



THE B.I.G. NEWS

BUFFALO IMPLANT GROUP

COMMUNICATING ▶ SHARING ▶ COUNSELING ▶ SUPPORTING

UPCOMING EVENTS

B.I.G. Picnic	Sept 17
DAW	Sept 18-26
Walk4Hearing	Sept 25

INSIDE THIS ISSUE

Lou Ferrigno - The Bionic Hulk	Page 1
President's Corner	Page 2
From the Editor	Page 2
Mourning Our Friend Steve Mogavero	Page 3
Rest in Peace Sr. Linda	Page 3
Separating Dues From News	Page 3
B.I.G. Award Scholarships	Page 4
Deaf Awareness Week	Page 4
Trying Times	Page 5
School	Page 5
Treasurer's Report	Page 5
Diary of a Bionic Listener	Page 6
New Roles, New Responsibilities	Page 7
Buffalo Walk4 Hearing 2021	Page 8
Movie Review	Page 8
Enjoy Your Time in the Kitchen	Page 9
Many Thanks	Page 10
Picnic Alert!	Page 10

MEETING NOTICE:

Sunset Dinner Picnic
Friday, September 17
5:00 – 8:00 PM
Westwood Park, Shelter #5
175 Pavement Rd., Lancaster

Lou Ferrigno – The Bionic Hulk

By Sean Cronin

Lou Ferrigno, actor and lifelong role model for people with hearing loss, has received a cochlear implant at the age of 69. Well known for being the first person to portray the character of The Hulk in the 1977 television show, Lou Ferrigno has been open about his hearing loss for his entire life. Ferrigno had lost 80% of his hearing by the time he was 3 years old and began wearing hearing aids at age 4. He took to comic books as his main entertainment as a kid, which inspired him to become as strong as the heroes he read about.

Lou Ferrigno went on to win the International Federation of Bodybuilding and Fitness (IFBB) Mr. America Bodybuilding competition right out of high school in 1969. He would continue his bodybuilding journey up to the IFBB Mr. Universe competition, which he won in 1973 and 1974. That year he also came in second place at the Mr. Olympia competition and trained with bodybuilding champion Arnold Schwarzenegger until coming in third place the following year. He would follow up this storied and staggering career as a bodybuilder with several acting roles. Speaking roles were difficult for him, but he found his most iconic role as The Incredible Hulk, which premiered in 1977 and ran for five seasons. While Bill Bixby portrayed the mild-mannered scientist David Banner, it was Ferrigno's role as the titular and superhuman Hulk that cemented the show's place in entertainment history. This iteration would go on to influence nearly every future version of the character, with Ferrigno having a cameo role in the 2003 Hulk film, as well as in 2008's The Incredible Hulk. He also voiced the Hulk in that film, as well as having his voice composited with that of actor Mark Ruffalo to produce the Hulk's voice in The Avengers and its sequel, Avengers: Age of Ultron. Ferrigno was also known as the physical trainer for Michael Jackson from the early 1990's up until 2009.

At 69 years old, Ferrigno decided that he wanted to increase his access to sound and chose to receive a cochlear implant. In February of 2021, he underwent the surgery to receive the Cochlear™ Nucleus® Profile™ Plus Implant. The implant was turned on in March of 2021. Ferrigno reported that after just 6 weeks of using his cochlear implant, his word discrimination increased from 20% to 66%, and he believes it will continue to better with time and practice. Ferrigno has described his immense joy at hearing his wife for the first time, who was able to whisper to him from 50 feet away. He is very much looking forward to hearing the cries of his new twin grandchildren as well.

While still training and going through hearing therapy, he described the process like his exercise routines. "The more you put into it, the better it is."



Lou Ferrigno has been a great role model to kids across the world, but he has been especially inspirational to kids who have hearing loss. B.I.G. member Sienna Nowicki and her twin brother Gunnar had the privilege of meeting Lou Ferrigno in 2013, when they were nine years old. Their uncle, pop-culture artist Shad Nowicki, is a friend of Lou Ferrigno's and has painted his portrait as The Hulk.

To learn more about Lou Ferrigno's journey, you can follow him at @LouFerrigno on twitter, and at theofficiallouferrigno on Instagram.



President's Corner

By Sue Wantuck



Hello Everyone,
It feels so good to be back! The Board met in person in June, for the first time since the COVID-19 pandemic began. It was so nice to see everyone again! I am looking forward to our first in-person

general meeting as well, which will be our annual picnic on Friday September 17, 2021. Please see the "Picnic" section for further details and RSVP information. I hope that this message finds you, your family and friends safe, healthy, and happy. This past year has been challenging in many ways and even devastating for some of our members who unexpectedly lost loved ones to the disease. COVID-19 has truly impacted everyone differently and I just want you all to know we are here for you! Do not hesitate to reach out if anyone is

in need. As we all try our best to return to "our new normal" we must do it together and support one another.

My mother passed away during the pandemic but she did not die of COVID-19. My last hug with her was on March 11, 2020, right before her facility was put in lockdown. I tried to explain to her what was happening and why I couldn't visit in person, but it was hard to understand and accept. She began to deteriorate rapidly due to the lack of physical contact/interaction with her loved ones. We visited her through the window, something I truly never imagined I would be doing, but it wasn't the same or enough. By October 2021, my brother and I agreed to take her out of the assisted living facility and drive her to Georgia where my sister lives. She spent the remainder of her life there before she passed away on Sunday, January 10, 2021. I am thankful for our decision, and for my sister taking her into her home. Losing my mom was very emotional and hard for me. Our bond and friendship was strong. She was always my best advocate and cheerleader, encouraging me

to follow my heart, passions and interests and not let my hearing loss get in the way. I miss her dearly and think of her often.

While I do support the right of choice "for" and "against" masks, you have to know that this has been a huge detriment to individuals with hearing loss with regards to communication. I rely on people's full faces, mouths, expressions/gestures to get the whole message. On almost all occasions of interaction I explain to people that I am deaf, and kindly ask them to remove their masks while speaking with me. Some people have been respectful and agreeable, while others not. If you have stories to share about masks, COVID-19 in general, or what you have been up to I strongly encourage you to write something and submit it to the newsletter. We are always looking for people to share their personal experiences and life happenings.

I look forward to seeing many of you soon and hope that you are enjoying the warm temperatures and sunshine! Stay well and take care!!

