

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 March 11
 BHSC Good Vibrations March 14
 NYSSLHA April 23-25

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MEETING NOTICE:

Wednesday, March 11

6:00 – 8:00 pm

Buffalo Hearing & Speech Ctr
 50 East North St. - Buffalo

My Cochlear Journey

by Jimmie Sorrento



Jimmie at the wheel

I've spent most of my life driving a taxi cab for a living. Having worn two hearing aids for close to 10 years, and having worn a single hearing aid for 25 years, my hearing was getting worse. I was no longer able to use the cab radio. I totally relied on fares coming from the airport terminals.

As my hearing decreased, I noticed that I rarely had problems understanding men. Most had deep low voices I could understand quite well. But women were another story. I had a heck of a time understanding them. This was the wake-up call that made me realize that hearing aids were not enough for

me anymore. I went to my hearing aid Audiologist. He tested me, and like I thought, my hearing ability even with hearing aids was less than 40 percent. He then gave me the strongest hearing aid he had, with an FM system, to try out for 2 weeks. It worked ok, but I still worried. He then mentioned a CI. I had never heard of that before. I asked, "What exactly is a CI?"

The audiologist explained that it involved a procedure of wrapping a computerized coil around my cochlea and using a processor and magnets. They can literally help people with profound deafness like myself. He took the liberty of making an appointment for me to see Dr. Ernesto Diaz-Ordaz. He explained further that I had to get my own doctor in on it. While this was happening I made an appointment with Buffalo Hearing and Speech Center. The operation took place on April 23, 2004 at Sisters Hospital. I remember waking up. The huge bandage on my head that kept falling off and I ended up staying overnight. I felt no pain, even the next day. I was given pain pills but never took one. The worst part of my journey was the wait.

I waited a month for my implant to be turned on. During that time I wore my hearing aid in my left ear. I heard very little with it. After two weeks of sitting at home I went back driving to my taxi. No work, no pay. That was one of the dumbest things I did during

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Greetings from the B.I.G. President! Welcome to 2015, another new and promising year. I hope that we will be able to recruit more members and continue with learning, sharing and supporting, as we have in the past. Our board has been doing a wonderful job working together, coordinating meetings, the newsletter, and fundraising events, and we look forward to

hearing feedback from you. Please feel free to contact myself, or any of the board members with comments, questions, and concerns.

The special event that we hosted in November "An Afternoon with FDR" was a success! A B.I.G. thank you goes to Margie Fitchlee, her brother Al McFadyen (the actor), and members who helped organize, advertise and volunteer their time to make this happen. Many friends and family attended, supported, and/or donated to help our organization. The show itself was very entertaining and informative. Al did an awesome job portraying his character and his singing was phenomenal! I wish more of our membership was able to attend such an inspiring and worthwhile performance.

In early December, Cochlear Americas hosted an informal presentation in downtown Buffalo at

the Embassy Suites. I had lunch with Alison Mendez at the Anchor Bar. She is Cochlear Americas' Engagement Manager. She was interested in learning about B.I.G. We had a wonderful conversation about our unique support group and discussed recent updates for implants and BAHA's. She stated that she would be happy and willing to come back to Buffalo to present at a future meeting.

There will be a general B.I.G. meeting on Wednesday, March 11 from 6 to 8 pm at BHSC. We are working on setting up a panel of adult CI and BAHA users. Jessie Holst will serve as panel moderator and will prepare questions to help guide the volunteers in sharing their personal stories. I encourage you to come and join us. I look forward to seeing many of our members.

See you soon and have a wonderful and healthy year!

From the Editor

by Gail Cronin



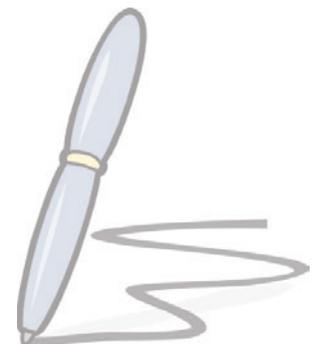
We're off to a great start this year. I hope you enjoy this first issue of the year as much as I have. The highlight of this issue for me is reading Jimmie Sorrento's story, and seeing the photo that accompanies it. Jimmie has been involved in our organization for as long as I can remember, and has consistently supported us over the years. Jimmie is the kind of person who flies under the radar. Everyone

knows who he is, but not everyone realizes how much he does. From the early days when Jimmie did all the cooking for our summer picnics to our last meeting when he was the only person who thought to bring a birthday cake for our Board member Gloria Matthews, Jimmie sees what needs to be done and he just does it. Don't you wish you had more people like that in your life? I do!

