A MAGAZINE FOR THE COMMUNITY

SPRING 2025

The Holley Institute

"You make a living by what you get; you make a life by what you give."

- Winston Churchill

President's Message

Dear Friends,

I have been thinking of what I would like to share with you for a few weeks now and I keep coming back to a quote hanging in our office.

"Rivers do not drink their own water,
Trees do not eat their own fruit,
The sun does not shine on itself,
And flowers do not spread their
Frangrance for themselves.
Living for others is a rule of nature
We are all born to help each other.
No matter how difficult it is.
Life is good when you are happy.
But much better when others are
happy, because of you."
- Pope Francis

Over these past thirty-three years, I have spent endless hours observing the families we have served; but more importantly, the parents who have served their children. I have watched them over these years and have seen parents looking at their children with radiant smiles on their faces as they view their plays/skits they created, the artwork constructed and friends they have made.

I have watched them totally absorbed in tears in the classroom as they express their limitation in serving their child.

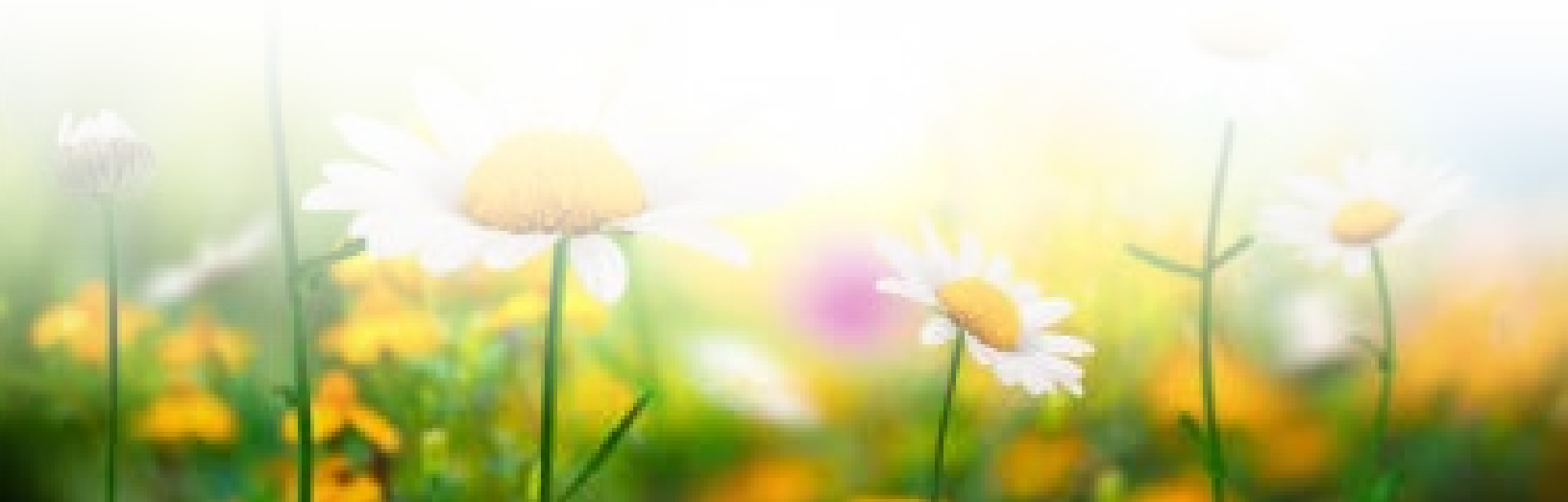
I have knelt in chapel observing parents or a parent in isolation hoping for their children's future. Sometimes with a blank stare that says, "Is it my fault? What else can I do, where do I go from here."

I watch more and more dads joining in the Family Weeks over the years and I am thrilled to see how they want to learn to communicate with their Deaf child. I can see it makes them happy and the child as well.

This is a ministry and mission that should be preserved, valued and appreciated. As I move toward passing it on to others, I have no doubt that this is God's will, God's work and He will see that it continues, "no matter how difficult it is, because we are born to help each other."