From the Editor

By Gail Cronin



Hello old friends!
It has been a long time. When I wrote to you in our last issue of The B.I.G. News, way back in March of 2020, none of us had any idea how our lives were about to change. Buffalo Implant Group had three events in the works, and all had to

be cancelled. With no events to promote or meetings to hold, there was no B.I.G. news to tell. Even our Board meetings were suspended for over a year. Although many of us were able to connect with one another via email, not everyone on our Board has computer and/or Wi-Fi access, so we couldn't all meet online. Prior to being vaccinated, several of us were not comfortable meeting in person without masks. The reality is that people with hearing loss usually need the additional visual cues that speechreading provides in order to fully communicate.

Our Board resumed meeting in person this summer and we have been quite busy. I hope that you have all either received our email blast or checked our website and are aware that we have a picnic set on the calendar for Friday, September 17, 2021. All the details are in this issue. Our picnic is normally held at the end of July or the beginning of August. Because we had to start the planning way back in February in order to reserve the shelter at Westwood Park, we made the decision to postpone the picnic until more members potentially had an opportunity to get fully vaccinated. Back in February, we had no idea how long it would take for people to be eligible for vaccination, let alone actually get a vaccine. Because, if you remember, back in February it was very difficult for even those who were eligible to get an appointment for a vaccine. My son and I had to wait for weeks and drive all the way to Rochester to get vaccinated, after finding appointments

online in the middle of the night. These days you have lots of choices of where to get vaccinated, all over town, and no appointments are necessary.

In addition to our planning for the picnic, we have also been in discussion about how to proceed with our newsletter and how to transition it to an online format of some kind. We are exploring many options. The first step to making any changes to our newsletter involves amending our by-laws. That will be up for a vote at the picnic. There is an article in this issue that spells out the details.

At this time we would love to plan more meetings and events, but it seems as if we are not quite able to exit this pandemic roller coaster ride just yet. With the increase in local cases and the rise of the Delta variant, we are not certain when we will be able to have indoor meetings without masks or what facilities are ready to host us again. Please check our website for any updates. In the meantime, if you have any ideas for outdoor meetings, please let the Board know.

Personally, I've gotten quite used to socializing outdoors this year, even in the winter. Last autumn, my husband and I invested in some new porch furniture (to make use of every inch of outdoor space), electric blankets, and outdoor propane heaters plus a couple of extra tanks. We found that we could get together with friends on outside on our front porch in temperatures as low as 27 degrees and still be quite toasty. I spent many evenings out on that porch last winter with someone who I met through this newsletter. Over the last year and a half, I became very close to Jeanette Berry, who used to do the layout for us at Zenger Group printers. The pandemic brought us closer together than ever before, and she has become one of my dearest friends. Another way that our family adapted to socializing outdoors was by having outdoor movie nights. My husband and I bought a fire pit, a movie projector and an outdoor screen, so that we could have other families over in the driveway to watch a show or play a video game and project it on the screen. That is how my family and I were able to get together with Gloria Matthews and her son Mike, even before we

were all vaccinated. Our kids experienced a lot of social isolation this past year, and these get togethers made a huge difference. My daughter Maeve would light up when Mike came over. They would talk non-stop, even during movies. It is my hope that we can all come up with some creative solutions like these to ensure that we can get together with one another safely in the coming months, until this pandemic is behind us. Please be assured that B.I.G. is still active and is not going away. We may not be meeting as often or in the same way as before, but we are looking forward to a time when we can resume our regular get-togethers, indoors and out.

This issue is packed with bits of news; some good news, some sad news. A few of our Board members shared about what is new with them. Also in this issue is Part 2 of Sam Spritzer's blog, which is a continuation of our cover story from the last issue in 2020. And speaking of cover stories, our cover story for this issue had an interesting evolution. My husband and kids are huge Marvel Comics fans. And my husband, who grew up in the 1970's, was enamored with The TV series *The Incredible Hulk* as a kid. When I complained to him recently that I didn't have a cover story for this issue, he suggested we cover the story of Lou Ferrigno, the original TV Hulk, getting a cochlear implant. I was completely caught by surprise, as I had no idea that Lou Ferrigno had received an implant. My son Sean, who follows Ferrigno on social media, volunteered to cover the story. Only later, when I mentioned this to B.I.G. Treasurer Lisa Hill Nowicki, did I learn that Lou was a friend of Lisa's brother-in-law Shad Nowicki and that she had photos of Lou with her kids and with Shad's artwork. Lisa shared two of those photos with us in this issue. What a fantastic connection!

I hope to see you all at the upcoming picnic on September 17. It should feel like old times, but maybe just a little bit more spread out. We are going to do our best. If you have any questions or concerns, just reach out to one of the Board members. I can be reached at gdcronin@roadrunner.com and would love to hear from you.

We Mourn the Loss of Our Friend Steve Mogavero



The Buffalo Implant Group lost a great friend on February 23, 2021, when Steve Mogavero, husband of Diane Mogavero, passed away from COVID-19. Steve often attended meetings with his wife and was always willing to step up and help us with anything we asked of him. In 2018 Steve was one of our guest speakers at a panel discussion of couples in which one partner had a hearing loss. Our hearts are with Diane, their children, and their grandchildren. Steve was a kind man with a great sense of humor, and we miss him very much.



Rest in Peace, Sr. Linda



Our dear friend Sr. Linda Glaeser, SSJ, passed away on March 26, 2020 after a year-long battle with cancer. Sr. Linda came to know B.I.G. through Sr. Dorothy Feltz, both members of the Sisters of St. Joseph. Dedicated to a life of prayer and active service, Sr. Linda was a nun, a physical therapist and a founder of the charitable organization Future in Our Hands - USA, which assists the people of Kenya in digging wells for clean drinking water and providing children with education. Sr. Linda regularly attended our B.I.G. Picnic each year and helped with our Basket Raffle. She would always buy tickets for our raffle to support us and when she won children's items, she would quietly give them to the children in attendance. Sr. Linda was a generous person who always lifted others up. Sr. Linda is greatly missed by all those who knew her and loved her.

Separating Dues from News

By Gail Cronin

Throughout this last year and a half, as we have dealt with the COVID-19 pandemic, we have all found ourselves relying on technology more than ever before. People are working from home. Meetings are held over Zoom. Children have "attended" school remotely. And just today, my husband learned that an upcoming convention that he was scheduled to attend in Texas has been cancelled and is being replaced by a virtual convention instead. This has only reinforced for several Board members what we have been thinking for a few years now. It is time to transition our newsletter from a print format to some type of digital format. We are not certain of the details yet, but in the coming months that will be worked out. We are considering perhaps one print version per year and a few digital versions. Or perhaps we would have an entirely digital newsletter that is smaller, but is produced more frequently. Transitioning to a digital format, either in part or entirely, will be a tremendous cost-saving measure for our organization. If you have an opinion to share about how our newsletter should be produced and distributed in the future, please email us or speak to any Board member.

