FEBRUARY 2023 VOL 16 | ISN 1



ILLINOIS E.A.R.S



E.A.R.S = EVENTS AND RESOURCES STATEWIDE

"What works for your child is what makes the choice right."™

WHO ARE WE?

The Illinois Families for Hands & Voices mission: A parent-driven, non-profit organization that supports families with children who are deaf and hard of hearing without a bias around communication modes or methodologies.

The Illinois Hands & Voices Guide By Your Side mission: Provides free, unbiased emotional support and resources by trained Parent Guides to families with children who are deaf and hard of hearing.

If you are looking for resources, parent support, events or anything else, we want to help! View our contact information on page 26.





What is Mom's Night Im

- An overnight retreat for moms and female care; ALL ages who are Deaf/Hard of Hearing.
- A place to meet and share experiences with other
- · Activities, games, crafts, socialization and more
- Eat a hot dinner SITTING DOWN!
- · Have time just for you!
- · Listen and learn from our Key-Note speaker
- · Eat CHOCOLATE/SUGAR!
- · Breakfast (for overnight registrants)

Sunday - Panel & Closing Circle
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Dear Readers,

It's hard to believe that it is almost time for spring break, trips to the park and the spring flowers to bloom! I look forward to this time of year, new goals are set and I like to think about the changes that will take place over the year.

However, sometimes new goals and changes can be overwhelming and scary too. I can stress over these things or I can do my best to prepare and just live in the moment. In my twenty two years of parenting I can tell you it's often the things that I didn't think I needed to prepare for that turn out to "test" me the most. However, as parents we learn to pivot, figure it out and move forward.

Over the years, I've learned to look for things that bring me joy each day. It could be as simple as my fresh cup of ice tea from Chick-Fil-A to hearing my kiddo laugh uncontrolably as they play a board game and give grandma another "draw two" card. It doesn't have to be anything expensive, new or extravagant. Just like when the kids love playing with the box more than the gift sometimes simple things bring the most joy.

Fostering Joy is a movement to celebrate the magic of raising children who are deaf and hard of hearing. Our organization is excited to be part of this movement and share more about it over the next year.

My Fostering Joy challenge to you is to take a moment to jot down something that you do that brings you joy or a moment of peace. Write it down and tuck it away. Then, on the days that seem to be "testing" you, bring out that piece of paper to remind you what brings you joy and schedule some time to do just that. When we are happy and relaxed we are better friends, co-workers and parents.

With a joyful heart,

Carrie Balian Parent of a son who is DHH ILHV GBYS Coordinator HV Region V Coordinator





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Awards & Promotions

Join us in celebrating amazing accomplishments within our programs.



Art of Camping

Camping with miedically complex kiddos.



Ante Up!

Casino Night



Removing Barriers

Partnering with parents to improve family outcomes.



All Ears Podcast

Exploring the benefits of parent support.



Learn More

Music scholarships for a variety of ages!



Help Wanted

We're looking for families with children who are DHH to provide feedback and get paid for doing so!



Events For All

From in-person to virtual, there are events for all!



Acronyms

So many acronyms! Start here to learn what they stand for.

CELEBRATIONS!

Every year, we recognize our board members and guides for their years of service within our programs. We formally recognize them at 2, 5, 10 and 15 years of service. We are excited to share and recognize the dedication and committment to our programs the following members have provided. Thank you for your contributions!

IL Hands & Voices Board Members



Anita Cervantes-Bowen





Lydia Hernandez



Christen Nolfi





Andrea Johnson

IL Hands & Voices Guide By Your Side Team Members





Alicia Aaron



Amy Keslinke



Ramona Martin



Sarah Esparza





Anita Cervantes-Bowen



Parent Achievement Award

2023 Nominations

Do you know an Illinois parent who has gone above and beyond serving other families with children who are deaf/hard of hearing?

Take a moment to nominate them! Nominations open through 4/1. Award given on 4/29 in Naperville, IL



Scan the QR code with your camera app to be taken to the nomination form



Nomination link: https://forms.gle/weWt9NuLNijNAjmp7





THE ART OF CAMPING

BY CORIE FULTON

My daughter, Louise, was born in 2020 with CHARGE Syndrome, a rare genetic disorder that results in many complex birth defects including profound deafness. In the last two years, she has had open heart surgeries, esophageal repairs, scopes, ER visits, and countless vision and audiology appointments across three states. She has also been to the zoo, circus, rodeo, mountains, boating, fishing, hiking and our favorite, camping. When I think back on these early years, I don't want to relive the despair and desperation of diagnoses and hospital beds. Instead, I want to remember digging in the sand, identifying plants and bugs on trails, and snuggling under the stars by the fire pit. But how is it possible to travel with kids who are medically fragile, who have hearing loss, who are also so young?

