

# THE B.I.G. NEWS

**BUFFALO IMPLANT GROUP**  
COMMUNICATING ▶ SHARING ▶ COUNSELING ▶ SUPPORTING

## B.I.G. STAFF

Gail Cronin	editor & publisher
Margie Fitchlee	writer
Sean Cronin	proofreader

## UPCOMING EVENTS

B.I.G. Meeting	April 7
B.I.G. Picnic	August 5

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## MEETING NOTICE:

Thursday, April 7

6:00 – 8:00 pm

BHSC

50 East North St. - Buffalo

## My Journey with Ménière's Disease

by Karen Ward

Having cochlear implants has had such a positive influence on my life. My left ear was implanted almost five years ago and I have been bilateral for almost three years. I have Cochlear N5 and N6 devices. I was born with and grew up with normal hearing. Ménière's disease caused my hearing loss over many years.

Ménière's disease is an inner ear disorder characterized by four symptoms: vertigo, hearing loss, tinnitus (ringing in the ears), and a feeling of fullness in the ears. It is named for a French physician, Dr. Prosper Ménière, who first described the condition in the 1860s. Because there are other ailments that can cause these symptoms, a diagnosis of Ménière's disease is usually made after a pattern of recurring attacks is established and other causes are ruled out.

When I was 14, there was a day when I woke up feeling not so good. My head felt funny and I had loud ringing in my right ear. Shortly after, I felt like the room was spinning. Moving my head at all made it worse and led to nausea and vomiting. It didn't last very long, and because I felt better the next day, my parents chalked it up to a 24-hour flu bug. However, over the next couple of weeks, I experienced the same symptoms two more times and I was treated for an inner ear infection. Later that year, I was diagnosed with a mild hearing loss in that ear during a hearing screening at school.



Every few years from then on, I would have a series of similar attacks and I was diagnosed with Ménière's

disease. Episodes of vertigo would last anywhere from a few minutes to many hours. While the room-spinning type of dizziness would subside between attacks, a feeling of imbalance would usually remain. Sometimes, I could slowly resume my daily activities, but often I would be very limited as to what I could do. On several occasions, I experienced what is called a drop attack. This is severe vertigo that comes on suddenly and causes the person to fall.

As time went on, I experienced more damage to my inner ear, increasing my hearing loss and worsening my sense of balance. There were a few times when the symptoms would last for months or years, but there were also times where I would be symptom-free for years. The tinnitus would fluctuate in severity but never go away completely. For a very long time, I felt like I was listening to a combination of a humming sound and water swishing like the dishwasher was running. It was very frustrating to have these noises interfere with the things you are

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# PRESIDENT'S

## CORNER

Hello! Happy New Year 2016! I'm hoping that many of you are starting out fresh and healthy and looking forward to improving your listening skills along the way. I plan on continuing to challenge myself by exploring different environments and situations for practicing my skills. Some on my list include: the telephone, presentations in



a small group without an interpreter, and some musical instruments. These three things that I just listed will be a great

challenge for me and I will try my best by taking a small step at a time.

I would like to share a personal experience related to "trains." When I was younger I can recall parking near the train tracks with my dad and waiting for the trains to cross by. At this time I wore a body hearing aid. It was very powerful, as it attempted to compensate for my severe-profound

by Sue Wantuck

hearing loss. My dad would ask me as soon as he heard it, "Do you hear it? I can hear the warning whistle. It sounds like..." and my father would imitate the sounds with his voice. Only when the train was in sight could I start to feel the rumblings of the wheels over the tracks shaking the ground and begin to take in all the noise. In the Fall of 2010 (about 3 months post first implantation) I was standing outside in my friend's driveway chatting. She interrupted me to ask, "What do you hear?" I looked around and focused really hard and replied. "Nothing?" She followed up by saying, "The train, can you hear that tooting? It running on the tracks?" And I replied, "No, not really." I barely heard something, quiet as a mouse. Once in a while when I was outside I would hear it. After becoming bilateral it took about a year and a half before I could recall the sounds again. Since the winter months have been so mild this year I have been spending more time outside than usual. Just over the weekend as I was picking up outside, I stopped what I was doing and realized

I had heard the train so clearly. I thought back to how different things were two years ago compared to now. What an amazing and rewarding experience for me! I continue to be very happy and thankful for the opportunities my bilateral cochlear implants provide me in allowing access to the sounds around me.