A few weeks ago when we found ourselves without a cover story for this issue, Gloria asked Jimmie if he could write one in a week's time. He had it done and emailed to me by the next morning! It's astonishing, really, that we had never asked Jimmie to write his story before. He's been such a huge part of our group for so long. And as much as I loved reading his story, I loved his picture even more. Jimmie drives a taxi for a living, and had driven some of our Board members places from time to time. Driving is in Jimmie's blood. So when he sent me a selfie with the dashboard and road ahead of him

clearly visible in the reflection of his sunglasses, I laughed out loud with joy. So clever! So creative! So Jimmie!

So let's all be like Jimmie and keep our eyes on the road ahead of us. Our future is bright. Thanks to the hard work of our Board and the generosity of our members and donors, we're finally in the black! And our new VP Margie Fitchlee has even more ideas for future fundraisers. We have a great and growing Board. We have a new website that is almost ready to go online, thanks to the hard work and talent of Will Licata. We have new logos and graphics. We are going places!



Learning to Listen to Music with a CI

by Gloria M. Matthews



For some time now, I've heard there are quite a few people struggling to "hear" music clearly through their cochlear implant's processor(s). As I write, I'm currently using my direct audio cable to listen to music on my desktop and the music sounds better through the audio cable than over the use of the speaker. Before I continue to go on, I would like to note that I am a Cochlear Nucleus 5 user and this is based off of my own personal experiences.

I have six plus years of playing clarinet, one year each for viola, piano, and harmonica. During my childhood up until teen years I was involved with my hometown church's Hand bell Choir and Children's Choir for the holiday seasons. I enjoyed music despite my hearing loss. During my early 20s, I participated in a couple of local bar gigs with friends playing my clarinet by ear. How? It's all in the count, the beat, the harmonies and the melody. What was more important was knowing the count, which was how my mother taught me. Everything else followed.

I am aware that each cochlear implant company has uniquely different designs, programs and functions, so this may or may not apply to some or all of you. So bear with me here. When I first got activated, I waited until I could get used to basic sounds and to slowly build up my brain's recognition of different sounds. Music is put together with just a simple note and builds up from there into a beautiful song or an award winning masterpiece. Getting your CI ear to learn the differences between sounds is vital to learning the differences in the sounds of music. What do I mean? First, pay attention to what sounds come to you

easily. Are they in the low frequency range which is equivalent to a bass, or are they in the mid-frequency range where you can tell the difference in the low to mid-high frequencies, or are they in the high frequency range? Where do you fall in terms of hearing the frequencies? Now, if the low frequencies come easily, listen to music that has that bass sound, the deep sounds that are low and loud. Some deep sounds can even be soft but have that bass in it, so that you can still make out the words and still have the music playing in the background.

Start by choosing music with minimal background arrangements. Some suggestions would be listening to a performance with a single instrument, or some "a cappella" music that has only people singing without instruments. If you feel confident move up to music that has a couple of instruments involved and listen to one that stands out to you, over and over again until your CI ear gets a better idea of what it's listening to. If you are a person who had more hearing at one time and enjoyed music then, you can also go back to your old music that you are familiar with and have it on repeat for about ten to fifteen minutes. Do this without forcing yourself to listen, or else the sounds will not come to you naturally. Just simply listen.

One thing many people may not be aware of is that when you first pick up on the sounds of music you may strain or force yourself to really listen to it and before you know it music doesn't sound like music. It sounds like just noise. Do yourself a favor; just relax and take it one step at a time. It's like with speech. Speech doesn't come in clearly right away, but eventually it does because you are able to listen passively and not actively all the time. Passive listening is listening without reaction and allowing someone to speak or sing,

without interrupting. This is when you are relaxed. Active listening is reacting or doing something that demonstrates you are listening and have understood. So this would be a response to what you heard and writing down information or giving a verbal cue. The active listening takes place in many different situations. However, do we always respond back or do we just decide to "just listen" (passive listening)? Most of the time, many of us are really in a passive listening mode. We don't always respond but when we do pick up on something there is a response, which means you were able to go from passively listening to actively listening without knowing it. With music, it requires passive listening skills first. Just allow the music to "flow" to your ears. Allow those notes to stream through your auditory processing center of your brain and let your brain get used to it. So, it's either training or retraining the brain to recognize musical notes and sounds before your brain can put it together. It's just like learning to recognize speech and environmental sounds. It's little by little.

What helped me was reading the music and playing the keys on a keyboard to hear the differences in notes. As soon as I got the sounds down, I was able to proceed on my clarinet to know how each note sounded and then play the song. Each instrument produces different sounds for the same note. This is because of how the instruments are designed and put together. The same note could have the same pitch but they are slightly different in how they sound on different instruments. But when played at the same time it like a harmony of different instruments coming together playing just that one note and holding it, and its rough starting out but then it starts to smooth out.