You may recall that in 2019 we officially changed our by-laws to reflect that The B.I.G. News would decrease from 4 issues per year to 3 issues per year. In retrospect, I wish we had gone further and made other changes to our by-laws at that time. The way the by-laws are written, your B.I.G. dues are in fact a subscription to our printed newsletter. We must re-write this so that it is clear that paying your dues makes you a member, not just a newsletter subscriber. In essence, we need to separate our dues from the publication of the news. This will allow us the flexibility to re-

imagine our newsletter to better fit the digital age.

This potential change cannot be made without the approval of our membership. At our upcoming Sunset Dinner Picnic on September 17, we will be taking a vote to amend our by-laws so that dues are no longer the equivalent of a newsletter subscription. All current members will have an opportunity to vote yes or no. If you are not planning to attend the picnic this year, but would like to voice your opinion with your vote, just email me at gdcronin@roadrunner.com and I will record your vote. We must make this decision now because we are not certain at this time when and where we will be meeting in-person again. We hope to resume some regular meetings in the coming months, however indoor meetings may be affected by the COVID-19 pandemic. The fact remains that most of our members have difficulty communicating when everyone is wearing masks. Indoor mask guidelines may cause us to limit or postpone our winter meetings. A partly digital newsletter will make it easier to keep in touch with you all in the event that we have to postpone indoor gatherings again.

Regardless of how the newsletter will be produced and distributed in the future, it is my intention to step down from being the editor. I still plan to write articles and be involved, but I think that it would be beneficial for our entire community to have other voices take the lead. There are also more tech-savvy members who could better transition us into a digital format. Gloria Matthews is exploring digital publication options now. She and I will be working with the entire Board to ensure that the newsletter continues in some capacity. Please feel free to email either of us with your thoughts.

B.I.G. Awards Scholarships to Two Students

Each year, Buffalo Implant Group awards a \$500 scholarship to a college-bound graduating high school senior. Due to the COVID-19 pandemic, the scholarship recipients for 2020 and 2021 could not be presented with their certificates and checks at a B.I.G. meeting, and there hasn't been a newsletter to announce the recipients until now. The B.I.G. Scholarship Committee selected Elise Watson to receive the B.I.G. Scholarship in 2020. During the early pandemic shutdown, the certificate and check were presented to Elise by B.I.G. President Sue Wantuck at Elise's home. More recently, the Scholarship Committee selected Jonathan Allen to receive the B.I.G. Scholarship for 2021. Sue Wantuck presented the award to Jonathan at St. Mary's School for the Deaf. Below are their submission essays.

B.I.G. Scholarship Winning Essay for 2020 I Can't Imagine Living Without My Implants By Elise Watson



I can't imagine living without my implants. They have helped me recognize the noises I thought I'd never hear. Cochlear implants have had a huge impact on my language because I hear people talk and catch on learning words and popular phrases.

When my twin sister and I were born, I was really sick. It got to the point where doctors told my parents I could die. Fortunately, I survived. The medication my doctor had given me made

me become deaf. At six months old, I started wearing hearing aids. Then my parents decided that I should get a cochlear implant because I wasn't responding to any sounds. I had surgery and was implanted on my left side. When I was ten years old, I decided to get another one because of the benefits.

Cochlear implants have helped me with the development of communication and furthered my education. I can hear animals' sounds and people talking, which helps me retain. Communication is the key as my family does not sign. My implants have helped me hear them, understand them, and feel a part of my family.

I have had so many accomplishments because of my cochlear implants. They help me focus on driving and made me more aware of things going on around me. Also, they will allow me to hear in need of help.

Thanks to my implants, my language development improves daily. I love having cochlear implants. They're awesome!

B.I.G. Scholarship Winning Essay for 2021 BAHA Abutment and How It's Helped Me By Jonathan Allen



I am a student at St. Mary's School for the Deaf. I have been a student here since I was 2 years old because I was determined to be hard of hearing. I am diagnosed with bilateral microtia, which is when both ears have undeveloped external ear canals. When I first got my BAHA's it was a life-changer for me, and more so when I got them implanted. My audiologist has told me I hear things that are almost silent. I can have conversations so much better now because I can understand the volume of things

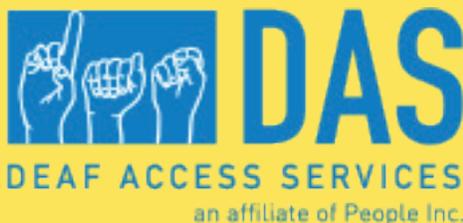
around me.

I haven't had this surgical implant for too long. I'd been using a headband for the last fifteen or so years of my life and as of recently I couldn't see myself using it anymore. It indents the skull, and causes frequent headaches. I was starting to feel self-conscious about it and how I looked as well. I was outgrowing the look and feel of the headband.

With my new device, I am very happy. The headaches are gone and I'm comfortable both physically and with how I look appearance-wise. I actually think it's quite funny showing people. I'm close to the open screw though I am still a bit conscious about it, and I'd probably be afraid of infections if I wasn't as resilient as I am. Honestly, I wished I'd gotten this surgery a long time ago. I'm very excited whenever I get to use my hearing aids again and I can't remember how long it's been since I've felt that way. Perhaps since I've gotten the BAHA 5's, which were a huge improvement processor-wise compared to the 4's.

I'll close by repeating that I'm glad I got the surgery. It's always been in a bad light for me, so I never considered it until I got really desperate recently. It seemed scary, to have even a chance to lose your hearing and when I thought about my friends who'd gotten cochlear surgery who couldn't hear without them on it was out of the question. But I'm happy I did it. I can hear and feel great. I'd honestly have gotten it sooner if COVID hadn't hit right as insurance approved it. Thank you for reading, and I hope you consider me for your scholarship.

Deaf Awareness Week



Deaf Awareness Week is returning in 2021. This will once again be a weeklong celebration recognizing the Deaf, DeafBlind, Hard of Hearing and Hearing Loss community. Deaf Access Services (DAS) is currently finalizing several events during the week of September 18-26, 2021 to bring people together and educate the hearing public about deafness and hearing loss. Details were still being finalized at press time, but you can get up to date information directly from DAS at wnydass.org

Trying Times

By Margie Fitchlee



These words stand out in my mind. “Trying times are for trying.” I have forced myself to do just that. If ever we were confronted with “trying times” I would have to say that it is now. It has been since the Pandemic took over our lives last March.

