

the **BIG** news

The Newsletter for the Buffalo Implant Group

Volume 25 • Issue 2 - 2013

BIGstaff

Gail Cronin - Editor and Acting
Publisher
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Shirley Jaskier - Writer

UPcoming Events

B.I.G. Open Meeting June 5
HLAA National Convention June 27-30
B.I.G. Summer Picnic August 2
BHSC Buffalo Brewfest August 9
BHSC Summer Golf Classic August 26

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Meeting Notice
Wednesday
June 5, 2013

6:00 – 8:00 PM

St. Mary's School
for the Deaf
2253 Main St. - Buffalo

GREETINGS FROM GLORIA

By Gloria Matthews

My name is Gloria M. Matthews, and I am honored to grace the cover of the newsletter this quarter! Some of you may have met me back in November 2011 when I attended my first B.I.G. meeting and won the gift basket that Margie Fitchlee had put together that evening - totally unexpected. I only knew one person there - Chrisann Hylann, the CART provider. She had been the CART provider for my classes at Buffalo State College. I have been studying for a degree in Business Administration - Management, but I am currently on medical leave.

I'm originally from the small lower Hudson Valley town of Ossining, NY. I lived there until I was twenty. Then I moved around quite a bit, including some time in Peekskill, NY and Philadelphia, PA. I've also lived a good chunk of my life in Western New York.

I lost my hearing at the age of four. I was born a perfectly healthy baby girl on October 31, 1983. Yes, I am a Halloween baby. I have been told my nickname was "Boo-Boo baby" or just simply "Boo." A lot happened with my family during my infancy that is still unclear. My maternal grandmother obtained legal guardianship of me from my mother when I was barely five months old. From then on she was my primary caregiver. I learned later that my mother had become an alcoholic and her behavior was unacceptable. At the time, my grandmother had just entered her 60's.

As a toddler and preschooler until age four I was treated for one ear, nose and throat infection after another. It took my mother one visit from her life in New York to see that I was walking like a drunk and that my balance was clearly off. Even though she wasn't always around, she is the reason why I was able to maintain some hearing in both ears a bit longer.

Before my mother fell into alcoholism she taught preschoolers. She had worked with a child who was hearing impaired. She convinced my grandmother to take me to that child's ENT specialist after arguing there was something seriously wrong with my ears. When my grandmother finally took my mother's suggestion, she learned that my mother was right.

I remember the big ENT chair and all the oddly shaped equipment at the ENT specialist's office in North Tarrytown, NY. The doctor was funny and nice to me. After the evaluation I had an emergency operation to remove both my tonsils and adenoids. It soon became apparent that my pediatrician might have misdiagnosed me more than once.

After the surgery I was checked for any post surgical infections and abnormalities. My ears were also given a lot of attention. I was placed in a testing booth with toys to play with and simple instructions. We then learned that I had a mild to moderate sensorineural hearing loss and I needed hearing aids.

At the time of my hearing loss discovery, I was already set to enter Pre-K in a few months in my local school district. I began receiving speech therapy at Westchester County Medical Center in Valhalla, NY. After completing a year or two of speech therapy there, I made the transition completely over to the school's speech therapy teachers for services two to three times a week. This was in 1987-1988, before the American Disability Act was put into place in 1991. So I believe not many schools at that time were equipped to handle



~ Continued on page 5

THE PRESIDENT'S CORNER

By Sue Wantuck



Sue Wantuck

Hello! Spring is finally here! It is time to adjust your CI processor(s) and head outside. Listen for the birds chirping, children playing, raindrops, lawnmowers, motorcycles, dogs barking and more. I love to be outside,

especially at this time of year when I can walk my dog in the evenings and just "listen" to what is going on around me. I especially look forward to the summer and heading to the Adirondacks for our annual family trip. One of my favorite things to do while we are there is go swimming. Last year I wore my processor for the second time in the lake. It was amazing to hear the splashing of the water as I swam around and kicked my feet. I hope that many of you are just as eager to get out there and listen to and experience the sounds of spring and summer for yourselves.

Our last B.I.G. meeting was held on March 20th at Buffalo Hearing and Speech Center. A BIG thank you goes to BHSC for allowing us to use their facility and handling the mailing of the newsletters. A special thanks goes to Joe Sonnenberg and JoAnn Hammer for supporting the group during our recent transition and restructuring. The main topic of the meeting was "re-organization." Many people shared their wants/ideas/suggestions with the group. The Board has been meeting monthly to review/discuss the feedback given and to plan accordingly for future meetings/events. Please feel free to send me an e-mail- my gmail address is suewantuck@gmail.com -if you are interested in signing up for a planning committee or have additional thoughts to add.

There will be an upcoming BIG meeting on Wednesday June 5th from 6:00-8:00pm at St. Mary's School for the Deaf. There will be a presentation on Cochlear Nucleus NU5 given by Brittany and Sonya from Cochlear Americas, followed by a brief meeting and of course time to socialize! I look forward to seeing you there! If you are unable to make it to the meeting, don't forget that the annual picnic will be our next get together. It will be Friday August 2nd at Westwood Shelter #5. Hope to see you there! Happy Hearing!

FROM THE EDITOR

By Gail Cronin



Gail Cronin, MS CCC-SLP

It is a new day here in the Buffalo Implant Group. If there was a theme in our last issue, it was optimism. We were really hopeful that we could reorganize and keep moving on in spite of a rough year in 2012. Note that I said "hopeful" and not confident. I must admit that I was a little concerned back in January and February that we might not get a great turnout at our March meeting, or that we might not get a great response to our newsletter after such a long absence. I couldn't have been more wrong. Within days of the newsletter's mailing our B.I.G. mailbox started filling up with membership renewals and donations. We received a lot of encouragement. The turnout for the March meeting surpassed our expectations. People not only spoke up with their ideas, they actually signed up for committees. So now we are beyond the point of optimism and into a state of enthusiasm. How fitting is that for Spring?