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Joe Sonnenberg, NYSSLHA President, Brings Convention to Rochester

Joseph Sonnenberg, Vice President of Buffalo Hearing and Speech Center and longtime friend to B.I.G., has been elected President of the New York State Speech-Language-Hearing Association Inc. for the year 2015. NYSSLHA is the statewide professional organization for Speech-Language Pathologists and Audiologists, which provides for professional networking, sponsors continuing education, participates in public relations, and engages in legislative advocacy for

speech and hearing professionals and the clients they serve.

Joe has worked tirelessly to bring the annual NYSSLHA Convention to an upstate city this year, and as a result it will be held on April 23 – 25 at the Hyatt Regency Rochester and Rochester Riverside Convention Center. This provides a rare opportunity for Western New Yorkers to easily attend the annual Convention, which is usually held downstate. NYSSLHA hopes to attract a large number of speech,

language, and hearing professionals from the Buffalo area this year. The topic for this year's Convention is "Technology: Changing the Face of Our Professions." If you are a Speech-Language Pathologist or Audiologist, please consider attending.

B.I.G. would like to congratulate Joe Sonnenberg on his election to the Presidency of NYSSLHA and thank him for his service to both his profession and the cochlear implant community.

B.I.G.'s New Website

by Fr. Bob McCartney

Exciting things are happening to the B.I.G. website! A complete make-over of all pages is underway. Continue to connect to our site at www.buffaloimplantgroup.com to keep up to date on B.I.G. events. Since the new site will use the same address, you will automatically view the new site when it goes online.

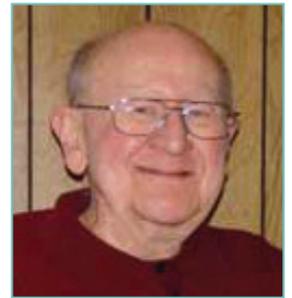
Our group is most fortunate to have a recent cochlear implant recipient able to do this web programming for us. Will Licata is a Network Engineer at the Catholic Health System (CHS). He has worked for CHS for over 13 years and spends most of his time working on the back-end systems that support

the clinical and financial staff to help deliver better patient care. In addition he has a degree in forensic chemistry and worked as a chemist before venturing into full-time IT.

It will be possible to view the website's pages whether you use a computer, a tablet or iPad, or a smartphone. Watch for the changeover

in the coming weeks. B.I.G.'s pages will continue to have links to resources

for those considering the possibility of a CI. On the site you can view pictures and email addresses of the Officers and Board members. Past newsletters can be viewed, downloaded and printed. It is B.I.G.'s policy to post The B.I.G. News after the next issue is sent to paid subscribers. Only by membership in B.I.G. (\$15/year) can one receive the latest issue by mail and the timely news it contains. May you benefit greatly by logging on to our website.



Learning to Listen to Music with a CI... *cont. from page 3*



The primary purpose of the implant electrode and speech processing programming is to hear better in speech, but many CI users would also like to hear music better as well. Music appreciation comes with patience and time. While companies are all working to maximize the ability of the electrodes and the processors to do better with music,

keep in mind how different music and speech are. I believe the only way to really get to know music is to experience it for ourselves and to take it on like a project, just how we took on speech and environmental sounds as a personal project in the beginning of our new hearing journey. Don't be easily discouraged however. Try using the audio cable (if your processor

came with one), start with music you are familiar with first and then in a silent room play the same music on speaker. With speakers you may have to readjust the volume to find your comfort zone and where you feel you pick up more of the lyrics or sounds or both equally! It really is a learning experience, so take it slow and don't force it. Let the music come to you.



REFLECTIONS ON:

Counting my Blessings - 2014 was a banner year!!!

by Margie Fitchlee

The year 2014 stands out in my mind as one of my all-time favorites. I celebrated my five year anniversary as a cochlear implant recipient. My brother Al McFadyen graced the Buffalo Implant Group with his performance of "FDR" at St. Mary's School for the Deaf raising much needed funds to help keep our wonderful group and newsletter afloat. My father-in-law Everett Fitchlee turned 91. My granddaughter Hana turned sweet 16. And my daughter Allison and her husband Michael blessed us with twin grandbabies, a boy Graham Michael and a girl Parker Rae. How much more could we have asked for? C.S. Lewis said, "When we lose one blessing, another is often most unexpectedly given in its place." In my case, many blessings were given!

I have written before about the subject of "time." I saw a sign that read, "2015: A Time for Change." The arrival of the new year sets the stage for us to reflect and ponder on not only the events of the past year but also the opportunities which will lie ahead for us in 2015. I suspect that for many of you change is in your forecast too! Those of us with cochlear implants still experience changes in our journey to better hearing. It is life long journey. Those of you who have scheduled implant

surgery in the year 2015 will most certainly see changes in your lives too! All my best is being sent your way. We all know that time truly does fly, but for those waiting to receive "the gift of hearing" it may not fly fast enough. Steve Maraboli, author of Life, the Truth, and Being Free, hit the nail on the head when he said "although time seems to fly, it never travels faster than one day at a time. Each day is an opportunity to live your life to the fullest. In each waking day, you will find scores of blessings and opportunities for positive change. Do not let your 'TODAY' be stolen by the unchangeable past or the indefinite future!"