Making the best of these times at home has been a challenge, but also a number one goal for me and I suspect it has been for you too. Adapting and keeping a positive outlook are the key words that I live by lately. Reinvent the wheel. I have done it before when I lost all my hearing. I can do it again! The life we were so accustomed to before has been taken away from us. The “new normal” reigns. It has been said many times before, that “this too shall pass.” With much of the population now being vaccinated we can finally start to resume a more normal life. Let’s hope that this situation continues and that our lives will get back to normal, sooner rather than later.

The summer has almost flown by and all my family birthday celebrations are over for another year. For the most part, all of our doctors appointments have subsided too and what I call our “maintenance program” is still in full swing. I have been “trying” to live

a healthier lifestyle these last several months and I am finally starting to see that it is paying off. Watching what I eat, walking and riding my bike, and trying to cut stress out of my life has kept me very busy.

I also find comfort in reading the words of others. Brittany Moses tells us, “You have to stop thinking that you will be stuck in your current situation forever. We feel like our hearts will never heal, or we’ll never get out of this impossible struggle. Don’t confuse a season for a lifetime. Even your trials have an expiration date. You will grow, life will change, things will work out.”

So I say, “keep trying.” Keep forging on, and most of all, keep the faith. I think of my mother, whom I considered a very strong woman, and wonder what she would think of all of this. Would she have been able to handle all of this? I know without a doubt that she would, for she lived through so many “trying times” herself.

We all know that time flies, that life goes on and that passing the time at home will some day be a memory for us. Maya Angelou is a woman I look up to for hope and inspiration. She tells us that, “No matter what happens or how bad it seems today, life goes on and it will be better.” Before I know it, I will be passing my time at home at my happy place on Eagle Bay Court in South Florida. I am so looking forward to that. God Bless!

School

By Lisa Hill Nowicki



Every parent worries about how successful their child will be in school. However, add a hearing-impaired child and remote learning due to COVID-19 and then you had my life as a parent during the 2020-2021 school year.

In my daughter’s IEP, I require a monthly meeting during the school year with her teachers to gauge how she is doing. I usually take the first meeting

to explain her diagnosis and her personality. This is very important because over the years I have discovered she has learned how to “play” the system. However, more importantly, as the school year progresses, I find this one of the few opportunity teachers have to collaborate with one another and focus on just her for one hour each month. I enjoy hearing how she is interacting with her peers, what she has tried to get away with and what successes and struggles she is facing.

This past year however, like so many others, threw my routine out the window. I questioned how our household was going to adapt

with two kids learning remotely while I still worked from home. I was especially nervous about how my daughter would do without her FM system and not being in the front row of a classroom to read her teachers’ lips. Would she hear them through the computer and understand the assignments? Would she ask for help? Not to mention the social side by not interacting with her peers in person. Ironically, I did not have these worries for my son. Boy, was I wrong! My daughter ROCKED IT! I still had monthly meetings with her teachers via GOOGLE MEET where I learned that she was the first to join her online classes, participate in the lectures and complete her assignments. She learned how to make “to do” lists and budget her time. Her brother, on the other hand, who had always been a straight “A” student, struggled. Remote learning highlighted his procrastination and lack of follow through in confirming that his assignments were posted for grading.

As we prepare for this school year and what is in store, I am in a much better place. I am reminded not to pre-judge. My daughter has shown me she has the skill set needed for college. My son continues to mature and has been reminded of what he must work on to have a successful year. Let the school year begin!

Treasurer’s Report

By Lisa Hill Nowicki

Hello everyone. I hope this note finds you healthy and happy. Due to COVID-19, the Board made the decision to extend everyone’s dues up to the date of 2021. For those of you who have continued to send your dues in during this past year plus ... THANK YOU! I have applied your dues to 2022. I will have a sheet at the picnic on September 17 if you are interested in knowing where you stand with your dues.

Going Bilateral - Diary of a Bionic Listener Part 2

By Sam Spritzer

Editor's Note: The following is a continuation of Sam Spritzer's story, which was printed in our last issue in 2020. This article contains his blog entries during the time when he went from being a unilateral cochlear implant user to a bilateral cochlear implant user in 2007. The content was edited due to space constraints. You can read more about his journey at www.samspritzer.com

The good and the bad

MARCH 12, 2007

One of my readers wanted to know if I have good days and bad days. And, if the growth in hearing ability is consistent, or does it come in waves. Since the CI is a major improvement over what I had, it would be hard to say I have bad days but I do have them. So, a good day would be considered as not having a bad day. And an exceptional day would be considered as something new, which hasn't happened too much over the last couple of weeks. On some days, the tinnitus, louder than others. But this is due mostly to lack of background noise which does a good job masking. The background noise can be both a good thing and a bad thing. Background noise to me is sound that I am not expecting. It can be as pleasant as the clicking of keyboards to as loud and abrasive as Vic's blowing his nose, two cubicles away. Another bad day can be where I have excessive facial twitching due to over stimulation. It doesn't really bother me as it's something that I expect although my audiologist does not want me to let that happen. Maybe it's because I have a high tolerance for pain and torture! In any case, it needs to be dealt with in order to avoid causing damage to the facial nerve. The growth in hearing ability will come to any newly implanted person in waves before subsiding and then coming in spurts. Most of the time, you don't realize it unless you are thinking about it. For example, last week I was trying to figure out why certain voices were more difficult than others so that I could describe the difficulty. It just didn't dawn on me that the trouble I was having with "Ahhhhhhh" was there all along - I just wasn't consciously aware of it. Tomorrow is another mapping session. At this one, we will be trying Fidelity 120 which people have said is an improvement over the Hi-Res strategy I currently have. I still haven't grasp what the difference is so that I can explain it to you but perhaps after tomorrow, I can.

Minor Setback

MARCH 13, 2007

With today being mapping session #4, it turned out to be somewhat of a minor setback. I was hoping to upgrade to Fidelity 120, a strategy that is supposed to be a more natural improvement over the Hi-Res version I am currently using. Instead, Michelle and Joanne tirelessly worked through an hour of tweaking, in an attempt to eliminate the involuntary facial twitching I was getting. This is due to my facial nerve being very closer to the electrical field of the implant. It's rare but it can happen. Guess it had to be me. Bummer! First, we tried turning each of the electrodes (there are 16 of them) on and off. We were able to isolate the twitching sensitivity to one of the electrodes so instead, a limit was placed on how strong it can fire. But still, certain sounds such as hands clapping were causing the twitch. Not that I can avoid situations that may possess a problem or lower the volume, but it is absolutely important that we eliminate anything, absolutely anything, that can cause the twitching. If I don't address this problem now, it will get worse and possibly irreversible. I do have to say that both Michelle and Joanne are so very dedicated to their work. While Michelle was doing the tweaking, Joanne was on the phone with Advanced Bionics. And the consensus was to lower the volume and give the nerve a chance to quiet down. At the same time, I am back with "Old Faithful" in my left ear at least until the next mapping session which is March 22nd. The idea was to let the left ear take some of the pressure off of the implanted ear. After a couple of hours, it actually sounds so good I might keep it that way. At least until I get my left ear implanted.

