SEPTEMBER 2023 VOL 16 | ISN 3



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 23.



Written by Lace Mandrell, Parent and ILHV GBYS Parent and D/HH Guide

Illinois is a long state. But distance did not stop families with children who are deaf/hard of hearing (DHH) from attending an event in central Illinois hosted by our own IL Hands & Voices GBYS Parent and Lead DHH Guide, Anita Cervantes-Bowen. On a sunny day in mid-July, several DHH families gathered in and out of a pavilion at Harmony Park. This was my first time attending an IL Hands & Voices GBYS event with my children in tow. The usual jitters of meeting both new and familiar faces fell away as our children moved about, seeming to make introductions for us.

















Dear Readers,

I can honestly share that there are only a few things I would change about our journey as a family with a son who was born with hearing loss. Our son is now 23 so we are certainly not new to this. However, looking back I can definitely see the "should of, would of, could of" moments.

One of those things would be to trust my gut more. Often I deferred to the professionals without doing more research on my own or asking more questions. Of course, early on, technology and resources weren't even close to what they are today. So, talk to other families, ask questions, connect with a Parent Guide from our team so that you can confidently make decisions from the unbiased information you have gathered.

Another experience I wish we had sooner was to connect with adults who had a hearing loss themself. I will refer to these individuals as D/HH adults. I think my son was 10 before he met D/HH adults. It really opened my eyes to see how important this was. He had the ability to learn how he could overcome challenges, that possibilities were endless and that he wasn't alone. I learned that the D/HH adults could guide me with resources and tips on how to help him be more independent with waking up in the morning, the best way to manage driving lessons, what to do at an interview and so much more!

Be sure to take advantage of the resources available to you so when you reflect back you can feel confident that you didn't leave any stone unturned!

Sharing from experience,

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





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A college senior shares about her summer internship experience.



Tips for Students

A teacher who is also D/HH shares tips for students and their families.



Popsicles in the Park

An afternoon of meeting other families while playing at the park.



Coming Soon

A new part to our program will officially begin in October!



PTI

Learn more about these resources for families!



A day in the Life

Insight from a high school student.



Fostering Joy

Join us to learn more and begin your Fostering Joy journey!



Events For All

From in-person to virtual, there are events for all! Check out all the pages so you don't miss out!



Acronyms

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

Insight to an Internship

An Interview with Samantha Marwah, Senior at RIT (Rochester Institute of Technology)

Can you share with us a little bit about you and your journey?

My name is Samantha Marwah, my major is MIS (management information systems) and I attend Rochester Institute of Technology. I was diagnosed with hearing loss at age 2. Besides attending Child's Voice, I went through mainstream schooling my whole life and thus, almost all of my friends were hearing. So attending RIT and getting exposure to an academic environment with other Deaf and Hard of Hearing students was a big learning experience for me.

Tell us about your summer internship. Where did you work, and what was your role?

I worked at ABM industries as a data analyst intern. I was recommended for this position and I was looking into many different kinds of internships, not really sure what I wanted to do. The description fit a lot of my interests and skills, so I decided to apply.

What strategies or tools did you use or that was provided to you to ensure effective communication in your workplace during the internship?

My role was remote, so communication tools such as MS teams or Outlook were vital to making sure deadlines were being met and the team was on the same track. There were no specific accommodations provided, mainly because I didn't request any. My manager knew about my deafness and was ready to provide accommodations once requested.

Can you share any challenges you faced as a college student who is deaf during your internship, and how did you overcome them?

Challenges included sometimes missing important things in meetings. Luckily, being remote meant meetings were always through MS teams which had a captions option and a recording option, as well as me taking my own personal notes and being able to email my manager or other colleagues in the meeting if I had any questions.

How did your summer internship contribute to your personal and professional development?