The Vera Bradley Bingo event was a wonderful success! A very BIG THANK YOU to all of those involved, especially Margie Fitchlee who developed the fundraiser, and her family from whom we received all of the bag donations in memory of a lost loved one. Also to the officers, member volunteers and UB students who helped make everything run smoothly. I received a lot of positive feedback from attendees who truly enjoyed themselves. My mother especially appreciated a fun day out of the house.

I look forward to seeing everyone at our next general B.I.G. meeting in April. Happy hearing!

## From the Editor

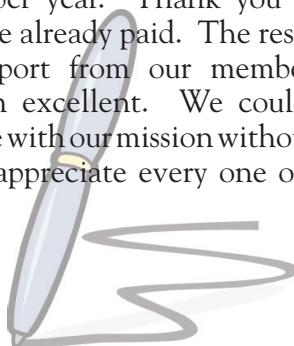
by Gail Cronin

In June we will be scheduling another meeting, and hope to cover the topic of legal issues for people with hearing loss. Your officers are working hard to make this come to fruition. There will be another issue of The B.I.G. News prior to the meeting once details are finalized. Please also keep an eye on our website as well.

Our summer picnic is scheduled for August 5. Please mark your calendar now before your summer schedule gets filled up. And speaking of the picnic, I neglected to provide credit in our last issue for all the beautiful picnic photos in the center pages. They were all taken by Will Licata, our web administrator and photographer. Will also provided all

the event photos in this issue. We are very blessed that he shares his time and talents with us. The photos in The B.I.G. News have never been better.

If you haven't already paid your 2016 dues, you can do so at the next meeting or you can mail us a check to our Clarence Center P.O. Box. Please remember that dues have increased to \$20 per year. Thank you to all who have already paid. The response and support from our membership has been excellent. We could not continue with our mission without you and we appreciate every one of you.



Welcome to our first issue of The B.I.G. News for 2016. We're starting off our year with our first meeting on Thursday, April 7. (For those of you who may be new to B.I.G., we start our quarterly meetings a little late in the year to avoid the snowy weather. Of course this year we haven't had much of that, but who knew?) Please make note of the fact that we are meeting on a Thursday, rather than our usually meeting day which is Wednesday. As a follow-up to our last, very well-received meeting, we are continuing to discuss assistive devices. Details can be found in this newsletter.

# Cochlear Implant Company Updates

## ADVANCED BIONICS

Advanced Bionics provides industry-leading solutions to help people with significant hearing loss communicate with confidence. The Naída CI Q Series sound processors combine AB's proven innovations with popular Phonak features relied on by hundreds of thousands of hearing aid users for better hearing in all situations. With technology designed to automatically adjust to different sound environments, reduce distracting noise for unilateral and bilateral recipients, maximize hearing comfort, and offer waterproof protection, Naída CI Q Series sound processors offer a range of options to suit every recipients' lifestyle and hearing needs. Also new to the Q Series are PowerCell™ innovations that reduce size and improve battery life.

New and current Naída CI Q70 recipients can also benefit from some of the advanced new Q Series features, including new innovations that automatically reduce obtrusive sounds, such as wind, echoes, and sudden loud noises to improve hearing in difficult environments. Available for the Naída CI Q70 and Q90 sound processors, Phonak Binaural VoiceStream Technology™ gives two Naída CI processors the unique ability to work together for improved hearing in challenging situations. Sound from one side is transmitted to the other side so that recipients hear the sound in both ears at the same time while distracting noise is reduced. No other manufacturer can offer the extraordinary binaural benefits this technology provides for effortless communication.

The only sound processor family that delivers hearing as unique as you are, the Q Series provides state-of-the-art technology designed to help recipients communicate with confidence, enjoy music, and stay connected to the latest consumer electronics. For more information about AB's innovative hearing technology, visit AdvancedBionics.

com, or follow AB on Facebook, Twitter, YouTube, Instagram and Pinterest.

Submitted by: Advanced Bionics

## COCHLEAR AMERICAS

### Communication Corner

Cochlear launched the Communication Corner - a new, free online resource to help maximize your hearing with fun and engaging activities. From early listening skills to more effective everyday conversations, the Communication Corner supports the needs of children, parents and adults with hearing loss. The website includes a range of training opportunities, online and printable resources, and practice tools developed specifically for each age group. It provides guidance on where to start and which program is best for you to ensure tasks are at the right level. Whether you use hearing aids, a bone conduction device, or a cochlear implant system, the Communication Corner gives you materials and activities to help you improve communication. Get started today! Visit [www.Cochlear.com/us/CommCorner](http://www.Cochlear.com/us/CommCorner)