The board has already held one meeting, and will be meeting once again before our open meeting in June. We will be welcoming Brittany Pellegra as our speaker. Brittany is an Awareness Network Manager for Cochlear Americas, and she will be sharing her journey as a deaf child who received her first cochlear implant at the age of four. Brittany has a rich family

experience with deafness and hearing loss and a fascinating professional life as an advocate for cochlear implant users. She and her colleagues will also present information on the latest Nucleus 5 product information from Cochlear Americas.

Our June meeting will be held at St. Mary's School for the Deaf. The meeting will also provide us with time for planning and socialization. An update will be provided regarding our annual picnic, which is scheduled for August at Westwood Park. Information on both of those events can be found in this newsletter. Please mark your calendars.

During the past quarter we have focused much more on our internet presence. Fr. Bob McArtney has been updating our new website. Thanks to volunteers Tina Pilkey and Gloria Matthews, we now have an active Facebook page as well. Both will take time to grow, and your participation is key. Please check us out on the web.

And finally, the biggest change in the last quarter is the addition of our new secretary, Melissa Burroughs. Melissa's hard work and wonderful ideas have been a breath of fresh air for our organization. I sincerely thank her for volunteering for such an important role. You can learn more about Melissa in this issue.

And if all that news isn't enough to get you excited about what you'll find in this issue, there is one more tidbit of good news. We have a wonderful article and pictures from our friends and founders, Craig and Jackie Carpenter, from their home in sunny Florida.

Support Buffalo Hearing and Speech Center

The 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

AN INFLUENTIAL LIFE

By Shirley Jaskier

My father recently celebrated his 90th birthday! I must say that we are very fortunate to have longevity in my family. It was a very happy and joyous time for my entire family, and we wanted to really celebrate and make this birthday special for "Grandpa Leonard."

I decided to create a photo book for my dad, and include pictures of him and his entire family. I asked his children and their spouses, grandchildren and great-grandchildren to write why they love him, or why they think he is awesome. The response was overwhelming!

I know what a wonderful man my dad is. I know how his influence has shaped my life, but I never considered what an impact he has had on the rest of the family. Each and every person provided his or her thoughts about my father. The responses ranged from serious to funny and really highlight just how he has influenced all our lives.

It was heartwarming to read the statements. Some documented events and times from years ago that would seem very insignificant at the time but made a lasting impression. Others wrote about what a kind, selfless, gentle soul my father is. They wrote about small acts of kindness shown by my

father, which made a difference in their lives. Sometimes they were the recipient of the love and concern, and other times they witnessed how my dad shows love and concern for others - especially his wife. More than one person remarked that one reason they love my dad is because he has always taken such good care of his wife, my mother. His way of life has set an example for his family that no amount of teaching could ever do.

Often times, people receive notoriety for large accomplishments and public success. While that may be all well and good, it is often not the big things in life that have the most influence. The small things seem to matter most - a smile, an inside joke, a simple conversation, or just the respect shown by listening to another person and showing interest in their life. A common denominator throughout the responses was the kindness and respect demonstrated by my father to all people. These are the things that last.

This experience illustrated the truth of a quote by Maya Angelou. "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel." Many of the snippets remarked how my father's actions made

them feel. Throughout his life, he has a way of putting others first and making you feel important.



Shirley Jaskier

It does not take much effort to show kindness and respect to others, and to make them feel good. A smile is free. If you treat others the way that you would like to be treated, you are on the right track. Although you may never be fortunate enough to actually know how your actions influence someone else, you can be sure that they do. An act of kindness you show can keep on living as that kindness is passed on to others.

The photo book turned out great! I included all the responses received and matched them up with pictures of the family members who provided them. The book turned out to be 42 pages! We presented the gift to my dad at the party. He was happy and overwhelmed! This gift for him actually turned out to be a gift for his entire family: the gift of realizing how small, simple acts of respect and kindness have a great influence on others.

MEET MELISSA - OUR NEW SECRETARY

Hello B.I.G. members! My name is Melissa Burroughs, and I am the new secretary. I grew up in the south towns and currently reside there with my husband Eric and my son Brenden. I am happy to take on this role and be more involved in the organization as well as the CI community. I hope to help educate and spread awareness about hearing loss, amplification options/technology, educational philosophies and rehabilitation. I also look forward to learning from other members and networking with area professionals.



I am a Speech-Language Pathologist at St. Mary's School for the Deaf and have worked there for almost four years. I currently provide therapy to a variety of students from birth to 21 years of age. I became interested in the field when I was a senior in high school. I always wanted to work with children and be a part of a school environment.

I received my undergraduate and master's degree at SUNY Fredonia. During my graduate work while taking some elective courses I became very interested in cochlear implants as well as processing disorders. I started my career

at Heritage Centers working with special needs and medically fragile children. I liked my job and was grateful for my experiences, but felt that my passion and interests were in a different population.

When I began working with deaf and hard of hearing children I knew I had found what I was searching for. My responsibility as an SLP is to help individuals communicate and to provide them the training and skills necessary to do so in whatever modality is most successful. The use of sign language continues to amaze me with how much you can "say" without even speaking, as well as how easily children can learn and use it functionally while simultaneously developing spoken language skills. Sign language is just one of the many tools I have added to my ever growing "speech bag of tricks."

Cochlear implant technology is constantly changing and providing more opportunities for individuals to be considered candidates. Children are also being diagnosed earlier because of the universal newborn hearing screenings and receiving early intervention services. I am eager to see what the future holds for past as well as future implant recipients. I am excited to be a part of this organization and participate in upcoming meetings and events.