This internship was definitely an experience. It goes to show that there are always new things to learn and getting exposure to corporate and different roles helped me figure out what kinds of roles I may or may not want to pursue. Aside from gaining skills, I feel that I enhanced many skills I learned through coursework or previous experience. Some skills include communication, MS office 365, SQL, organization, and more.



Could you describe the level of support and understanding you received from your colleagues and supervisors during your internship?

I kept in touch with my manager often and those on my project team. If I had a question or concern or needed something to be rephrased, I was not afraid to go and ask for help. For the most part, my manager and colleagues were understanding.

Were there any instances of inclusivity or accessibility that made a significant impact on your experience?

I don't think inclusivity came from my disability, but just from being an intern (and the only one on my team). I think it was more along the lines of an attempt not to overwhelm me with things that are not necessary to what I was working on within my project.

What advice would you give to other college students with hearing loss who are considering pursuing internships or entering the workforce?

I would say to apply to wherever you want, and follow your interests. If the business is not willing to accept you or accommodate you, find another place that will better accommodate you. But don't only limit yourself to certain places that you think will be best for you in terms of having a hearing loss.

Are there any resources or organizations you found particularly helpful in navigating your internship journey as a deaf student?

I think just being at RIT and having NTID (National Technical Institute for the Deaf) there for me really helped as all of my professors have been understanding when it comes to working with students that have a hearing loss and may need extra explanation or rewording things that are said in a lecture. Also having a counselor for my college and in NTID has really helped, especially in terms of my past internship.

Tips For Children With Hearing Loss

Going back to school can be an exciting, yet potentially challenging time for children with hearing loss. Here are some tips to help ensure a successful and positive experience:



Educate Teachers and Peers

Inform teachers and classmates about your child's hearing loss, its impact, and how they can provide support.
Raising awareness can create a more inclusive classroom environment.



Teacher Support

Regularly communicate with teachers to discuss your child's progress, challenges, and any adjustments needed in the classroom.

Collaboration between parents and teachers is crucial.



Work with your child's teachers and support staff to establish a communication plan that suits your child's needs. This may involve using sign language interpreters, captioning services, FM systems, or other assistive listening devices.



Encourage Self-Advocacy

Help your child develop strong social skills, including self-advocacy and effective communication. This can empower them to express their own needs and preferences.



Promote Inclusivity

Advocate for inclusive practices within your child's school. Encourage teachers to implement strategies that benefit ALL students, such as using microphones, minimizing background noise, and facing the class when speaking.





Use of Technology

Utilize technology to enhance learning. There are various apps, speech-to-text tools, and captioning services available that can assist your child in accessing information.



Prepare for IEP Meetings

Review your child's current IEP, strengths and concerns before the meeting. Diplomatically advocate for your child's needs and goals. Work with your child's teachers to design accommodations and services. Ask for data and evidence supporting the services chosen!



Connect with Support Groups

Join local or online support networks for parents/caregivers of children with hearing loss. Sharing insights and advice can offer valuable guidance.

Remember that each child is unique, so it's important to tailor these tips to your child's individual needs. Open communication, collaboration, and a positive attitude can make a significant difference in your child's educational journey!

Written by: Lily Plummer, Teacher of the Deaf and Hard of Hearing Thomas Metcalf Lab School - Heart of Illinois Low Incidence Association (HILIA) POPSICLES IN THE PARK

Written by Lace Mandrell, Parent and ILHV GBYS Parent and D/HH Guide

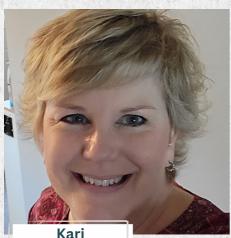
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COMING SOON







SHARING THEIR STORIES...

Written by Carrie Balian

When my son was diagnosed with a hearing loss I felt so unprepared. How would he get a job, would he drive, would he be bullied? All of those thoughts and many more ran through my mind. Problem was, I didn't know of any deaf adults to ask and to guide me allowing me to grow as a parent. Deaf adults have so much knowledge for us to learn from such as how they manage social situations (larger gatherings/meeting new people), if they request accommodations for special events (concerts/plays), navigating their day to day life (waking up/fire alarms), traveling (intercoms at airports) and any other questions you may be wondering about.