CI reflections

MAY 20, 2007

Not much has been happening over the past couple of weeks CI-wise. So, I thought I would take this opportunity to reflect on the past and what the CI has meant to me, thus far. To refreshen, the implant date was Jan. 12th and the activation date was Feb. 6th. It is without a doubt the CI has made my life much easier and open. Easier as in not having to strain to lip read others as my hearing aids were slowly becoming useless and, open as in not having to shy away from conversations. The CI has given me a sense of confidence in knowing that a conversation or meeting is not going to be a lot of "what" or "can you repeat what you said" or relying on others. It has been a lot of work and a large amount of effort. Some of which is required on my part but for which I have not been following through on such as practicing. There is only so much time in a day. I am supposed to have speech therapy twice a week, but this has been cut back to once a week. Have I been procrastinating? Maybe. Am I determined? Always! Conversations with those around me, family and co-workers have definitely improved. So even though I have not been practicing as much as I should, the improvement is there; it's just taking a little longer.

I recently upgraded the software to Fidelity 120 (see Upgrade). Sounds are becoming more clearer and crisper and each day brings a subtle yet sub-conscious improvement. Even the spoken word is becoming more distinguishable as I am able to differentiate between like sounds such as "sh" / "ch". The only thing is to be careful not to start the day out at too high a volume which might provoke facial twitching...a no-no. The telephone remains a mystery, but the expectations are for that to happen sometime at the end of this year, possible next year. After all, the brain is a complex structure. No one understands it enough to be able to accurately predict when I will be able to use the phone, unassisted. With that, low expectations - high hopes. Am I pleased? Definitely! Am I happy with the results? Well yes...but I want better (patience prevails). Was it worth it? ABSOLUTELY! And to elaborate, I am going for an evaluation at the end of the month to do the other ear sometime at the end of this year.

CI Updates - Going bilateral!

MAY 31, 2007

Today, I visited Dr. Diaz-Ordaz's office for the express purpose of taking the steps necessary to have the other ear (left) implanted. While I originally considered the cochlear implant last year, Dr. Diaz-Ordaz and I were discussing whether to do both at the same time or only one. It was then decided that we would do the right ear since it was my worse and I had "nothing to lose, everything to gain". I don't regret making that decision because I think it would have been more difficult to get used to the implants in both ears rather than one at a time. This proved to be the case when I found the hearing aid in my left ear to be more of a distraction instead of being an assistance to the CI in my right ear.

Anyway, the visit was rather routine, and a script was written for me to be evaluated at Buffalo Hearing and Speech. We did discuss the issue of the facial twitching I was experiencing and Dr. Diaz-Ordaz explained that he now grafts a piece of bone to keep the electrode array away from the facial nerve. He did indicate that he has been having success with doing this and this was also confirmed by the audiologists. In addition, by going bilateral I can reduce the dependency on my right ear and lower the volume to a point where the twitching is a non-issue. Assuming my insurance company approves, I'll probably schedule the surgery for January, 2007. In the meanwhile, a few more "CI moments" - hearing the birds and especially the \$%@\$# Canadian Geese that love to paint anything in their path, green. I am also hearing the planes take off from the airport nearby; Vamoosé's meowing; the rain (when it rains which has been happening pretty sparingly this spring); the rustling of the leaves in the wind. Speech comprehension is coming somewhat slowly but a lot of that is my fault...I have not been practicing lately. BAD ME! So, that's it for now! Time to scoot off to the tv for the Yankee game and more "practicing" using the tv as a "teacher"!

"...bilateral cochlear implants have not been medically proven to be effective..."

June 10, 2007

That is the reason my insurance company, Univera, will most likely deny authorization to cover my other ear. Nope, I am not giving up. Not by any means. I don't quit; it's not an option. As far as I am concerned, surgery for December 2007 or January 2008 is still on. With Steph's help, I am going to fight this tooth and nail. Let the battles begin!

A CI moment

JUNE 26, 2007

Thought I would share with you how things are going with the CI. At the last mapping session, I had one of my old HiRes programs put back into the 3rd slot. This program is somewhat softer and not as sharp as the other 2 programs which are Fidelity 120. And I don't experience the twitching I had when I was all Fidelity 120. The reason...when I put the CI on in the morning, I start off with the HiRes program for about a half hour. This gives everything a chance to "wake up" more gently. Then I switch to one of the Fidelity programs, usually the one for all purpose hearing (the other one is for loud situations). As a result, not only do I not have twitching, but the tinnitus also stays away. On other hand while BBQing last night, I heard an interesting sound...boiling liquids inside the aluminum foil fish wrap Steph made herself for dinner. Really cool! Unfortunately, on the other hand, I am more responsive to her calling my name from all over the house (not that I don't want to hear it but it's usually some boring chore or something...hehehe). And lastly, 2 family reunions (hers and mine) coming up. Both of which none of either families have seen or talked to me since I had the surgery. Oh boy, is that going to be for some really interesting moments!!

A kinda bad CI moment

July 24, 2007

This one definitely ranks right up there. We went to a little town in Quebec just west of Montreal called Beaconsfield where my nephew and his family live, for a family reunion. I actually thought it was going to be easier to read the French and try to figure out what it means than listen to them. It turned out to be the opposite. It turns out that I was able to understand the Canadian Customs Officer quite clearly and answer her questions, to the best of my knowledge. And vice versa for the U.S. Customs on the way back. I remember when I was wearing my hearing aid and having to clear customs at the Buffalo border, either way, was a 50/50 proposition...between interrogation and getting through! Now for the CI moment...and it wasn't the French accent. On the way back, we were stopped at a traffic light when I thought I heard noise. Listening carefully, it was hip-hop music coming from the ear buds of my sons iPod. I was so floored I actually had to ask just to confirm the "noise"! If I could hear it with my CI-corrected 5% loss, imagine what it is doing to Mike's ears. Poor kid...I guess I am going to have to donate my used hearing aids to him.

Approved!

July 27, 2007

"Univera Healthcare has authorized your request for Implantation with Cochlear Prosthesis in the left ear, the device itself and follow-up care by Dr. Ernesto Diaz-Ordaz from 7/19/2007 to 12/31/2007." THANK YOU UNIVERA! And thank you Steph for pushing buttons to make this work....MUAH!!