- 1. Travel local. You don't need to be hours from home to feel like vacation. Our favorite campsite was in the same town we lived in, or sometimes even our backyard. This can ease the stress of packing all the odds and ends that you may not need. Staying local gives you the ease of mind to run home if needed or be within range of familiar hospitals.
- 2. Prepare language and safety before the trip. We learned relevant signs in our limited ASL before we went camping the first time -- tent, fire, camping, outside, hot, marshmallow. Provide your child a way to express if they are stressed or overstimulated -- I'm tired, I'm hot, I need a break. Read books or watch YouTube videos about camping, and discuss safety rules ahead of time.
- 3. Invest in equipment that will make life easier on the go. A backpack with a stroller clip make a feeding pump and pulse oximeter hands free, and a clamping IV pole allowed us to easily hang a feeding pump anywhere— a stroller, a chair, a picnic table, or a play pen. A waterproof container can protect extra batteries, clips, or amplification devices. Multiple sources of light, like lanterns, headlamps, and flashlights are important to see faces and hands for communication after dark.
- 4. Plan ahead and reserve sites. Many campgrounds have accessible spots that are concrete rather than dirt or gravel that are great for strollers, walkers, and wheelchairs. You can also reserve RV or tent sites that have electric hookups to charge equipment.
- 5. Take advantage of perks. Individuals with permanent disabilities, including sensory impairment, may be eligible for a lifetime Access Pass to America's National Parks at no cost. There is no age limit to the pass. In addition to free entry, the pass covers discounts on camping, swimming, boating, and guided tours. Check out https://store.usgs.gov/access-pass for more information.
- 6. Have fun! Even though traveling can be daunting with all the extra equipment and prep, experiencing nature is a great way to relieve stress, receive visual stimulation, and spend quality time together as a family.



Far left picture: Outdoor breakfast with vacuum suction, pulse oximeter, and feeding pump in tow.

Middle picture: Using concrete pad at accessible campsite for better mobility

Far right picture: Camping provides many opportunities for exploration and visual stimulation.



ricut | Explore Air 2 | Smart Cutting Machine



ANTE UP

AT THE CASINO NIGHT FUNDRAISER

By Andrea Marwah

ILHV Executive Director

On Saturday January 28th, IL Hands & Voices hosted a Casino Night Fundraiser. Amidst inclement weather we stood strong and went forward with our event. We were ALL IN! The evening began with welcoming 123 people in from the cold. They were dressed in their best and ready for a great night. The evening did not disappoint. With the ever-popular gift card roulette where a spin was only \$15 and all gift cards were over \$20. WIN-WIN!! Sorry folks, we sold out in an hour and a half. But fear not... we had more. ChocoEARS, yep you read it right Chocolate ears! YUM! With milk, dark and white chocolate to choose from, this is always a big hit, and this year was no exception. Wine Pull anyone? We made sure that no matter what bottle you bought, it was a good one. With wine ranging in price from \$25 to \$60, everyone got the HIGH CARD when the cost to buy a bottle was only \$20. Not only that, but everyone was entered to win a fun raffle prize just for participating in the Wine Pull and ChocoEARS. We began selling 50/50 tickets about 4 weeks prior to the event and it paid off, we had over \$5500 in the pot when we pulled the lucky winners. The Slaters from Naperville won the POT, but the true winner was our organization when the Slaters turned around and donated their half back to us! Thanks Slaters, you are ONE OF A KINDI

Over 30 participants bought beads to participate in a fun game of Heads or Tails! The winner was going to walk out with a 55 inch Smart TV, the LAST POSITION included our very own state EHDI (Early Hearing Detection and Intervention) Coordinator Ginger Mullin and her husband Doug. It was down to the two of them, wait don't they live together? Hmm, what happened next was a KICKER, Ginger won and told us to raffle the television off! Wow, Thanks Ginger! So we called on Raj Wadhwa to be our auctioneer and we raffled that TV until there were only two bidders. Finally one FOLDED, Congratulation to Mr. Manon who happily walked away with a brand new TV, hope he enjoyed watching the Super Bowl on it. The night ended with the raffles. Individuals played roulette, craps, blackjack, or poker all night long and their winning chips turned into raffle tickets. The raffles this year did not disappoint with everything from a flight over Chicago to a basket filled with items to create a backyard oasis. Everyone walked away hoisting their winnings with a smile on their faces. The evening ended for most with a HIT and RUN, meaning leaving a winner in poker. The intent of the funds raised by this event is to continue to provide support to families in Illinois who have children who are deaf/hard of hearing, thanks to the success of the event we will do just that!

WORKING TOGETHER TO REMOVE BARRIERS TO EFFECTIVE EHDI SERVICES

Written by Tina Grieco-Calub, PhD, CCC-A
Audiologist, Associate Professor of Psychiatry & Behavioral Sciences, Board Member of
the Illinois Chapter of Hands & Voices



In the late 90s, I had the opportunity to co-develop the newborn hearing screening program at the medical center where I worked. The prospect of identifying hearing loss and providing intervention to infants earlier in life was something that the field was striving toward, and I was grateful to be a part of it. Well over 20 years later, the benefits of Early Hearing Detection and Intervention (EHDI) programs are clear: children who are deaf or hard of hearing (D/HH) who receive support earlier in life for whatever communication mode their family chooses have better developmental outcomes. This means earlier access to sound for those children whose families elect for spoken modes of communication, earlier access to spoken and/or signed language, and peer-to-peer mentoring for families.

