

# Newborn Screening in Nebraska

Newborn Bloodspot Screening for Congenital Inherited Disorders and  
Early Hearing Detection & Intervention



**2020 Annual Report to the  
Legislature**

**NEBRASKA**

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

# **Annual Report to the Legislature 2020**

## **Nebraska Newborn Screening Program & Early Hearing Detection**

**NEBRASKA**

Good Life. Great Mission.

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**DEPT. OF HEALTH AND HUMAN SERVICES**

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# One Family's Story

*Tiffany A. Moore, RN, PhD*

***"We will forever be grateful to the scientists and clinicians who have worked so hard to develop, maintain, and advocate for the Newborn Screening Program. They saved Jace's life."***

It was a Thursday. My son, Jace, was six days old, and he was perfect. I finished feeding, rocked him to sleep, and took a shower. When I got out of the shower, I looked at my phone to find 3 missed phone calls from my pediatrician. My heart sank. Something was wrong, and I had a feeling it was the newborn screen. I quickly called the pediatrician. "Your son has an abnormal newborn screen." My mind raced through the list of congenital diseases included on the newborn screen. You see, I was a NICU nurse for over 10 years, so I had collected the newborn screen hundreds of times. Never had I imagined, however, that I would receive this phone call.



*Jace Moore*  
Courtesy of the Moore Family

"Your son's thyroid levels are extremely abnormal. Can you come to the hospital to run some more tests today?" Today? Already today? At that moment, my euphoria of being a new mom quickly turned into fear, confusion, and shock.

When we arrived at the hospital, we had to get his blood drawn, ultrasound, and send him to CT. Everything was a blur. And I just remember my husband held my hand the whole time. I knew he was also filled with fear as we had to wait a couple of days yet to meet with the Endocrinologist because it was the weekend soon. The Endocrinologist, Dr. Kevin Corley, made an appointment at 7:30 am on Monday. I remember being so grateful but nervous that it did not take a couple of weeks to get in to talk to anyone.

Although I was scared and numb, I clung to every word he said that day. He was gentle but real; he told us what we needed to know and everything we needed to hear at that moment. "Your son has congenital hypothyroidism." He shared the importance of the newborn screen for detecting this disease early because he had been a doctor long enough to see patients before the newborn screen. These patients had severe intellectual disabilities. He explained that Jace would need to have frequent blood draws and likely would need to take medicine every day for the rest of his life. He emphasized the importance of maintaining his thyroid levels because of the critical role of the thyroid in growth and

development. He said that Jace was automatically considered "high-risk" for developmental delays and would need to be periodically screened by early childhood programs. But then he again emphasized how important the newborn screen was and that Jace's real risk of major complications was very minimal since we caught this early.

I remember receiving my hospital bill a few months later and looking at the cost breakdown of the newborn screen. I do not recall the exact numbers, but I believe the thyroid tests were less than \$20. As tears rolled down my face, I could not believe that \$20 just saved my son's life. Twenty dollars for a priceless outcome. Twenty dollars is all it took to completely change the trajectory of my son's path. As I have learned more and more about congenital hypothyroidism, I have become more and more thankful for the simplicity of a newborn screen.

Today, Jace is doing amazing things! He faithfully takes his thyroid pill every day and still gets his blood drawn about every 4 months. He gets mostly "A's" in school, excels in math and science, practices Judo, plays football, and loves to make everyone laugh. He still is my perfect little man, but now he is the big man on campus as he is a fifth-grader in Elkhorn Public Schools. His main goal is to be in the army when he grows up.

We are sincerely thankful to Dr. Corley and to all who have, and currently are, involved in the Nebraska Newborn Screening Program. We will forever be grateful to the scientists and clinicians who have worked so hard to develop, maintain, and advocate for the Newborn Screening Program. They saved Jace's life.

# Screening



Photo Courtesy of Hessam Nabavi

Nebraska's statutes governing newborn screening (Neb. Rev. Stat. §§71-519 through 71-524) require every baby born in Nebraska to receive the screening.

If not detected and treated in time, the variable effects of conditions that are screened for can include brain and nerve cell damage, resulting in severe intellectual disability, damage to the infant or child's heart, kidney, liver, spleen, eyes, and/or hearing. Physical growth problems, stroke, overwhelming infection, and infant death.

Newborn Screening is a system coordinated by the Nebraska Department of Health and Human Services (NDHHS) Newborn Screening Program. The system requires collaboration with hospitals, laboratories, health care professionals, and families and involves many elements, including:

- ❖ Proper and timely collection of quality specimens.
- ❖ Appropriate and timely transport of specimens to the newborn screening laboratory.
- ❖ Rapid quality testing methods.
- ❖ Timely notification of the infant's physician and parents.
- ❖ Timely recall of the infant for confirmatory or repeat testing.
- ❖ Appropriate referral of family to specialists for diagnosis, treatment, and counseling.
- ❖ Evaluation and Quality Assurance/ Improvement efforts.
- ❖ Ensure access to needed specialized services and treatment for diagnosed infants.

*The goal of newborn bloodspot screening is to identify otherwise well-appearing newborns with life-threatening and debilitating conditions that would likely not be detected until damage has occurred.*

## System Overview

The Department of Health Human Services, Division of Public Health, administers the program. The program partners with pediatric sub-specialists who see infants with positive screens to establish diagnosis and treatment.

An advisory committee meets quarterly to discuss technical and policy issues, monitor quality, and update professional and parent education. The advisory committee's membership consists of pediatric sub-specialists, pathologists, chemists, pediatricians, neonatologists, family practitioners, and representatives from the Nebraska Hospital Association, the Nebraska Medical Association, Medicaid, and families of affected children.

The Inherited Disease Clinical Specialists who work at the Department of Health and Human Services ensure that the health care provider for every newborn who requires additional testing receives the necessary information to take the correct action. The Clinical Specialists continue to follow-up with calls, faxed letters, and education until a diagnosis is made or ruled out. The program conducts ongoing evaluation and quality assurance activities throughout the year.

The program administers a contract for the ordering and distribution of metabolic formula, in addition to a reimbursement system for metabolic foods, which ensures access to treatment for eligible individuals with inborn errors of metabolism.