### Cochlear™ Nucleus® 22 Nucleus® 6 Upgrade

The Nucleus 6 Sound Processor Upgrade for the Nucleus 22 Implant has been available to order since October 1, 2015. Nucleus 22 Implant recipients are now able to place their Nucleus 6 Sound Processor upgrade order online at [www.Cochlear.com/US/BuildN6Upgrade](http://www.Cochlear.com/US/BuildN6Upgrade) or by contacting Cochlear Americas directly at [upgrade@cochlear.com](mailto:upgrade@cochlear.com) or 1-800-587-6927. To learn more about the Nucleus 6 Sound Processor Upgrade, visit [www.Cochlear.com/US/N6Upgrade](http://www.Cochlear.com/US/N6Upgrade)

### Wireless

With a full range of wireless accessories, Cochlear is the first and only company to deliver true wireless freedom without the need for wires or neck-worn loops. Utilizing the same 2.4 GHz wireless protocol that

Bluetooth® and Wi-Fi devices depend on, Cochlear Wireless Accessories provide a streamlined connection to popular electronic devices (TVs, smartphones and MP3 players) without the interference and signal drops that may occur with traditional wireless systems. Now you're free to do the things you've always done—and to keep looking for new favorites. Visit [www.Cochlear.com/us/wireless](http://www.Cochlear.com/us/wireless)

Submitted by: Cochlear Americas

## MED EL

The U.S. Food and Drug Administration has approved the new SYNCHRONY cochlear implant. For the first time, a cochlear implant has been approved for use with 3.0 Tesla (T) MRI without the surgical removal of the internal magnet; it is the only implant available with this indication in the USA. SYNCHRONY is compatible with all current MED-EL audio processors. It is the smallest and lightest titanium cochlear implant on the market.

To celebrate the arrival of our SYNCHRONY Cochlear Implant System, we're launching our limited-time PlusRONDO offer\*. Choose a MED-EL Cochlear Implant between now and December 31, 2015 and receive a free RONDO Single-Unit Processor with your CI system. Recipients must complete a short survey regarding their experience with RONDO after three months of use. The PlusRONDO offer allows new CI recipients the opportunity to enjoy the very best of our two revolutionary processors: the freedom of nothing behind the ear with the RONDO's fully integrated, cable-free design, and the new SONNET Audio Processor – all backed by MED-EL's industry-leading five-year warranty.

Submitted by: MED EL

# Greetings From Your B.I.G. Friends in Florida

by Craig Carpenter

First of all, I would like to thank you all again for the wonderful reception and gift we received at the summer picnic. We were taken aback by the beautiful blanket we received as a memento of our 30 years involvement in B.I.G. We are very proud of it and keep it on display for our friends to see.

I have no real excuse for not writing sooner except that time slipped by so rapidly once we returned to our Florida home. I had melanoma cancer surgery a week after we returned and have recovered from that nicely although I do have a scar in the middle of my forehead now. At this point in time all signs of cancer in any form have been taken care of and I go back on a regular basis to be sure nothing comes up. (None of this was from the Florida sun.) Jackie too had some basal cell surgeries but she also is out of the woods now and like me goes back for regular checkups.

On September 10 we became Great Grandparents of lovely Victoria Simone Carpenter, a beautiful well mannered, happy little girl. Mom Aimee and daughter are doing well.

I am currently working to obtain my new N-6 Nucleus processor upgrade. I had problems with insurance coverage for Jack Wazen, MD, FACS whom I need to see at the Silverstein



Institute in Sarasota. This has been resolved and I will see him in January to get the necessary paperwork done.

On October 1 Jackie and I attended our first Cochlear Community Chapter event in Sarasota at the AmericInn Sarasota. The meeting was sponsored by Cochlear Corporation and was attended by some 25 people. CART services were provided, the meeting was opened by Katie Figueroa, Cochlear Engagement Manager, who gave us the agenda and then turned the meeting over to Joan Haber, a bi-lateral Cochlear Volunteer who talked about the new N-6 processor and the advantages it has over the older Freedom Processor. She also told us that there is a HLAA group in Sarasota that has a large number

of implant users as members. We may try and hit up one of those meetings, although I would prefer to try and get something going a lot closer to home. (I now know how Eddie Bastian must have felt having to drive all that distance to attend our B.I.G. meetings)

The information obtained at the meeting was very helpful to me as I made my decision on which accessories I would like included with my N-6. Also the CART reporter was superb. She kept right up with everything that was being said, even with the questions being asked by those in attendance. Cochlear provided mini lunches and we met a few new faces while we were there.