Despite the positive influence of EHDI, anecdotal and clinical data suggest that not all children benefit equally from EHDI services in their states. As clinicians, we know that many children are either lost in the system, either due to lack of follow up or to poor documentation. In addition, we know that many families who seek services and support do not have the same opportunities to receive those services or support for a variety of reasons. To be better able to support all children, we need to identify the barriers to services to facilitate mitigation strategies. We also need to lean into facilitators of services. Recently, two different review papers – one paper from a group of EHDI stakeholders in Ohio and Missouri (Findlen et al., 2022) and one paper from the Department of Communication Sciences and Disorders at the University of Iowa (Kingsbury et al., 2022) – addressed both issues.

By systematically reviewing existing studies that have been published on the effectiveness of EHDI programs, the papers identified similar individual and family factors as well as system-level factors that either hinder or promote service provision for children who are D/HH. When we think about the EHDI program, we often focus on the EHDI milestones: complete a hearing loss screening by one month of age, confirm hearing loss with a diagnostic evaluation by three months of age, and enroll children in early intervention by six months of age. Although newborn hearing screening programs have very high screen rates (in other words, they screen most of their newborn infants prior to discharge), Findlen et al. (2022) reported that the percentage of children who are D/HH who achieve all the milestones is low: approximately 20% if you evaluate national data. This suggests that once families leave the hospital with their newborns, there is variability in the extent to which they follow up with healthcare and early intervention providers.

By reviewing existing literature in the field, the Kingsbury et al. (2022) and Findlen et al. (2022) studies identified several individual and family factors as well as system-level factors that disrupt the EHDI journey. For example, individual and family barriers to care include low income, limited parental education, lack of or insufficient health insurance, and limited access to healthcare due to distance or lack of transportation are barriers to EHDI services. System-level barriers include structural racism, knowledge gaps among physicians and parents, and poor documentation of services for individual children.

At first consideration, there is a tendency to feel a bit deflated. Given the large variability in factors that prohibit families from receiving services, where do we even start as a community to combat these barriers? However, the outlook may not be as bleak as it may seem. Findlen et al. (2022) noted that one of the facilitators of effective EHDI services is family support. "The overarching theme of system-level facilitators identified in this review is having systems that meet the family where they are.", the authors wrote. Included among these facilitators are family-based organizations that collaborate with state and local agencies to provide resources to families. Related to this is the availability of peer-to-peer mentoring groups where families are matched to mentors with similar demographics, communication choices, and other considerations related to childcare. Findlen et al. (2022) also reviewed a study that showed how care coordination or navigation, especially for families in rural geographical areas, facilitated diagnostic follow-up, achieved earlier EHDI milestones, and increased parent knowledge. Finally, coordinating documentation across agencies helped professionals locate families who were lost to follow up. In summary, by providing multiple layers of support, we can close the gap in service provision.

As a member of the Board of Directors for the Illinois Chapter of Hands & Voices, I have had firsthand experience seeing how community-government partnerships and peer mentoring for parents facilitate effective EHDI services. In our state, the EHDI program works closely with the Guide-By-Your-Side program to ensure that the parents of newly identified infants with hearing loss are paired with an experienced parent who has had a similar journey. Through this partnership, parents realize that they have an advocate in their mentor as well as a door that opens to a large community where they can find resources, support, and recommendations. It is programs like this that give me hope. Although it may not always work the way it was designed for every family, it is a roadmap that we can continue to refine and use a model to overcome barriers to care, even for the most vulnerable children and families.

References:

Findlen, U. M., Davenport, C. A., Cadieux, J., Gehred, A., Holt, R. F., Vaughn, L. M., ... & Hunter, L. L. (2022). Barriers to and Facilitators of Early Hearing Detection and Intervention in the United States: A Systematic Review. Ear and Hearing, 1-12. DOI:

10.1097/AUD.0000000000001312

Kingsbury, S., Khvalabov, N., Stirn, J., Held, C., Fleckenstein, S. M., Hendrickson, K., & Walker, E. A. (2022). Barriers to equity in pediatric hearing health care: A review of the evidence. Perspectives of the ASHA Special Interest Groups, 1-12. DOI: 10.1044/2021_PERSP-21-00188

Given the large variability in factors that prohibit families from receiving services, where do we even start as a community to combat these barriers?





EPISODE 39:

How to Support Families Walking Through a New Diagnosis

Featuring
Carrie Balian with
Guide By Your
Side



On episode #39 of All Ears at Child's Voice: A Hearing Loss Podcast, Wendy and Haley sit down with Carrie Balian about her advocacy work supporting other parents of children with hearing loss. Carrie is a mom to five, whose oldest son, Jack, was born deaf.