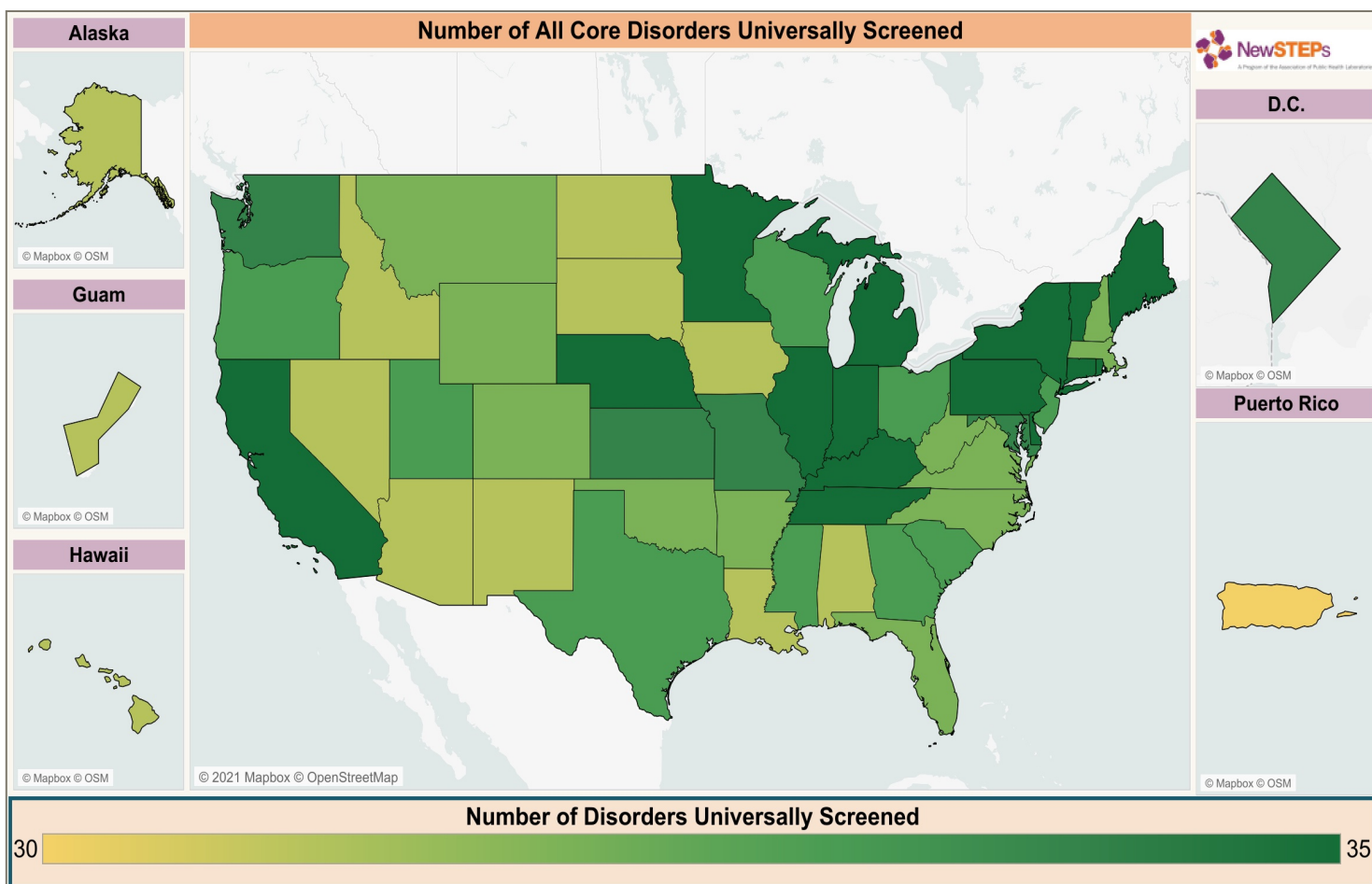
## Metabolic Foods and Formula

The statute governing newborn screening in Nebraska also requires the Department to provide metabolic formula and metabolic foods to eligible patients. Patients can be reimbursed up to \$2000 per year for qualifying foods, and those meeting financial hardship criteria may be able to have the foods ordered for them by the Department. The dietitians at Children's Hospital and Medical Center in Omaha work closely with the program to advise what foods are available that comply with statutory requirements as pharmaceutically manufacture foods that aid individuals in keeping the best control of their metabolic disorders which this food is prescribed. New guidelines were developed by our metabolic food specialist, Michaela Howard, RD and Children's Metabolic Dietician's, Dr. Jill Skrabal, RD, LMT, Ph.D., Kathryn Heldt, RD, LMT, this year to define better what available foods would meet statutory requirements so that there was less confusion around these definitions. The Metabolic Dietitians at Children's are specially trained. The state of Nebraska is very fortunate to have two of them that work closely with our program to ensure that affected individuals receive the best care possible. These dietitians' efforts have helped improve the percent of people utilizing the metabolic foods program. Program participants have benefited from the availability of a general dietician when ordering from the approved food list when calling or emailing the state program directly.

*The Nebraska Newborn Screening Program screens for 35 diseases with the heelstick test that would likely not be otherwise detected until they, in fact, became symptomatic. Better results are seen when infants are treated when they are asymptomatic, up to including the ability to save the infants life or keep them from a lifetime of disability. In 2020, this resulted in identifying and treating 59 newborns in time to prevent or reduce problems associated with identified conditions.*

# Nebraska Newborn Bloodspot Screening vs. Other States and Territories

Nebraska is one of 13 States Screening for ALL disorders recommended by the Recommended Universal Screening Panel, including Spinal Muscular Atrophy, which was added following legislation on November 14, 2020.

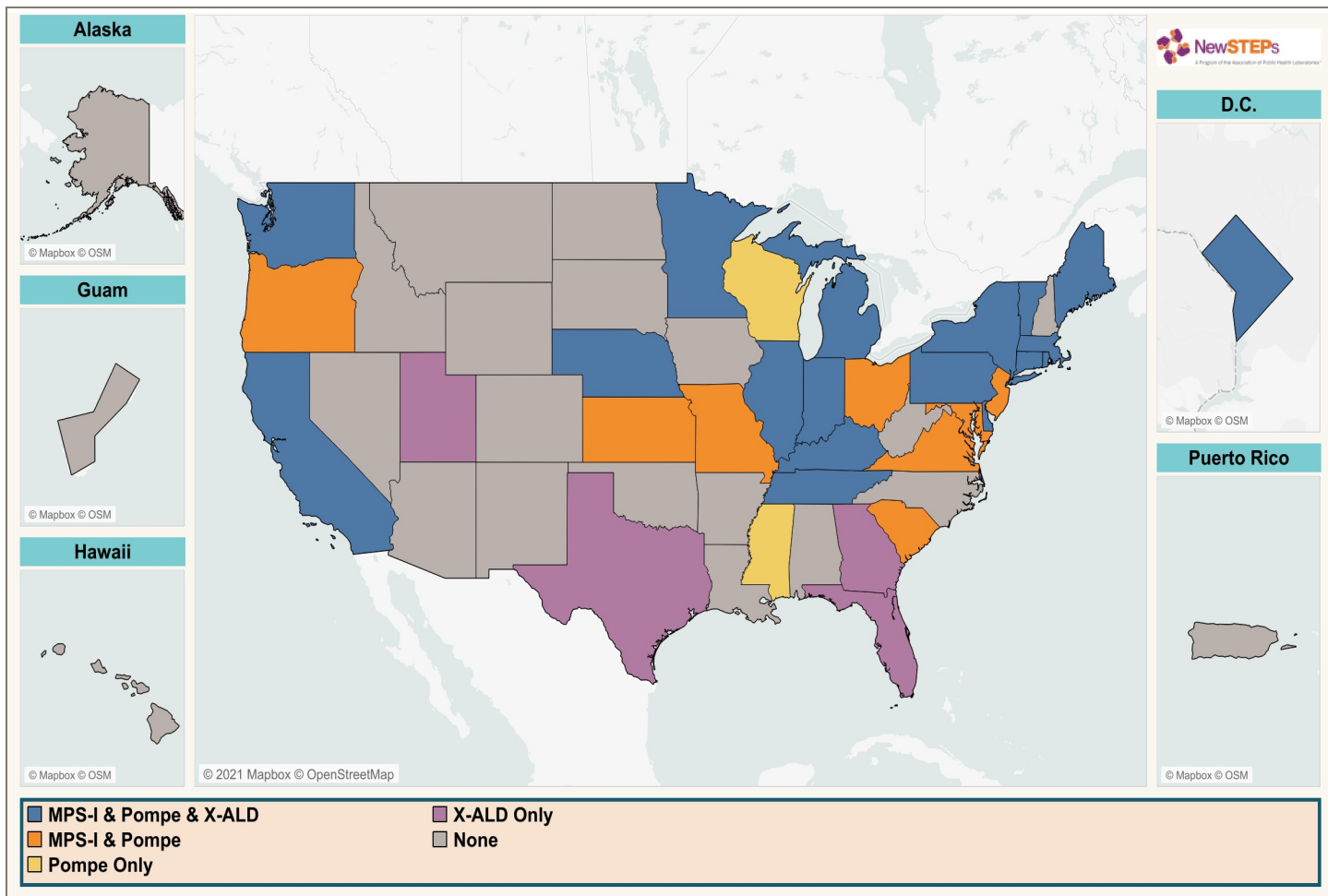


*Heat Map by Number of Disorders Screened*

Chart Courtesy Association of Public Health Laboratories (APHL)

Spinal Muscular Atrophy is the leading genetic cause of death in young children. Nebraska had been prepared for some years to add this disease to its panel due to the laboratory's ability to run advanced genetic testing. Much larger states have only recently begun screening for this disorder due to the complexity of the screening and often do not provide as much genetic information as PerkinElmer, Nebraska's contract laboratory. State public health laboratories in our region have not yet begun to screen for this devastating illness in part due to these technical restraints. Hence, infants born in Nebraska benefit from the State's commitment to Newborn Screening.