I am excited to share that as of October 4th all of our Deaf/Hard-of-Hearing Guides (D/HH) will have officially completed their training and will be available to start meeting with families. Families will be able to arrange one-on-one conversations with any of our D/HH Guides for FREE!

To learn more or to connect with one of our D/HH guides please reach out to ILHVGBYS@gmail.com or call/text 224-343-1873. See page 13 to register to meet D/HH guides over zoom.



D/HH Guides are a diverse group of D/HH adults who complement the work of Parent Guides by working alongside them. D/HH Guides share with children and families their unique life experiences, use of technology, how they navigate social situations, how they developed their personal identity, etc.



PTI? WHAT'S THAT?

Written by Kelly Fulton

Each state has a Parent Training and Information Center (PTI). PTIs are federally-funded agencies designed to educate and empower parents of children with disabilities about their early intervention and special education rights. The PTI is primarily staffed by parents of children with disabilities. Illinois has two PTIs: the Family Resource Center on Disabilities in the Chicagoland area and Family Matters located in Central Illinois. They offer free training, resources, referrals, a lending library, individualized assistance, support groups, and special education advocates. PTIs offer a variety of resources about topics such as basic rights, evaluation and assessment, early childhood, response to intervention, and parent leadership. While the PTIs serve more than 1.4 million families of children with disabilities each year, less than 5% are families of children in early intervention (National Parent Technical Assistance Center, 2016).

If you are searching for a place to connect with more parents, learn about advocacy and you/your child's rights, have questions about early intervention or special education, or are in need of someone to talk to for consultation about an individual issue, then contacting your local PTI is right for you!

For the Chicagoland area reach out to:

The Family Resouce Center on Disabilities https://frcd.org
11 E. Adams St, Suite 1002
Chicago, IL 60603
312-939-3513
email: info@frcd.org





All of Illinois outside of the Chicagoland area reach out to:

Family Matters https://www.fmptic.org/ 1901 S. 4th St., Ste. 209 Effingham, Illinois 62401 1-866-436-7842





SA Day In My Life AS A DEAF HIGH SCHOOL STUDENT

Written by Tessa Brannigan

When I think about a typical day as a deaf high school student, my day technically starts the night before. Before getting ready for bed, I must prepare my cochlear implants for school. I remove my processors, slipping the receivers off to retrieve the used batteries and plug them into the rechargeable storage unit so they'll be ready in the morning. I then place my processors in the dry and store unit, and when the blue light turns on, I know it's working correctly.

The following day, I wake to my alarm clock in the morning; it shakes my bed so I can start getting ready for school. I prefer a quiet start to my morning so I leave my implants off. I gather my school supplies into my backpack, put on makeup, and do my skincare routine, then return to my bedroom to assemble my cochlear implant by doing the nighttime routine but in reverse this time. I place the spare batteries in my implant bag, then into my backpack, where they will be waiting when a battery loses its charge. Before heading out the door, I always make breakfast and scroll through social media while reading the closed caption. The last thing I do before leaving for school is finally putting my implants on so I'm ready for the day.

The first thing I do after walking through the school door is head down to the nurse's office, where I pick up my FM systems, my Luna microphone that captures sound 360 degrees around me, and my closed captioning microphone. I turn all of these devices on and then sync them to my receivers. But I especially look that the FM touchscreen is working since this is the microphone that my teacher uses for lectures. I know it is working correctly when the indicator light blinks green, and I double-check that the microphone strap is adjusted to the correct length to be correctly positioned for when my teachers wear it. For all of my class periods, I always enter the room with the microphone ready for my teachers in advance. In class, I switch between the different closed captioning devices depending on whether it is the Luna mic that I use during group discussions, or the Roger Neckloop, which is used when the teacher is lecturing. They are both connected to my computer using Bluetooth, so I can see what is being said using closed captions. The teachers know to press the mute button when they talk to other students individually so that I don't hear their conversations. However, I occasionally have to remind them to unmute themselves when they begin presenting to the entire class again. At the end of the day, I return all of the microphone equipment to the nurse's office, where I store them and charge them overnight.