Carrie is the Coordinator of the Illinois Hands & Voices Guide By Your Side Program (ILHV GBYS), and serves on both the Illinois Universal Newborn Screening Advisory Committee and Illinois Hands and Voices board. ILHV GBYS provides free one-on-one support through trained parent guides to families with children who have been diagnosed with hearing loss. Wendy, Haley, and Carrie discuss how to support parents going through a new hearing loss diagnosis and the resources that are available to everyone.



To listen to the podcast scan the QR code with your smart device or go to https://childsvoice.org/ahearing-loss-podcast-episode-39-featuring-carrie-baliannotes-and-transcript/



This newsletter is supported in part by grant funding through the IL Early Hearing Detection & Intervention (EHDI) Program.



Hands & Voices 2022 New Year "Freeze Your Fanny" 5k



WRITTEN BY SARAH ESPARZA

This year Hands & Voices headquarters hosted a virtual 5k titled "Freeze your Fanny." This virtual 5k encouraged each state chapter to participate and help raise money for their local chapters. All proceeds from the race went directly to the participating chapter of Hand & Voices.

Hands & Voices is an international organization with 43 chapters that support families of children who are deaf or hard of hearing across the United States. This year's event was held over the New Year's weekend, Friday, December 30, 2022, through Monday, January 2, 2023. Participants were encouraged to; Run. Walk. Bike. Hike. Roll. Crawl or use whatever mode they choose to ring in the new year and help support families throughout their state. The first 500 participants to sign up received a medal, a shirt, and a fanny pack included in their registration fees.

This year we had 637 registrants raising over \$28,300, and 35 out of 43 state chapters participated. Our top winners were:

- 1. South Dakota 72 participants
- 2. Nevada 53 Participants
- 3. Nebraska- 49 Participants

Illinois had a total of 23 participants as well as some additional donations in support of our families. These proceeds will go directly to our IL Hands & Voices Chapter, allowing us to help continue offering resources and support to families.

Participating in fundraisers like this virtual 5k has always proved to be a successful way to show unity across states from chapter to chapter. Our organization represents people from all different approaches to and experiences with deafness or hearing loss. We are the largest parent organization for families raising children who are d/hh in the U.S. Our organization is called upon for thought leadership in health education and parenting arenas, and we work with families and systems that support them from hearing screening, identification, early intervention, school-age and transition into school programs.

Every year our numbers of participants and donations continue to grow. We are so excited to see where 2023 will take us! Stay tuned for updates.





Music To My Ears Scholarship

FHSR celebrates the joy of music and the power of hearing by offering Music Scholarships for deaf and hard of hearing children in the Chicagoland area

This program provides a year of tuition-free music classes for DHH children Ages 0-4 for music enrichment and instrument classes for 4-16 at our partner schools

MUSIC & MOVEMENT - GLENVIEW

MERIT SCHOOL OF MUSIC - CHICAGO OLD TOWN SCHOOL OF FOLK MUSIC - CHICAGO MUSIC MAKERS OF WESTERN SPRINGS COMMUNITY SCHOOL OF THE ARTS - WHEATON **ENCORE MUSIC ACADEMY - CRYSTAL LAKE** SCHOOL OF ROCK - OAK PARK & NORTHBROOK



For more information and to apply for a scholarship visit





Illinois Sound Beginnings has a NEW LOOK!!!

Illinois EHDI

Early Hearing Detection and Intervention

Everything you need to know about hearing screening, diagnostics to intervention and beyond.

Illinois EHDI Program

at Illinois Department of Public Health

Phone: <u>217-782-4733</u>

Email: <u>DPH.newbornhearing@illinois.gov</u>





Get paid for your input!



We need Illinois parents of children who are deaf/hard of hearing to help review parent materials



Review meetings will be held in the evening and some work will be done on your own beforehand.

Only 6 participants needed per session, 3 hours a month, 3 consecutive month commitment.

We are looking to host multiple review committees over the next year. Selection is ongoing, and we will keep all submissions on file to potentially contact for a committee at a later date.



Scan the QR code.
It will take you to the google form with more information and to submit your name as a potential participant.

IS THIS FOR YOU?

As part of tasks related to our grant funding for ILHV GBYS, we have started a quality improvement (QI) project by establishing parent workgroups. Our first QI workgroup consisted of five parents, our GBYS program coordinator, and a Parent Guide. This group met monthly during the first quarter of the year. For each meeting, the parents were assigned documents used in the GBYS program to review and provide honest feedback on. We received great, thoughtful feedback on the documents, including everything from the design to the content to the links provided for additional information. Our goal for creating each parent group is for it to be made up of parents with a variety of diverse cultural, geographic, linguistic, etc. backgrounds as well as those with children of various ages and type/level of hearing differences.

We plan to continue this QI project and are looking for parents who are willing to participate. The monthly time commitment is 1.5 hours of material review and 1.5 hours on Zoom sharing feedback, and parents are paid for this time. Groups typically meet once a month for three months on Thursday evenings, but can shift based on the group members' common availability. If you are interested, please use the QR code above to apply.

We are looking to host two specific QI sessions this year. For these meetings, we are seeking participants who are African American/Black and Latinx/Mexican to provide recommendations and brainstorm with us how we can reach and support more families within these specific communities.