# Nebraska is one of 17 States that Screens for MPS-1, Pompe, and X-ALD.



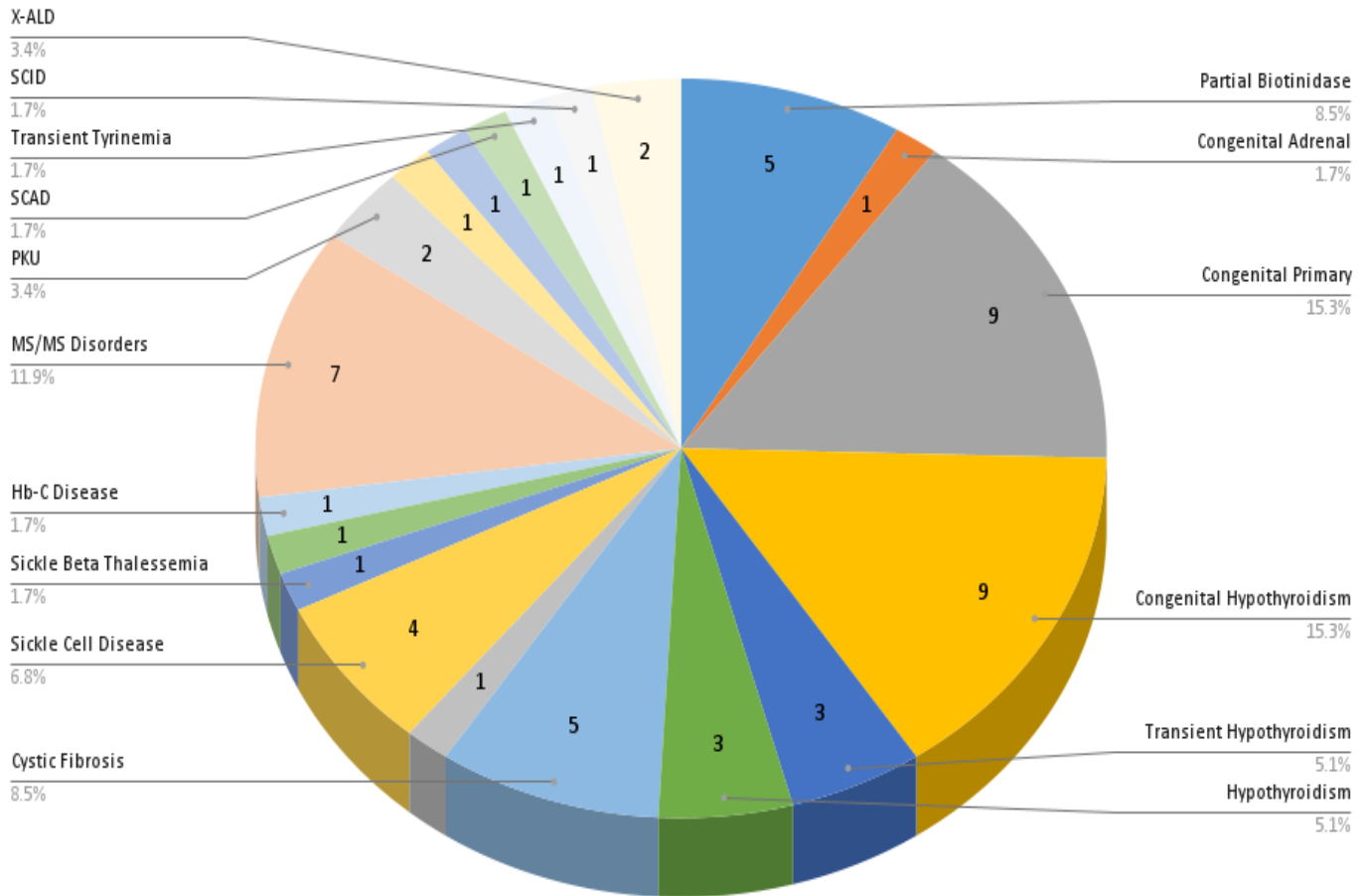
*States Which Added the Latest Disorders Recommended by the Recommended Universal Screening Panel (RUSP)  
Chart Courtesy of APHL*

Nebraska began screening for MPS-1, Pompe, and X-ALD on July 1, 2018. Nebraska would not have been able to have started screening for these disorders without the legislature's support in the form of an increase in the per infant screening fee. In addition, Nebraska received support in the form of a three-year grant from Health Resources & Service Administration (HRSA) through the Association of Public Health Screening Labs, NewSTEPS project. These HRSA funds were in addition to the generous support that Nebraska Newborn Screening program receives annually from HRSA Title V funding.



# 2020 Data

## 2020 Confirmed Positive Cases



Number of births 2020 24,674  
 Birth data courtesy of Nebraska EDHI

### Percent of dried blood spot specimens that were unacceptable due to improper collection and/or transport

Count / Denominator	Percentage	Regional Percentage	National Percentage
216 / 28601	0.76%	2.37%	1.21%

Chart Adapted form APHL/NewSTEPS

**Time elapsed from Receipt by Screening Laboratory to Reporting out for Non-Time Critical Disorders Requiring Clinical Diagnostic Workup by an Appropriate Medical Professional**

<b>Quality Indicator</b>	<b>Count / Denominator</b>	<b>Percentage</b>	<b>National Percentage</b>
Same day as receipt at lab			1.45%
Day after receipt at lab			14.85%
Day 2 after receipt at lab	35 / 54	64.81%	32.23%
Day 3 after receipt at lab	8 / 54	14.81%	20.15%
Day 4 after receipt at lab	11 / 54	20.37%	12.72%
Day 5 after receipt at lab			6.75%
Day 6 after receipt at lab			4.42%
Greater than or equal to Day 7 after receipt at lab			6.05%
Time elapsed unknown			1.38%

*Chart Adapted form APHL/NewSTEPS*

**Average Time from Birth to Confirmation of Clinical Diagnosis in Time Sensitive Diseases**

<b>Disorder Category</b>	<b>Nebraska Total</b>	<b>Days to Diagnosis</b>	<b>Region Total</b>	<b>Median Days to Diagnosis</b>	<b>Nation Total</b>	<b>National Days to Diagnosis</b>
Amino Acid Disorders	3 infants	6 days	17 infants	12 days	64 infants	18 days
Endocrine Disorders	20 infants	7 days	156 infants	14 days	654 infants	12 days
Fatty Acid Disorders	2 infants	4.5 days	22 infants	35 days	106 infants	31.5 days
Other Disorders	5 infants	14 days	42 infants	17.5 days	383 infants	32 days

*Chart Adapted form APHL/NewSTEPS*

## 2020 Advisory Committee

The committee monitors national recommendations, trends, and reports, and advises the program on recommended next steps, methods, or strategies. Much of Nebraska's success can be directly tied to the Committee's recommendations and guidance. Members committed at least a half-day, four times a year, to advise the state program. Nebraska's newborn population, families, and the program all benefit from the advisors who provide technical expertise and policy guidance to the Nebraska Newborn Screening Program. Special thanks to Dr. Zoe González-García, MD (Children's), for chairing the committee, and to Dr. Jill Skrabal, Ph.D. (Children's), who served as Vice-Chair in 2020.

Jill Allen, RN	Nebraska Hospital Association
Khalid Awad, MD	Neonatology
Craig Baker, MD	Pediatric Genetics
Lawrence Bausch, MD	Neonatology
Angela Brennan, MD	Family Practice
Catherine Brooks, DO	Neonatology
Alyssa Cady, MS, CGC	Genetic Counseling
Jeanne Egger	Parent /Advocate
Zoe González-García, MD (CHAIR)	Pediatric Endocrinology
Jessica Hansen, MSN, FNP-C	Pediatric Genetics
James Harper, MD	Pediatric Hematology
Kathryn Heldt, RD	Metabolic Nutrition
Mary Kisicki, RN	Parent / Advocate
Richard Lutz, MD	Pediatric Endocrine, Metabolism, Genetics
Bev Morton	Parent / Advocate
Hana Niebur, MD	Pediatric Immunology
Deborah Perry, MD	Pediatric Pathology
Samuel Pirruccello, MD	Pathology
Geetanjali Rathore, MD	Pediatric Neurology
Robert Rauner	ALD Foundation Advocate / Parent / Advocate
William Rizzo, MD	Pediatric Metabolism, Genetics
Kathy Rossiter, EJD, MSN, APRN	Medical Ethics Advisor
Jill Skrabal, Ph.D., RD (VICE CHAIR)	Metabolic Nutrition
Heather Thomas, MD	Cystic Fibrosis Clinic
Jamise Williams, MS	Parent / Advocate

# Nebraska Early Hearing Detection and Intervention Annual Report

The Nebraska Early Hearing Detection and Intervention Program develops, promotes, and supports systems to ensure all newborns in Nebraska receive hearing screenings, family-centered evaluations, and early intervention as appropriate.

## Introduction

Approximately one to three in 1,000 babies are born with permanent hearing loss, making hearing loss one of America's most common birth defects. Before the newborn hearing screening, deaf or hard of hearing (D/HH) children were sometimes not identified until 2½ to 3 years of age. Delayed identification can negatively impact the child's speech and language acquisition, academic achievement, and social and emotional development. If detected soon after birth, the negative impact can be reduced and even eliminated through early intervention.

