



**2019 Annual Report to  
the Legislature**

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# **Newborn Screening In Nebraska**

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

**NEBRASKA**

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DEPT. OF HEALTH AND HUMAN SERVICES

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# One Family's Story

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**H**ello, our names are Tia and Mike Jilg and we are from Broken Bow, Nebraska. We have a daughter, Alle, who was born in November 2017. When Alle was born, we thought God brought a healthy baby girl into the world. Seven days later, we got the news that Alle was born with SCID, "Severe combined immunodeficiency," or the "Bubble Boy disorder." The easiest way to describe her disease is that she was born without an immune system.

We got a call stating we needed to get Alle to UNMC now. The severity of her disease is that a common cold for us could kill her in less than 24 hours. Over the last two and a half years, she has had endured chemotherapy, stem cell transplant and multiple hospital stays due to infections and other procedures. The first six and half months were spent in complete isolation. Two weeks after Alle's transplant, the effects of the chemo started to appear, and they ended up sedating Alle to help her heal.

**Alle will never be cured, but the stem cell transplant is the best chance at life.**

If it weren't for the Nebraska Newborn Screening, we more than likely wouldn't have Alle here today. Though the diagnosis and outcome from the screening isn't what we wanted to hear, it's obviously better than the alternative.

*The screening is a vital need in our state, and we are grateful that Nebraska does the screening, as not all states had the newborn screening up to just two years ago.*

Those that didn't screen got hit with the hard reality of something was wrong with their child after it was too late. We are the type of people that we want to give you as much information as we can, but also want as much info as possible. It helps to educate the professionals in the medical field as well as the families that are affected by a diagnosis by the screening. Even though the screening doesn't define Alle's outcome in life, it does give her a higher chance at life due to having the screening to tell us something was wrong. All in all, we want to thank those that pushed to have the screening passed in Nebraska; it gave our daughter a greater chance at life.

*Mike and Tia Jilg*



**Alle Jilg**

*Photo Courtesy of: Mike and Tia Jilg*



# Screening



Photo Courtesy of: [Isaac Del Toro](#)

Nebraska's statute governing newborn screening ([Neb. Rev. Stat. §§71-519 through 71-524](#)) requires 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:

- ☀ Education of health care professionals and parents, and efforts to increase public awareness.
- ☀ 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.
- ☀ Ensure access to needed specialized services and treatment for diagnosed infants.
- ☀ Evaluation and Quality Assurance/Quality Improvement efforts.

**Nebraska's newborn screening panel targets 32 core conditions but several more may be detected on the secondary panel.**

**In 2019, this resulted in identifying and treating 66 newborns in time to prevent or reduce problems associated with identified conditions.**

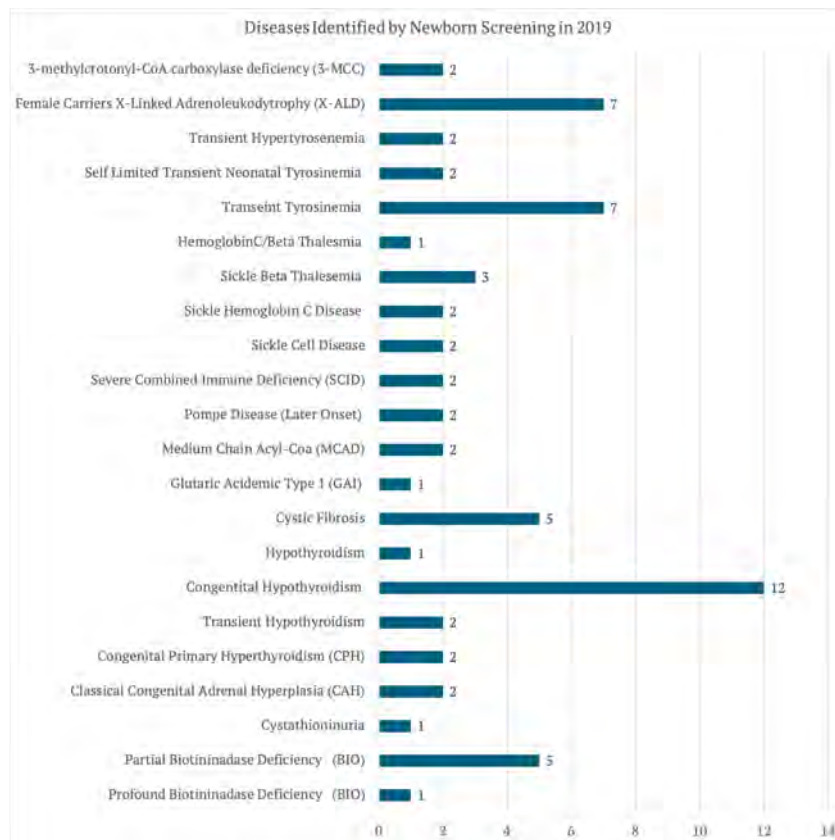
# System Overview

In 2019, fifty-four birthing facilities in Nebraska shipped specimens overnight for 25,842 babies Monday through Saturday to PerkinElmer Screening Laboratory (all but eight hospitals had Saturday pick-up available to them).