REFLECTIONS ON: SPRING 2013

The Chaos, the Helpers and the Hope for the Future

By Margie Fitchlee



Margie Fitchlee

I was so thrilled when Gail Cronin contacted me to see if I would be willing to submit another article for the next issue of The B.I.G. News. I am more than honored to do so and have grown to love putting my thoughts on paper. More than that I have hoped that some of what I write about can be of help to others out there who are facing the same or similar kind of hearing loss experiences that I have encountered.

I consider the members of the B.I.G. organization a very special group of individuals who have given their time, their expertise, their knowledge, and most importantly their hearts over and over to help people with profound hearing loss and deafness find their way and cope with the circumstances they have been faced with. They have been a Godsend to me and to countless others.

Where would we be without all of you? Gandhi said, "The best way to find yourself, is to lose yourself in the service of others." That is exactly what they have done. I am so proud to submit articles to this wonderful publication.

The last article I wrote about talked of how I welcomed the summer of 2012 with open arms. Fall and winter have also passed, and now we are in the middle of springtime. The seasons come and the seasons go, and I know that I shall never forget this particular spring. Ellis Peters says that "Every spring is the only spring - a perpetual astonishment."

Unfortunately for me and for countless others this spring in all its glory has been tarnished. An old Irish proverb states that no matter how long the winter, spring is sure to follow. Among the many traditions that take place in our country is the famed Boston Marathon. Runners from all over the world each spring converge on Boston for this classic event. A city so proud with tradition became the number one news event that day, not for the accomplishments of its participants, but for the horrific bombing that took place at the finish line and on the streets of this historic city. This is now another almost surreal event embedded in the mind of myself and everyone else.

The reality of that day and the next several days will linger with me always. "Chaos" is what I call it. George Santayana tells us that "chaos is a name for any order that produces confusion in our minds." This event left me confused that day and still leaves me confused. PURE CHAOS for sure. All I can wonder is WHY?

This event left me frightened so I could not help but wonder what kind of effect it has had on our children? Our minister spoke about that very subject in his sermon today. He talked about the beloved Fred Rogers and how he said, "When I was a young boy and I would see scary things in the news, my mother would say to me 'LOOK FOR THE HELPERS.' You will always find people who are helping."

This is so true in the city of Boston and so true within the Buffalo Implant Group. Hats off to the brave policemen, firefighters, paramedics, doctors, nurses, and civilians on the street who stepped up to the plate to do whatever they could do to help the injured and the scared. It is so true that "It's not what happens to you but how you react to it that matters." React they did, and I applaud their efforts.

Hats off to the volunteers in the B.I.G. organization too. They step in and give support, advice, invaluable resources, and friendship to all those who are lucky enough to be referred to or contact them.

I have often found that words like perseverance, determination, persistence, and hope go a long way in helping myself and others like me cope from day to day. I find these very same words will help all those dealing with the Boston bombings to forge on. I believe words like these are the very foundation on which this country has been built. As far back as we can remember these very words have been written about and applied to our very lives. Calvin Coolidge gave us this advice: "Press on. Nothing can take the place of persistence. Talent will not; nothing is more common than unsuccessful men with talent. Genius will not; unrewarded genius is almost a proverb. Education will not; the world is full of educated derelicts. Perseverance and determination alone are omnipotent."

We saw the helpers "PRESS ON" in Boston. They did not let up until justice prevailed and the accused was captured. We see the helpers in Buffalo "PRESS ON." Even with the loss of Craig and Jackie Carpenter, they forge on and continue to provide their services to us.

Lastly, we see the leader of our country, President Obama, "PRESS ON" when he reassures us with his words: "On every front there are clear answers out there that can make this country stronger, but we're going to break through the fear and frustration people are feeling. Our job is to make sure that even as we make progress, that we are giving people the sense of hope and vision for the future." I hope we can all have the strength and faith to "PRESS ON." The city of Boston will "PRESS ON." My wish for the runners in the marathon next year is a wish from the Irish: "May a rainbow run beside you in a sky that's always blue. And may happiness fill your heart each day your whole life through."

They say that for every storm there is a rainbow. I look forward to seeing many of them. God bless all of you.

Planning Ahead for Summer

Save the Date for Our Annual Sunset Dinner Picnic

Friday, August 2, 2013 • Westwood Park, Shelter #5 • 5:00 – 8:00 PM • Dinner served at 6:00 PM

We will be accepting donations for our annual basket raffle at the picnic. Please consider putting together a basket for this worthwhile fundraiser. The money raised is used to offset the costs of the picnic.

Look for the final details and RSVP information in the July issue of The B.I.G. News.

GREETINGS FROM GLORIA..... *Continued from page 1*

different kinds of disabilities, especially a hard of hearing student. My teachers tried to understand me the best they could, but I could tell at times they were frustrated and lacked the necessary resources and/or knowledge in understanding how hearing loss can affect social settings, language development, speech development and more.

Growing up was not easy. I struggled in school with teachers and peers. Instead of being the student, I had to teach them how to help me at times. Making friends was hard. I can name very few childhood friends. Fitting into the hearing world was rough. I did not feel like I could be myself at all. I just did as I was told even when I felt like I didn't really matter. So for me, the hearing world was brutal.

I eventually caught the eye of one of my elementary school principals. She gave me an opportunity that opened my eyes to a whole new world, a world out there that no one had mentioned. I was given a Scholar Invitation in 1994. I was invited to attend a conference called "Women Helping Girls with Choices" at Manhattanville College in Purchase, NY. In the workshops we attended, many professional women in every possible field talked about how young women can achieve and be successful if we only put our minds to it. It inspired me to think beyond what I knew. I eventually met a few women who had some disability but overcame it, and because of their stories and struggles, I was like, "WOW!" That was an inspiration.

