly has surpassed our dreams and expectations. All the struggle in the beginning has surely paid off. We are excited to see what happens in the years to come.

WE NEED YOUR EMAIL ADDRESS

In the event of pressing news between the publication dates of our quarterly newsletter, or in the event of an unexpected meeting cancellation, we may need to contact you. Please remember to provide B.I.G. with your most current email address. Your email address will NEVER be shared with a third party.

DAS ANNOUNCES BUFFALO DEAF AWARENESS WEEK

By Gail Cronin

Deaf Adult Services is preparing for Buffalo Deaf Awareness Week 2013. The events of the week will take place from Sunday September 22 to Saturday, September 28. These will include a kickoff celebration at the Walden Galleria Mall, a "Lunch and Learn ASL" program at the Tri-Main Center, the unveiling of History Hall at the DAS offices in celebration of DAS's 20 years of service to the community, the 160th anniversary of St. Mary's School for the Deaf, and an ASL interpreted tour of the Darwin Martin House. Wednesday, September 25 will be "Wear Purple Day" for DAS. More events are being planned. For information on these and other events for Deaf Awareness Week 2013, visit www.wnydas.org

Buffalo Implant Group



Subscription/Membership Form
- \$15.00 per Year -

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Address _____

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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:
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DID YOU KNOW?

Over 219,000 people are now using cochlear implants worldwide. In the United States alone there are over 70,000 cochlear implant users and more than half of them are children.

According to the National Institutes of Health, research has shown that the use of two cochlear implants typically offers better hearing than one cochlear implant. People with bilateral implants are better able to locate the direction a sound is coming from and have better understanding of speech in noisy environments.

All federal health plans including Medicare, TRICARE, and the Veteran's Administration provide benefits for cochlear implant services. Federal law also requires all state Medicaid agencies to provide benefits for cochlear implant services to children under age 21. Medicaid coverage for adults varies by state.



CI USER BECOMES RHODES SCHOLAR

Only a small number of elite students are selected to become Rhodes Scholars. Each year 32 Americans are selected by The Rhodes Trust, founded by Cecil J. Rhodes, to receive this prestigious scholarship to Oxford University in the United Kingdom. In 2013, Rachel Kolb of Los Ranchos, New Mexico became one of the elite Rhodes Scholars after being selected from a group of almost 900 nominees. Rachel is a graduate of Stanford University, where she majored in English and minored in biology. She is currently continuing her studies at Stanford, pursuing a master's degree in English. She is an award winning writer and an accomplished equestrian. She is also profoundly deaf.

Rachel has been profoundly deaf all her life and uses American Sign Language. She had an ASL interpreter present at her Rhodes interview. Rachel also received a cochlear implant in 2010. Rachel will be entering the M.Sc. program in contemporary literature at Oxford this September when she begins her Rhodes Scholarship.



BUFFALO IMPLANT GROUP

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Awards our Newsletter has Received:

Best National Chapter Newsletter by CIAI

Service to the Hearing Impaired by Kenmore Lions Club

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