I'm not sure if we will travel up that way very often, instead we will try and work with Lynda Nally, AuD, FAAA, CCC-A my Audiologist in Fort Myers to put together some kind of a group similar to B.I.G. I do know one bi-lateral CI user who lives in Fort Myers now and was a good friend of mine when I was affiliated with the Buffalo Club of the Deaf. What a coincidence, eh? She happens to be a representative of Sorenson Communications and came to my house to set up my video phone. Some of you may know her, Rachel Slike. I do have a beginning!



Erie County's Local Early Intervention Coordinating Council (LEICC) continues to support the efforts of a workgroup specific to hearing loss. The most recent work of this group is focusing on making connections for parents of children with hearing loss in Erie County. Teaming with Parent to Parent of New York, this group will be hosting

## Connecting Parent-to-Parent

by Jessica Holst

a two-hour Support Parent Training for family members of children with hearing loss in the spring of 2016. A Support Parent is a parent or primary caregiver of an individual with a disability or special health care needs. They volunteer to help other families in situations similar to those they have faced, usually by telephone. Parent to Parent of New York State builds a supportive network of families to reduce

isolation and empower those who care for people with developmental disabilities or special healthcare needs to navigate and influence service systems and make informed decisions. Please email jessicah@smsdk12.org or tbalon@askbhsc.org if you are interested in participating in this training or any other future social networking opportunities for families of children with hearing loss.

# REFLECTIONS on: 2015-Perilous Times

by Margie Fitchlee

The past year has come and gone and many may say good riddance to it! A young writer for our local newspaper Rich Lowry said just that, "good riddance to a year of hysteria." He called it the year we could barely hold it together.

Hysteria over the murders in Charleston SC, the issues with the confederate flag, Ferguson MO, black lives matter, the San Bernardino attack, Paris, climate change, the hysteria on our college campuses, etc. Many could say the hysteria was justified, many could argue that the panic brought on by this hysteria will not go away.

Uncertainty has surely ruled! It has ruled all the way from these worldwide issues down to personal issues. Many out there who have been drawn to Buffalo Implant Group for support with hearing issues have felt those perilous times too. We can take comfort in the wisdom of others. We can band together with support, knowledge, and guidance helping those out there confront their vulnerability and face the uncertain feelings that they may face as they go forward with cochlear implant surgery.

The Queen of England in her holiday message even felt compelled

to comment on these very issues. She made us realize that we should never underestimate the power of hope when she said, "Light can triumph over darkness in these perilous times." She told us that the world has had to confront moments of darkness this year, but reminded us that the Gospel of John contains a great verse that we should all be reminded of: "The light shines in the darkness, and the darkness has not overcome it." This is what I have often referred to as my human spirit.

The holiday season and the coming of the new year always make me think of my mother and what she might have thought of these times we live in. I have often thought to myself, mom would never have believed this! ... but of course she would have... she lived through so many perilous times herself, as did so many before us.

We must move forward in 2016 and pray that it will be different. Maya Angelou in all her wisdom has written much on this subject. I want to share her thoughts with you: "We may encounter many defeats but we must not be defeated" and "We have to confront ourselves. Do we like what we see in the mirror? And, according to our light, according to our understanding, according to our

courage, we will have to say yea or nay and rise! Nothing can dim the light that shines from within move forward. No one can go back and start a new beginning but anyone can start today and create a new ending."

May the year 2016 be the year we start that new ending. May the perilous times subside and may the light overcome and shine bright for all of us. May those approaching upcoming cochlear implant surgery find strength, happiness and amazement as they continue on their journey to better hearing. May those of us continuing on our journey to better hearing, continue on with hope, dignity, and perseverance.

Let's gather up our strength and make the hysteria go away. May these wise words of Martin Luther inspire all of us in 2016 and always: "Even if I knew that tomorrow the world would go to pieces, I would still plant my apple tree." Some of us may feel that world closing in, going to pieces, please know that Buffalo Implant Group cares, and I care too! God Bless!

## Treasurer's Report

by Lisa Hill Nowicki



Thank you again to everyone who help to make B.I.G. a success by continuing to see value in the newsletters and meetings and by participating and paying their dues. Our 2015 year ended in the black thanks, in part, to the extra fundraisers – Vera Bradley Bingo, 50/50 raffles, pop cans, and Macy's Shop for a Cause. Without these events we would have been in the red as our memberships alone do not cover our expenses of the newsletter, summer picnic and pizza at our B.I.G. meetings. As we look to 2016 we are hoping that the increase in our dues from \$15 to \$20 will help to close this gap. I look forward to seeing each of you and will have a table set up at our April meeting to collect dues for the 2016 year. Have a great day!

