

THE *VoicE*

2019 Edition



THE NEWSLETTER OF THE COCHLEAR IMPLANT AWARENESS FOUNDATION



Dear friends, I'd like to share how CIAF came to be.

I was working as a teacher, my dream job, and pregnant with my first child. Life couldn't be better. And so, as it seems to do, life decided to see if I could handle some adversity. If I was up for a challenge. Life came down on me hard.

First, I completely lost my hearing, which in turn took away my ability to teach. And then, worse than all of that, my daughter Ellie was born deaf. It was devastating to think of all of the wonderful sounds that my sweet girl would never get to hear. Like, "I love you."

But if life thought that it had me down, it didn't know me very well. I adjusted to our family's new reality, but was also determined to get back what I lost. In time, I discovered that groundbreaking work was being done in the field of cochlear implant technology. It wasn't long after, in 1999, that Ellie had the surgery and received the miracle of hearing. The next year, I received cochlear implants. In 2005, we became the first mother-daughter pair to have bilateral implants.

the options that existed. Ten families turned into 50, and 50 suddenly became hundreds. Then one summer morning in 2005, I woke up and matter-of-factly mentioned to my husband that, "I'm going to start a non-profit today!" And with that, the Cochlear Implant Awareness Foundation was born. Over the next year, I worked relentlessly to achieve the organizational status of being a 501 (c)(3). It would be a way for me to pay it forward and share the love that is sound with as many people as I could.

Don't get me wrong, starting a non-profit does take a lot of time and hard work, but once I made that declaration, the path was clear to me. I knew the road I needed to take and I've never looked back.

The desire to grow CIAF led to the creation of District 23 as a way to fund our charitable dreams. One boutique led to a second, and then a bigger boutique to expand our location. Shopping for a Cause has been successful beyond my wildest expectations.

That brings us to today. We've been able to help thousands of people by donating \$1.2 million dollars worth of equipment. It's a wonderful achievement that we never could have dreamed of when we first started. And one we could have never reached without you.

All of my best to you and your family,

Michelle Tjelmeland

CIAF & District 23 Founder & Director

I just couldn't help thinking of all of the other people in the world who could benefit from cochlear implants, but they either didn't know about it, or they couldn't afford it. That didn't seem right to me. I started IloveEllie.com. It was just a simple blog where I could share my experiences and answer questions for people who were going through the similar experiences. Twenty years later, the problem still exists but hopefully we are making a difference.

You never know when you're writing a blog if anyone is actually reading it. It didn't take long to realize that there was a real need for this type of information and advice. Before long I was helping people connect with doctors, information, support, and resources.

Advanced Bionics, an industry leader in cochlear technology, got wind of what I was doing and asked me to work with them. It all happened quickly and it felt so inspiring to help people like this. This gave me the opportunity to work with Heather Whitestone, the 1st Deaf Miss America. We joined forces on Capitol Hill to educate lawmakers about the amazing benefits of cochlear implant technology and eventually legislation was passed to ensure that insurance companies covered the costs associated with cochlear implant surgery.

Along the way, I continued on my mission to counsel families on their choices in deafness and

DISTRICT23 BOUTIQUE

In addition to owning D23, Michelle also operates e-websmart.com, a web site development and online marketing business. So you can expect wonderful and hassle-free shopping based on the latest in technology.

Ready to start shopping? Check out all of our amazing merchandise that is continuously changing at:

www.district23.com



♥ Testimonials: ♥

What a great Christmas present to get Violet's charger in the mail!! We cannot thank you enough! That's all I needed for Xmas!
Love, **Nancy (Violet's mom)**

I just received the best surprise in the mail today!! Not just one battery cover, but a whole rainbow of colors! Thank you so much! It's so nice to not have a sticky bandaid behind my ear!
Thanks again! **Kathy Conant**



One of the biggest honors in our neck of the woods is the Illinois Times' annual Best of Springfield contest. What makes it so great is that the winners are chosen by the paper's readers. And this year, they chose us. Twice!

CIAF took top honors for Best Non-Profit and District 23 was

voted Best Boutique. Needless to say, there are a lot great non-profits and boutiques in the area, so coming out on top is quite an honor.