Embrace those days and always count your blessings, as he says "live your truth, express your love, and share your enthusiasm. Take actions towards your dreams. Walk your talk. Dance and sing to your music. Embrace your blessings. Make today worth remembering." Next year you may find yourself saying, "2015 was your banner year." That is my hope for all of you.

Having babies in our lives has brought us so much happiness and joy. But, having TWINS in our lives reminds me always that sometimes miracles really do come in pairs. For me, being able to hear them "coo" and "cry" brings tears to my eyes. What a true blessing has been bestowed upon me. I said it before and I will say it again. Dr. Ernesto

Diaz-Ordaz, you are the man who saved me! It has been said that "twins are yet another one of God's hilarious curve balls." To Graham and Parker I say I am so happy to play ball with you. Robert N. Munsch wrote one of my very favorite children's books, Love You Forever. I paraphrase a quote from it that I changed up just a little to suit how I feel about my grandbabies: I'll Love you forever, I'll Like you for always, as long as I'm living, my twin grandbabies you'll be. I am more than ready and eager to catch those curve balls.

May much joy enter all of your lives in the year 2015. That is the wish I have for all of you



this upcoming year. May it be a year filled with joy and blessings galore. Maya Angelou, in all her wisdom, tells us that "when you wish someone joy, you wish them peace, love, prosperity, happiness... all the good things." God Bless all of you!

Treasurer's Report

by Lisa Hill Nowicki

What a year! Thank you all for renewing your memberships. We ended 2014 with over \$1,700 in the black due to memberships, our FDR fundraiser, and the always generous donations. This is the first time since 2011 that our expenses were smaller than our income. Congratulations! To reiterate, our largest expenses in 2014 were the newsletter at over \$1,500, and picnic at over \$600 for the year.

Now as we look to 2015, we started our membership drive at our Oct 2014 meeting. Thank you all who have already renewed. There will be a table set up at our next meeting on March 12. Please look to the right of your name at on your newsletter mailer to see when your membership expires.



An Update on the EARS Program: SMSD's Oral Education Program

by Jessica Holst

Your child has a hearing loss and now it is time to choose a program that will best fit the needs of your family. The EARS (Educational and Auditory Resources for Sound) program at St. Mary's School for the Deaf welcomes you to begin that journey together! The EARS program teaches children ages birth-five to listen and speak through oral education. St. Mary's School for the Deaf is a nationally accredited school that has been educating children with hearing loss for over 160 years. We are excited to now provide families in the Western New York area educational options--Total Communication and now EARS, our new Oral Education program.

The EARS program uses listening and spoken language to foster excellence in communication, academics and social achievement. SMSD boasts the delivery of comprehensive audiological services in addition to individualized parent-infant and preschool programming. Our audiological clinic specializes in newborn hearing screenings,

diagnostic testing, pediatric hearing aid fitting and programming, pediatric BAHAs services, as well as pediatric cochlear implant candidacy assessment, initial stimulation and ongoing mappings. Our pediatric Audiologist maintains strong collaborative relationships with area pediatricians and ENT offices.

The EARS Parent-Infant program focuses on enhancing a child's listening and spoken language skills through natural communication opportunities. Parents are equal partners in their child's education. Together, parents and therapists develop practical strategies to encourage listening and speaking in their child. Parents receive a combination of center-based and home-based one-on-one therapy sessions in addition to weekly play groups where both parent and child are encouraged to promote social language opportunities. Current EARS families appreciate our intimate, individually-tailored approach and have felt empowered as their child's best advocate.

The EARS preschool program supports the development of listening and spoken language

through fun, play-based activities providing meaningful language learning opportunities. Weekly interaction with same-age hearing peers in the community allows our children to learn from their friends through imaginative play. Our team supports each family's educational goal, whether that is mainstreaming, partial mainstreaming or other educational placement. Parents are regularly welcomed into the classroom to support learning and fun

We would like to thank our community partners including Barnes and Noble Amherst location, Diversified Hearing and Rehabilitation Services, Music Together and the University at Buffalo Child Care Center for supporting the well-rounded, family-centered services provided by EARS. Most recently, EARS has added weekly Music Together music and movement classes for families within our program—well loved by all!

For more information, or to arrange a tour, please contact Kristen M. Cotter, EARS Coordinator at 716.834.7200 ext. 147 or kristen@smsdk12.org.