In fact, the 12/31/2007 date is now sometime in 2008 since I originally plan to have it done sometime in January which is a slow month, race-wise. And yes, we do have 5K races in January and February! I am really looking forward to going "stereo" and judging from conversations with other bi-lateral implantees, the difference is as good as being implanted the first time. And I'll definitely go for the Advanced Bionics Harmony BTE. No doubts there! So folks...look for part 2 in my saga to better hearing!

Becoming fully bionic

August 12, 2007

The decision has been made, the insurance has been approved and now the date has been set. Its January 15th, 2008-same time, same place, same doctor, same device. Only the ear is different. This time, its my left side-my "good ear" which was good only because it sounded better when I wore the hearing aid. Oh yeah, the countdown clock on the right sidebar has been turned back on! I chose such a late date since it was when the running season at its slowest (who likes to race in a blizzard or through slush or on ice?) and it was the earliest Steph could get off so she could play nurse/maid/babysitter.

Going bi-lateral means becoming stereophonic. They say your right ear is more for conversations and your left ear is more for music. I have always thought that to be the case. When I was wearing my hearing aid, I would switch back and forth since the mold would irritate the ear. The right ear seemed to favor the highs while the left favored the lows. I have found this to be true with the CI. When I am listening to music, the lows (bass) was rather indiscernible; I felt it more than I heard it. By having my left ear implanted, I should once again hear the bass and perhaps, even better than when I wore my hearing aid. I will also gain more of a sense of balanced hearing. I should be able to identify exactly where sound is coming from instead of having to crock my head to find it. And perhaps, speech recognition will be easier since I will be picking up more tones and pitches than now. Music should be even more enjoyable.

On the current front, I am going for testing and a remapping. I am not sure what kind of mapping I'll go for, but I think I want one of the slots to be set for the telephone

where the background noise is cut out or reduced. I got my employer to install a phone so that if and when I get a chance, I can practice by listening to those 800 numbers where all they do is blabber about some subject or the weather.

That's it for now...time to get this butt out of the chair and on the road. The next race...and our favorite...the Moonlight Run right here on our home course in Williamsville. Steph will be going for her fourth straight Amherst Triple Crown. Hopefully, the weather will cooperate and not be so humid!

Another mapping session

December 30, 2007

Last Friday, I had what would be considered an emergency mapping session. I really wasn't expecting to have another one until my left ear activation date (2/15/2008) but it turned out that I maxed out on the settings from December 20th and was having a very hard time with the mid-range to low frequencies. But Michelle, my audie, was nice enough to squeeze me in. Basically, we increased the low and mid-range frequencies and left the highs alone. That became program #1, and then we took that and increased it overall by 10% and put that into program #2. Program #1 would become my everyday program and #2 is available in case I max out on #1. Program #3 will remain my old HiRes-P program which I'll probably will never use but when I go "bi", it will become my low volume HiRes-S program so that I can get my new ear up to speed without it having to compete with the right one. What a difference the adjustments made and despite the increases which were above the thresholds of my old HiRes-P programs, I did not experience even one little hint of a twitch. As of this writing, a little more than 15 days remain before I go fully bionic. Am I nervous? Nah! Am I excited? You bet! Anyway, this will probably be my last post for 2007....

New Roles, New Responsibilities

By Gloria M. Matthews



2020 was a brutal year for everyone. It was also a year where most of us had to start working from home, and some of us had to advocate to get not just captioning available on Zoom calls but getting government officials and employers to provide sign language interpreters for those who are Deaf and Hard of Hearing. This pandemic revealed so many flaws in communications that even those with normal hearing were struggling to understand speech behind the mask's requirement. It has been a

tough, heartbreaking and a trying year for all of us.

Before March 2020, I was working at the downtown library as a part-time page. Unfortunately, in early February of 2020, I was let go due to sudden ongoing new medical issues that made it impossible for me to travel to and from my job. I've been suffering from migraines and vertigo and I am currently still under treatment. I loved working at the library because it was relaxing, predictable and my former supervisor and coworkers were very easygoing and well-meaning folks. This wasn't my first time working in a library. My first job was working as a part-time page during the summers as a high school student and again in my early days of college. I do hope that one day I can go back.

After the pandemic shut down much of the world, I started to see folks looking to vent online and talk about how masks have become a new barrier to communication accessibility and how video call platforms such as Zoom, WebEx and others lacked close captioning options for those with hearing loss. It was such a huge issue that folks started to advocate for these video call platforms to make closed captioning easily accessible. I started my new work-from-home position in March as Community Outreach Director for VüSpeech LLC (aka Vü LLC). In this role, my job requires me to not only continue my advocacy but to also to provide peer support for those who need it. I re-started the hard of hearing peer support group online, which I used to host at Deaf Access Services, an Affiliate of People Inc., when I was employed there. I am hoping to host the group there for in-person peer support down the road, but for now it'll be online under the new name VüChat. It's pretty much a place to talk about issues most of us with hearing loss must deal with daily. I held it on Google Meet, which has free closed captioning for all to use, and many who did participate enjoyed it. I will start it back up some time in October.

My job also involves program development, outreach to community agencies, participation in conference calls and ongoing

training. I do enjoy it, as I am learning a lot along the way. I am also the bookkeeper for VüSpeech and in charge of account payables and payroll. I do budget workups, guide the team in how to break down costs, and work with a CPA who can verify that my work is up to par. Oh, it doesn't end there, I am still the Buffalo's Walk4Hearing Walk Treasurer and handle funds for this annual event as a volunteer. I do enjoy working with the amazing Walk Managers at HLAA (Hearing Loss Association of America).

Speaking of HLAA, earlier this year, I was invited to join the NYS HLAA Board of Directors. Meeting online, and when I saw the agenda, I got the message. I now represent not just Buffalo but the WNY region as well. I am also a member of their Advocacy and Legislative Committee which requires its members to write to lawmakers regarding bills that would affect the Deaf and Hard of Hearing Communities across the state of NY. Plus, we are working with the Empire State Association for the Deaf (ESAD) to unite in our common causes. This fall will be a busy one for sure!

As some of you may know, back in 2014, I was nominated as a HearStrong Champion, as someone who has overcome social, educational and personal obstacles to be in my current position today. As a champion, it is my duty to continue to advocate on behalf of those with hearing loss and to provide solutions available to them. But it's not enough to just educate those with hearing loss. We also have to continue to educate the hearing world about hearing health overall.