With kind personal regards,

Ardis J. Gardella
President, The Holley Institute



Board Chair's Message

Dear Friends and Colleagues,

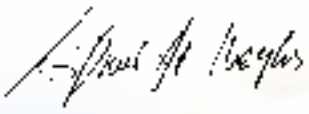
As we mark the first quarter of the 21st century, I find myself reflecting on the remarkable journey The Holley Institute has taken in supporting hearing health across our communities and beyond.

Twenty-five years ago, as we entered this new millennium, the landscape of hearing health was vastly different. Digital hearing aid technology was in its infancy, awareness of hearing protection was limited, and many lived with untreated hearing loss due to stigma, cost barriers, or lack of access to care. Today, I am proud to say that through your unwavering support and our collective dedication, we have helped make strides in transforming this landscape. We've provided thousands of infant hearing screenings in our community and advocated successfully for policies that recognize hearing health as an essential component of overall wellbeing locally and abroad, and most importantly provided critical programming and support to families who are affected by deafness and hearing loss.

Yet for all our progress, we know our work is far from complete. Globally, hundreds of millions still live with untreated hearing loss. Economic disparities continue to determine who receives care. And as our population ages, the need for accessible hearing healthcare grows more urgent each day.

As we look to the remaining three-quarters of this century, I am filled with both hope and determination. Hope, because I've witnessed firsthand the dedication of our staff, volunteers, and partners. Determination, because I know the transformative impact of our work on individual lives and entire communities.

Thank you for being a part of our journey thus far, I invite you to continue this journey with us as we write the next chapter in our organization's story.



Daniel DJ Megler, MD
President, Lakeshore ENT
Chairman, Board of Directors

Love in Action:
Our 2024 Impact Report

The Holley Institute is so grateful for yet another year of creating transformative change in the Hard of Hearing, Deaf, and Deafblind community. Our programs not only provided much needed education and resources, they instilled hope in parents of HHDDB children for a successful future.

Thanks to our donors and supporters, we can continue to grow our programs and expand our reach to support even more families. Your generosity doesn't just support programs – it creates ripples of love throughout our community.

Here's how your support has touched hearts and changed lives in 2024:

Love by the numbers

Summer Family Programs

- Delivered over 480 hours of vital programming to families during our Family Week Programs at the Carls Family Village
- Provided over 40 families with invaluable experiences to create deeper family bonds and understand their HHDDB family members
- Delivered an additional 200 hours of ASL Week, Volunteer Week and Jesus' Deaf Crew Week programming

Community Health and Literacy Program

- Delivered over 2,100 hours of communication skill building education to families
- Mentored 18 HHDDB families from across the state of Michigan
- Hosted 12 ASL Story Time Events throughout the Metro Detroit Community
- Hosted our first ever 'Family Literacy Weekend' where families learned ASL literacy and English literacy skills in an immersive environment

2024 Community Health and Literacy Program Highlight

"I enjoy learning and watching my family learn ASL with our mentor. She is good at turning conversation into learning. When we started this spring, my child would not sign with us or attempt to sign. Now he will sign and will ask me about signs even when our mentor is not there. The most memorable part of our experience this year has just been seeing the ASL improvement in our family. The desire to learn the language from the kids and share what signs they do know with others."

-CHLP Family

Infant Screening Program

- Screened over 3,200 newborns for hearing loss at Henry Ford St. John Hospital
- Over 1300 total hours of volunteering per year
- Volunteers help conserve over $300,000 of hospital resources annually

ASL Classes

- Delivered over 150 hours of ASL classes to our community

Deaf marine biologist Barbara Spiecker discusses accessibility in STEM with UMich ASL Club

By Meghan Somerville

Barbara Spiecker gives talk titled "Hands-on, Minds-on: Exploring STEM through deaf perspectives" at the Michigan League

About 40 attendees gathered at the Michigan League Thursday evening to attend a lecture by Barbara Spiecker, a deaf marine biologist at the University of New Hampshire and creator of the non-profit Atomic Hands, focusing on deaf accessibility in the fields of science, technology, engineering and mathematics. The event, hosted by the American Sign Language Club at the University of Michigan, highlighted both Spiecker's personal story as a deaf scientist as well as her work on ASL inclusivity in STEM spaces.