Many Thanks

Molly Anthony
Charles Baker
Sr. Kathleen Barrett
Patricia Batina
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Kathy Bucierka
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Melisa Burroughs
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Margie Fitchlee
Jean Frigioni
Marie Giovineti
Eleanor Groff
Marge Harrington
Mary Healy
Karen Hornung
Peter Hurley

Lisa Hill Nowicki
Jessica Holst
Shirley Jaskier
Joe Kolis
Pam Kruger
Will Licata
Tony Mannino
Kathleen Maroney
Gloria Matthews
Joanne Mayers
Fr. Bob McArtney
Albert McFadyen
Barbara Meyer

Paul Meyer
Chrisann Militello
Kristin Miller
Robin Miller
Diane Mogavero
Norma O'Brien
Jack Phillips
Janet Richter
Norine Rinker
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St. Mary's School
for the Deaf
Maxine Schwertfager

Joe Sonnenberg
Jimmie Sorrento
Jan and Carl Telban
Mary Thorpe
Marcia Tilney
Sue and Dan Wantuck
Karen and Mike Ward
Zenger Group
Marcia Zunner

My Cochlear Journey... *cont. from page 1*

the wait. I was not supposed to lift more than ten pounds. I was hurling hundred pound bagged luggage up flights of stairs. Then it hit me. I had the worst case of vertigo imaginable. I was so uncoordinated. I was worried that if someone saw me they would have thought I was drunk. I drove home through city streets, got into bed, and curled up into a ball until the vertigo passed. It was my own fault. I pushed it and I paid for it.

Finally the day came. Hooray! Break out the balloons and champagne! I went to 50 East North Street, where Buffalo Hearing and Speech Center is located, for my first mapping. Audiologist Joann Hammer hooked all the parts for the body processor together. Then she hooked me up. I was hearing squeaks and beeps. She asked me, "Can you hear this?" She sounded like she was part Alvin the Chipmunk. My heart sunk. Crash. What had I gotten myself into?

Joann saw that I wasn't quite my happy self. She told me to relax and that she could fix it. She did too! It wasn't perfect, but far better than it had been. My early mappings were two to three in a week. I still had problems grasping some words and sentences. Joann called in a colleague, Speech-Language Pathologist Carm Bauer. For two years I went to her twice a week to relearn how to hear. The high pitched sounds were still not there yet, but I never gave up hope with Joann and Carm. It was the start of a journey.

To me, my cochlear implant gave me a new lease on life. Prior to it, life could be a very lonely place at times. I am eternally grateful for my hearing friends who struggled with me. I'm eternally grateful to them. My mentors in the CI world are many. Shirley Jaskier's son Jeff, who is way younger than me, had more time with a CI than I had. And Jillian Kolis, who is an extraordinary young girl, had five years on me with the CI.

There were also people like Craig Carpenter and the late Ed Bastian. Those two men were deaf. They were the pioneers, and an inspiration. They knew both sides of it, the deaf world and the hearing world. They created a bridge. Then there was the late Don VanAuken. I wish I had met him in the earlier part of his life. He was a whirlwind. I was so saddened when we lost him. He was a good man who really cared for everyone around him. He was a true advocate for people with hearing loss and he helped so many people.

Now I'm waiting for the newest processor from Advanced Bionics. After almost eleven great years I'm going bilateral. I've been a member of Buffalo Implant group since becoming implanted. I have met so many dedicated people that sometimes it is overwhelming. These people really look out for others. I am also a member of the Hearing Loss Association of America. Sadly, the HLAA Buffalo chapter bit the dust, but that hasn't stopped me. I now truck down the New York State Thruway to Rochester, and joined their chapter, going on 4 years now. I'm game for more. The people I've met in person could fill volumes of notes stored in my head. I've been to three HLAA conventions and met hundreds of people like ourselves. Many of us experience similar things. For instance, forgetting to turn off the water because we don't hear it running. I know many who do this, including yours truly. There are so many things that come up that it's really comical, but you feel good when you suddenly find out that you're not the only one.

I know many people who wish to cover up their CI's and pretend as if they can hear everything. Some people even lie about it so as not to make waves. Sadly they live the great lie. More than once you get caught and you end up being a bigger fool for not saying anything. It's better to just be honest about your hearing.

So where I am now? I love my CI! I know you shouldn't really say it's a miracle. But for myself, it's the closest thing to it. My biggest wish is to have everyone who has a cochlear implant, or people who have family members implanted, help get the word out. There are still people who have never heard of CI's and what they can do. We CI users know because our lives changed. We've gone from, "What did you say?" to, "I heard you the first time!"

To all the many people who now hear, I'm very proud to be a part of this ongoing miracle. It tickles me to no end when I see or read about a very young child who was born deaf and they are getting turned on. The look on that child's face when they first hear their mother's voice is priceless. When I was in the beginning of my journey I loved watching the young kids in the playground at Buffalo Hearing and Speech Center. One young toddler was having the time of his life climbing up the slide. His CI magnet fell off. Seeing this, his teacher walked over to him to place his magnet back on his head. The kid beat her to it! Here is a 2-year-old who wants to hear! Who would want to be left out in the quiet? To me, that said it all.