Every day after school, I practice for two hours as a competitive figure skater, doing lots of spins, jumps, and edge work. When I first started skating, it took a while before we could figure out how to keep my implants on my head. We initially tried headbands, clips, and tape, but nothing could keep them on, especially during the faster spins and the jumps. But we finally figured it out- in addition to using ear molds, I use toupee tape to keep the processors on behind my ears while I cover my coil magnet with my hair that is pulled tight into a ponytail or bun. I sometimes also clip barrettes over the cables that connect my processors to the magnets for extra security.

When I get home from skating, I need to immediately start doing homework and hours of studying. Depending on the day, I either want to listen to music or, at other times, take the opportunity to study in silence by taking off my implants. If I want to listen to music, I use my over-theear headphones to cover the microphones on my implants. Sometimes, I take them off entirely and put them in my dry and store case to allow me to focus more in silence, and other times because I feel overstimulated. My mom always knows the possibility of me choosing to be deaf while I study, so when she calls me down to dinner, she texts me instead. After I finish my homework, I like to relax, maybe watch a show, scroll through social media, or snuggle with my dog. Then, at the end of my night, I repeat the same steps as I did the night before so that I am ready for another day.



Resources for Families

Illinois EHDI

Early Hearing Detection and Intervention

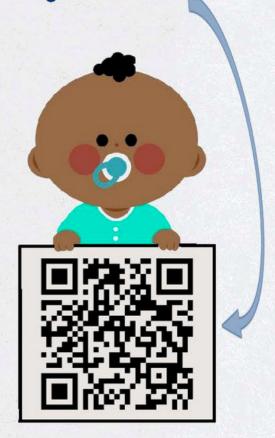
Everything you need to know about hearing screening, diagnostics to intervention and beyond.

Illinois EHDI Program

at Illinois Department of Public Health

Phone: 217-782-4733

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.

CHARGE Family Liaison

Hello Illinois families.

My name is Corie Fulton and I am your new CHARGE Syndrome Foundation Family Liaison. I am a volunteer for the CHARGE Syndrome Foundation and work as a liaison between the Foundation, our state deaf-blind project, and the families in our state that have a child with CHARGE syndrome of any age. As your Liaison I will share the latest CHARGE resources with you and the state project, assist in helping both the Foundation and the state project identify and refer families that have a child with CHARGE syndrome, update the Foundation on available state resources, and promote connections among the CHARGE families in our state.

My husband Andrew and I have two children: Harry (4), and Louise (2 - CHARGE Syndrome). We lived for 8 years in Carterville, IL and currently live in Petersburg, northwest of Springfield. Our family likes to camp, ride horses, swim, play sports, garden, and travel.

I look forward to hearing from you, hearing about your child, and any ideas you may have for family connections in our state. Please join the new Facebook page "CHARGE Syndrome Illinois" to help grow our local community. I hope to keep our families better informed and connected.



Join our Fostering Joy zoom meet up

Register to receive a free journal and learn more!

November 8th - 7pm On Zoom







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

Illinois families for Hands & Voices is a 501c3 Non-Profit EIN 06-1724201

Celebrating our Children Focusing on Joy

Live OSA

MONDAY 8:30 PM OCTOBER 9TH

What do you like to do for fun?

Join us for an opportunity to ask questions and learn more from our team of deaf and hard of hearing (DHH) Guides.

Register through the QR code or at https://forms.gle/5Y4rJWBh1eNvWpoE6 to receive the zoom link.









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



Pumpkin Picking and Painting!

Fall treats!

Deaf clowns!