During the event, two interpreters translated Spiecker's remarks for the hearing audience members. Spiecker discussed her journey as a deaf individual discovering her love for biology and marine science. She said she faced many challenges as she transitioned from a deaf high school to a public college environment with less accommodations for deaf students.

"My first two years were a struggle," Spiecker said. "I look back and I believe the reason is because I had to experience interpreters. I had hearing professors. It was a hearing world."

Despite these challenges, Spiecker remained determined to pursue her passion for biology as well as ASL advocacy. After Spiecker completed her doctorate degree, she founded Atomic Hands with her colleague Alicia Wooten. The organization aims to create accessible content in ASL for STEM education.

Spiecker said her motivation for creating Atomic Hands stemmed from her struggles in college, as the lack of resources made it difficult for her to understand complex scientific topics.

"During grad school, there was a lot of information that I realized that I missed," Spiecker said. "There was a lot of video captions and conversations that I didn't have access to. I did have great interpreters, but they weren't specialized in my field and able to catch specific, important information that I needed."

Spiecker also discussed the difficulties the deaf community faces in accessing STEM education and said she hopes STEM-specific signs could increase inclusion for the deaf community in the future.

"English, Japanese, French — they're all different," Spiecker said. "They have different words for STEM concepts but the foundation is always the same. It's just expressed differently in a different language. STEM concepts do not belong to English. We want to try and separate English and focus just on how can we talk about STEM."

One of Atomic Hands' forms of advocacy is collecting ASL dictionaries to provide resources on STEM-specific signs. Spiecker highlighted various signs used by the STEM community and said scientific signs like "gene mutation" have roots in real research.

"Many people realize in English, when you make up a word, there's always a reason behind it, and that reason is obviously one of many," Spiecker said. "One reason is that we want words to be related to each other. In ASL, if we have a concept and there's a related concept, we also want the science to be similar. We want them to be visibly related."

In an interview with The Michigan Daily, Engineering sophomore Saima Rahman reflected positively on the event and expressed a desire to learn more about ASL.

"I've always had an interest but never got the chance to learn ASL," Rahman said. "I think I am going to try to learn this summer, or at least start."

LSA senior Abigail Kohn, an ASL Club board member, expressed the significance of events like Spiecker's talk in creating better understanding and accessibility for the deaf community.

"It is always our goal to increase deaf accessibility at the University, as well as general public knowledge about ASL," Kohn said.

Published March 27, 2025

Recap of the 2025 Early Hearing Detection and Intervention Annual Conference (EHDI)

Each year Holley Institute staff attend the Early Hearing Detection and Intervention Annual Conference (EHDI) Conference. The goal of the conference is to enhance the implementation of comprehensive state-based Early Hearing Detection and Intervention programs. This year's conference was held in downtown Pittsburg, Pennsylvania. Program Coordinator, Jonathon Klotz, Community Health and Literacy Program Director, Maria Klein and Mentor, Chelsey Munger learned valuable information and strengthened their understanding of the complex issues facing Hard of Hearing, Deaf and Deafblind (HHDDB) children and their families.

Over 850 professionals, researchers and advocates were in attendance and topics discussed ranged from best methods of outreach to families, analysis of other organizations, their performance, and the structure of and outcomes of effective Deaf mentoring programs. Topical sessions highlighted how important early engagement and intervention is to a HHDDB child's language development whether that be through a Deaf-Mentor program like the Community Health and Literacy Program or Family programs, both of which the Holley Institute offers.

As an exhibitor at the conference, the Holley Institute staff were also able to network and spread the word about program offerings and our mission. Program Coordinator, Jonathon Klotz remarked, "Attending the EDHI Conference was such a great experience to meet and engage with other key organizations in serving the HHDDB population, and I am looking forward to implementing and utilizing information learned to better serve the HHDDB community in our state and beyond."