African American / Black Registration Link



<u>Latinx Registration</u> <u>Link</u>





"No Time for Siesta, It's Time for Fiesta"

Mom's Night Inn 2023

April 29th - 30th



- An overnight retreat for moms and female caregivers who are raising children of ALL ages who are Deaf/Hard of Hearing.
- · A place to meet and share experiences with other moms/caregivers who are on a similar journey.
- · Activities, games, crafts, socialization and more!
- Eat a hot dinner SITTING DOWN!
- · Have time just for you!
- · Listen and learn from our Key-Note speaker
- · Eat CHOCOLATE/SUGAR!
- · Breakfast (for overnight registrants)
- · Sunday Panel & Closing Circle

Registration Coming Soon



Hilton Garden Inn - Warrenville Saturday, April 29th to Sunday, April 30th at 12:00_{PM}

Illinois Families for Hands & Voices is a 501c3 Non-Profit Organization, EIN 06-1724201

"What works for your child is what makes the choice right."™



FEBRUARY 2023 VOL 16 | ISN 3



7:00 - 8:00 PM CST (LINOIS 1/18, 2/15, 3/15, 4/19, 5/17, 6/21)

GETTING TO KNOW YOU

Please join us on an informal Zoom meeting to get to know other families with children who have a hearing loss from across the state of Illinois.

PLEASE REGISTER AT THIS LINK

HTTPS://FORMS.GLE/XN4W2PIMEBXCVPKF6 OR

USE THE CAMERA OF YOUR SMART PHONE TO SCAN THE QR CODE

TO TAKE YOU DIRECTLY TO THE REGISTRATION LINK.

A ZOOM LINK WILL BE SENT TO YOU 24 HOURS BEFORE THE EVENT.



THIS EVENT IS HOSTED BY OUR ILLINOIS HANDS & VOICES GUIDE BY YOUR SIDE PROGRAM. ALL FAMILIES WHO HAVE A CHILD THAT HAS ANY TYPE OR DEGREE OF HEARING LOSS ARE WELCOME TO JOIN THIS EVENT.

"WHAT WORKS FOR YOUR CHILD IS WHAT MAKES THE CHOICE RIGHT."0

WE WANT YOU!

Have you wondered how you can help other families with children who are deaf/hard of hearing? Maybe you want to help plan events for families to gather? Serving as an Illinois Hands & Voices Board member is a wonderful way to connect with other like-minded individuals while helping others. The board is looking for professionals, parents and deaf adults. Contact Andrea Johnson, Board President if you are interested or want to lear more:

andrea.johnson@ilhandsandvoices.com



DOES YOUR CHILD HAVE A HEARING LOSS?

This changed my world...(the Institute) opened my eyes to the diversity of hearing loss. development, amplification, social-emotional development and school programs?

All of your questions can be answered in one place!

INSTITUTE FOR PARENTS OF PRESCHOOL CHILDREN WHO ARE DEAF OR HARD OF HEARING

JUNE 11-16, 2023



What is the Institute?

The Institute is a one-week program (Sunday-Friday) for parents of children (through age 7) who have a significant hearing loss. Parents and caregivers will learn about hearing loss and their child's individual strengths and needs. Participants will also meet other parents of children who are deaf or hard of hearing.

Mission Statement

The Institute provides information and support to families so they can make informed decisions on behalf of their child who is deaf or hard of hearing. The Institute was summarized by one parent as "an incredibly useful week to... prepare my child for a life of learning."

Continuted on page 17

"Very well worth our time.
Like others, I wasn't sure what
to expect, but I can tell you
it exceeded my expectations.
All parents of deaf or
hard-of-hearing
children should
attend."

Who Sponsors the Institute?

The Institute receives support from:

- Department of Human Services (DHS)
 - Division of Rehabilitation Services (DRS)
- Illinois School for the Deaf (ISD)
- University of Illinois Chicago's Division of Specialized Care for Children (DSCC)
- Illinois State Board of Education (ISBE)
- Department of Public Health (DPH)
- Ann & Robert H. Lurie Children's Hospital of Chicago



"This was a wonderful and absolutely overwhelming experience. I have learned so much about deafness while here at ISD..."

How Do I Get More Information About the Institute?

Contact Division of Specialized Care for Children at (800) 322-3722 or dsccinstitute@uic.edu.

Visit our website: dscc.uic.edu

More About the Institute

What do children do? Each morning the children go to classrooms overseen by experienced teachers of children who are deaf or hard of hearing. Children receive hearing, vision, psychological, speech, language and educational evaluations. Children will also have the chance to play with other children who have a hearing loss.

What do parents do? Parents attend daily lectures by experts in the field to learn about raising a child with hearing loss. They also meet in small groups to discuss specific concerns and connect with other caregivers. Parents meet with professional staff to review the evaluations for their child. They also have the opportunity to learn about various communication modes used with individuals who are deaf or hard of hearing.