The Infant Hearing Act became a state law in Nebraska in 2000 and required the hearing screening of newborns in birthing facilities in Nebraska as a standard of care. Also in 2000, the Nebraska Department of Health and Human Services (DHHS) started the Nebraska Newborn Hearing Screening Program. Today the program is known as the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program and is funded through federal grants. This program strives to fulfill the following four primary purposes of the Infant Hearing Act (Neb. Rev. Stat. §71-4735):

- To provide early detection of hearing loss in newborns at the birthing facility or as soon after birth as possible for those children born outside of a birthing facility.
- To enable these children, their families, and other caregivers to obtain needed a multidisciplinary evaluation, treatment, and intervention services at the earliest opportunity.
- To prevent or mitigate the developmental delays and academic failures associated with late detection of hearing loss.
- To provide the state with the information necessary to effectively plan, establish, and evaluate a comprehensive system for identifying newborns and infants who have hearing loss.

The act also requires birthing facilities to educate parents about newborn hearing screening and any necessary follow-up care. The education includes information about the hearing screening test, the likelihood of the newborn having a hearing loss, follow-up procedures, and community resources, including referral for early intervention and a description of children's normal auditory, speech, and language developmental process. The act also requires that regulations be promulgated to mandate newborn hearing screening if less than 95% of newborns in the state receive a hearing screening.



Inpatient Newborn Screening  
Photo Courtesy of NCHAM

# Newborn Hearing Screening Data

## Birthing Facility Screening Programs

Since 2003, 100% of the birthing facilities in Nebraska have been conducting hearing screenings, consistent with the Neb. Rev. Stat. §71-4742 requirement that a hearing screening test be included as part of the standard of care for newborns. In 2020, there were 52 birthing facilities conducting hearing screenings.

The COVID-19 Pandemic has been challenging and changed many aspects of NE-EHDI's work since April 1, 2020. The following information describes those changes.



Outpatient Newborn Screening Photo  
Courtesy NE-EDHI

- COVID info was added to the NE-EHDI Website <http://dhhs.ne.gov/EHDI>. “EHDI Process during COVID-19 Pandemic” was the first topic of information on the first page of the NE-EHDI website through 2020. It stated, “During the current COVID-19 Pandemic, NE-EHDI will continue to follow our current follow-up process of contacting families and medical professionals via e-mail, regular mail, secure e-fax, or phone. We will strive to meet the Joint Committee on Infant Hearing (JCIH) 1-3-6 recommendations to complete the hearing screen by 1 month of age, complete the audiologic diagnostic evaluation by 3 months of age, and complete enrollment into early intervention (EI) by 6 months of age. However, we understand that there may be delays in the follow-up process during this uncertain time, and we will work with families and professionals to accommodate any changes due to limited access to care”.
- NE-EHDI collaborated with the Newborn Screening Program to create a COVID-19 & Newborn Screening Guidelines document. This document and COVID-19 resources provided by the American Academy of Pediatrics (AAP) and the National Center for Hearing Assessment and Management (NCHAM) are posted on the NE-EHDI website.
- NE-EHDI added COVID-19 infographic documents to the parent follow-up letter and Primary Health Care Provider (PHCP) follow-up e-fax letters.
- Starting the end of March through May 2020, NE-EHDI met weekly with other State EHDI Programs through EHDI Chats to share information and ideas regarding COVID-19. The special COVID-19 EHDI Chats meetings continued every other week in June and July 2020. NE-EHDI provided updates regarding our COVID-19 work with the National Center for Hearing Assessment and Management (NCHAM), Health Resources and Services Administration (HRSA) EHDI, and the Centers for Disease and Prevention (CDC) EHDI.
- More follow-up work has been needed from the NE-EHDI team during COVID-19. The average working queue increased from 90 - 100 cases up to 200 cases weekly. Fortunately, the working queue decreased by the end of 2020. The reasons for the increase in follow-up work include: 1) There were some babies discharged from the birth hospital before 24 hours, resulting in higher refer rates and fewer opportunities for a 2nd screen before discharge; and 2) Audiology clinics had reduced hours, were closed, or parents didn't feel comfortable taking their infant to the appointment.

# Hearing Screening at Birthing Facilities and Centers

The following shows the hearing screening/testing status of the 24,674 births for 2020:

<b>Passed the screening or diagnostic testing</b>	<b>24,332</b>
<b>Expired (inpatient or outpatient)</b>	<b>108</b>
<b>Pending final screening or diagnostic testing</b>	<b>35</b>
<b>Diagnosed deaf or hard of hearing</b>	<b>70</b>
<b>Parents refused screening and/or diagnostic testing</b>	<b>63</b>
<b>Unresponsive (did not complete protocol after communication with NE-EHDI staff)</b>	<b>50</b>
<b>Lost (no response to NE-EHDI letters and phone calls)</b>	<b>9</b>
<b>Moved out of Nebraska</b>	<b>7</b>
<b>Late-onset deaf or hard of hearing (passed initial screening)</b>	<b>0</b>

"Inpatient hearing screenings were reported on 24,442 newborns, or 99.7% of the 24,495 newborns available for an inpatient hearing screening. The percentage of newborns screened during birth admission has increased dramatically since reporting began in 2000 when only slightly more than one-third of newborns received a hearing screening during birth admission.

In 2020, 23,061 (94.4%) passed the screening of those who received an inpatient hearing screening in Nebraska. An outpatient hearing screening or audiology evaluation is recommended for infants who do not pass the inpatient screening."

## Parent Education

Recommending a hearing screening has been operationally defined as educating parents about newborn hearing screening, hearing loss, and normal communication development as required by Neb. Rev. Stat. §71-4740. The NE-EHDI Program provides print and video educational materials free of charge to hospitals to help fulfill this requirement. Print materials are available in 14 languages. Birthing facilities reported educating approximately 99% of parents about newborn hearing screening, hearing loss, and normal speech and language development in 2020. The statute also requires the Nebraska Department of Health and Human Services to educate parents of newborns who are not born in a birthing facility about the importance of newborn hearing screening and provide information to assist them in having the screening performed within one month after the child's birth. This is accomplished through letters and printed materials sent to the parents, along with phone calls. When an infant is identified as deaf or hard of hearing, parent(s) receive the Parent Resource Guide (PRG) from the audiologist. A notification letter is sent to the primary health care provider. Hands & Voices (H&V)/Guide By Your Side (GBYS) Parent Guides also discuss the PRG with families to provide support and stress the importance of starting early intervention as soon as possible. The PRG was developed by NE-EHDI shortly after the program began, with the collaboration of many partners, and is available in print or online at <http://dhhs.ne.gov/EHDI-PRG>.

# 2020 Activities

## Funding

The NE-EHDI Program continued to receive only federal funding in 2020. Funding was received from the Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB), the Centers for Disease Control and Prevention (CDC), and the Maternal and Child Health (MCH) Title V Block Grant. The HRSA/MCHB grant funds the basic operations of the NE-EHDI Program. NE-EHDI received an additional \$10,000 HRSA COVID-19 Funds in September 2020 to purchase clear masks, clear shields, and other personal protective equipment (PPE) to be distributed to families of children birth - 3 years of age who are D/HH and to anyone who serves this population. This was added to the Nebraska Hands & Voices (NE H&V) sub-award agreement to purchase and distribute. The CDC cooperative agreement primarily funds the development, implementation, and maintenance of the integrated electronic data reporting and tracking system. The MCH Title V Block Grant supplements funding for a small amount of the necessary operations costs for the NE-EHDI Program since the HRSA and CDC funding guidelines have changed the requirements regarding how the funding can be allocated.

The NE-EHDI Program was developed based on requirements identified in the Nebraska Infant Hearing Act of 2000, and the NE-EHDI Program Advisory Committee recommended protocols. The purpose of the Advisory Committee, according to its charter, is to provide direction and guidance to the NE-EHDI Program regarding the newborn hearing screening system. Specific Advisory Committee activities include, but are not limited to, the following:

- Discussing goals and advising the NE-EHDI Program.
- Recognizing improvement's to reporting, tracking, and follow-up protocols to effectively link the NE-EHDI Program and early intervention systems.
- Assisting with increasing the program's responsiveness to new or differing cultural and linguistic communities in the state.
- Guiding the long-term planning and evaluation of the NE-EHDI system in the state.
- Reviewing the newborn screening statistics and making recommendations for program improvements.

There were changes to the NE-EHDI Advisory Meetings in 2020, due to COVID-19. The May 14, 2020, advisory meeting was postponed and was not able to be rescheduled. The October 15, 2020 advisory meeting was scheduled at the Nebraska Educational Telecommunications (NET) meeting room. NET informed NE-EHDI they were canceling all external meetings through the end of 2020 due to COVID-19. After many discussions with NDHHS Legal, it was determined that NE-EHDI wouldn't be compliant with the Open Meetings Act if a virtual meeting were held since there wasn't an in-person meeting in the 2020 calendar year. With the approval of the federal funders, NE-EHDI shared PowerPoint slides and asked questions through a survey to receive feedback. The slides are posted on our NE-EHDI website. The link to the slides and the survey through Survey Monkey were e-mailed to all the advisory committee members. NE-EHDI received helpful feedback from the survey for future program planning.