My life outside of school was pretty sheltered. I was the kid who hated the rules of games. I really didn't make it easy for anyone to play with me. I was taught one set of rules per game, and other kids would make up their own rules. I disagreed with "bending of the rules." Then of course I got picked on because at times I would not hear all the rules and would get kicked out of a game for it. I tried my best, but after a while I stopped playing with the kids and stayed inside. If one of the neighborhood kids were looking for me, my grandma would call me and then I would come out for a bit to play then go back inside to draw and practice my clarinet. It was in a way very lonesome.

During middle school (1995-1998) I started to shine in academics, music, art and even participated in Varsity Track and Field in seventh grade as a sprinter, long and high jumper. Later on I joined the first-ever modified cross-country team and continued to run and compete year round until 1999. I collected about 18 medals, five trophies and many awards for academic and physical education achievements. I was mainstreamed 100% in seventh grade because I begged my guidance counselor: if I got out of the special ed classes I promised to deliver on obtaining straight Bs by the end of each quarter. And that I did! I love learning!

After that year, I continued to make an impact in changing how the school placed a student with a hearing impairment and how to determine the kind of accommodations provided. It wasn't until eighth grade that I learned that there was another hearing impaired student transferring into the school district, and then another. Both students were younger than I, but I was pretty much the one teaching the teachers how to be of more help in the classroom along the way. I believe I was in eighth grade when they decided to hire a teacher for the hearing impaired. It was a long time coming, but I was just about to graduate middle school.

High School - let's say it was not all that great. I had a good start but a horrible time between freshman and senior years. The bottom line is that I graduated in 2002 from Ossining High School - just barely.

My early college years were awesome! I was happily away from home. I met so many amazing people during my freshman year at Genesee Community College in Batavia. I was able to be myself and speak my mind, but the best part was that my hearing loss for the first time did not impact me so much. The faculty, staff, and the student body were just so open and accepting and understanding that it became like my second home. I still communicate with those I met eleven years ago. I never thought I could get along with my hearing peers, let alone have lifelong friendships.

Unfortunately, I had to leave GCC to transfer to another college closer to home for third semester. My mother had told me she was not feeling well. I could tell she had lost a lot of weight, and one side of her neck grew outwardly enlarged. She knew how I felt about not wanting to come back home or even to live with her, but we both knew it would be her last walk in this life. So I enrolled in January 2004 at the College of Westchester in White Plains, NY.

In February I had to literally drag my own mother to finally get seen by a doctor. As typical, she kicked me and then hit me because she hated needles and doctors! But that was me being the parent and her being the daughter. Talk about reversed roles!

We both knew what the doctor would say. It was a huge mass. I worked two small part-time jobs and was going to school full-time as an honor student while my mom underwent aggressive chemo and radiation treatments. It was rough. My mother passed on January 4, 2005. She was 44. Unfortunately, she did not get to watch me graduate in May.

I'm so proud to be an alumna of The College of Westchester. They really helped me through a lot, and they did not have a disability office. The faculty and staff went above and beyond to make sure I walked across that stage. VESID helped with books and financial aid. I also had an amazing outside college counselor from a non-profit organization called College Careers, as well as the counselor who worked with me at my hometown clinic. If not for their professional help, I honestly don't think I would be here writing this. My extended family, the Gilchrests, helped me out greatly after my mother passed away. I took it hard. I lost my way for a few years.

My mother had cleaned up her act in early 1994, and she stayed sober up until her death. But she was a long time smoker. Just last April, my grandmother passed away at 93 and was the last of my family remaining. Now everyone lies in the same cemetery back home.



Fast-forward to now; I have been through a lot. I am a proud single mom of a wonderful little boy, Michael. He is my joy and my biggest blessing. He will be five in June.

I noticed a decline in my hearing ability a few years ago, as Michael started to talk more. I could not hear his softly spoken words well enough. It was frustrating for us both. When I went on interviews here in Buffalo, I had the worst possible time understanding the questions being asked. I felt once again isolated.

~ Continued on page 9



OUR STORY

By Craig Carpenter

a spell over us. The final straw that broke our resolve to remain in Clarence Center was my health problems, so in May 2012 we began the search for a house we could purchase.

We found the house we presently call home almost immediately. It was the first of about 15 homes we looked at and we kept coming back to this one, which had a great location being only 13 houses from Jackie's sister and just two miles from our other friends. We put in an offer and it was accepted. Now we had the daunting task of cleaning out fifty years of our life from our Clarence home and getting it ready for sale. We put it up for sale in early July and guessed we would have about six months before we had to move. Our house sold within two weeks to a cash buyer, which meant that there would be no mortgage paperwork or anything else to delay the sale of the house. So we had to get moving and pack or sell or distribute to our children and the B.I.G. Officers everything in the house. It had to be empty by the first of August. We were lucky to have our children and their spouses to help us with this chore. We did not keep too much of our furniture nor our cold weather items. We had two pods delivered to our house, which we packed with what we wanted to bring with us including my beloved Harley. Now you all know why we had to move so quickly and why there was not enough time for a get together with our friends.

We are both doing well, basking in the warmth and sunshine, having daily dips in the pool and hot tub, and taking walks. Most of all we are enjoying a much friendlier cost of living, especially as it relates to taxes. We have been spending the past seven months furnishing our home, putting in a new pool and are now working on landscaping. I have several small projects going on but I am taking my time, enjoying taking short trips and exploring new places.