I would like to thank all the people who had patience with me. I would like to thank my daughter, who never complained when I had her make phone calls for me. I would like to thank my son, who also was a great help when I needed to borrow his ears. I would like to thank all those people I worked with for letting me work, even though I could not use the taxi radio. They made me part of a great thing. I'm forever grateful to all the professionals and CI users who helped me on this journey. I never knew there was such strong dedication to make our world better for people with hearing loss. I'm humbled!

-Vincent (Jimmie) Sorrento

A Cochlear Implant Book Review

submitted by Fr. Bob McArtney

Not Fade Away: A Memoir of Senses Lost and Found By Rebecca Alexander with Sascha Alper

Rebecca Alexander is the sister of Peter Alexander, a correspondent for NBC news. She tells her story of being afflicted with Usher Syndrome which often leads to complete deafness and blindness at an early age and how she dealt with it while living a fairly “normal” life. Eventually she found some relief from her growing deafness by obtaining a cochlear implant. Many of our B.I.G. readers may be able to identify with her struggles and joys, whether they are deciding if they should receive their own implant or they have one already.

Ms. Alexander obtained two masters degrees and had an active practice as a Psychotherapist. She accomplished this despite the increasing shortcomings brought on by her disease. She became active as a competitor in sports and competed in foot racing for as long as it was safe to do so for someone with diminishing vision. Her athleticism helped her cope physically and emotionally.

She took part in “spin” classes where participants ride special stationary bikes through a workout routine led by an instructor. Recognizing her difficulty in conversing with others because of her growing deafness she learned American Sign Language (ASL). Her good friends were willing to learn ASL too, so they could communicate with her.

Ms. Alexander’s book describes well her feelings of fear and sadness, as well as her joyful and humorous moments. Her many loyal friends provided great help as her vision narrowed and faded. As if Usher Syndrome were not enough trouble in itself, she fell out of an upstairs window and shattered many bones. And at one point her parents separated,

which added to her grief. She recognized that she could not handle all this by herself. “I was the one who was sneaky, who had a disability, who didn’t do as well in school. I was the one who needed help, and I hadn’t yet connected the help I needed to my disability.” (Chap. 7; p. 31)

Eventually she would embrace what her condition brought to her life, a love of silence, gratitude for what she still had, and joy in the small pleasures of life. The author seems totally honest in describing her life, even explaining how she would steal small objects from stores as a youth.

Advice from her 96-year-old grandmother provided her with something to live by: “Nobody wants to hear you complain, so keep the bitching and moaning to yourself. Embrace the world with a positive outlook, and you will get so much more out of life.” (Chap. 17; p. 80)

She explains her social concern as she says, “I hate the idea that people may think I’m rude or insensitive if I don’t notice them. I was raised to be incredibly polite, and my entire professional life is responding to people’s feelings. But I know that I am missing things. That I could offend people by putting them off and hurting their feelings.” (Chap. 29; p.148)

A word (caution?) should be expressed about the language Rebecca uses in this book. At times she uses words that would be unacceptable in a Sunday school or even in polite society of a bygone age. Most of these words are simply vulgar and seem to fit into the ordinary dialogue of people today. Do not be shocked by even some use of the “F...” word.

As her hearing became worse she experienced what an audiologist called “head noise.” This bothered her mostly at night and took the form of sounds of someone walking on a creaky stairs or someone screaming,

and other sounds like a chorus of crickets singing in her New York City apartment. She also put up with tinnitus. She noticed also that she could no longer hear whispers.

Ms. Alexander wondered, “If I am blind and deaf, will I still be able to know and love new people? A part of me is skeptical, but then I think of Helen Keller, of how much she loved others and loved the world.” (Chap. 40; p. 199) She thought she’d be able to live without sight and hearing, but, she felt that touch with other people was essential, an important part of how she communicates. She explains how hard it is to have lost the ability to hear in a group of friends, how she misses the jokes they are telling, etc.

The author comments how people often tell her that she is an inspiration, for her zest and enthusiasm for life as well as her lack of self-pity. However she says, “...It’s the things that people don’t see or know about” such as walking down crowded city streets and taking the subway. (Chap. 41; p. 201) She credits her brother, Peter, as her best advocate and supporter.

She learned in February, 2013 that she could be a candidate for a cochlear implant. At first she felt that this was the answer; that she would be cured. She was to learn that the implant would make it possible to hear but that the sounds would not be what she remembered hearing. Clearly there was a lot to research and decide.

