Having a newsletter from the Ear and Hearing Team is a great way to provide updates both on our team and the families we serve.

We intend to provide information on events in the community and new technologies pertaining to our deaf and hard-of-hearing families. Our new and ongoing research efforts will also be shared as we will likely be looking to recruit participants in the near future. This is an ongoing effort to evolve and expand the scope of our center to serve our patients in the most comprehensive way possible.

In addition to our updates, we also want to hear from our patients and families as well! If you would like to share updates pertaining to your own hearing journey or accomplishments send them to me directly, we’ll make sure you get highlighted in the next addition of this newsletter. Send your information and pictures to Joshua.Sevier@uchospitals.edu
As many of you may know, Advanced Bionics has issued a recall of the HiRes Ultra 3D Version 1 internal implants. The recall involved an issue with the seal around the base of the implant leading to the electrode array. Any patients implanted with the specific device in question were sent a letter to notify them and asked to look for drops in performance and remain in regular contact with their audiologist regarding their outcomes.

While this has not been an easy time, we can report the vast majority of these implants have been revised and the new model of devices is only being used moving forward. As always, please let the team know how your hearing journey is going and any issues that may arise. The team is committed to providing our patients with everything needed to succeed on their hearing journey.

UPDATE ON ADVANCED BIONICS V1 RECALL

by Josh Sevier, Au.D., LL.M.

At the Forefront Live!

by Josh Sevier, Au.D., LL.M.

Recently, members of our Ear and Hearing team were recorded for an episode of *At the Forefront Live* at the University of Chicago Medicine’s studio.

Drs. Imbery (neurotology) and Sprouse (audiology), Michelle Havlik (speech-language pathology) were joined by one of their cochlear implant patients, Dr. Pam Huang. They discussed the hearing loss journey and the impact it may have on social, personal, and professional aspects of life.

The team discussed the services offered by our Ear and Hearing team across pediatric and adult populations discussing the importance of multidisciplinary care plans. Individualized care plans are critical in hoping to optimize the outcomes for each patient on their own hearing journey.

The episode will soon be posted on the UChicago Medicine’s *At the Forefront Live* page for full viewing. Please reach out with any questions!

Dr. Pam Huang, Michelle Havlik, Dr. Imbery, and Dr. Sprouse (Left to Right) following the taping of *At The Forefront Live*
NEW PARENT ADVISORY BOARD

Josh Sevier, Au.D.

While our team strives to better the lives of all of our pediatric patients using a multidisciplinary approach, it is not uncommon for the parents of those patients to be more involved with the plan of care for their child. After careful thought and development, that involvement has now become a reality.

In late April, the new Pediatric Parent Advisory Board launched its inaugural meeting. Members of the initial board were selected by completing interest forms and stating their level of involvement. Established following work by Caitlin Egan, MS, Josh Sevier, AuD, Brittney Sprouse, AuD, and Ashleigh Teasley the new members were guided through the flow of a typical meeting. They were given a broad set of by-laws and encouraged to grow and expand them as they saw fit to better support the board and their children. The board members will raise funds for hosting events and providing feedback to our team concerning suggestions to help us better serve the needs of their children. Elections will be held for members every couple of years to ensure new voices provide thoughts.

We are excited to be starting a Parent Advisory Board for the Pediatric Hearing Loss Department at UChicago. Below is information about the board members. If you have any questions for the Parent Advisory Board please email the board at UChicagoPAB@gmail.com

Diane Heimlich

Hi. My name is Diane Heimlich. I am the mother of Brooke who is 14 years old and deaf. When Brooke was born, she passed her newborn screening, but at age 2 she kept failing her hearing test when she was referred for speech therapy. At age 3 she was diagnosed with EVA (enlarged vestibular aqueducts). This syndrome comes with progressive hearing loss.

At age 7 Brooke received bilateral hearing aids. At age 13 Brooke received bilateral cochlear implants. She is currently uses oral communication, is taking ASL classes and she is a lip reader. I look forward to getting to know many of you through this Parent Advisory Board.

Above: Diane Heimlich (Left) and her daughter Brooke

Marisol Rodriguez

My Name is Marisol Rodriguez and I live in Summit IL. My daughter is Ilena Alicia and she is 5 yrs old and she has {ANS} Auditory neuropathy spectrum disorder in both of her ears. Ilena was diagnosed at 4 months and was aided with Hearing Aids. With time her hearing has gotten worse and just this last Dec 3 she went through surgery to get a CI in her left ear. We are hoping to have her right ear done in July of this year. Ilena relies on reading lips a lot. She also knows the basics in ASL and now going on 5 months she has begun speaking in small sentences and is very Bossy. I might add LOL!!!
One thing that I hope the PAB accomplishes is helping families to connect with other families as well as making sure they have all the resources they need to help their child thrive. My main goal is to let other families know they are not alone.

My husband, Eric, and I have two children. Our son, who is hearing, is seven years old and finishing first grade. Our daughter, Joren, is five years old and finishing her second year at Child’s Voice. Joren failed her newborn screen at birth and was diagnosed with moderate to severe hearing loss at 4 weeks of age due to Connexin 26. She received her first set of hearing aids at 2 months old and was implanted with Advanced Bionics cochlear implants when she was 15 months and 18 months. Joren has responded to listening and spoken language beautifully and is set to transition to mainstream Kindergarten in the fall.