We miss our family, our friends, our church and senior center. It took us a long time to get to where we were comfortable in our new area of Clarence Center. Now we are doing the same down here in Cape Coral, one small step at a time. We have just signed up to be Eucharistic Ministers at our new church, which should help us make some new friends. I am looking into joining the Patriot Guard Riders of South West Florida, a motorcycle group that upon request provides escorts for deceased members of the U.S. Armed Forces, as well as peacefully police the funeral grounds against protestors out of unwavering respect for those who risk their lives for America's freedom and security.

Jackie has looked into the senior centers down here but at this time is not going to become a member and get involved like she was with the Clarence Senior Center.

One drawback to the move is the location of the nearest implant center, which is in Tampa, a good two hour drive. Now I know how Ed Bastian feels about driving all those miles for mapping and to attend B.I.G. functions.

Our new city is a large one situated just west of Fort Myers with access to the Gulf of Mexico. The city is known as a "Waterfront Wonderland" since with over 400 miles (640 km) of navigable waterways. Cape Coral has more miles of canals than any other city in the world.

We enjoy nearly daily sunshine and warmth in a basically residential area. There are shopping centers along a few of the main roads and plenty of places to go, but for the most part we have been pretty much home bodies as we work to make this place our own.

Our pool has been very good to both of us as we do our daily exercises in it. A GREAT side benefit of having a pool is there is that much less lawn to care for! Kidding aside, keeping the pool and deck clean take up as much or more time than mowing the lawn would. I think I move more muscles taking care of the pool though. Our life is good. It would have been better if we could have brought all our friends down with us instead of having to start all over.

This photo of Jackie and me was taken a couple of days after the pool was completed. It is a beautiful pool, sized just right for our needs. The pool is entirely enclosed with a screened cage, which allows us to keep our sliding doors open all day long so that we can enjoy the gentle breeze off the Gulf.

Thanks to all who contributed to the previous newsletter. Jackie and I had an emotional time reading it. I'll close with one of my traditional Irish toasts/poems.

***May your thoughts be as glad as the shamrocks.
May your heart be as light as a song.
May each day bring you bright happy hours,
That stay with you all year long.
For each petal on the shamrock
This brings a wish your way
Good health, good luck, and happiness
For today and every day.***



*God Bless You All,
Craig and Jackie
cicarp85@yahoo.com*

WINTER MEETING REPORT

By Gail Cronin

The Buffalo Implant Group's March 20th meeting was held in the conference room at Buffalo Hearing and Speech Center. BHSC graciously provided the space at no charge, which included the use of their kitchen as well as free parking. Close to fifty people attended, including implant users, family members, implant candidates, and professionals in speech, hearing, and education.

Sue Wantuck, our B.I.G. president, called the meeting to order. Because this was our first meeting following an eight-month period of inactivity, the Board opted to focus on our reorganization rather than bring in a speaker.

Sue explained the reasons for the inactivity and our need for more volunteers. She discussed the development of committees and asked people to sign up after the business portion of the meeting. Some areas in desperate need included social media, our summer picnic, and the unfilled office of secretary. Many of those in attendance offered their services.

Melissa Burroughs, a Speech-Language Pathologist from St. Mary's School for the Deaf, offered to fill the role of secretary and got right to work taking minutes of the meeting. Gloria Matthews and Tina Pilkey volunteered to develop our underutilized Facebook page. More than a dozen other members signed up for committees that will be formed this year.

It was reported that we are on track to have four full-size newsletter issues this year, but submissions of articles will be necessary. New writers are always welcome. Craig and Jackie have received our gift of the "thank you" messages that were printed in the centerfold of our last issue, printed in a format suitable for framing. They wrote to us that they appreciated the gift. The newsletter is not a large expense for our organization due to the substantial discount we receive from the generous Zenger Group printers, as well as the kindness of Buffalo Hearing and Speech Center for covering our postage costs.

Sue opened the floor for suggestions and feedback as we look toward the future. Janet McKenna, who is involved in the HLAA Rochester chapter, suggested that we consider some joint meetings or events with that active group. Gloria Matthews noted that we needed to go beyond Facebook and look at other forms of social media such as Twitter. Several members stated that we need to be a presence in the community in order to counter the erroneous depictions often seen in the media. Shirley Jaskier noted that she would like to hear speakers discuss insurance reimbursement issues for cochlear implants and other technology.

Jimmy Sorrento stated that he would like to see a return to more frequent meetings. He noted that he loves the guest speakers and is particularly interested in new technology. Melissa Franusiak, who is the mother of an eight-year-old CI user, also stated that she would like to learn more about upcoming technology, particularly what the cochlear implant manufacturers are currently working on and expect to release in the near future. Several other members voiced agreement, some saying that they would like to see demonstrations of technology. Members particularly noted interest in the Med El Opus 2XS, which is the smallest and lightest audio processor, and the Advanced Bionics Neptune, which is the first waterproof processor.

Joe Kolis and Toni Vega, both of whom are parents to children with CI's, would like to see more support and activities for CI kids. Several ideas for activities, such as bowling parties and other family events, were discussed.

It was clear from the discussion that members were disappointed with the lapse in activity we experienced in 2012 and were dedicated to rebuilding our organization.

Sue also reminded our members that May is Better Hearing and Speech Month, and several of our members would be participating in the Walk4Hearing in Rochester. Members were also encouraged to submit an annual membership fee of \$15 to treasurer Lisa Hill Nowicki. Sue closed the meeting by reporting that we would have another meeting prior to our annual picnic, which is already scheduled for August 2nd.

Following the meeting there was time for socializing and snacking. Pizza and beverages were provided. Many members generously brought desserts resulting in quite a buffet. Socializing continued long past the scheduled end time of the meeting. We are all very grateful to Joe Sonnenberg of Buffalo Hearing and Speech Center for accommodating us late into the night.