Special thanks to Dr. Stacie Ray, Au. D., CCC-A for serving as chair and to Katie Brennan, MS., CCC-SLP for serving as Vice Chair, and all the committee members for their guidance to the NE-EHDI program.

## 2020 NE-EHDI Advisory Committee Members:

Mark Anderson	Nebraska Association of the Deaf
Nina Baker	Health Information Coordinator and Family Voices, Family to Family Health Information Center at Parent Training Information (PTI-NE)
Laura Beshaler, Au.D., CCC-A	Educational Audiologist, Millard Public Schools
Katie Brennan, MS, CCC-SLP	Speech-Language Pathologist, Special Education & Communication Disorders, University of Nebraska - Lincoln
Amy Bunnell	Early Development Network, Nebraska Department of Education
Carlena Conard, BSN, RN	OB Director, York General Hospital
Brad Czaplewski	Deaf Educator, ESU#10
Sue Czaplewski	Educational Service Unit #9, Nebraska Department of Education
Linsay Darnall, Jr.	Deaf Advocate/Advisor, Darnall Consulting LLC
Julie Docter	Early Development Network, Nebraska Department of Health and Human Services
Heather Gomes, M.D.	AAP Chapter Champion/Otolaryngologist, Boys Town Research Hospital
Jessica Hoss	Nebraska Hands & Voices/Guide By Your Side Parent Guide
Shelli Janning	Nebraska Hands & Voices/Guide By Your Side Coordinator/Parent
Jayden Jensen	Deaf/Hard of Hearing Advocate/Advisor
Cole Johnson	Special Education Office, Nebraska Department of Education
Kristin Jolkowski, Au.D., CCC-A	Educational Audiologist, Lincoln Public Schools
Ashley Kaufman, Au.D., CCC-A	Clinical Audiologist, Boys Town and National Research Hospital
Jessica Larrison	Education Advocate, Nebraska Commission for the Deaf and Hard of Hearing
Joan Luebbers	Head Start State Collaboration Office, Nebraska Department of Education
Sara Peterson	Deaf Educator, Educational Service Unit # 13, Nebraska Department of Education
Kelly Rausch	Parent/Advocate Advisor
Stacie Ray, Au.D., CCC-A	Associate Professor/Nebraska Hearing Aid Banks Director, Special Education & Communication Disorders, University of Nebraska – Lincoln/Parent
Colleen Richart	Parent/Hard of Hearing Advocate/Advisor, on Nebraska Hands &Voices Board
Karen Rolf, Ph.D.	Retired University of Nebraska – Omaha Associate Professor of Social Work/Parent
Merry Spratford, Au.D., CCC-A	Research Audiologist, Boys Town and National Research Hospital
Anne Thomas, Ph.D.	University of Nebraska-Lincoln, Dept. of SPED & Communications Disorders
Joanna Webster, Au.D., CCC-A	Clinical Audiologist, Children’s Hospital & Medical Center
Jana Wiblishouser	Parent/Advocate Advisor
Pam Zegers, M.D.	Pediatrician, Complete Children’s Health



# 2020 Projects

## HearU Nebraska

HearU Nebraska through the University of Nebraska-Lincoln began providing loaner hearing aids to young children in January 2008. HearU Nebraska didn't start with income guidelines; however, with changes in funding and increased difficulty in finding grants or receiving donations, a financial criterion was implemented on January 1, 2018. The NE-EHDI Program continued to provide funds for the program's administration and to help purchase loaner hearing aids in 2020. In 2020 there were 45 hearing aids provided and fitted for 28 children (age range of 1 month to 18 years) with "free" hearing aids provided by HearU Nebraska. From 2008-2020, 818 hearing aids were supplied and fitted on 490 children.

## Nebraska Hands and Voices (H&V)/Guide By Your Side (GBYS)

NE-EHDI began contracting with Nebraska Hands and Voices (H&V)/Guide By Your Side (GBYS) Program on May 1, 2017. NE-EHDI has collaborated for several years with GBYS to assist in connecting families with family support. The current sub-award agreement involves an H&V/GBYS Parent Guide assisting with EHDI follow-up for families and medical professionals, and providing education and family support. This is a more streamlined process that allows families to connect with a GBYS Parent Guide during their first EHDI contact and allows the guide to share experiences and knowledge as appropriate.

The GBYS Parent Guides are parents of a deaf or hard of hearing (D/HH) children, who are trained to provide support and advocacy for other families. The guides are available to respond to the individual needs of each family to assist families in helping their child reach their full potential. In 2020, 14 trained Parent Guides provided family support throughout Nebraska.

The H&V/GBYS staff, through the sub-award agreement with NE-EHDI, worked with 1,175 families for EHDI follow-up during 2020. As of December 31, 2020, GBYS Guides actively served 165 families, and 114 of those families were referred by NE-EHDI (69%).

### Quotes from families served by GBYS in 2020

*"She has been extremely helpful as our family has been dealing with the diagnosis & initial treatment steps. She has been a great resource to ask all of our questions or simply just to listen."*

*"I love the parent to parent interaction! It is great to get firsthand experience of what to expect at different stages of life while coping with hearing loss."*

*"Her personal input, her encouragement to follow our own path, her persistence in involving me in activities even though I'm not always ready (mentally). When I'm frustrated and ready to give up, she always provides an extra bit of encouragement to help me through."*

*"This program has given me the exact and correct help I needed, they contacted me, offered me and guided me to where I am now. They gave me emotional support when I most needed it and that is priceless especially in my first language (Spanish). I will be infinitely grateful. God bless you always."*

*"The Guide by Your Side Program has given me the confidence I needed when I needed it the most. Having a child with hearing loss at birth is scary! You can't know what to expect or how you will navigate those waters when you get there. Knowing I have The Guide by Your Side Program and my guide in particular, I have the confidence that when we get there I will have the support and resources that will ensure success for both me and my child!"*

*"When we were first introduced to the program it accompanied an overwhelming diagnosis. Our guide reached out and continued to support me in ways that I didn't know I needed. This program pushes me to be a better advocate for my son. It gives me a safe place to express frustrations and fears with nothing but understanding and support in return."*

## **Monitoring, Intervention, and Follow-up Care**

The NE-EHDI Program's tracking and follow-up processes are conducted for each baby reported as not passing the hearing screening during birth admission and for infants not receiving the inpatient hearing screening. A total of 1,445 infants (2020 hospital and non-hospital births) were tracked by the NE-EHDI Program to encourage parents to have the infant receive an outpatient hearing screening or audiologic diagnostic evaluation.

## **Timeliness of Follow-up Screening**

*The purpose of the Infant Hearing Act (Neb. Rev. Stat. §71-4735) is to "... obtain needed multidisciplinary evaluation, treatment, and intervention services at the earliest opportunity and to prevent or mitigate the developmental delays and academic failures associated with late detection of hearing loss."*