2025 Summer Family Programs

A renewed focus on the parents of children who are Deaf, DeafBlind or Hard of Hearing and how the Holley Family Village can help.

The Holley Institute was envisioned with the goal of providing support to hearing parents of Hard of Hearing, Deaf and Deafblind children. Organizations that supported these parents were in their infancy until the latter part of the 20th century and 65 years later, there are many more organizations supporting these parents.

As we enter into the 32nd season of Summer Family Programs, the Holley Institute is renewing its focus on serving the unique needs of these parents. Of these organizations throughout the nation, the Holley Institute's Carls Family Village remains the only site of its kind, serving parents and the whole family. Understanding early language development and communication skills are vital to hearing parents. Parents are tasked with making early decisions about communication methods regarding ASL, oral language and English literacy. There's often an added urgency to learn ASL quickly to provide early language exposure during their child's critical developmental periods.

Parents often need resources and support to learn ASL while simultaneously teaching it to their child. Family Week One provides parents with an opportunity to learn strategies for ASL literacy and how English and ASL differ, while simultaneously being educated about their child's deaf culture in an immersive environment.

Parents are also tasked with finding pathways to attaining educational support, navigating complex educational choices, advocating for appropriate accommodations and support services in educational settings, and understanding and securing legal rights and civil rights for their HHDBB child. Cultural navigation is also key, learning about and connecting with Deaf culture while not being direct members of it themselves, balancing their own hearing culture while supporting their child's potential involvement in the Deaf community, understanding the distinction between medical and cultural perspectives on deafness...and many more that are supported with the Family Weeks programming.

This list is not exhaustive, that's why the Holley Institute has been committed to helping and supporting parents on their journey and providing access to these crucial skills and information. What's more, the Holley Institute connects parents with other families in similar situations, helping them know they are not alone.

To learn more about the 32nd season of Summer Programs at the Carls Family Village, please visit our website at www.holleyfv.org

Wearable ring translates sign language into text

SpellRing is trained on 20,000 words in American Sign Language

By Andrew Paul

American Sign Language (ASL) has long enabled real-time conversations for English-speaking people who are deaf and hard-of-hearing. But discussions often face significant lags when one or more conversants aren't fluent in the language system. By combining deep learning artificial intelligence and micro-sonar technologies, researchers at Cornell University are developing a new wearable to help overcome the communication barriers. With further refinement, SpellRing may one day facilitate entire conversations regardless of your ASL comprehension skills.

ASL's earliest iterations developed in the early 18th century at the American School for the Deaf in Hartford, Connecticut. Today, around 400,000 people in the US utilize modern ASL, including a large number of children of deaf adults (CODA). Like any language, ASL often takes years of education and practice to reach fluency. Given that the majority of Americans don't regularly occupy spaces requiring it, the language still remains mostly relegated to populations that are deaf and hard-of-hearing. In the meantime, technological innovations haven't caught up with them.

"Many other technologies that recognize fingerspelling in ASL have not been adopted by the deaf and hard-of-hearing community because the hardware is bulky and impractical," Hyunchul Lim, a Cornell information science doctoral student, said in a university profile on March 17. "We sought to develop a single ring to capture all of the subtle and complex finger movement in ASL."

Lim and his colleagues previously worked on similar inventions, including interpretational tools for facial expressions, virtual reality hand poses, and silent speech recognition.

SpellRing builds off a previous iteration called Ring-a-Pose and relies on multiple inputs to analyze, interpret, and translate ASL fingerspelling gestures. The principle component is a quarter-sized 3D-printed ring casing that contains a small microphone and speaker, and is worn around the thumb. When the user begins fingerspelling, the microphone emits inaudible soundwaves that are subsequently detected by the microphone as a miniature gyroscope measures the hand motions. Meanwhile, a

computer featuring a deep-learning algorithmic program analyzes and translates the resultant sonar images into individual letters in real-time on a computer screen.