OUR READERS SAY...

HEARTFELT GRATITUDE FROM SISTER DOROTHY FELTZ

First of all I wish to thank you, Gail, for the tremendous amount of time and energy you put into again producing such a wonderful and informational B.I.G. newsletter. When it arrives in my mailbox I immediately read and reread every page of it from cover to cover and enjoy it so much.

Also, my heart is filled from joy and gratitude to you, Sue, and to the wonderful staff and Board members for finally getting us all together for the B.I.G. meeting. It was so great that you were able to find a place for our meeting. Thanks to you, JoAnn Hammer and Joe Sonnenberg for making the BHSC conference room available for us. It is a super environment for our meetings.

It was so exciting for me to see so many familiar faces as well as so many newcomers. I particularly liked not having a speaker for a change. That gave us more of an opportunity for the President's report, to ask questions, share ideas and to begin some reorganizing. The ample time for socializing was also appreciated.

The idea of setting up committees is a good way to give members an opportunity to be more involved in various aspects of

the B.I.G. Perhaps those that attend the upcoming meeting would consider signing up to be a committee member.

The concept of wearing nametags was very helpful. I personally benefited from the nametags. I had seen so many of you before at meetings and at the picnic but never knew any of you by name.

Several of us have developed a basket raffle committee for the August 2nd B.I.G. picnic at Westwood Park in Lancaster. We'll be there before the picnic begins to set up tables, number baskets and cans for ticket returns and, of course, selling tickets.

If anyone wishes to be a part of our committee or to donate a basket for the raffle just let the Chairperson of our committee, Fr. Bob, know at rmcartney@roadrunner.com or 716-827-5982.

I'm looking forward to seeing everyone at our upcoming B.I.G. meeting. Check the B.I.G. website for up-to-date news and photos at www.buffaloimplantgroup.com.

EASY TO READ CAPTIONS AT THE MOVIES

By Janet McKenna

Foreign language films shown in the US are subtitled in English. It matters little if the actors speak in French, Italian, Iranian or obscure languages. Films are easy to understand and usually of higher quality than most American productions. I became an expert on foreign movies because even with two cochlear implants, understanding English language dialog on the big screen has been tedious and futile for me.

Local film captioning efforts have been a sometime thing. The Regal Entertainment Group theater complex at 2001 Elmwood Avenue made some stabs at captioning during the past few years. They offered open captions, where all viewers watched selected films with subtitles. But the films would change from day to day. You never knew in advance which single film would be open captioned until you saw the little "OC" designation in the Buffalo News advertisements. It was (and still is) necessary to squint carefully to read the "OC."

Ultimately I abandoned searching for any English language captioned films in Niagara Frontier movie houses. Instead I enjoyed many excellent foreign films, especially at the Jewish Film Festival. In April while checking the Regal Theater film listings, I noticed that of its 16 screens, ten or more were marked "CC" for closed captioned and "DVS" for descriptive video service for visually challenged people. I wanted to see the Jackie Robinson biography "42." This would be a good opportunity to investigate the captioning situation further.

Access glasses

A polite staff member at the theater service desk gave me an eyeglass device attached by a thin cable to a receiver about one inch by three inches and perhaps half an inch thick. Regal's publicity calls them "Access glasses." No fee was requested, nor did I have to leave a driver's license or credit card as at other theaters with fm systems or headsets. I was asked to sign my name and address when I took my captioning glasses.

I settled the glasses on my nose like any glasses. I don't use eyeglasses for distance. Presumably a wearer of glasses would place their Access glasses on top of their prescription glasses. There were slight problems with knocking my cochlear implant headpiece microphones off my head while trying to settle the glasses. Once settled, the glasses were surprisingly comfortable.

As the film rolled, so did the captions. They were bright green. Since the captions and the glasses are paired, the green type moves around the screen as the viewer moves her head. Look up and the text is at the top of the screen, look left or right, and it moves left or right. I concluded that captions were best viewed against a dark background. With "42" this meant the bottom of the screen. The letters were sharp and clear. The captioning was quite accurate.

Less fuss, more comfortable

The "Access glasses" are immeasurably less fuss to access than rear window captioning which formerly



was briefly available at one local theater. The viewer simply puts on the glasses to view the text. The receiver, which controls volume, can be clipped on your clothing or left on your lap. The volume was more than sufficiently loud. Best of all, if a party of viewers goes to a movie, only the hard of hearing person wearing the Access glasses sees the captions. So people with normal hearing listen to the on-screen dialog and music in their native language while their companions can enjoy the captioning and still understand the plot.

When the film ended I returned the glasses to the service desk with no problem. I was told that although many films can be viewed on Regal Elmwood's screens with captions, not every single attraction of its 16 is captioned. Still I think there is sufficient choice.

According to Regal's web site, the chain has made a nationwide effort along with Sony to provide Access glasses in its theaters. My experience at their Elmwood Avenue location was totally positive. I clearly and happily understood the entire movie for once. This was my first attempt at using Access glasses, and I expect to try them again. I recommend that any person with hearing loss try them; you may actually find yourself returning to the movies after having abandoned cinema years ago.