### Reminder:

**Buffalo Implant Group annual dues have increased to \$20 per year**





## Vera Bradley Bingo Was a Resounding Success

by Gail Cronin

When Margie Fitchlee first brought the idea of a Vera Bradley Bingo fundraiser to the B.I.G. Board in 2015, it sounded like fun. But truthfully, I didn't know what Vera Bradley was and I wasn't much of a bingo player. I soon learned that Vera Bradley is a very hot commodity among ladies.

This wasn't the first time that Margie and her family members gave of their time and talents to B.I.G. in order to help us raise funds. In 2014 Margie organized a very successful fundraiser for our organization with the help of her brother, actor Albert McFayden, who gave a breathtaking performance as FDR in a one-man show. One year later, Margie came to us with a proposal for this wonderful bingo fundraiser, thanks to the generous donation of Vera Bradley merchandise from her family members Greg and Marybeth Fitchlee from the estate of their late sister Vickie Fitchlee who had sold Vera Bradley merchandise prior to her passing.

Margie quickly went to work assembling a fundraising committee made up of our Board members and several additional volunteers including Kathy Danahy, Diane Mogavero, Jan Telban, and Karen Ward. The committee immediately went to work securing donations from many area business in order to provide food, materials, and décor for the luncheon portion of the event. Our event sponsor was BJ's wholesale club, with additional donations coming in from Tops, Wegmans, Wise, Pepperidge Farm, Mayer Brothers, Hostess Bakery, Home Depot, and several donors who wish to remain anonymous. As a result we were treated to a beautiful

luncheon of sub sandwiches, chips, fish crackers, coffee, tea, cider, pop, cheesecake, donuts, cookies, and more. Second helpings were available to all.

Of course our event would not have been possible at all if it weren't for the generosity of St. Mary's School for the Deaf, which provided us with an excellent venue, as well as use of tables, chairs, etc. Our committee did an excellent job of setting up the St. Mary's gym and decorating with an autumn theme. Gloria Matthews and Shirley Moorehouse shared their artistic talents by creating beautiful centerpieces for each bingo table.

Thanks to the diligence of our committee, ticket sales were brisk and we were sold out of our 125 tickets well in advance of our event. On the day of the event, November 14, check-in went smoothly. Participants received their bingo cards and were given the opportunity to purchase an additional half card and/or raffle tickets. Then our participants could find a table they liked and then go get their lunch. During this time participants also had an opportunity to look over the prize table, where each Vera Bradley bag, valued between \$55-90, and wrapped elegantly in cellophane by Margie and Hana Fitchlee, could be viewed. Following lunch there were announcements and instructions and then we began playing bingo.

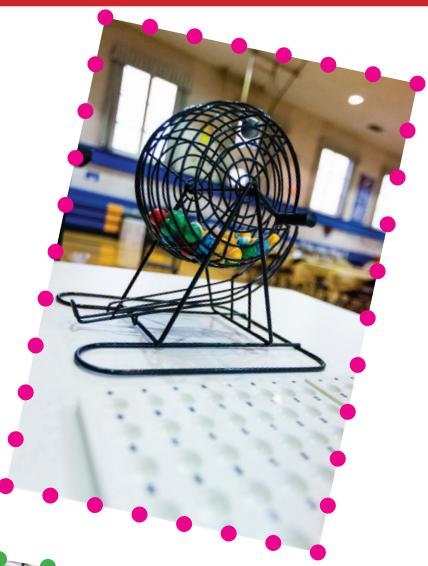
Our bingo games were accessible to all. The numbers were called and signed by an ASL interpreter simultaneously, and the called numbers were also projected visually on a large video screen. Multiple games were played on each bingo board, allowing for many opportunities to win prizes.

In total, over 60 Vera Bradley bags were given away. What really pleased the winners was learning that they could pick the bag of their choice. Halfway through the bingo we took an intermission for dessert before resuming our games. At various times throughout the afternoon, admission tickets were pulled from a jar and door prizes were awarded to lucky winners. Forty of the door prizes were smaller Vera Bradley items such as wallets, lunch bags, belts and book covers. At the conclusion of the bingo, the table centerpieces were also given away to lucky participants who found a B.I.G. business card taped beneath their chair. Finally, raffle winners were announced.