Lecture topics include:

- Child Development
- · Language Development
- Types of Hearing Loss
- · Parent Rights
- Communication Choices
- School Programming
- · Hearing Aids, Cochlear Implants
- · Deaf Culture

Where is the Institute? The Institute is at the Illinois School for the Deaf in Jacksonville, Illinois. Jacksonville is 30 miles west of Springfield on Interstate 72.

What about siblings? Brothers and sisters can come to the Institute. They participate in activities for their age group. Siblings also stay with their families in the dorms and go to recreational activities.

What does it cost? There is no cost for families who come to the Institute. Meals and housing are provided at no charge on the campus of the Illinois School for the Deaf. This week is free!

Who works at the Institute? Professionals from all over Illinois come to the Institute. They come from hospitals, schools, colleges, private centers, ISD, DSCC and DPH.



State of Illinois

J. B. Pritzker, Governor

Illinois Department of Human Services Grace B. Hou, Secretary DSCC, DPH and DHS/DRS do not discriminate on the basis of disability in admission or access to, or treatment or employment in, their programs and activities in compliance with Section 504 of the Rehabilitation Act of 1973. The Directors are responsible for compliance. DSCC (217) 558-2350 and DHS/ISD (217) 479-4200 (voice/TTY) or http://illinoisdeaf.org.







JOIN US FOR OUR TUITION-FREE Winter 2023

Music Therapy Program







Created specifically for deaf and hard of hearing (DHH) children, ages 5-8
This unique program will meet one hour a week

Saturdays from January 21 thru April 22 at 2 locations:

Child's Voice. 9:00 - 10:00 am 1846 W. Belmont Ave Chicago, Il

Music Makers of Western Springs 11:00 - 12:00pm 4332 Howard Ave, Western Springs, IL 60558

Our professional music therapists will sharpen your child's listening skills while boosting their self-esteem, socialization, and articulation along with their DHH peers in a fun musical setting.

The 12 week tuition-free music therapy program will focus on:

Listening to and making music to encourage careful listening (auditory training)
Singing and playing songs to support speech and language development
Making music together as part of social and cultural connection with others
Music making as part of personal enrichment and self-esteem

Listening to and making music with friends and family can provide fun adventures and new, exciting sounds to explore. **Age appropriate siblings are welcome.**

Register now at www.fhsr.org

For questions or more information please contact:
Kristen Van Dyke, Executive Director
kjvandyke@fhsr.org

DADS MEETING OTHER DADS

On the Following Wednesdays
8:00_{PM} — 9:00_{PM}

January 25
February 22
March 22
April 26
May 24
June 28

December 14



All dads or father figures of children who are deaf/hard of hearing are welcome to join this safe space to talk about you and your kids.

REGISTER TODAY:

 $\underline{https://fs4.formsite.com/rh1RZR/q20ivmj8ux/index.html}$

You must register to receive a zoom link to attend the event. ADA requests must be made within 1 week of the event, don't delay — register today!



Illinois Hands & Voices is a 501c3 Non-Profit Organization EIN 06-1724201
"What works for your child is what makes the choice right."™





Sessions are on the following Monday's

7:00pm-8:00pm

February 6th March 13th April 3rd May 1st June 5th Hands & Voices ASTra™Advocates will answer your special education questions.

Advocates from these states will be present:









Register today:





https://forms.office.com/r/JPRZRbo97M

A Movement to Celebrate the Magic of Raising Children who are Deaf and Hard of Hearing



Throughout the next year ILHV GBYS will be providing presentations and trainings to parents and professionals on Fostering Joy.

Fostering Joy provides support and resources for families and professionals to positively help the growth and development of a child who is D/HH.

For more information please contact ilhvgbys@gmail.com.

ASTra - Advocacy

Support and Training is a nationally recognized Advocacy support organization led by Hands & Voices. States can add this program as a service offered to families. This program will provide trained advocates to assist families in IL who have children who have hearing and/or vision concerns. The program should be rolled out by August 1, 2023. Join us at this Q&A to get some

insight on how we can

support families.



2023

EARLY INTERVENTION Vision & Hearing Conference





WHEN:

June 26 -27, 2023 8:30AM — 4:00PM

WHERE:

ISU Alumni Center, Normal IL

WHAT:

FREE EI and ISBE PD Credit

TOPICS (topics subject to change):

COMBINED TOPICS INCLUDE:

Abuse/Neglect in the Home: What Providers Need to Know

Fostering Joy: Journals for families

CHARGE Syndrome Co-morbid Autism Communication Matrix Deaf Mentors - Vision Mentors

Communication Science Updates

VISION SPECIFIC: Babies Count Information, Fundamental Skills

HEARING SPECIFIC: CID Curriculum Early Listening at Home.