My involvement with different agencies has led me to understand the needs and the issues that affect everyone. All the agencies and organizations I work with, including being a B.I.G. Board Member and it's Social Media Manager, have a common goal. We all want the hearing world to know that communication accessibility is about leveling the playing field for those with hearing loss and those without. Our lives depend on the ability to communicate effectively with one another, and we must also accommodate one another when needed. It is important for all of us to know that not all folks with hearing loss will utilize a sign language interpreter, but the Deaf will insist on having a sign language interpreter as it is clearly their first language and/or their secondary depending on their background. We must ensure and respect the needs of the Deaf community and show that by securing a sign language interpreter on screen and before they meet with you. For an individual with hearing loss, they would rely on captioning and lip-reading more. What I find baffling is that CART (Communication Accessibility Realtime Text) is not well known and it's something that needs more exposure aside from automatic closed captioning. I am for total communication accessibility, which combines using sign language, captioning and other communication methods all together. It's time for us to normalize it.

Buffalo Walk4Hearing 2021

By Gloria M. Matthews



This year's HLAA Buffalo Walk4Hearing 2021 is back on as an in-person event! Last year's Buffalo Walk4Hearing went virtual due to the pandemic, as many other events did. It was a unique experience for all involved and we all made it work. This year's walk will be held again at the Buffalo and Erie County Botanical Gardens, located on South Park Avenue in Lackawanna, NY on Saturday, September 25, 2021. That is just one week after B.I.G. Picnic. Registration will begin at 9:00 am and the walk will begin at 10:00 am. This is a family friendly event, and all are welcome!

If you want to join Team B.I.G. please go to <http://hlaa.convio.net/goto/BIG> and register! I will once again serve as Team B.I.G.'s Team Captain and hope to raise money as well. If you cannot participate, please feel free to make a donation directly to B.I.G., or if you want to support both HLAA and B.I.G., you can utilize the "donate" option on the site. Your continued support for our group, or even both groups, will help us spread awareness about hearing health and hearing loss.

If you have any questions or concerns, please feel free to contact me at glomk08@yahoo.com.

Movie Review - Moonlight Sonata: Deafness in Three Movements

By Gail Cronin

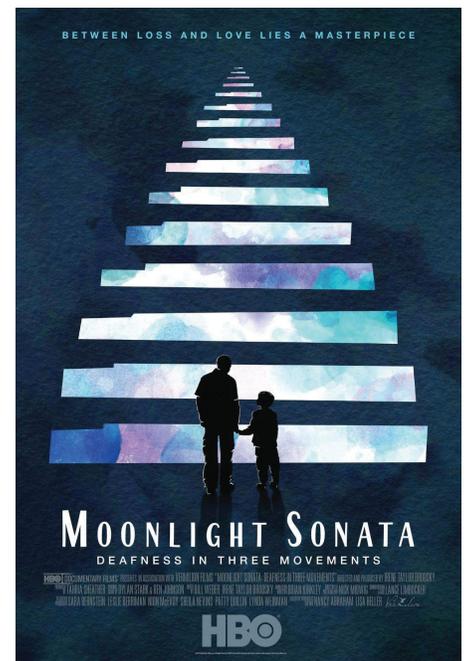
In late 2019, an HBO Documentary film entitled *Moonlight Sonata: Deafness in Three Movements* premiered. This film, by critically acclaimed documentarian Irene Taylor Brodsky, follows the journey of her musically gifted son Jonas who was born hearing in a family of both Deaf and hearing grandparents. Irene Taylor Brodsky not only wrote, directed and produced this film, but serves as narrator as well. Some may see this film as a follow-up to her award winning 2007 HBO Documentary, *Hear and Now*, which chronicled the lives of her Deaf parents who received cochlear implants in their 60's, prior to Jonas' birth. However, this is a stand-alone film which can be enjoyed by anyone regardless of whether they are familiar with the backgrounds of Jonas' grandparents.

Jonas grew up in a music-filled home since birth. He experienced a rapid hearing loss at the age of four and underwent cochlear implant surgery. At the age of 8 he received a second implant, making him a bilateral cochlear implant user. Throughout this time, he continually studied music and honed his piano playing skills.

Moonlight Sonata: Deafness in Three Movements is a film that contrasts the Deaf experience for children today like Jonas, who have access to the life-changing technology of cochlear implants in early childhood as well as a supportive Deaf community, to that of Jonas's grandfather, a brilliant scientist who had a different experience of deafness, and also to that of composer Ludwig van Beethoven, who composed the piece "Moonlight Sonata" while losing his hearing at a time when there was no technology available to him nor the support of a Deaf community. It is the story of three different people with three different experiences of deafness spanning three centuries.

This film is a unique piece of art that takes a moving family story and combines it with historic perspective, beautiful vignettes of animation, and stirring music. With a running time of 1 hour and 30 minutes, it can be streamed by HBO subscribers on HBO Max. Two trailers for the film can be viewed by anyone on YouTube, along with several different interviews with Irene Taylor Brodsky.

I highly recommend *Moonlight Sonata: Deafness in Three Movements*. Not only is it a must-see for anyone considering a cochlear implant for their child, but also for anyone regardless of their own experience with or knowledge about deafness. This is a story about a family, and how people struggle with loss and change, as well as overcoming and acceptance. It also serves to affirm deafness as both a challenge and a gift.



Enjoy Your Time in the Kitchen

By Margie Fitchlee

Home is where the heart is, and these days since the pandemic has taken over our lives, home is where most of us have been. Luckily for us, COVID-19 has slowed down enough to allow us to get back in the swing of things.

I think we have all heard the saying “everything old is new again.” Americans everywhere are still trying to adapt to the “new normal” that this pandemic has thrust upon us. Many are reverting back to doing things that were popular back in the day. One of those things is home canning. The summer months leave us with an abundance of locally grown vegetables. This affords us with the chance to get back in the kitchen and back into canning.

I used to do a lot of canning. Pickles, pepper jelly and chili sauce were just a few of the items I used to can. I am hoping that perhaps this summer I will once again get back to doing just that! Perhaps some of you might like to join me too? I would like to share some of my favorite recipes with you. So, when in a pickle (a situation that has left us searching for answers) get busy and get gratified by making your own assortment of homemade pickles, pepper jelly and chili sauce. Your friends and relatives will love you for it!