Thanks to everyone who voted for us. We work hard to please the people we serve, and these awards will only inspire us to work even harder. We appreciate the loyalty and support of our customers, employees, volunteers and stakeholders. We're the best because you're the best.

Finally, congratulations to all of the other businesses, organizations and individuals that were chosen as the Best in Springfield. We're proud to be in your company.





Partnering with leaders in the field of hearing



In furthering our mission, CIAF has the pleasure of working with some of the most accomplished individuals and organizations providing hearing care to patients and advancing cochlear implant science. One of those individuals is Dr. Laura Holden, AuD, CCC-A, a research scientist at Washington University School of Medicine in St. Louis. Dr. Holden also serves as a clinical audiologist, work that has put her in direct contact with the services we provide.

"I personally have three patients who have obtained a new speech processor from CIAF, and other patients here at Washington University who have obtained speech processors from them as

well," Dr. Holden said. "CIAF has been instrumental in helping a number of our patients continue to function at their job because of the new equipment that they have been provided."

For Dr. Holden's patients, the need for equipment came after they changed employment after receiving cochlear implant surgery, in each case leaving them without adequate insurance coverage.

"The patients all depend on their hearing to do their job. We unfortunately have limited loaner equipment, especially if the patient needs the equipment for an extended period of time," she said.

Dr. Holden graduated with a Master's degree in Audiology from the University of Illinois in 1986 and began working at the Washington University School of Medicine as an audiologist at the inception of their adult cochlear implant program. She went on to earn a doctorate from the Arizona School of Health Sciences.

Throughout her career, Dr. Holden has seen cochlear technology become more commonplace and has played an important role in its advancement. She has taken a particular interest in assisting patients

with speech understanding, while dealing with background noise and other difficult listening situations, and improving the use of cochlear implantation for patients with asymmetric hearing loss and single-sided deafness.

Despite the improvements that have been realized through research and more widespread use, there are still significant barriers that prevent more people from benefiting from the hearing technology.

"The high cost of cochlear implantation is a huge issue for many patients," she said. "Also, patients need to be fully aware that they will need to maintain their equipment throughout their life which is a huge issue. Speech processor repairs and upgrades are very costly and insurance companies may not pay for upgrades or repairs. CIAF has really helped our patients improve their communication in daily life by providing them with new, updated equipment."

We're honored to be able to assist Dr. Holden in serving her patients and are grateful for her work in advancing cochlear technology so that more people can benefit to an even greater extent.



In 2018

\$1.2 Million

worth of CI equipment given to over 200 deserving recipients



D23 Rochester
130 South John Street
Rochester, Illinois 62704
217.498.1369

D23 Springfield
New location
830 South Grand Avenue West
Springfield, Illinois 62704
217.679.1352

D23 Hours:
Monday - Friday 10 am - 6 pm
Saturday 10 am - 4 pm
Sunday 12 pm - 4 pm

It takes a group of talented, organized individuals to make a great team!



Lori Von Behren Buyer

Lori has been a volunteer and employee for District 23 since the doors opened. She has done every job, from computer work to keeping things neat and organized. Lori now assists Michelle in buying the merchandise for all three locations. She knows our suppliers well and what our

customers want to see on D23's racks. Lori loves the family environment and the many close friendships she has made at the boutique. She is married to Nick, and they have two grown children and are blessed with grandchildren. We lean heavily on Lori's experience and role as the D23 Mom!



Hayley Simpkins Manager

Hayley graduated from Illinois State with a degree in Fashion Merchandising and started working retail in high school and continued throughout college. Her favorite part about working at District 23 is the people she gets to interact with on a daily basis and helping

women find outfits that they love and that also make them feel confident. In her free time, Hayley enjoys staying active, going to the movies with her friends and family and reading.



Ivy Molen Patient Care Coordinator

Ivy has been our Patient Care Coordinator for six years. Her organizational and personal skills are paramount as she works with implant doctors, hospitals, and clinics to make sure our recipients receive the correct equipment in a timely manner.

She also coordinates donations of CI equipment, cleans the parts, and inventories everything into the computer system. CIAF@ thrives because of Ivy's dedication!