1:00-4:00

OCT 14

ROLLINGBROOK PARK BLOOMINGTON, IL



REGISTER NOW



HTTPS://FORMS.GLE/XFZW WDKEACQY2WBX9

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

In the choice of the



Chicago



Support our team!



ILH&VGBYS has a team walking at the event on October 1st. We hope you can support us with a donation toward our team and come cheer us on at the event!





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





7:00 - 8:00 PM CST 8/16, 9/20, 10/18, 11/15

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/XN4W2P1MEBXCVPKF6 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."

Illinois families for Hands & Voices is a 501c3 Non-Profit EIN 06-1724201

Illinois Hands & Voices Guide By Your Side

DADS
MEETING
OTHER
DADS



On the following Wednesdays

8:00pm - 9:00pm

October 25
November 22
January 24
February 28
March 27
April 24
May 22

Join us for an informal Zoom meeting to get to meet other dads of children who are deaf/hard of hearing across Illinois.

All dad's 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:





https://fs4.formsite.com/rh1RZR/g20ivmj8ux/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."™





Advocating for your DHH Child/Students

Meets on the following Mondays 7:00pm—8:00pm

 Sept 11
 Oct 9

 Nov 6
 Dec 12

 Jan 8
 Feb 5

 Mar 4
 Apr 1

 May 6
 June 3

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

Illinois Deaf Campers

Host

Scarecrow Field

October 6th - 8th, 2023

TIMBERLINE CAMPGROUND

1467 Timberline Road Goodfield, IL. 61742 www.timberlinegoodfiled.com



Any Question to contact: Keith: VP: 1-815-220-5097

Anita: Executor_idcnfp2014@outlook.com



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

Barly Intervention Clearinghouse OR 217-300-1226











Please Join Us to Socialize & Connect DHH Family Game Night



Sponsored by ISRC & John A Logan ASL Club



Date: Thursday, October 12th, 2023

Time: 5:30-7:30 PM (Doors Open at 5:15 PM)

Lincoln Elementary School 400 Morningside Dr. Marion, IL 62959

There will be pizza, games, and prizes for the whole family. Come out and have some fun and socialize with other families with deaf/hard of hearing children.

Help us make the evening a success - RSVP by Monday, October 9th, 2023 Scan Below to Register

https://www.eventbrite.com/e/dhh-family-game-night-registration-721627506297?aff=oddtdtcreator



Illinois Service Resource Center

Behavior support for students who are Deaf, Hard of Hearing, or Visually Impaired
A Service and Resource Center of the Illinois State Board of Education











ISRC (Illinois Service
Resource Center) is
starting a Deaf and
Hard of Hearing
Student Pal Program!
Students connect
with other students
who have a hearing
loss that have similar
interests!!

To sign up, go to www.bit.ly/ISRC-Pals

DHH Student Pal Program

Interested students will be paired with another student with similar interests for asynchronous written or video exchanges throughout the year.

ISRC will provide monthly prompts for the communication.







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

MERIT SCHOOL OF MUSIC - CHICAGO MUSIC MAKERS OF WESTERN SPRINGS MUSIC & MOVEMENT - GLENVIEW

MUSIC - CHICAGO OLD TOWN SCHOOL OF FOLK MUSIC - CHICAGO
VESTERN SPRINGS COMMUNITY SCHOOL OF THE ARTS – WHEATON
MENT - GLENVIEW ENCORE MUSIC ACADEMY - CRYSTAL LAKE
SCHOOL OF ROCK - OAK PARK & NORTHBROOK



For more information and to apply for a scholarship visit

fhsr.org



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.

FIND US HERE...



Follow us on Social Media:



@illinoishandsandvoices



@ilhandsandvoices

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

Carrie Balian, Program Coordinator

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Andrea Marwah, Executive Director

Email: executivedirector@ilhandsandvoices.com

Web: www.ilhandsandvoices.org

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Phone: 217-782-4733

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