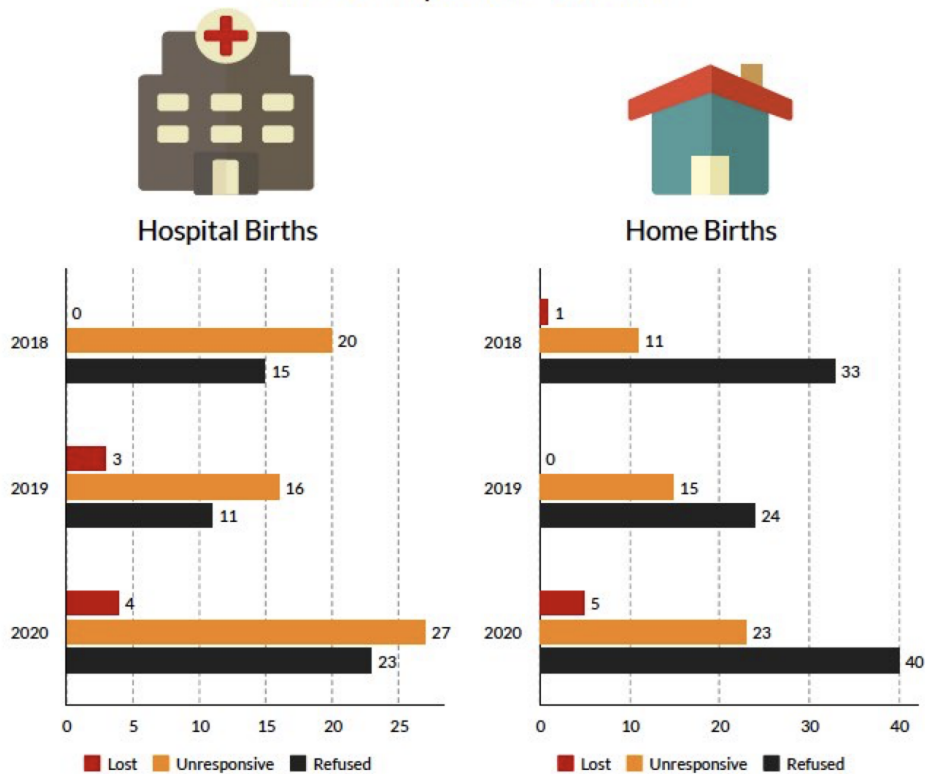
To meet the state and national guidelines of "1-3-6" (hearing screening completed by 1 month, audiologic diagnostic evaluation completed by 3 months, enrolled in early intervention by 6 months), established by the Joint Committee on Infant Hearing (JCIH), the timeliness of initiation and completion of follow-up activities is an important aspect of the quality of services. Almost 96% of infants completed the inpatient/outpatient screening within one month of age. For the newborns who were recommended for an audiologic diagnosis, nearly 53% received the evaluation by 3 months of age, according to individual data reported to the NE-EHDI Program by audiologists (as of July 2021). This percentage is preliminary and will likely decrease due to infants having an initial diagnostic evaluation and needing a confirmatory evaluation.

*Note: Because 35 hearing records are still waiting for the final screening and diagnostic testing results, the "1-3-6" numbers above are preliminary as of July 2021 and will likely change.*

Records for the Early Development Network (EDN), Nebraska’s Part C Early Intervention indicate that 88% of infants residing in Nebraska that were diagnosed as deaf or hard of hearing were enrolled in EDN services by 6 months of age for families accepting Part-C services (as of July 2021). It is projected that the final percentage for enrollment within 6 months will be less than 88% since there are still 66 infants needing a confirmatory diagnosis, and some will be referred to early intervention later than 6 months of age. The reasons for those infants not enrolling in EDN include: parents declined services, unable to contact the family, the family moved out of state, and no indication of developmental delay (slight or mild hearing loss).

## 2018-2020 - Not Completed Cases

Lost - Unresponsive - Refused

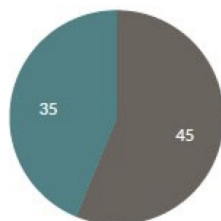


### Combined Totals by Year

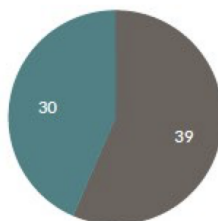
2018 (80 Total)

2019 (69 Total)

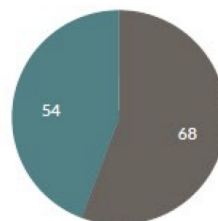
2020\* (122 Total)



Home Births (56.25%)  
Hospital Births (43.75%)



Home Births (56.52%)  
Hospital Births (43.48%)



Home Births (55.74%)  
Hospital Births (44.26%)

\*Preliminary data-numbers may change.

Data Courtesy of NE-EDHI

# Family Support Events 2020

NE-EHDI collaborated with H&V/GBYS for many family support activities and events in 2020.

**Monthly “Rising Stars” Deaf & Hard of Hearing Youth Leadership Award** –This is an opportunity to recognize a youth (up to age 21) once a month who is D/HH. It is empowering and helps promote youth to become positive role models in the D/HH community. The selected youth receive an award certificate, a \$15 gift card, and are recognized on Nebraska H&V Facebook.

**H&V Monthly Newsletter** – The Nebraska Hands and Voices monthly newsletter is sent out to H&V/GBYS families. Each month, a different Parent Guide prepares the content, and is featured in the Parent Guide Spotlight. The Newsletter also includes the monthly Rising Star award recipient which recognizes a youth who is deaf or hard of hearing that has shown excellent leadership skills, and other sections of interest including humorous and humbling parenting fails, helpful tips, suggested apps and websites, collaborations of interest, resources, and upcoming events.

**Moody Monday** – A question is posted on Facebook every Monday. There are a wide range of topics for the questions. This is a way to educate parents and professionals about D/HH topics and to share fun information. A winner is chosen randomly from the comments and they receive a prize courtesy of NE-EHDI (book, accessory, case for equipment etc.) This has been an effort to increase activity on Facebook to learn more about NE Hands & Voices, and it has been working well.

**ASTra Training Jan 17 (Omaha) & Jan 18 (Lincoln), 2020 (Zoomed statewide)** – A one-day training for professionals and parents interested in learning about education and advocacy.

**Parent Café Jan 19, 2020 (Training for GBYS Guides)** – This was a guided discussion that allowed parents to connect with other parents in a safe and structured environment.



Parent Café  
Photo Courtesy Nebraska Hands and Voices

**Moms Night Inn Feb 8-9, 2020 (Lincoln)** –This was an opportunity to experiences provide support to each other. Topics included-Self Advocacy, Empowerment, Literacy, Socialization , & more."



Moms Night Inn  
Photo Courtesy Nebraska Hands and Voices

## Zoom Series H&V/GBYS offered during COVID-19 in April and May 2020:

**APRIL 10 Unilateral Hearing Loss** –This presentation about unilateral hearing loss was given by Shelli Janning (parent) and Brooke Janning (youth). Brooke shared her experience using a hearing aid and a Cochlear Implant. It provided an opportunity for parents to connect with other parents and children who have a unilateral hearing loss.

**APRIL 11 Meeting other moms who have children age 0-3** –This session was facilitated by trained parents facilitated this event, and provided an opportunity for moms to have conversations about raising their little ones. The parents discussed problem solving, how things are going, and how to deal with temporary situations.

**April 17 – These kids are driving me nuts!** – This session was presented and discussed by parents about various topics regarding things to do with their kids, from self-advocacy to sports. There were different presentations by parents for ages 0-3, ages 3-5, ages 5-13, and ages 14 & older.

**April 21 – “How do I manage all of this equipment?”** – This session was presented by an audiologist who helped parents and grandparents better understand the child’s equipment, including information for hearing aids, Baha, and Cochlear Implant.

**April 24 – “I am just here for the Beer.”** – This session was facilitated by trained parents facilitated this event, which provided an opportunity to get to know others and talk about what types of challenges and support parents see as beneficial when raising children who are D/HH. There were prepared questions were provided along with time for discussion.



HearU Care Kit  
Photo Courtesy of HearU Nebraska

**April 28 – Hearing Aid 101/ Explaining the Audiogram**–This session was presented by an audiologist and a parent of a child who has a hearing aid. The presentation provided information to help understand different issues relating to the use of a hearing aid. This was another excellent opportunity to share information with extended family.

**May 1 Raising a Child with Microtia and Atresia** – This session was Presented by two moms who have children with Microtia and Atresia. This was another good HearU Care Kit opportunity for extended family to learn about these."

**May 1 Understanding Baha’s**– This session was presented by two trained parents

**May 8 Dads Meeting/Virtual Poker party.** This session was facilitated by two dads. It gave dads a chance to talk with other dads. Virtual poker was also incorporated.

**May 14 Communication Options** – The session provided an opportunity to help understand various modes of communication in an unbiased manner. The three parents shared the methods of communication they chose with their child and how they made the decision. The parents also shared about their child’s perspective about communication.

**June 2020 H&V Disseminated the NE-EHDI Survey** – to parents asking about speech and language services used outside of EDN – Part C Intervention services to report to CDC EHDI.

**August 2020 H&V Disseminated the NE-EHDI Survey** – to parents asking about their needs and wants for a D/HH Role Model or Mentor Program in Nebraska.

**August 2020 H&V/GBYS Coordinator** – recorded a presentation for the Genetics Class at University of Nebraska Medical Center (UNMC) through Krystal Platt.

**August 2020 H&V/GBYS Coordinator** – Cody McEvoy, Tory Vilotta, Dillon Curren, and Anne Thompson who are D/HH to share their story so others can learn from them. The interviews are posted on the Nebraska Hands and Voices website, interviews is posted on the NE-EHDI website. and a link to the

**Virtual Parent Café Event 2020** - This was an opportunity for parents who have children who are D/HH to connect with other parents in a safe and structured environment. Parents enjoy having a safe place to talk about deep issues and to meet other parents from across the state. This is an excellent opportunity to learn from others. It included a short presentation of personal protective equipment (PPE) targeted at families with younger children.