Erica Garrison Manager

Erica recently joined us after a Marketing position with a large food company. She has been married to her husband, Roger, for 25 years and they have a daughter, Sydney who is a Senior in High School. They also have 2 dogs, Samson and Millie.



Erica was drawn to District 23 because of the mission we serve. She loves helping women find an outfit, item, or piece of jewelry that will make them feel confident and beautiful. In her free time, Erica enjoys staying active, attending church, gardening, and playing board games with her family. We are thrilled to have her on our team!

DISTRICT23
BOUTIQUE

Meet Augie

an amazing kid overcoming the odds

Success can be measured in many ways for a non-profit. We get excited when we set a new annual record for money raised or for the amount of gifts we give away. That's the big picture stuff. But what keeps us working hard everyday are the things going on behind the scenes that we don't always get to see. We'd like to share one of these stories with you.

Augie Geving was only three months old when he was diagnosed with profound hearing loss. A couple of months later, an MRI revealed that he was a candidate for cochlear implants.

"In January 2013, Augie had his first cochlear implant surgery at St. Louis Children's Hospital," said his mother, Tara. "It was the goal to have him bilaterally implanted at that time, but the surgeon was only able to implant his left ear. The left ear was turned on on Valentine's Day. On March 9, Augie could hear us singing Happy Birthday to him."

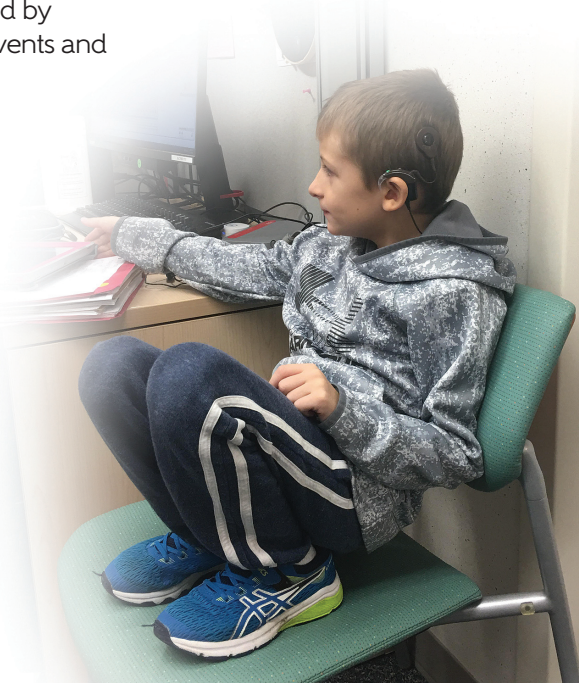
Subsequent attempts to have an implant placed in Augie's right ear proved unsuccessful due to infections. It hasn't been an easy road for him, having undergone surgery 13 times in his young life.

Today, six-year-old Augie is a kindergartner at the Illinois School for the Deaf in Jacksonville. He's doing great, but facing the same challenges that almost all cochlear recipients have to deal with - outdated or broken equipment that's expensive to replace. In Augie's case, it was his processor.

"For the past year, we knew Augie needed an upgraded model," Tara said. "However, due to the out of pocket costs it was not something that my husband and I could make happen right now. I reached out to Michelle at CIAF with an insurance question and much to our surprise, she offered to provide Augie with an upgrade kit. CIAF gave us a gift worth \$10,000, but it was worth much more than that to our family."

Michelle and her team have provided Augie new ear hooks and cable cords in the past, and the Geving's responded by supporting CIAF by attending events and shopping at District 23. But the upgraded processor, with its wonderful new features, really has Augie excited.

"Recently, I was at the store and called home," Tara said. "My husband sent the call to Augie's processor and he screeched with excitement and said, 'My mom is in my implant!' Imagine being told your baby is deaf and then six years later you are having a conversation with him on the phone. That is amazing. We cannot thank CIAF enough for their generous gift."



The High Cost of Hearing

For almost everyone fortunate enough to receive cochlear implant surgery, the experience is miraculous. But it's just the first step in a life-long journey to maintain that ability to hear. For many people, from all walks of life, it unfortunately comes down to finances.