Structured Work Groups - Sharing Tips Session

REGISTRATION:

Coming Soon

FOR MORE INFORMATION

andrea.marwah@illinois.gov





FREE Conferences for Parents of Children who are Deaf and Hard of Hearing

And the professionals who work with their children

2023 Illinois School for the Deaf Outreach
Statewide Parent Conferences

THREE Locations to choose from:

- South of Eighty Springfield Saturday, April 15 8:30AM 3:30PM
- North of Eighty Wood Dale Saturday, April 29 8:30_{AM} 3:30_{PM}
- South of Seventy Carterville Saturday, May 6 8:30AM -3:30PM

2023 Conference Topics:

- All About Technology Accessories
- Fostering Joy
- · Growing Up Deaf/Hard of Hearing
- Services & Supports in Illinois: Discover them All
- · Self-Advocacy Skills from School to Home



1 FREE journal per family attending

General Conference Information you should know:

- No childcare is provided at this conference, we welcome your children age 15 or older to participate in the conference.
- Reasonable ADA accommodation requests must be made at least 3 weeks prior to the event date. ASL interpreters are provided at all conferences.
- These conferences are parent safe, meaning the topic of individual amplification or communication choices is not discussed. All families, regardless of the choices they have made are encouraged to attend.
- Parents: Financial assistance may be available to help with travel, lodging and/or childcare costs. See page 2 for more information.
- Professionals: IL State Board of Ed PD and El credit available
- Lunch Included

Register Today

https://forms.office.com/g/bYhdNcccnv

Questions or requests - Contact: andrea.marwah@illinois.gov



Additional Conference Information:

Financial Assistance may be available to reimburse expenses for childcare, travel or overnight accommodations. Some options are:

- The ARC of Illinois Consumer Stipend Project provides funding for families of children with developmental disabilities. Application deadline is 30 days before the event. For more information: www.thearcofil.org or 815-464-1832.
- UIC Specialized Care for Children may have funds available. Contact your DSCC representative. For more information: http://dscc.uic.edu/.
- STAR NET offers assistance to eligible families. Eligibility, application guidelines and amounts available vary by region. Application deadline is 15 days before the event. For more information about opportunities for financial assistance from STAR NET find your region on the Starnet website https://www.starnet.org/map-of-regions/:

Region I/III: <u>r-slaght@wiu.edu</u> - 309-298-1634

• Region II: <u>sthomas@cntrmail.org</u> - 224-366-8574

• Region IV: <u>skraus@sccroe50.org</u> - 618-825-3969

• Region V: <u>starnet@cps.edu</u> - 773-553-5596

• Region VI: <u>starnet@swcccase.org</u> - 708-342-5370

Conference Contributors:

- Childs Voice School Wood Dale, IL
- ITAC IL Telecommunication Access Corp
- ISRC IL Service Resource Center
- II School for the Deaf
- John A. Logan

Conference Planning Committee:

- Illinois Hands & Voices, Guide By Your Side
- Illinois School for the Deaf Outreach
- Illinois Service Resource Center
- Illinois State Board of Education
- · Parents of Children who are Deaf/Hard of Hearing
- Chicago Hearing Society (CHS) Youth Connections









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SHARE YOUR EXPERIENCES IN EARLY INTERVENTION

THE DIRECTOR OF THE BUREAU OF
EARLY INTERVENTION IS HOSTING
FOUR VIRTUAL TOWN HALLS WITH
FAMILIES OF CHILDREN IN EARLY
INTERVENTION. DURING THIS TIME,
YOU CAN SHARE YOUR
EXPERIENCES, ASK QUESTIONS, AND
VOICE YOUR SUGGESTIONS TO
IMPROVE EARLY INTERVENTION.



- Tuesday, February 7, 2023
 9:30 am to 10:30 am
- Tuesday, May 2, 2023
 7:30 pm to 8:30 pm
- Wednesday, September 6, 2023
 - o 9:30 am to 10:30 am
- Thursday, November 9, 2023
 7:30 pm to 8:30 pm

TO REGISTER FOR THE TOWN HALL
MEETING, CONTACT MEGHAN BURKE AT

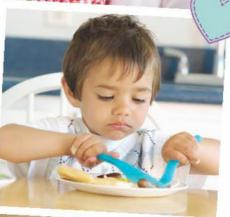
Illinois
MEGHANBM@ILLINOIS.EDU

Early Intervention Clearinghouse OR 217-300-1226











camp Lions Summer Camp

CAMP DATES

2023

JUNE 25th-JULY 1st

Youth Week
Red Leaf Village Camp

(Formerly known as Henry Horner)

26710 W Nippersink Rd, Ingleside, IL 60041

JULY 2nd-JULY 8th

Helen Keller Week
Red Leaf Village Camp

(Formerly known as Henry Horner) 26710 W. Nippersink Rd, Ingleside, IL 60041

JULY 16th-JULY 22nd

HoH/Deaf Week East Bay Camp

24248 Ron Smith Memorial Highway, Hudson, IL 61748

JULY 23rd-JULY 29th

LV/Blind Week East Bay Camp

24248 Ron Smith Memorial Highway, Hudson, IL 61748

JULY 30th-AUGUST 5th

Youth Week
Camp Dubois Center

2651 Quarry Road, DuBois, IL 62831

VISIT US AT
LIONSOFILLINOISFOUNDATION.ORG







Camp Lions Summer Camps 2023

Eligible campers for Youth camps must be between the ages of 7-17 years old, at the start of camp and have visual acuity range of total blindness or a vision loss of 20/70 in both eyes after best correction and/or a hearing loss which requires daily use of communication alternatives such as sign language, lip reading and/or use of a hearing aid, cochlear implant, or similar auditory device.