Ms. Alexander became overcome with sadness and began mourning for what she would lose – her natural ear. She even “apologized” to her ear for what she must do. But after months of exhaustive concern she “hoped – prayed – that things would get easier.” She thought, “That’s why I was doing this, to make my quality of life better.” (Chap. 50; p. 266)

On the day when her implant was “turned on,” as she put it, she

continued on page 11

B.I.G. Fundraiser a Huge Success

by Gail Cronin

On Saturday, November 15, 2014 our organization sponsored a fundraising event. The program was a performance of "An Afternoon with FDR" by local actor Albert McFadyen, which was held at St. Mary's School for the Deaf. Mr. McFadyen, who is the brother of our current Vice President Margie Fitchlee, donated his time and talent to us at no charge. In addition, St. Mary's School for the Deaf allowed us to use their assembly hall without cost. Thus, 100% of the ticket sales and concession sales, as well as additional donations from our patrons, will go the support the Buffalo Implant Group. Over \$1,200 was raised at the event.

The program was heavily advertised through all free sources that could be obtained by our hardworking board members and officers. Margie Fitchlee, Melissa Burroughs, and Lisa Hill Nowicki put in countless hours in advertising arrangements and ticket sales. The majority of the patrons in our audience were Western

New Yorkers who were not associated with our organization. Margie Fitchlee spoke at the beginning of the program to inform the audience of our mission and thank them for their support. Sign language interpretation was also provided.

Mr. McFadyen's performance was awe inspiring. From the moment he arrived via wheelchair, he embodied the character of President Franklin Delano Roosevelt. His demeanor and voice were uncanny. He performed for over 90 minutes, with a brief intermission, as a one man show. With the assistance of B.I.G. member Carl Telban, "FDR" transitioned from wheelchair to podium, to chair in historic fashion. The performance included audience interaction and songs as well, and was followed by a question and answer period.

It was apparent from the audience's laughter, responses, and singing along that they truly were enjoying the performance. Many people lined up to speak to Mr. McFadyen personally



after the show. I would urge anyone who missed the performance to seek out other opportunities to see Mr. McFadyen perform this role in other Western New York productions.

Much thanks go to all the members of B.I.G. who volunteered before and during the event to make it a success, to all who attended and provided us with support, and especially to Albert McFadyen for sharing his remarkable talent so generously with us.

Support BHSC It's Groovy!

Buffalo Hearing and Speech Center will host their annual Good Vibrations gala fundraiser on Saturday, March 14 at the Hyatt Regency Hotel starting at 6 pm. The psychedelic 60's event will conclude with a midnight fireworks display. For tickets and information, contact BHSC at 885-8318 or www.askbhsc.org



Our Next B.I.G. Meeting and Social

by Gail Cronin

The Buffalo Implant Group will be hosting a panel of adult cochlear implant users at our next B.I.G. meeting, who will share their stories and answer your questions. The panel will represent devices by all manufacturers and will include unilateral CI users, bilateral CI users and bimodal (CI and hearing aid) users. Speech-Language Pathologist Jessica Holst will serve as moderator.

Please Join Us

Wednesday, March 11, 2015

6:00 – 8:00 pm

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

The meeting will be held in the lower level conference room. Limited free parking is available in the lot behind the building. Sign Language interpretation and CART transcription will be provided.

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. A 50/50 raffle fundraiser will take place, and the officers will be available to accept your 2015 dues.



Meeting Report *by Gail Cronin*

Our last general meeting was held on Wednesday, October 29 at St. Mary's School for the Deaf. Thirty five members were in attendance. Sign language interpreting was provided by Kristin Miller and Barbara Meyer and CART reporting services were provided by Chrisann Militello of WNY Court Reporting Services.

Our members enjoyed pizza during a brief business meeting conducted by President Sue Wantuck. Announcements about upcoming events were made, a treasurer's report was given, and suggestions were taken for future meetings. Officers for the 2015 year were all running unopposed, so a formal election

was not necessary. Sue Wantuck will continue as President, Margie Fitchlee will become Vice President, Lisa Hill Nowicki will continue as Treasurer, and Melissa Burroughs as secretary. At the meeting Lisa and Melissa also manned a table to collect dues for the 2015 year. There were multiple door prizes provided by Sr. Dorothy Feltz, and she and Marie Giovinetti organized a 50/50 raffle which raised \$42 to our organization.

Sue then welcomed our guest speaker, Pam Kruger from Advanced Bionics. Pam gave us an update on the technology and connectivity of AB devices. We heard about the Naida CI Q70 and the Universal Headpiece available for it. Pam

discussed the various battery options including rechargeables, zinc air buttons, and AAA in an extra power pack. For people with binaural CI's there is new Binaural Voice Streaming Technology. We also had an opportunity to look at the latest in remote controls. In addition we were introduced to the new Neptune swimmable sound processor as well as the Aqua Mic and Aqua Case. Pam also updated us on telecoil use and FM system compatibility.