Take the batteries, for example. Because the user needs to maintain around four or five batteries at all times, and the life is around one year. At a cost that averages \$250 per battery, that's a significant amount of money for even middle-class families.

Cable coils are another common expense. They cost around \$195. Some insurance policies will pay for a new one every five years, but for an active person they might only last a few months. An accident, of course, can knock a cable out of commission at any time. No matter when it happens, it's going to be a hit to the family budget.

So, when we donate cochlear equipment, we're not only helping the actual recipient, it's a gift to their family as well. Every dollar we can save them is a dollar that can go to some other need. That's why every dollar you donate or spend at District 23 is greatly needed, and appreciated. Just thought you'd like to know.

Hear Again™ Program

If you or someone you know can benefit from one of our programs, please visit our website at www.ciafonline.org/application-page to access our application, or contact us at www.info@ciafonline.org for more information.



CIAF Hear Again™ Children's Program

Hearing loss can dramatically affect a child's ability to develop communication, language, and social skills. This affects their ability to fully function in a school setting, as well as their ability to reach their full potential as adults.

As CIAF's founder, Michelle Tjelmeland knows it is important to give a child the hearing resources they need at an early age. Her daughter Ellie was born deaf and received cochlear implants as a small child. Since then, Ellie has experienced a rich and full life with the gift of sound.

As the parent of a child with severe hearing loss or deafness who is eligible for cochlear implants, you may have many questions and concerns regarding treatment options, resources and its effects on your child's future. CIAF is here to help. As the nation's only cochlear implant bank, we are willing and able to answer your questions, provide support and equipment to those in need.

CIAF Hear Again™ Seniors' Program

According to the Hearing Health Foundation, 50 million Americans experience hearing loss. Anywhere from nine to 22 out of every 1,000 people have a severe hearing impairment or are deaf.

At least half of these people reported their hearing loss after 64 years of age.

In addition, a large portion of people past the age of 65 with profound hearing loss have lived in a world of silence their entire lives because of the lack of technology available to help them hear. For them, the option of receiving a cochlear implant is life altering.

CIAF is dedicated to giving seniors a chance to restore their hearing by offering support through information and equipment should they choose to explore the option of receiving a cochlear implant.

CIAF Hear Again™ Veterans' Program

Hearing loss and other hearing-related problems are the most common disabilities reported in military veterans.

While much of the public concern about injuries suffered by post-9/11 troops has focused on missing limbs, brain injuries, and post-traumatic stress disorder, Scott C. Forbes, past-president of the Association of Veterans Administration Audiologists, finds that auditory injury is the signature injury of veterans. In recent years, it is estimated that 60% of veterans returning from Iraq and Afghanistan come home with hearing loss. Since severe hearing loss is not fatal, it is often overlooked as a significant injury, even though it dramatically alters the life of the affected individual and his/her family.

Because of these staggering statistics, CIAF created the Cochlear Implant Veteran's Program to help military

veterans who have sustained severe hearing loss while serving their country. We welcome the opportunity to offer our knowledge, resources, and database of cochlear implant equipment to qualified veterans.

CIAF Hear Again™ Women to Women Program

In this modern day, women have important responsibilities and are significant contributors in making a better society. Women with hearing impairments or deafness play a pivotal role as well, while facing obstacles that others aren't forced to navigate.

Limited resources for hearing healthcare, fewer educational opportunities, and even depression may prevent a hearing-impaired woman from realizing her full potential. Michelle fully empathizes with her hearing-impaired peers as they chart their course through life.

CIAF developed the Hear Again™ Women to Women Program to provide these women the resources and support they need when considering cochlear implants or other hearing-related treatments or technologies. We want to help hearing-impaired women everywhere reach their goals and live fulfilling lives.

If you or someone you know can benefit from one of our programs, please visit our web site at www.ciafonline.org/application-page to access an application, or contact us at www.info@ciafonline.org for more information.

A donation to CIAF® is a perfect gift anytime

CIAF® is supported by generous individuals and community sponsors who often tell us that the joy of giving to our efforts has blessed them in numerous ways. If you want to share in the love and generosity, we have several opportunities for you to give:

- Make a one-time financial gift securely through Paypal at www.ciafonline.org/donate-pay-it-forward.
- Arrange a planned financial gift, including will/bequests, life insurance, and charitable remainder trusts.
- Donate CI equipment.