Throughout the event, volunteers, including a group of wonderful graduate students from the University of Buffalo Department of Communication Disorders and Sciences, kept things running smoothly. Will Licata shared his photography talents by taking pictures all afternoon. At the conclusion of the event, there was a sea of smiles. It certainly appeared that everyone had a good time. The fundraising committee, and several guests, pitched in after the event to clean-up.

In total, over three thousand dollars were raised at this one-day event. A great deal of work went into this event by our Board members, committee members, family, friends, and additional volunteers. But most of all, Margie Fitchlee put in a tremendous amount of thought and heart into making this event the memorable afternoon that it was. We are all indebted to her and her generous family for their support.

# Vera Bradley Bingo



## My Journey with Ménière's Disease... cont. from page 1

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trying so hard to listen to! Hearing in that ear seemed garbled during those times and I would score poorly on the discrimination portion of a hearing test. During symptom-free times, the clarity of speech would improve, but I would need more amplification.

I got my first hearing aid in my twenties. Although I still had one "perfect" ear, I had started to struggle to hear in some situations and with determining the location of sounds. The hearing aid helped a great deal and lessened the tinnitus. The majority of people diagnosed with Ménière's are only affected in one ear. Unfortunately, in my late thirties, my other ear became affected. The progression of hearing loss was much quicker this time and I was soon wearing two hearing aids.

The cause of Ménière's disease is thought to be an excess of fluid in the structures of the inner ear. There is no cure but there are a number of things that can help control the symptoms. Motion sickness medications like Antivert can help lesson or eliminate vertigo. Diuretics and a low salt diet can help control the fluid buildup. I found these to be helpful over the years. Oral steroids help some people but did not help lesson my symptoms at all. Sedatives like Valium and Ativan help diminish the severity of the dizziness. They left me groggy and not good for anything but sitting around all day, but provided welcome relief from the vertigo.

Dr. Diaz-Ordaz has been my doctor for many years. I had several surgeries over the years to help control the dizziness when medication was just not enough. By 2008, I had lost all hearing in my left ear. For three years, I struggled with one hearing aid in what had previously been my bad ear. It was stressful and very tiring to put so much energy into trying to hear. TV was difficult no matter how loud it was. The telephone was almost impossible to use. Any situation other than a being in a quiet place and conversing with

just one person was very difficult.

One day during an otherwise symptom-free period, I woke up to discover my remaining hearing had become very distorted. I could hear sound, but could not understand speech at all. At times, I could not even discern speech from non-speech sounds. Dr. Diaz-Ordaz referred me to Dr. Joel Bernstein, who treats Ménière's with intra-tympanic steroid injections. A ventilation tube, like kids often get for chronic ear infections, was inserted into my eardrum. Dr. Bernstein has a specialized mixture of steroids compounded and delivers it through the tube directly into the middle ear, where it can be absorbed by the inner ear. The steroids have a much better chance of alleviating symptoms than they would if taken orally, and there are no unpleasant side effects. It was painless and I got great results from a series of injections. Garbled speech became clearer, and, remained so for almost two years, but again the level of hearing was not quite what it had been.

In 2011, the garbled hearing returned. It was then that I was referred to Buffalo Hearing and Speech for a cochlear implant evaluation. I knew that if I qualified, I would go ahead with the surgery. My remaining hearing was of very little value to me. I was wearing my hearing aid, not because it was providing useful sound, but because it was very unsettling to me to go about my day in complete silence. There is the big unknown of what things will sound like with a cochlear implant, but I believed that anything would be better than the way things were. There was the question of whether or not I would qualify because I often received a decent score on the discrimination portion of the hearing test. I usually attributed that to being familiar with the word list after many years of hearing tests. I am certain my family knew that I didn't understand 50% of what they said. Well, when I was evaluated, I absolutely qualified. Because the tests are specifically for

CI candidates, it was all new to me. I guessed at some of the words and sentences but for others, I could not even come up with a guess before the next one was read. I was never so excited and relieved to have failed a test! I learned during the evaluation that I had become a much better lip reader than I thought. I knew that I was watching people's lips as they spoke, but I have no strategy for deciphering what they were saying. It just developed over time and I still rely on it today.