Researchers trained SpellRing with the help of 20 experienced and novice ASL signers as they spelled out over 20,000 words. SpellRing's accuracy eventually ranged from 82–92 percent.

"There's always a gap between the technical community who develop tools and the target community who use them. We've bridged some of that gap," said Cheng Zhang, an assistant professor of information science.

Despite the advances, SpellRing's designers know it is only an early phase. The wearable is currently limited to fingerspelling. ASL relies on a wider set of upper body movements, facial expressions, and other physicalities, and has more than 4,000 word signs.

"Fingerspelling, while nuanced and challenging to track from a technical perspective, comprises but a fraction of ASL and is not representative of ASL as a language," said Jane Lu, study co-author and a linguistics doctoral student. "We still have a long way to go in developing comparable devices for full ASL recognition, but it's an exciting step in the right direction."

Moving forward, the team plans to expand on SpellRing's capabilities to adapt the micro-sonar system for eyeglasses that assess a user's face and upper body.

On the verge of reversing deafness

A revolutionary approach to treating hearing loss is emerging.

By Jack Dillon Carter

Sheffield researchers are developing novel cell therapies that could repair the damaged inner ear, potentially reversing deafness for many.

Hearing loss is a widespread issue affecting millions of people worldwide. It can significantly impact quality of life, leading to social isolation, depression, and even dementia.

Unfortunately, current treatments like hearing aids only manage the symptoms rather than addressing the root of the problem, as they do not repair the underlying causes of hearing loss.

The most common form of hearing loss globally is sensorineural (SNHL). This type of hearing loss is different from conductive hearing loss, which occurs when sound waves are prevented from reaching the inner ear due to a blockage in the outer or middle ear. SNHL is caused by age-related wear and tear, exposure to loud noise, certain medications, or underlying medical conditions.

SNHL occurs when the inner ear, the cochlea, is damaged. The cochlea is a spiral-shaped cavity filled with fluid containing the critical hearing cells. The primary hearing cells are the hair cells, which convert sound waves into electrical signals, and the cochlear neurons, which transfer this information to the brain via the auditory nerve. When these hair cells or their associated neurons are damaged, the brain cannot properly receive the sound signals, leading to hearing loss.

There is currently no cure or therapy for sensorineural hearing loss; the only treatments to manage the condition are hearing aids and cochlear implants. While these improve hearing for many people, they do not restore natural hearing or function for people with neural SNHL.

One of the biggest hurdles in developing effective hearing loss therapies is the loss of the inner ear cells' regenerative capacity. We are born with all the hearing cells to last a lifetime, and when these are damaged, they are lost forever, and we become deaf.

However, researchers at Sheffield are developing a breakthrough stem cell-based therapy to reverse SNHL that involves repairing the damaged inner ear with auditory stem cells.

Rinri Therapeutics

Rinri Therapeutics is a near-clinical-phase biotechnology company. They are now using Sheffield's science to develop an allogeneic regenerative cell therapy, known as Rincell-1, to regenerate damaged auditory nerves in people with neural forms of SNHL.

This means that the therapy uses stem cells from a donor, not the patient themselves. These new cells are hoped to regenerate the damaged nerves and restore hearing. Rinri Therapeutics is on the verge of a medical milestone, with plans to initiate the first human trial of Rincell-1 for hearing loss in 2025.

Understanding gene therapy and cell therapy

Recent advancements in gene and cell therapy offer significant hope for restoring hearing in patients with limited treatment options. Gene therapy is a molecular approach that seeks to correct faulty genetic code by introducing healthy gene sequences into a cell using a modified virus 'vector' as a carrier. A viral vector is a genetically engineered virus that is used to deliver genes into cells. For these conditions, scientists can now replace defective genes, restore normal protein production, and reverse disease. However, gene therapy is limited in its application when the underlying issue is the absence or loss of whole cells, tissues, or organs.

Regenerative cell-based therapy seeks to replace dysfunctional cells to alleviate disease. It involves introducing stem cell-derived progenitor cells - cells with the ability to become specialised cell types - into the body. This approach is particularly promising for conditions like Parkinson's Disease, where neurons are lost, Macular Degeneration in the retina and tissue regeneration following musculoskeletal injuries.