**Oct 4, 2020 Nebraska Commission for the Deaf and Hard of Hearing (NCDHH) Zoo Event at Omaha Zoo** – This was a collaborative event with the Nebraska Association of the Deaf (NeAD) and NE H&V. It was a great turnout that allowed families to have the opportunity to meet D/HH adults and children. NE-EHDI paid for books that went to families who had young children. The Author, Kelly Brakenhoff attended, read, and signed both books for the group. After the formal activities, families gathered for lunch supported by NE-EHDI. This included a short presentation on ways to keep your child’s equipment on and protect the equipment. Each family had the option to choose an item of their choice.



Zoo Event Omaha Zoo  
Photo Courtesy Nebraska Hands and Voices



Kelly Brakenhoff Book Signing.  
Photo Courtesy Nebraska Hands and Voices

**Fall Bash – Oct 11, Omaha**– This is an Annual event with activities and fun for families with children who are D/HH. This is an opportunity to network with other families with D/HH children and individuals in the D/HH community. The Omaha Street Percussion performed. Other activities included pumpkin painting, storytelling, leaf tracing training, and outdoor games.

**Moms Night Inn - Nov 7 & 8, 2020 Scottsbluff**–The topics presented included “You are the perfect mom,” mental health and your D/HH child, a social-emotional perspective from a teenager, Parent Café, and a craft. There was a question and answer with a Deaf adult, then various resources were reviewed including the NCDHH, who discussed the Nebraska Specialized Telecommunications Equipment Program (NSTEP) program. Especially during the pandemic, moms were appreciative to get out and network with other moms.

# Recipients of the NE-EHDI Parent Scholarship for the EHDI National Meeting



Photo courtesy of Victoria Gaughen

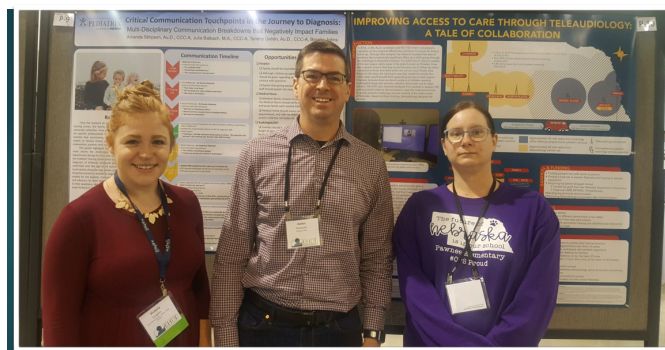
NE-EHDI provides at least one scholarship for a parent of a child who is deaf or hard of hearing to attend the EHDI Annual National Meeting per our HRSA funding requirement. This is an opportunity for parents to network and learn about the many resources available for their family and child. It is also another opportunity for NE-EHDI to involve parents in our program and ask for feedback for program improvement to better serve the families in Nebraska.

*The parent representatives who attended the meeting in Kansas City, MO 2020 stated the following:*

**Victoria Gaughen** – “Being a parent of a child with Special Needs can feel very lonesome. Attending the Annual EHDI Meeting in Kansas City in March gave me an overwhelming feeling of home, community and belonging. So many parents from so many different places shared struggles, joys and sense of fellowship. I LOVED getting to meet many professionals that were so passionate about creating equality and awareness.”

**Aaron Thompson** – “Truly enjoyed all aspects of the conference....plan to attend again. Meeting other parents, professionals, and vendors. Parents that truly understand your problems. Professionals that helped me find resources. Vendors that I use today, that I have actually met in person. Increased Deaf culture awareness. An opportunity to laugh, talk about our own experiences, and look at how others are fine-tuning similar situations.”

**Laura Kautz** – “Mom to Ryan, Ella, and Evan Carr. Ella and Evan were born Deaf. I was able to really learn and appreciate the 2020 EHDI Meeting in Kansas City. I attended different lectures and programs and was able to see a deeper view of the Deaf Community advocates and how everyone was working to improve the lives and educational outcome for Deaf children. I was able to take away more knowledge and confidence than I thought was possible. I know my family is unique and what works for some may not work for me. Regardless of differences we want the same thing. Happy successful children. I am not alone on that quest.”



Left to Right: Victoria Gaughen, Aaron Thompson, and Laura Kautz  
Photo Courtesy of Aaron Thompson

# Tele-Audiology

NE-EHDI continues to receive updates regarding tele-audiology in Nebraska since the program led the planning and implementation with several partners. The University of Nebraska-Lincoln's Barkley Speech Language and Hearing Clinic can complete follow-up re-screening and/or diagnostic hearing testing for infants who did not pass their newborn hearing screening via tele-audiology. The appointments are via tele-practice with test sites at ESU 13 in Scottsbluff, Sidney, and Chadron, as well as ESU 16 in North Platte and Ogallala.

Appointments are conducted using end-to-end encryption via Zoom HIPAA-compliant conferencing. The testing is completed by a Doctor of Audiology in Lincoln, with a Teacher of the Deaf and Hard of Hearing as a trained facilitator at the test site.

## Communication & Educational Outreach with Medical Professionals

The annual quality assurance (QA) reports were e-mailed to birthing facilities in March and April 2020. Birthing facilities in Nebraska continued to conduct inpatient hearing screenings the majority of the time during COVID-19. Information about guidelines during COVID-19 was e-mailed to birthing hospitals in March and April 2020. In-person meetings were placed on hold. Correspondence continued via e-mail and phone. NE-EHDI started conducting virtual platform meetings again in September 2020. The EHDI team determined after the last meeting in November that hospitals were too busy at the time with Nebraska's high COVID-19 numbers to even have virtual meetings unless there is a significant problem. Communication continued via e-mail and phone.

Some of the primary pediatric audiology clinics remained open, some reduced staff and hours, and some had to close for a period of time during COVID-19. All the primary pediatric audiology clinics started resuming regular hours in July 2020. NE-EHDI communicated regularly through e-mail with the primary pediatric audiology clinics during March-July 2020 and then as needed. COVID-19 information was included in the biannual audiology newsletter e-mailed in April and November 2020 to all audiologists who see pediatric patients. The annual QA reports were e-mailed to the primary pediatric audiology clinics in May 2020. In-person meetings were placed on hold for a while and then started scheduling virtual meetings again in December 2020.

In-person education training for Primary Health Care Providers (PHCPs) and ENTs about EHDI and newborn hearing was been placed on hold during COVID-19. The Chapter Champion, who is an ENT and a pediatrician from the NE-EHDI Advisory Committee has not been available to help educate/train about the EHDI system to medical professionals during COVID-19. This work will resume when COVID-19 slows down and our partners can fit into their busy schedules. Information for PHCPs is available on the NE-EHDI website, provided via phone and with the letters that are faxed to PHCPs.

NE-EHDI has provided training to the birthing hospitals through the Nebraska Newborn Hearing Hospital Champion training program that was disseminated in December 2019. The Parent Perspectives training video and education cards are key elements of the training. Once completed, hospitals are presented with a certificate to display in their hospital, and their facility is listed on the NE-EHDI website as a Champion. At the end of 2020, there were nine hospitals that have completed the training and fourteen more hospitals that have pledged to complete the training. Champions will complete an audit form annually to show they are continuing to utilize the training in their hearing screening protocols. Full details about the Hospital Champion Program can be found on the NE-EHDI website at Nebraska Newborn Hearing Hospital Champion Campaign.



The National Center for Hearing Assessment and Management (NCHAM) training at <http://www.infanthearing.org/nhstc/index.html> provides a free streaming online video with step-by-step modules for conducting Otoacoustic Emissions (OAE) and Auditory Brainstem Response (ABR) screening. This training is included in the NE-EHDI recommended Hospital Protocol that is posted on the website, shared during hospital visits, and included with the birthing hospitals' Annual QA reports. Hospitals are informed that it is helpful for new screeners and as a refresher course for those who are already conducting hearing screens.