BOARD MEETING MINUTES -- APRIL 22, 2013

Meeting was held at Sue Wantuck's home. In attendance: Sue Wantuck, Melissa Burroughs, Lisa Hill-Nowicki, Gail Cronin, Fr. Bob McCartney and Kathy Maroney. (6:30 – 8:00 pm)

Topics Discussed:

- Gloria and Tina are looking for pictures to add to the Facebook page
- Adding Gloria and Tina to the board as "Facebook Coordinators," Jessica Holst as "Company Liaison" and Fr. Bob on the B.I.G. website
- Move around pictures on the website as well as add all emails below pictures
- Newsletter update--possibly one week behind but still on track
- waiting for a few more things
- Sue to put out sign-up sheets for committees again at the next meeting
- Picnic committee to be run by Joe Kolis
- Lisa unable to attend the picnic--will need to know cost to write check in advance
- Sue is going to ask Joe Kolis to contact a person to set up CART for the next meeting
- Lisa sending out a "Save the Date" email reminder for the next meeting at SMSD
- Lisa emailing master list to Melissa to keep in a safe place
- Discussion of possible future meeting topics/presentations: Emergency 911? Interpreting laws/rights? Enjoying music? Ask again for suggestions at next meeting from members
- Update on DAS name change etc.
- Sue proposed B.I.G. officers and Board members to meet once a month; next meeting will be May 20th or 22nd.
- Look into general B.I.G. email address listed on website and pens-
- Melissa will check often when we get the password.

GREETINGS FROM GLORIA..... *Continued from page 5*

On some days, I would leave my hearing aids off and sit in complete silence. I never thought I would be dealing with misinformed hearing individuals again. I really don't mind being an advocate for myself, but I can get easily tired of just one person asking me the same questions constantly even after I have given them the answers to those very questions. It annoys me after a while; especially when the person has no idea what it is really like to be hard of hearing or late deafened. My only advice to those who want to understand is you really have to experience it yourself. You can't really be of help if you keep making assumptions, or pointing out what the person missed, or correct their speech. I find it offensive. I know when I miss something that I am responsible for letting people know. If I missed something and you noticed I'm not saying anything, I may have lost interest in the conversation or topic or I'm just too tired to even care to listen. If I drop off my "s" it's because my brain can't hear the hissing sounds or the silent sounds. I'm well aware of what I don't and do hear. Sometimes it's too much work to focus on the little things. So, I decide when to listen and when not to listen to conserve energy that I need for another part of my day. Is that offensive to those without a hearing loss? Maybe, but its what I find to be a part of the hearing loss culture.

I first learned that I might be a candidate for a cochlear implant in 2006. I did a lot of reading up on the subject. I'm not one to jump at getting the newest technology. I like to wait it out a bit longer until I feel science has improved. I wanted to see that the percentage of

failures was not so high and the risks were outweighed by the benefits. I did not tell anyone that I was considering this because it was to be my own decision, when I felt the time was right for me. Another reason I kept it to myself is because a few people asked me to get the surgery so that they would not have to constantly struggle to communicate with me in noisy environments. Did I find that offensive? BIG TIME! If I were to have this surgery, it would have to be based upon my own decision-making skills for myself and not to make it easier for other people. They honestly had no idea what they were talking about or what they were asking of me. You either accept the fact that I'm gradually losing my hearing or you don't. I felt if they could not handle that dreadful truth, then they just told me in not so many words, "I cannot accept you for who you are." Hearing loss has been a huge part of my life and still is and that will never ever change. I have accepted it and continue to deal with it until this very day. I definitely "ain't no newbie." I am who I am and if I want to change it would be my choice, not someone else's.

In November 2011, I finally decided to attend a B.I.G. meeting. Chrisann Hylann did encourage me to come, but I had shied away because I wasn't sure if I was up for another long process of rehabilitation or if I was ready to get a cochlear implant. I had undergone three surgeries in less than a year after my son was born and really had to think about another. After 18 years of speech therapy, going through learning how to pronounce syllables and consonants and vowels - half the time I would have

preferred to be a mute because it was such a long process that involved constant listening and trying to articulate the lips and get the "lazy tongue" to do its job. It was exhausting! I had to ask myself, "Will I be able to get through this since I know the brain will have to undergo its own rehabilitation process to interpret the signals from the electrodes?" When I heard the stories of some of the B.I.G. members and saw how warm and welcoming the group was I was glad I went to the meeting. I met people who were in my shoes for a long time, or some maybe less, but the bottom line I actually felt like I found my group.

A friend of mine, Dr. Jerome Evans, encouraged me to get a cochlear implant. He himself had lost all his hearing and decided to finally get bilaterally implanted as he was just entering his professional field of Audiology. I was chatting to him about how it had gotten difficult to hear and to keep up with what was going on. He was helpful in my research of companies and was my go-to person if I had any questions. I still go to him with questions. Thanks Jerome!

I wore bilateral hearing aids for 26 years. I knew I had to make a tough decision to get a cochlear implant. So, in early 2012, I decided to undergo the evaluation process for getting approval for the cochlear implant. I first met with Dr. Diaz-Ordaz to get the referral to Buffalo Hearing and Speech Center. There was a little hiccup with my insurance plan. It only covered rehabilitation in Rochester, not Buffalo! I thought, "Are you kidding me?"

Finally, with the insurance ordeal taken care of, I set up an appointment

~ Continued on page 10

MANY THANKS

Molly Anthony
Buffalo Hearing and Speech Center
Melissa Burroughs
St. Mary's School for the Deaf
Sr. Dorothy Feltz
Margie Fitchlee
Carleen Fix
Karen Hornung
Shirley Jaskier
Gloria Matthews

Joanne Mayers
Fr. Bob McArtney
Janet McKenna
Lisa Hill Nowicki
Norma Ann O'Brien
Jack Phillips
Tina Pilkey
Donald Walser
Zenger Group
Michael Zogaria

TREASURER'S REPORT

By Lisa Hill Nowicki

For the first quarter of 2013 we received in \$375 in membership and \$305 in donations. Our expenses for the quarter were \$585.45 (with 72% of the expenses around the newsletter and website renewal).