A recent breakthrough in gene therapy has offered hope to those with a specific type of genetic hearing loss. Researchers from the US, UK, and China successfully treated patients with a mutation in the Otoferlin (OTOF) gene, which is crucial for auditory signal transmission between the inner hair cells and neurons in the cochlea. By delivering a healthy copy of the OTOF gene using a viral vector, scientists were able to restore hearing function in these patients.

This achievement marks the first successful application of gene therapy for deafness, and it definitively shows that biological interventions can repair the damaged cochlea.

While it is a significant step forward, it is important to note that this treatment is currently limited to patients with OTOF mutations which are quite rare. As each genetic form of deafness has its unique genetic causes, it will require a tailored gene therapy for each condition.

Most people with hearing loss do not have a genetic problem, so they will not benefit from gene therapies. However, cell therapies have the potential to treat many more people with SNHL which has been acquired over time through damage or simply through ageing.

Regenerative cell therapies

Researchers at Sheffield have been working on developing a breakthrough cell-based therapy to reverse SNHL. As the loss of hearing cells causes SNHL, the therapy will repair the damage by replacing them with new functional cells made from pluripotent stem cells. Pluripotent stem cells can produce any cell in the human body and are key to this groundbreaking research.

The initial research created cells that targeted the loss of cochlear neurons. The loss of neurons is also a common feature in presbycusis, e.g., the loss of hearing produced by ageing.

These cochlear neurons generated from the stem cells were able to reverse hearing loss, resulting in a massive improvement in the hearing threshold.

Overcoming challenges

Rinri has successfully transitioned the cell production process from an academic setting to meeting the stringent demands of industrial manufacturing and is now focused on collecting essential safety data to meet regulatory standards.

Looking ahead

Rinri Therapeutics envisions a future where its cell therapy becomes a standard of care for millions suffering from sensorineural hearing loss. Their pioneering research and innovative approach offer renewed hope for individuals with hearing loss.

An Outstanding Night of Giving: **2024 St. Nicholas Christmas Event**

The spirit of Christmas was in full swing at our annual St. Nicholas Christmas Event held on November 30th, 2024 at the Grosse Pointe Yacht Club. This year's event brought together over 200 members of our community for an evening of giving, connection, and Christmas cheer.

This year's event raised over $275,000 net and we are profoundly grateful to have also received a 1-million-dollar gift which we announced at the conclusion of the event.

Every year we are reminded of the incredible commitment our donors and volunteers have to our mission and ensuring a bright future for DDBHH children. Generous financial gifts not only fueled our St. Nicholas celebration but turned Christmas spirit into real-world impact for DDBHH children. Thank you for your continued dedication to empowering DDBHH children – it is truly inspiring.

Save the Date for the 2025 St. Nicholas Celebration on Friday, December 12th!

National Volunteering Week Appreciation for Infant Screening Program Volunteers

The Holley Institute celebrates National Volunteer Appreciation Week from April 20th-26th. We are deeply thankful for our committed and dedicated volunteers who screen all infants born at St. John Hospital.

Screening infants for hearing loss in Henry Ford St. John Hospital is critical to ensure those infants who do not pass the screening are given a complete hearing test before 3 months of age. Infants identified with hearing loss before 3 months of age can begin early intervention and avoid speech and language delays; as those with late diagnosis and intervention may never catch up.

The Institute's Infant Screening Program continues to be the first line of early intervention at Henry Ford St. John Hospital ensuring hearing health, and long-term success of children in our community.

Volunteers, Barbara Leising, Donna Stoner and Minal Ahmed pictured left to right represent a wide range of extremely talented professionals, students and community members who chose to donate their time to help make a difference.

Barbara is a retired electrical engineer and enjoys screening infants because of the complex computer technology used. Her expertise in this area allows her to deeply understand how the computers work to complete the hearing screenings. Barbara was very grateful to have ensured that after an infant she screened did not pass, she was able to report to the Holley Institute's Lead Audiologist, B. Jill Courson, AuD and it was later determined the infant had substantial bilateral hearing loss.