Applications will need to be filled out in full and received by May 1st to receive your FREE Camp Lions T-Shirt.

June 25, 2023 to July 1, 2023: For Low Vision/Blind-HoH/Deaf Youth 7-17yrs Camp Red Leaf (formerly known as Henry Horner) Ingleside, It. Offers canoeing, archery, nature, crafts, cookouts around the fire, a dance and so much fun it's hard to imagine. Top it off with a pool party and camp talent show and you have it all!

July 2, 2023 to July 8, 2023: For Low-Vision/Blind-HoH/Deaf Adults 18 & older Camp Red Leaf (formerly known as Henry Horner) Ingleside, IL at Camp Helen Keller: Eligible adults have the opportunity to relax and participate in activities in the great outdoors while still being in an accessible environment. Camp Lions Helen Keller is a great place to meet other individuals with similar life experiences. Activities at Camp Lions Helen Keller are geared to adult participants. They include swimming, team sports, card and board games, arts and crafts, a talent show, even a dance. Fun activities make this an active camp!

July 16, 2023 to July 22, 2023: For HoH/Deaf Youth 7-17yrs East Bay Camp Hudson, IL This camp offers specially designed activities for youth who are Hard of Hearing/Deaf. The camp site has many activities to do! Such as, paddle boats, canoeing, archery, nature walks, crafts, cookouts around the fire, a dance, fun times at the beach and even heading to the pool. They end the camp week with a talent show. This camp is fun for all who attend!

July 23, 2023 to July 29, 2023: For Low Vision/Blind Youth 7-17yrs East Bay Camp Hudson, IL While many activities are identical to our other camps, this session highlights activities that accommodate youth who are Blind or have low vision. Our daily schedules, which are posted in large print and in braille, may list some of the following choices: swimming, beeper baseball, beeper archery, and crafts such as painting, beading, or small handmade items. Every day is different and perfect for the creative spirit. A beach party, dance, talent show, cookouts, songs around the campfire, pool swims, braille bingo & cards, plus a wide assort- ment of tactile games, described videos, and more will fill this week with fun! Every cabin is one level and has a modern bathroom with a walk-in shower. Our counselor to camper ratio is 1:4 to make Camp Lions a positive and safe experience.

July 30, 2023 to August 5, 2023: For Low Vision/Blind-HoH/Deaf Youth 7-17yrs Camp DuBois Center DuBois, IL At this campsite there are many activities to do, such as, water sports, fishing, teams courses, ga-ga ball, basketball, beeper baseball, archery, horseback riding, swimming, boating, water mat, arts & crafts, cookouts with s' mores and talent night to top it off! Plus time to relax and talk with new friends under the shade of a tree.

Visit our website at lionsofillinoisfoundation.org for more information about our summer camps for Low Vision/Blind-HoH/
Deaf Youth and Adults. Or email us at camplions@lifnd.org visit our FB page Facebook.com/CampLionsIL

Adult and Youth Campers please use our website online registration form.

ACRONYMS

HERE ARE SOME ACRONYMS THAT YOU MAY SEE THROUGHOUT THIS NEWSLETTER OR IN INFORMATION ONLINE

1-3-6 - Hearing screened by 1 months of age, Diagnostic testing by 3 months of age, and enrolled in Early Intervention and parent support by 6 months of age

AAP - American Academy of Pediatrics

ADA - Americans With Disabilities Act

ASL - American Sign Language

CMV - Cytomegalovirus

DBA - Doing Business as Agreement

DEI - Diversity & Equity Infusion

DHH - Deaf Hard of Hearing

EHDI - Early Hearing Detection &

Intervention

IDEA - Individuals with Disabilities

Education Act

IDPH - Illinois Department of Public Health

IEP - Individualized Education Program

ILHV - Illinois Hands & Voices

ISRC - Illinois Service Resource Center

GBYS - Guide By Your Side

JCIH - Joint Committee on Infant Hearing

LTF - Lost to Follow-up

L2L - Leadership to Leadership

NCHAM - National Center for Hearing

Assessment and Management

PG - Parent Guides (parents of children who

are deaf/hard of hearing)

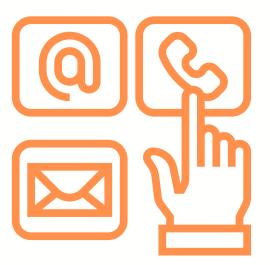
SNIPPET - Simple N Informative Parent-to-

Parent Education Tools

Illinois Hands & Voices, Guide By Your Side does not support or endorse any specific organization, communication or amplification choice.

The information in this newsletter is to simply share with families and professionals the resources and events available to them.

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IL Hands & Voices Guide By Your Side (ILHV GBYS)

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Phone: 217-782-4733

Email: DPH.newbornhearing@illinois.gov Web: www.illinoissoundbeginnings.org