## Exhibits and Presentations

### NE-EHDI exhibited virtually at:

- Boys Town Pediatrics Newborn Expo (Virtual July 11)
- Nebraska Speech Language Hearing Association (NSLHA) Conference (The virtual forum was open from 9/14/2020 – 11/30/2020)

### NE-EHDI presentations:

- Presented to the Sertoma Club (March 2020)
- Presented virtually to the UNL Auditory Electrophysiology Class (April & October 2020)
- Presented virtually to the Nebraska Head Start Association (April 2020)
- Presented virtually for the NSLHA Conference (September 2020)

## NE-EHDI Website Updates

The following education and resources were revised/added to the website:

- Revised the “Newborn Hearing Screening – Did You Know?” Video after receiving feedback from the NE-EHDI Advisory Committee. (Available in English, Spanish & captioned.)
- Revised the “CMV Stops with Me” Video after receiving feedback from the NE-EHDI Advisory Committee. (Available in English, Spanish & captioned.)
- Added an EHDI Family Support Page with all our partners, which also includes the “Resources for children who are D/HH” YouTube Video for families and those who provide services to the families and children. Dr. Stacie Ray provided the leadership on this project and organized the collaboration with NE-EHDI, UNL Barkley, Nebraska Commission for the Deaf and Hard of Hearing, Nebraska Hands and Voices, Early Development Network (EDN), and Regional Programs.
- Revised the NE-EHDI Recommendations for Hospital Hearing Screening Protocols, the NE-EHDI Summary and Reporting Guidelines for Audiologists document, and the Risk Factor Reporting form to align with the 2019 Joint Committee on Infant Hearing (JCIH) Position Statement.

## NE-EDHI Award



NE-EHDI Received the National Website of the Year Award at the 2020 Annual EHDI Meeting in Kansas City, MO.

## **New Special Projects Started in 2020**

1. Expand capacity beyond newborn hearing screening to support early childhood hearing screening up to 3 years of age. This will be collecting and reporting early childhood hearing screenings, diagnosis, and early intervention. NE-EHDI gave a presentation in April 2020 to the Nebraska Head Start Association, which included Early Head Start (EHS) programs. All the EHS programs that were in attendance are interested in sharing data with NE-EHDI. The NE-EHDI Coordinator and Business Analyst met in December 2020 with the Head Start Association Director and the Nebraska Head Start Collaboration Office Director to discuss data-sharing agreements, parent consent forms, review National Center for Hearing Assessment and Management (NCHAM) Early Childhood Hearing Outreach (ECHO) hearing screening and diagnostic follow-up forms, NCHAM ECHO hearing screening and diagnostic log spreadsheet, discuss the data EHS programs currently collect when conducting OAE hearing screens, the EHS data system utilized by the majority of Nebraska EHS programs, and how to simplify the format for the diagnostic log spreadsheet. The plan needs to be in place by 3/31/2022 per HRSA funding requirements.

2. Families of young children who are D/HH will have access to a D/HH Role Model/Mentor by the time their child is 9 months of age (HRSA funding requirement). There were many discussions with external partners to see what services are currently being provided in Nebraska for D/HH Role Models or Mentors. NE-EHDI understands that some areas of Nebraska have D/HH role models or mentors for parents with children who are D/HH and for students who are D/HH to be connected for guidance. However, there is no statewide formal D/HH Role Model or Mentor Program in NE with the focus of connecting parents by the time the child is nine months of age. A survey to ask parents' needs and wants for planning a D/HH Role Model or Mentor Program in Nebraska was disseminated to parents by NE H&V, Regional Programs for Students who are D/HH, other deaf educators, audiologists, and NSLHA 8/31/2020. Ninety parents completed the survey. An Organizational Meeting to start planning the D/HH Role Model or Mentor Program in Nebraska was held on 10/23/2020 via Zoom. At the time of the meeting, there were several individuals interested in helping with the planning of this program that included parents, individuals who are D/HH, advocates of individuals who are D/HH, deaf educators, early intervention specialists, family support professionals, and audiologists.

NE-EHDI updates and reminders are posted quarterly on the NDHHS Facebook and more often for special events and circumstances.

# Key Summary Points

- All of the 52 birthing hospitals in Nebraska conducted newborn hearing screenings in 2020 prior to discharge from the hospital or birthing center.
- In 2020, birthing hospitals reported screening the hearing of 99% of newborns prior to discharge from the hospital.
- 99% of the 2020 infants passed an inpatient screening, an outpatient screening, or a diagnostic evaluation.
- Of the 1,445 infants (born in 2020) followed by the NE-EHDI Program, 93% have completed the recommended follow-up of outpatient screening/diagnostic testing, 2% are still in the process of completing the outpatient screening/diagnostic protocol and 5% chose not to complete the protocol (or expired as an outpatient).
- For 2020 births, there were confirmatory audiologic evaluations within 3 months of age for 53% of newborns when the newborn did not pass the inpatient/outpatient screening or did not receive an inpatient screening (preliminary percentage).
- There are 164 infants born in 2020 (as of July 2021) with unknown hearing status due to: 1) parents who are noncompliant in following the recommended hearing screening/testing protocol (n=113), 2) medical conditions causing postponed final hearing testing (n=35), 3) families moving out of Nebraska (n=7), and/or 4) unable to contact families (n=9).
- The incidence of Permanent Congenital Hearing Loss of 2.9 per thousand screened is within the anticipated range of one to three per thousand.
- 88% of the infants born in 2020 who were identified as D/HH and residing in Nebraska were enrolled in the Early Development Network (EDN) and received special education services by 6 months of age when the parents accepted Part-C intervention services (preliminary percentage).
- In 2020, NE-EHDI had a sub-award agreement with HearU Nebraska through the of University Nebraska-Lincoln for the loaner hearing aids program and had a sub-award agreement with NE H&V/GBYS for a Parent Guide to assist with EHDI follow-up for families and medical professionals, and provide education and family support. The agreement also included collaboration on family support events.
- NE-EHDI provided scholarships for three parents of a child who is D/HH to attend the 2020 EHDI Annual National Meeting in Kansas City, MO.

This report, along with additional information about the Nebraska Early Hearing Detection and Intervention Program can be found on the website at <http://dhhs.ne.gov/Pages/EHDI>.

**The staff of the Nebraska Newborn Screening (BloodSpot) Program is available to help with your questions at the numbers listed below. General areas of responsibilities are listed:**

**Jillian Chance, RN, BSN, Newborn Screening/Genetics Program Manager (402) 471-6733**

Program planning, evaluation and management, professional and patient education, metabolic formula

**Krystal Baumert, Inherited Diseases Clinical Specialist (402) 471-0374**

Metabolic, endocrine and lysosomal storage condition,

**Karen Eveans, MD, Inherited Diseases Clinical Specialist (402) 471-6558**

Hemoglobinopathies, Cystic Fibrosis, SMA, SCID, X-ALD & transfusions

**Sarah Ward, NBS Follow-up/QA Specialist (402) 471-6759**

Biotinidase Deficiencies, CCHD, Drawn early and unsatisfactory specimens, hospital QA monitoring and home births

**Michaela Howard, RD, Metabolic Foods Coordinator (402) 471-9731**

Patient education materials, advisory committee and staff support, metabolic foods program

Website:: <http://dhhs.ne.gov/Pages/Newborn-Screening.aspx>

E-mail contact: [dhhs.newbornscreening@nebraska.gov](mailto:dhhs.newbornscreening@nebraska.gov)

E-FAX: (402) 742-2332

Regular Fax: (402) 471-1863

Nebraska Newborn Screening Program  
Department of Health and Human Services  
P.O. Box 95026  
Lincoln, NE 68509-5026

PerkinElmer Genetics Screening Laboratory Director, Joseph Quashnock, PhD 412-220-2300 (Pennsylvania)

PerkinElmer Genetics Screening, General Manager, PJ Borandi, 412-220-2300

\*\*\*\*\*

**The staff of the Nebraska Early Hearing Detection & Intervention Program is available to help with your questions at the numbers listed below. General areas of responsibilities are listed:**

**Brenda Coufal, Program Manager (402) 471-6770**

Program planning, evaluation and management, professional education, systems development

**Jim Beavers, Business Analyst, (402) 471-1526 (Contract, part-time)**

Data system planning and testing, development of reports, system security, training and technical assistance

**MeLissa Butler, Community Health Educator Senior, (402) 471-3579**

Follow-up coordinator, medical community and parent education, data management

**Mary Maraist, Community Health Educator, (402) 471-6746 (SOS, part-time)**

Follow-up, complex diagnostics, community outreach, special projects

**Shelli Janning, Community Outreach Coordinator, (402) 237-9007** (works through a sub-award between NE-EHDI and H&V/GBYS, part-time)

Follow-up, community outreach, education, family support

Website: <http://dhhs.ne.gov/EHDI>

E-mail: [DHHS.NEEHDI@nebraska.gov](mailto:DHHS.NEEHDI@nebraska.gov)

E-Fax: (402) 742-2395

Nebraska Early Hearing Detection & Intervention Program  
Lifespan Health Services, Division of Public Health, DHHS  
P.O. Box 95026  
Lincoln, NE 68509-5026

# Disclosures

The Nebraska Department of Health and Human Services is committed to affirmative action/equal employment opportunity and does not discriminate in delivering benefits or services.

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