CIAF Gives the Gift of Hearing to Romania with a **\$564,000** Donation

Cochlear implant technology has dramatically changed the lives of hearing impaired individuals, not only in the United States, but throughout the world. Established in 2005, the Cochlear Implant Awareness Foundation (CIAF) has been providing cochlear implant (CI) equipment to qualified applicants in need through its Hear Again™ program. CIAF is the only organization in the world doing what we do.

This fall, the news of our work reached an incredible organization in Romania called the Romanian Hearing Project of International Teams, lead by Dr. Tricia Towle. Dr. Towle left her home and medical practice in Pennsylvania in 2003 to go to Cluj, Romania to help hearing impaired individuals. In 2010, Dr. Towle became an advocate for deaf children to receive cochlear implants provided for by the Romanian Health Ministry. Her first patient is now 15 years old and has exceeded all expectations with speech and language. The cochlear implants are helping children thrive in Romania.

Dr. Towle's advocacy for children in the Eastern bloc extended into Albania this past summer where she met a girl named Armela. Armela and her brother, Arjeni, are both deaf and their family is very poor. While Arjeni received a cochlear implant at age two, Armela was denied at age five because the Armenian government said she was "too old," but the real reason was more likely because she is a female. Armela's mother was not dissuaded in finding help for her daughter and was put into contact with Dr. Towle through a mutual missionary friend. Dr. Towle contacted the Albanian government



Dr. Tricia Towle



Armela & Arjeni



Armela, Nesha & Arjeni

regarding the Albanian Health Ministry's decision, but after tireless months of inquiry, there was no move forward. Undeterred, Dr. Towle told Armela's story to countless people in the United States and Romania. In September, Dr. Towle received an email from an American doctor who has a medical foundation in Albania and wanted to contribute a large sum to Armela's implant. Other donors from Romania stepped forward to pay the remaining sum and by the end of October, Armela had surgery in Romania. Such a miracle for this eight-year-old girl and her family!

Romania is a very poor country, but by comparison, has more resources than Albania. A government program does exist within Romania for children to receive cochlear implants, however support for updating equipment is lacking. In most countries, the processors are replaced every five years, but some children in Romania have used theirs for more than 12 years. There is a dire need for cochlear implant equipment in Romania.

CIAF corresponded with Dr. Towle and the Vice President of Asculita Viata (Hear Life) Cosmin Brasov in Romania to better understand what cochlear implant equipment was needed to make the biggest impact within the hearing impaired community. CIAF puts forth countless hours every year to ensure all our CI equipment is efficiently cataloged and documented. It is for this reason that in October we were able to send a comprehensive donation of \$564,000 worth of CI equipment to Romania. We are confident Dr. Towle and her staff will deliver this equipment to those most in need and help more children with similar stories to that of sweet Armela. We are also thrilled CIAF can make this global impact.

If you would like to help CIAF continue our efforts to help more people hear, please visit us at www.ciafonline.org

What's new at

DISTRICT 23 BOUTIQUE



As our Springfield-area friends know, District 23's flagship boutique moved to a new location in early 2018. The bigger showroom has been a hit with shoppers. After we settled in, it was time to make some upgrades and renovations.

"This building has a long history of success as the former site of The Wardrobe, one of the great boutiques in town. But we wanted to put the District 23 brand on it as well, along with making some other improvements," Michelle said.

When customers drive up now, they'll see two large District 23 signs affixed to the building. They'll also notice the new landscaping. Old, overgrown plantings and timbers were taken out and replaced with bushes, flowers,

mulch and rock. New permanent exterior lighting was added, along with electrical boxes to accommodate seasonal displays.

Other exterior improvements include new gutter and fascia, and a new coat of paint for the back of the building.

Inside, the loft area received new flooring and lighting, and was made into a private office setting and photo studio. Most of the interior was also repainted. We also went green by replacing all the fluorescent tube lighting with LED's that really compliment the merchandize displays, and installing energy efficient NEST thermostats.

"Everything looks incredible," Michelle said. "Curt, our handyman, has done a great job. If you haven't been in a while, come by and see us."