Donna Stoner is a full-time top real estate agent in the Grosse Pointe communities but still makes time in her busy schedule to help screen infants.

Minal Ahmed is a first-year student in the Master of Arts in Speech-Language Pathology program at Wayne State and she commutes from Canada to get needed volunteer hours to complete her degree. Minal enjoys screening infants because she is grateful to be part of such a meaningful part of someone's life. She hopes to treat children born with cleft palates as part of her speech language pathology career.

Our volunteers are the heart of our mission, and we deeply appreciate them.

Do you want to be a part of the Infant Screening Program and make a difference in our community? Contact the Holley Institute's Lead Audiologist, B. Jill Courson, AuD by phone at 313-343-4436 or by email at bcourso1@hfhs.org to learn more.

2025 Family Literacy Weekend at the Carls Family Village

The Family Literacy Weekend returned this year to the Carls Family Village from April 4th-6th. The weekend provided expert presentations and activities designed to strengthen ASL and English Literacy skills of participating families.

Families worked one on one with Deaf Mentors on various arts and crafts activities and group activities focused on the family's comprehension of the stories read throughout the weekend.

Activities also included learning about hand shapes, using classifiers, and learning how to read books in ASL. Families applied what they learned and then created their own stories using ASL inspiring their creativity. The hands-on style activities keep children engaged while making learning fun with emphasis on ensuring activities are tailored to meet the needs of the varying literacy levels.

Each participating family took home a copy of one of the books read during the weekend to add to their libraries at home along with solid foundation to continue their literacy journeys.

The Holley Institute

The Holley Institute
Ardis J. Gardella, President
Olivia Abrahamian, Development Officer
Jonathon Klotz, Programs Coordinator

Audiology Department
B. Jill Courson, Au.D., CCC-A, Lead Audiologist
Gerilyn Jones AuD., CCC-A, Audiologist
Sharon English, AuD., CCC-A Audiologist

Holley Family Village, Inc.
Ardis J. Gardella, Executive Director
Fr. Michael Depcik OSFS, Spiritual Director
Paul Kuplicki, Finance Manager
Maryann Muller, Facility Director
Olivia Abrahamian, Development Officer
Jonathon Klotz, Programs Coordinator

Program Director
Community Health Literacy Program
Maria Klein, Director

Mentors
Chelsey Munger
Christina Whetsel
Courtney Gunville
Deidri Hines
Diana Rice
Diane Hines
Jennifer Berrigan
Joanne Forbes
Michaela Jitaru
Monique Balcarcel
Nicole Faino
Sarah Elwood

Founded in 1993, The Holley Institute is a nonprofit organization dedicated to:

- Service to those in need
- Reverence
- Compassion
- Integrity
- Creativity and innovation
- Forward thinking
- Dedication
- Education

The mission of The Holley Institute is to provide life-enhancing programs for those experiencing hearing loss, vision loss or deafness. We also provide programs for parents with children with hearing loss, vision loss or deafness. We screen all infants for hearing loss and provide outreach programs and services and education relating to hearing loss for the community at large.

Please contact us for more information at:
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HENRY FORD HEALTH®

2025 Calendar of Events

The Holley Institute

Date	Activity	Location
May 13	Board Meeting	The Country Club of Detroit
June 26-29	Staff Orientation	The Carls Family Village
June 29-July 4	Family Week 1	The Carls Family Village
July 6-11	Family Week 2	The Carls Family Village
July 13-18	Family Week 3	The Carls Family Village
July 20-25	Family Week 4	The Carls Family Village
July 27-August 1	ASL Immersion Week	The Carls Family Village
August 3-8	Jesus Deaf CREW	The Carls Family Village
August 10-15	Volunteer Week	The Carls Family Village
December 12	St. Nicholas Christmas Event	Grosse Pointe Yacht Club

These dates are tentative and subject to change