Bread and Butter Pickles

4 quarts thin sliced cucumbers (medium size)
6 medium white onions (sliced thin)
1 green pepper
1 sweet red pepper
3 cloves garlic
1/3 cup canning salt
3 cups distilled white vinegar
5 cups sugar
1 ½ teaspoons turmeric
1 ½ teaspoons celery seed
2 Tablespoons mustard seed

Do not pare cucumbers. Just wash them thoroughly, slice them thin, add sliced onions, peppers cut in thin narrow strips and add whole garlic cloves. Sprinkle salt over the layers in your container. Now mix a tray of ice cubes thru the pickles. Put another tray on top. Let stand for 3 hours. You may need more ice. It's the ice salt mixture that makes the pickles crisp. Drain the cucumbers thoroughly. Discard the icy salt water. It's a good idea now to divide the cucumbers into 2 batches and cook in 2 kettles. Small batches keep pickles crisp and a green color. Combine sugar, vinegar and spices. Pour over the cucumber slices. Heat just to boiling. That's all the cooking! Ladle hot pickles into hot sterilized jars & seal. Makes 8 pints.

Dill Pickles

In each quart jar add:
1 ½ teaspoon canning salt (not heaping)
¼ teaspoon alum
¼ teaspoon (little less) turmeric
3 dill flowers & some stems
4-5 pieces of garlic (depending on the size)
¼ cup Heinz or 5% acidity vinegar (white)
Fill quart jar with water that has been boiled and cooled down a little bit. (It takes about 1 pint water to fill a quart jar)
Process in a canner 3 minutes or longer

Sweet Gerkins – process takes 4 days

(I got this recipe years ago from the farmer's wife where we bought our pickling cucumbers. It is special and these pickles taste so good!)

7 lbs of pickles
½ cup canning salt
8 cups sugar
6 cups white distilled vinegar
¾ teaspoon turmeric
2 teaspoons celery salt
2 teaspoons pickling spices
8 1-inch pieces of stick cinnamon
½ teaspoon fennel (if desired)

2 teaspoons vanilla

On morning #1 - Scrub and cover pickles with boiling water. That night, drain and cover with new boiling water.

On morning #2- Repeat the process. That night, drain and add the salt and cover with new boiling water.

On morning #3 - Drain and prick the pickles with a fork. Make the syrup using the 3 cups vinegar, and 3 cups of the sugar. Add the spices. Heat to boiling and pour over the pickles. That night, drain (reserve the syrup) and add 2 more cups vinegar and 2 more cups sugar to it. Boil and add back to pickles.

Morning #4 - Add 2 more cups of sugar and 1 more cup vinegar to pickles. That evening, add 1 cup sugar and 2 teaspoons vanilla. Heat to boiling. Pack pickles in hot sterilized jars and seal.

Pepper Jelly

¼ cup finely ground hot peppers
¾ cup ground bell peppers
6 ½ cups sugar
1 ½ cups vinegar
1 bottle Certo
Red or Green food coloring

If you chop peppers in a blender or food processor, mash in a strainer to remove excess liquid. Bring peppers sugar and vinegar to a hard boil. Remove from stove and let sit for five minutes. Add Certo and red or green food coloring. Put in hot sterile jars. You may use all green peppers if you do not want the jelly to taste hot. Serve on cream cheese or cheddar cheese on crackers. It is also a good condiment for meats and makes a great hostess gift too!

Note: If using hot peppers, it is best to wear gloves. The hot peppers can burn fingers. I like to make an assortment of red and green.

Chili Sauce – process takes 2 days

Grind together:

1 8-quart basket of tomatoes, skins off
8 large onions
8 green peppers
1 hot pepper or 8-10 (for very hot chili)
Add ¾ cup canning salt

Let stand overnight. In the morning, drain in colander for a couple of hours. Do not squeeze.

Mix in:

1 quart of cider vinegar
1 teaspoon cinnamon
1 teaspoon celery seed
1 teaspoon allspice
4 cups white sugar
½ teaspoon cloves

Boil until thick. Can and process in canner for 5 minutes. Makes 9 pints

Enjoy your time in the kitchen. My family used to love getting a basketful of these goodies at Christmas time. Moments like these really give meaning to that old saying “There's no place like home.”

I wish all those contemplating having cochlear implant surgery all the best as you embark on this journey. I wish all of us that have the implants success with navigating the challenges that this pandemic has given us. I myself find it very difficult to understand speech while wearing a mask. I also hope that as we stay closer to home, and that we don't lose sight of the day when we can all freely get back together and share the benefits that socializing with The Buffalo Implant Group offers us. I so look forward to that day!

Stay healthy. Stay safe and make the best of your time at home. At least now that most of us are vaccinated and can get out to all those farmers markets, it should be much easier to get back into canning and much easier to share our bounty with family and friends.

Many Thanks

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Tracy Schaeffer
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Sandra Swaciak
Jan Telban
Mary Thorpe
Sue Wantuck
Karen Ward
Valerie Ward
Carol Wesley
Zenger Group

PICNIC ALERT!

Mark your calendars for the return of our...

SUNSET DINNER PICNIC

Friday, September 17, 2021

5:00 – 8:00 pm

Once again, dinner will be catered by Bobby J's Italian American Grille, served at 6:00 pm.

Water and pop will be provided. Please bring an appetizer or dessert to share. Finger foods are encouraged in order to limit shared utensils.

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

The entrance to Westwood Park is on Pavement Road between Walden Avenue and Broadway. Shelter #5 is just past the enclosed pavilion (where restrooms are located) on the left side, with parking right in front. The children's playground is a short walk away.

This event is outdoors, and masks/face shields are optional. We will attempt to spread out as much as possible in order to allow for some measure of social distancing. Please give others space. Feel free to bring your own folding chairs so that the tables are less crowded. We want everyone to be as safe and comfortable as possible.

The picnic is **FREE** to all who want to come. We do encourage you to participate in our fundraisers if you are able to do so.

Our Basket Raffle fundraiser helps provide funds for our new annual scholarship, awarded to a student entering college. Additional basket donations are appreciated. A basket donation form can be found in this newsletter. Please fill one out for each basket you are donating in order for us to have a description of the contents of your basket. Baskets that appeal to men and children are always needed. The Basket Raffle is once again being coordinated by Sr. Dorothy Feltz.

This year we are using up raffle ticket rolls that we have on hand. Ticket strips will be sold, rather than ticket sheets. Thus, you will have more ticket numbers to keep track of during the game. We will call the number of each winning ticket, but it would be easier if you place your name on the back of each ticket you purchase. You can write your name on the back of each ticket, or you can bring return address labels with your name on them to affix to the back of each ticket.

We need a general idea of how many members will be attending, so RSVP to Karen Ward at by email ward_karen@verizon.net or text 716-432-0824 by September 9 (one week prior to the picnic) if possible, to let us know that you are coming and how many people will be with you.

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



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