I did not find the surgery and recovery to be very difficult at all. As most of you know, the wait to have the CI activated is the most difficult part. It was my left ear that was implanted and during the wait, I saw Dr. Bernstein for another series of steroid injections in my right ear that again managed to improve the clarity of the small amount of hearing I had remaining. At my initial activation appointment with JoAnn Hammer, she told me to take out my hearing aid so I could focus on just what I would hear with the cochlear implant. I was so relieved to hear those first few beeps that confirmed that the implanted device actually worked and would allow me to hear sound. After many beeps, we tried speech. My husband, Mike, sounded exactly the same as JoAnn. Their voices sounded very high-pitched and somewhat electronic, but I could understand what they were saying. My sole purpose of getting the cochlear implant was to understand speech and to have reached that goal on the very first day of activation was beyond my expectations. So the process of listening to things in the world and figuring out what I was hearing began. It was sometimes amusing to hear what things sounded like. Running water had a metallic sound, like BBs being poured into a glass jar. With each mapping, the sound quality improved. Speech and other sounds did not sound exactly "normal" or what I remember them sounding like, but communication

*continued on page 10*

## B.I.G. Has Lost a Friend

On December 19, Thomas White, retired audiologist from the Buffalo Otological Group, passed away at the age of 74. Tom had been an early believer in the power of cochlear implants and was a founding member of Buffalo Implant Group. Longtime members of B.I.G. and speech and hearing professionals throughout our community remember Tom as a caring and compassionate man who supported and encouraged those with hearing loss. He will be greatly missed.



Tom White and Craig Carpenter  
1987 B.I.G. Christmas Party

## The United States DOT Officially Requires Closed Captioning in Airports

The United States Department of Transportation (DOT) recently issued a ruling that requires closed captioning on all televisions in U.S. airports that receive federal funding and experience at least 10,000 flights annually. All public-facing audio-video displays must include captions, whether they are at ticket counters, security areas, gates, lounges, restaurants, or airport shops.

Our Fall meeting was held on October 28 at Buffalo Hearing and Speech Center. We welcomed wonderful speakers who were knowledgeable about assistive listening systems. Our own treasurer, Lisa Hill Nowicki, served as moderator.

Al Colucci from Ronco Specialized Systems installs communication systems, call systems, and public address (PA) systems in schools, churches, hospitals and other institutions. Audience members were saddened to learn from Al that the majority of systems that are purchased are never activated or used. Al's mission is to educate consumers so that systems are activated and used properly.

Kasey Kaumans from Listen Technologies in Utah talked about the law known as the Americans with Disabilities Act (ADA) and how it applies to the availability of assistive listening systems. He noted that many people are surprised to learn that churches are exempt from having to provide assistive listening systems, yet they are in fact the most common institutions to install systems because they are proactive and are more likely to see it as part of their mission to provide access to all. Kasey also noted that there are often tax benefits to institutions that install an assistive listening system.

Both gentlemen encouraged our audience to speak up or even complain when a facility they use does not have a functional assistive listening system. It is up to us, the consumers, to be vocal and advocate for ourselves and others. This prompted a lively conversation about local venues that do and do not have functioning systems.

Our guest speakers explained the differences between various systems. A Radio Frequency (RF) system, also known as an FM system, has low installation and maintenance costs, excellent sound quality, allows for multiple stations including language translation stations, can be mono signal, and can allow for audio to be

## Meeting Report

by Gail Cronin

picked up outside of a room. Infra-Red (IR) systems use a stereo signal and although they need to be in the line of sight of the transmitter, newer receivers are improved and can pick up a signal better than before. They tend to be more expensive than RF systems, but are more suitable for a performance space. They are used by courts and government facilities so that the audio can't go outside the room. Induction Loop (IL) systems only work with a t-coil on a person's hearing device. Those without a t-coil cannot use this type of system. On the plus side, the user needs no other equipment other than their hearing aid or cochlear implant with t-coil.

Al and Kasey installed temporary systems in our meeting space so the various types of systems could be tried by members of our audience. Many members asked for more information at a future meeting about additional personal assistive devices for use at home.

Our gathering also included a business meeting during which the current slate of officers, who were all running unopposed, were re-elected for 2016. We also voted to increase annual dues to \$20 per year. Sign language interpreters were present. Pizza and dessert were provided. Approximately 45 people were in attendance, and social time was available at the conclusion of the meeting.



Guest Speaker  
Al Colucci

# My Journey with Ménière's Disease... cont. from page 8

was so much easier than it had been in a very long time. I realized how relaxed I now felt all day long and I was surprised that I could hear very soft sounds like a clock ticking. I had forgotten that when you click on something with your computer mouse, it really does make a clicking sound. It really was not very long before the electronic sounding voices were completely replaced by the voices of my family and friends exactly how I remembered them.