ITEMS FOR NEXT NEWSLETTER DUE

Monday, June 10

GREETINGS FROM GLORIA Continued from page 9

with JoAnn Hammer for my Audiological Evaluation and Monica for my Speech Evaluation. After that, everything went so fast! On October 5th, 2012 at Women and Children's Hospital I received a right ear implant with Cochlear Americas CI422. I had Sister Dorothy Feltz as my ride. It was such a pleasure to have her with me before, during and after the surgery. She kindly stayed with me for three days. My brother kept watch over my son during this time. I did end up back in the ER the next day after the bandage was removed. As soon as the air hit the incision and the pressure came off, I felt flushed and passed out. I was low on potassium and calcium, so I was hooked up to an IV bag for hours. It took me a couple of weeks to recover and slowly get back into my routine.

I was activated on November 19th, 2012 with the Nucleus 5. That is when I met Michelle Dube, my audiologist. I did not go in with high expectations because I understood it would take time for my brain to get used to interpreting the signals from the electrodes. The very first thing I heard was Michelle's clap. Other sounds came later that night. The second sound was my annoying living room clock. I didn't know it was that loud. I still find it annoying but have learned to block it out. Then I heard the electric kettle. I had no idea it made a bubbling sound as it boiled! Then as I was pouring my son his juice, I couldn't believe there was a "pouring" sound. Then I heard the clacking of my keyboard and finally understood why my classmates said I typed loudly. It was just wonderful to hear little sounds that I never heard with hearing aids. The highlight was when I finally heard my son's soft sing-song voice, "da-di-da-di-da." I was like, wait a minute... did I just hear ... "Michael, can you sing that again please for mommy?" I had to beg him for a few minutes and he finally decided to sing again and yes, it confirmed, I heard his soft voice for the first time. Following that were the tv characters on his tv show, which sounded like the chipmunks speed talking! I have noticed that at night I pick up more sounds. It may be because I used to be a night owl before becoming a mother, and my best ideas came to me late, such as my art, my poems, and my writings.

If it wasn't for my own faith, I don't think I would have gotten this far in life. I always had my faith to tell me to keep going even when I was hurting and in tears. I always take time to be alone because it is only then that I reflect on life and pray to keep going strong even when I know there will be times of weaknesses. I find solitude in complete silence. I wish my mind could do that at night, but it's one big party of ideas, creativity and brainstorming!

My grandmother taught me how to be an independent woman and a strong one on top of it. My mother taught me to look past the imperfections of those who struggle with internal and external issues and to always be a listening ear. I learned from so many others over the years, that I have indeed been called an "old-soul" or a "kinder-spirited" person. I'm always listening. Even when I'm not, I listen with my eyes as well.

So I end this with advice. Appreciate yourself, your families, your friends, your associates, your support groups and life. Enjoy each moment as much as you can. Last of all, smile and know you are loved and never truly alone. It is such a joy to finally meet people who have gone through the ups and downs of experiencing a hearing loss. It is also a humbling experience, and I want to thank those far and near. Thank you for being a part of my life and I do think of all of you. Peace.

"My Eyes Are My Ears" A poem by Gloria Matthews

Every day I worry about "fitting in."
Every day I wonder about whether I'll be accepted
for just being me or would someone try to change me to
"fit in" more with their "groups?"

If you could only see,
see what I see.

Your actions, words, and body language
tells me enough to know...

How you feel and what you think.

Don't you know my eyes are my ears?

Don't you know I can tell when one is not being fully honest?

Don't you know I can tell you secretly wish I could hear so
that it would be easier on you and everyone else?

Don't you know my eyes are my ears?

Everyday I walk with my head held high.

Everyday I do my very best to stay positive.

Yet, deep down on some days, I want to scream and curse out
people who have the worst possible misunderstanding of
what's it is like to be hard of hearing and/or deaf.

Don't they understand my eyes are my ears?

I guess they don't.

Yet, some wonder why I walked away.

Don't you know I'm tired?

Don't you know every day I gotta deal with misinformed individuals?

Don't you know their attitude is expressed through body language?

Don't you know my eyes are my ears?

I see it all.

I don't ask for help all the time. So?

I want to be my own person.

My own voice. MINE!
I want to be able to speak for myself!

Just because of my hearing loss,
I'm not anymore less of a person,
I'm still whole, just with a challenge.

I see all things.
I read all things.
I visualize all things.
My eyes are my ears.

It is not my pride.
It is my independence that I love the most.
It is my confident ability to actually take time to
be a GOOD LISTENER.

It is my confident ability to actually be patient.
It is my confident ability to do my BEST to
understand the 5 W's and the How.
My eyes are my ears.

So please don't feel sorry or pity for me.
Understand, I know the concerns well.
But I'm a big girl now.
I'm strong.

Yet, I also acknowledge I'm also human.
I also know I'm allowed to feel.
I'm allowed to be heard and be able to express myself
with my own words.

Don't you know now, my eyes are my ears?
Do you understand now, that my eyes are my ears?

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OUR NEXT **B.I.G. MEETING** AND SOCIAL

Wednesday, June 5, 2013

6:00 – 8:00 PM

St Mary's School for the Deaf
2253 Main St. Buffalo 14214

The meeting will be held in the Assembly Hall.

Our guest speaker will be Brittany Pellegra, Awareness Network Manager for Cochlear Americas.

Brittany will share the story of her own deafness and use of cochlear implants.

She and her colleagues will then update us on the latest Cochlear technology, the Nucleus 5.

General business will also be discussed, followed by social time.

Pizza, pop and water will be provided. Please consider bringing a snack or dessert to share if possible.
 But most importantly, we need YOU. Friends and family are welcome.

Free parking is available in the lot behind the building.
 Enter on Main Street in the driveway marked "Main Entrance."

CART transcription service will be provided.



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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