Following the presentation we enjoyed birthday cake in honor of our board member Gloria Matthews, thanks to Jimmie Sorrento. Additional desserts were also provided by our members, and we all enjoyed some social time before the evening was through.

PARENTS' CORNER: *Do you know what a Hearing Loop is?*

by Lisa Hill Nowicki

I recently read an article entitled "Hearing Loop Technology" by Juliette Sterkens, AuD, published by the AG Bell website. It is about David Myers, a professor of psychology, who while travelling in Europe was able to hear the minister loud and clear in an 800 year old Scottish abbey due to a "hearing loop." After using this technology that is common in the United Kingdom, Mr. Meyers returned home and had a hearing loop installed in his house. This got me to thinking that we should consider this for our own home for our daughter Sienna, 10, who was diagnosed at a very early age with Auditory Neuropathy, a form of deafness as a result of Kernicterus, where sound travels to her cochlea but does not reach her brain properly either due to an issue with her inner cochlear hair cells or the eighth cranial nerve. As a result, Sienna wears two hearing aids and either has to have the TV very loud or she wears Sennheiser headphones, that until recently only worked on our "old" TV but will now work on a flat screen with a connector cable.

So, what is a hearing loop? A hearing loop transmits the audio,

through magnetic energy, directly to the telecoil in a hearing aid or cochlear implant sound processor. The loop can be one simple loop of wire (or an array of looped wires) which surrounds a seated area, a meeting room, the back seat of a taxi cab or a check-out counter. The listener in a loop hears the speech signal at a much improved signal-to-noise ratio, which reduces the work the brain of the listener must do in order to comprehend the speech. The telecoil in the hearing aid or cochlear implant receives the sound without any background noise, reverberation or distortion. To hear the signal from the public address system (the TV or the microphone) wirelessly in a hearing aid or cochlear implant, the hearing device must be equipped with an activated telecoil (also known as T-coil or telephone switch). Fortunately, all cochlear implants and most behind-the-ear hearing devices recommended for children offer the telecoil option. In order to hear in a loop, the telecoil or "T" program in the hearing aid or cochlear implant needs to be activated. If the hearing device is set to "T," the device's microphone is

turned off. This means that your child would only hear the signals coming through the loop. In order to hear environmental sounds as well as the signal coming through the loop, such as TV signals, ask your audiologist to program a microphone plus telecoil or "M+T" setting, rather than a T-coil only setting. This will facilitate conversation with your child as he or she listens to TV through the loop.

After consulting with our very knowledgeable neighbor who works for Ronco Specialized Systems (a privately held company here in WNY that specializes in communication platforms), he stated the cost would be around \$200 to loop our living room by running the loop in the basement just below the living room. Having recently updated Sienna's hearing aid to the "T+M" setting (since we were having issues with the FM system in school) we have a Sarabec Loop System LA215 to test over the next few months. So stay tuned for our article in the Spring issue of The B.I.G. News, where we will discuss setup and Sienna's impression of having the living room "looped."



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A Cochlear Implant Book Review... *cont. from page 8*

explained the scene. "The room was silent as she turned it on, and the first sounds started to come through. I couldn't tell yet what I was hearing. I felt a pulsing like I would during a hearing test; it was as though I could both hear and feel the reverberations from the side of my head. Laurel (her audiologist) and I were signing to one another as she sent me tones, which all sounded high and eerie. Then she spoke: 'We're on. Can you hear me?' It was shocking. I felt as though I had just unknowingly walked into a room full of people who'd yelled, 'Surprise!' and my brain was trying to catch up with what was happening." (Chap. 52; p. 271)

She goes on to explain her efforts to make sense of the new type of sound she was hearing but she acknowledges that what she hears is much more crisp and clear than her hearing aid had been. She muses, "I have found so many times that

there is no way to accept pain and sadness other than facing it head-on and allowing myself to feel it. I don't think most people can really move on unless they do that." (Chap. 54; p.281) She adds, "I do think that, for most of us, it's a choice. We can learn to accept the ebb and flow of life, that we wake up in a dynamic body every day, one that is also cyclical and ever changing. Some days, mine can feel different from hour to hour. I'll wake up sometimes thinking, Hey, I can see pretty well, and by nighttime I feel as though I can't see a thing. My implant will seem to really improve things one day, and the next I'll be asking, 'What?' all day. I have to accept it, because without acceptance I can't live in the present." (Chap. 56; p. 293)

Note regarding this book: I found this book of great interest even to one who hears fairly well for an "old-timer." The 58 chapters are mostly

short and written in a way that teases the reader to want to continue reading. While I cannot speak as one who has received an implant, I believe this book should hold interest both for those who have a cochlear implant, reminding them of their own experiences, and might provide an in-depth guide to those who may choose to have an implant in the future.

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