Danielle Claxton

My name is Danielle Claxton from Chicago, IL, Larry, and I have two daughters Jessica age 17, and Gabriella age 15. Their father is hearing; however, my daughters and I have Bilateral Bone Conduction Hearing Loss caused by Treacher-Collins Syndrome which was diagnosed at birth. My daughters each wear Bilateral Bone Anchored Hearings Aids and I received my Unilateral BAHA implant in November 2015. The modes of communication that we use are ASL, Lip reading, and Oral. My hope for PAB would be to grant accessibility, equity, and resources to create a community for families affected by hearing loss.
Growing up in a hearing family and mainstreamed at school, our teen does not have opportunities to learn alternate modes of communication, hone their listening skills, develop effective coping strategies, or share their frustrations with others who have similar experiences.

When our child asked their audiologist for an over-the-ear hearing aid in 4th grade, they heard continuous sound for the first time. Throughout the years my child has asked to learn ASL for credit, but ASL is not offered in our schools. Recently, I have been amazed to learn that our child’s struggles are actually common to kids with mild to moderate or unilateral hearing loss.

I am hoping this group will create an environment in which my teen will be able to find peers and mentors that understand how challenging life can be with hearing loss. I am hoping to learn from others and share strategies that will help our children cope with the psychological and educational impact of hearing loss, especially when they are unable to obtain direct services at school. Perhaps, we can even work together so that our schools understand and adequately support our children.

Elizabeth Hibel

We have two children who are now in their late teens. Our oldest is in college and has difficulty processing language, but normal hearing. Our youngest is in high school and was diagnosed with hearing loss in pre-school. At that time, we discovered that the newborn screening was also abnormal. Our child’s hearing loss is stable, mild to moderate-severe, left ear, high-frequency sensorineural hearing loss, and both ears also have minimal to mild hearing loss in lower frequencies. This means that our child has never consistently heard the sounds K, T, F, Th, S, Sh, G, Ch, P, H, Z, V, running water, rustling leaves, or bird-song. Our child acquired language without making a distinction between sound, vibration, lipreading and body language.
"It hurts to say goodbye..."

Josh Sevier, Au.D., LL.M.

As many of you may know, each year our program takes externship students completing their last year of on-the-job training before graduating with their doctor of audiology (Au.D.) degree. Once selected, they represent universities all over the country coming to Chicago to learn the complexities associated with our patient population. Whether it be surgical ears, genetic anomalies, or any form hearing loss takes, our program strives to ensure they are prepared to care for any patient they see after they leave us. Our externs from this past year joined us from Purdue University, the University of Illinois Urbana-Champaign, and Salus University.

The year flies by and before we realize it, it’s time to say goodbye. While we are sad to see them leave us, they are going to make an enormous impact at the Americans for Better Hearing Foundation, the University of Chicago Medicine, and Duly Health and Care! It hurts to say goodbye, but the team wishes you the best of luck in your careers! We will most certainly miss you all!

Above: (From left to right) Avia (V), Ali, and Anna at the departmental going away dinner.
Research Initiatives at UChicago Ear and Hearing

Josh Sevier, Au.D., LL.M.

The team is currently working on a grant which will focus on the literacy of children with cochlear implants and compare across both socioeconomic status and race. Our goal is to identify particular groups needing a little extra help and hope to use the information as a public health matter advocating for additional educational resources in underserved areas.

We are also developing a database to monitor outcomes in all of our cochlear implant patients. The goal is to use the information to streamline clinical processes and also find gaps in underperforming patients to determine if anything may be done to improve their hearing situations. Other research is in the works as well, and more information will come soon!

The Parent Advisory Board Wants to Hear From You!!

Josh Sevier, Au.D., LL.M.

As the Parent Advisory Board starts to evolve, expand, and become integral to the UChicago Ear and Hearing Program, they want to hear from you!

The link below is for a short Google Forms Survey designed to find out what’s important to the patients and families in the UChicago Deaf and Hard of Hearing Community. If you have a few moments, please go to the link below to participate in the information-gathering process!

https://forms.gle/642zkvQDWNnApWuwN6
Back To School Webinars!

*Josh Sevier, Au.D., LL.M.*

During the month of August, our department will be hosting free, webinars for back-to-school time this fall. There will be one each week and will be held on zoom. If you miss one don’t worry as they will be recorded and uploaded to our Youtube page. The agenda will be as follows:

**August 3rd:** A UChicago Ear and Hearing Team Panel, including ENT, Speech, and Audiology

**August 10th:** Educational Panel included Child’s Voice, CPS, and CO-OP

**August 17th:** Advocacy

**August 24th:** Bi-Lingual/Spanish

The zoom link for these webinars will be posted on all of our social media pages. If you have any questions, please feel free to reach out to us.

New Addition to the Team!

In the coming weeks, we will have an addition to our team, Ali Marquess, Au.D. She recently finished her final externship training year with us at UChicago Medicine and will be joining us as a full-time member of the staff. She will primarily focus on inpatient pediatrics, and we are excited to have her on the team.

Team News and Updates

*Brittney Sprouse, Au.D.*

I hope that your summer is getting off to a great start! As we approach the end of our fiscal year, it is important to take a step back and reflect on our program. The Comprehensive Ear and Hearing Program has continued to grow with new providers in Audiology, expanding Audiologic services to include pediatrics at our Orland Park location; expanding adult and pediatric Speech services to our Orland Park location, and expanding Audiologic and Otolaryngology services at our Ingalls Flossmoor location. Members of the team have completed a number of presentations at our national conferences, submitted to grants to further the growth and care of our practice, as well as hosted internal and external webinars for our community, patients and families.

We appreciate the confidence that all of our patients and families have placed in us and in our work at UChicago Medicine. We hope you enjoy this information and look forward to working with you!