During the first two years of having my cochlear implant, I continued to use my hearing aid in the other ear. It really did add a fullness to sound and help with directionality. I often thought about having my other ear implanted. After all, my natural ears had failed me and there was always a chance that the internal or external components of the implant could fail. I never wanted to go back to struggling to hear again. In May 2013, I became bilateral. The difference in sound quality is astounding. We are supposed to have two ears. I can very easily remove either processor and experience what it is like to go back to one functioning ear. It is hard to believe that I thought I was hearing so well with only one ear implanted.

I had received a copy of The B.I.G. News from Buffalo Hearing and Speech Center during my cochlear implant evaluations. I had thought about coming to a meeting, but I never seemed to make it. For so long, something like attending a meeting was pointless because I would never be able to follow what was happening. After my second CI surgery but before my activation, I told myself it was time. There was a meeting at St. Mary's School for the Deaf and I emailed President Sue Wantuck to ask her where to go once I arrived for the meeting. Well, as it turned out I had written down the wrong date and missed the meeting. Sue was so nice and invited me to meet her out for coffee the following week to chat. We met at a Wegman's Café. It was the first time that I had met another person with a cochlear implant. Sue had just become bilateral herself and her second implant had been recently activated. We joked about always having to go back to our mapping appointments and tell our audiologist friends that we were ready for more volume. Without our cochlear implants, we would both be deaf. With our implants, we had no trouble conversing in a noisy supermarket. Truly amazing!

I have not had any issues with vertigo in almost 8 years and I am hopeful that my Ménière's has "burned out," as some say it can. I experience some tinnitus with my processors off but it goes away instantly when I put them on. Presently, I hear pretty well in most situations. Noisy places are challenging, as expected. Music does not always sound so good to me but has been improving with time. Cell phones are still difficult but I hear very well using a landline with the telecoil setting. I absolutely love the room loop that my husband installed in our family room for listening to TV and I still use the closed captioning quite a bit. I have to thank my very supportive family and friends, as well as my doctors, Buffalo Hearing and Speech Center, and the members of Buffalo Implant Group for their knowledge, guidance, and patience that has helped me get to where I am today. If anyone has questions for me or would like to try out the room loop in our Hamburg home, please feel free to contact me at [ward\\_karen@verizon.net](mailto:ward_karen@verizon.net).



There are many theories about what illness 19th-century Dutch painter Vincent van Gogh, who was often described as "mad", may have suffered from. One theory suggests it may have been Ménière's disease, not epilepsy or mental illness as previously thought. The swirls in his *The Starry Night* painting could be his representation of vertigo that he experienced, and he may have been trying to rid himself of persistent tinnitus when he cut off his own ear.

## Many Thanks

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Donna Johnson  
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Sue Wantuck  
Karen Ward  
Wegmans  
Carol Wesley  
Wise Products  
Zenger Group  
Sr. Jean Marie Zirnheld

### Save the Date!

Our annual Sunset Dinner Picnic will once again be held at Westwood Park in Lancaster this August. The date has been set for Friday, August 5. Please mark your calendars!



# Quarterly Newsletter

## Subscription/Membership Form

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

## Our Next B.I.G. Meeting and Social

### Assistive Listening Devices for Personal Use

With guest speakers from Buffalo Hearing and Speech Center:

Tracy Balon, Dr. JoAnn Hammer,  
Dr. Alison Ulatowski

Please Join Us  
Thursday, April 7, 2016  
6:00 – 8:00 pm

Buffalo Hearing and Speech Center  
50 East North St. Buffalo 14203

Come learn about what assistive devices are available to enhance your listening experience at home and in other environments, which you can use with your cochlear implant. Our guest speakers will

cover the issue of which devices are compatible with the technology of each cochlear implant manufacturer.

There will also be a brief business meeting to discuss planning for future events. The treasurer will be available to accept your 2016 dues. The meeting will be held in the lower level conference room. Limited free parking is available in the lot behind the building. Pizza, pop and water will be served. Please consider bringing a dessert to share if possible. But most importantly, we need you! Friends and family are welcome.

Please note that this meeting is scheduled for a Thursday, rather than our usual Wednesday time slot.



## Wegmans Stores Installing Induction Loops

Wegmans has pledged to outfit all of its stores with assistive listening systems so that customers with hearing impairments can potentially have better communication with employees. The induction loop (IL) systems being installed will be helpful to those whose hearing aids and/or cochlear implants have a telecoil (T-coil). The systems will be used at customer service desks, pharmacy counters and by cashiers at select checkout lanes. The first Western New York location to be fitted with the new loop systems is the Dick Rd. location in Depew. Additional locations are scheduled to have their induction loop systems installed throughout 2016. Cochlear implant users should discuss the possibility of a T-coil program with their audiologist



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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