The Department of Health Human Services administers the program. The program partners with pediatric subspecialists 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 membership of the advisory committee consists of pediatric subspecialists, pathologists, chemists, pediatricians, neonatologists, family practitioners, as well as representatives from the Nebraska Hospital Association, the Nebraska Medical Association, Medicaid, and families of affected children.

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



**Nebraska Newborn Screening Program Data as of June 16th 16,2020**

The follow-up staff at the Department of Health and Human Services ensures that the health care provider for every newborn who requires additional testing receives the necessary education to act accordingly and continues to follow-up with calls, faxed letters, and education until 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.

# Program Performance

## Intervention and Outcome Data

Collecting specimens correctly the first time, at the right time, and processing them for shipment is just the beginning. Working to optimize shipping times with the commercial overnight shipping company, and maximizing the efficiencies at the testing laboratory are also key to timely reporting of results on babies who need follow-up.

Several factors can conspire to create delays in treatment, so speed and persistence in follow-up are essential. Some examples of events that can delay screening and treatment:

- Prolonged treatment requirements for babies in NICUs
- Severe weather affecting shipment times
- Parental misunderstanding or other barriers to obtaining confirmatory testing
- Problems locating parents because of inaccurate contact information

All parts of the system must work for babies to reap the most benefits of early identification, treatment and intervention.

| Quality Indicator   | Count / Denominator | Nebraska Percentage | Regional Percentage | National Percentage |
|---|---------------------|---------------------|---------------------|---------------------|
| <b>Percent of dried blood spot specimens that were unacceptable due to improper collection and/or transport</b>   |                     |                     |                     |                     |
| Number of dried blood spot specimens on which laboratories cannot report a complete newborn screening panel of results due to collection errors / Number of dried blood spot specimens received at state newborn screening laboratory | 183 / 29,333        | 0.62%               | 1.90%               | 1.54%               |

Source: NewSTEPS Data Repository

## Follow Up

The two follow-up coordinators, and the at the NDHHS NNSP, Krystal Baumert and Karen Eveans, MD, receive results from the laboratory and then coordinate with health care providers around the state to provide them with time-critical next steps based on their interpretation of the results they were given. They follow-up with phone calls, faxes, letters, and information sheets until either a satisfactory screen has been completed, an inconclusive result has had a repeat screen, a positive result has received confirmatory testing, or a diagnosis is either made or ruled out. In 2019 alone this was an essential function for more than **4,000 results or distinct reasons for follow-up**.

Sarah Ward, the state's QA/Follow-up Specialist, handles all cases that were drawn early, or born out of the hospital. Approximately half of those were specimens collected early (NICU admissions) as required to avoid interference from parenteral nutrition and transfusions. All drawn early samples must then be repeated at a later time to ensure that all screened diseases are fully ruled out.

| Nebraska Mandated Disorders<br>Average Age At Intervention (In Days) |     |
|--|-----|
| Profound Biotinidase Deficiency                                      | 6   |
| Congenital Adrenal Hyperplasia                                       | 6   |
| Congenital Primary Hypothyroidism                                    | 6   |
| Cystic Fibrosis  | 20  |
| Glutaric Acidemia Type I   | 4   |
| MCAD 2   | 2   |
| PKU  | 5   |
| 3-MCC Deficiency   | 8   |
| Pompe Disease (Later On Set)   | 7.5 |
| Sickle Cell Disease  | 17  |
| SC Disease   | 45  |
| Hemoglobin C Disease   | 21  |
| Sickle Beta Thalassemia  | 33  |
| Hemoglobin C + Beta Thalassemia                                      | 21  |
| SCID   | 5   |

**(This Table represents newborns with conditions that were the primary target of screening. Not all conditions screened were present in Nebraska births in 2019)**

The hard work and persistence of our NE DHHS NNSP follow-up coordinators who work with the professional lab, and pediatric subspecialist partners result in Nebraska's infants with positive newborn screens being diagnosed. Timeliness in reporting significant results is essential, but treatment and diagnosis are critical factors in long-term health and well-being.



## Days From Positive Screen To Diagnosis Nebraska Vs National And Regional Mean

| Disorder Category           | Nebraska   | Nebraska Median | Region      | Region Median | Nation      | Nation Median |
|-----------------------------|------------|-----------------|-------------|---------------|-------------|---------------|
| Amino Acid Disorders        | 3 infants  | 5 days          | 30 infants  | 13 days       | 58 infants  | 19.5 days     |
| Endocrine Disorders         | 17 infants | 6 days          | 158 infants | 20 days       | 587 infants | 17 days       |
| Fatty Acid Disorders        | 2 infants  | 4 days          | 24 infants  | 31.5 days     | 65 infants  | 28 days       |
| Hemoglobin Disorders        | 6 infants  | 23 days         | 41 infants  | 57 days       | 412 infants | 48 days       |
| Lysosomal Storage Disorders | 2 infants  | 7.5 days        | 2 infants   | 7.5 days      | 78 infants  | 31 days       |
| Organic Acid Disorders      | 3 infants  | 6 days          | 11 infants  | 14 days       | 26 infants  | 13 days       |
| Other Disorders             | 7 infants  | 11 days         | 86 infants  | 17.5 days     | 384 infants | 34 days       |

Source: NewSTEPS Data Repository

Nebraska outperforms in all disorders, but in areas such as endocrine disorders, it is well established that days without treatment are days in which IQ can permanently be diminished. In some Hemoglobin disorders, such as Sickle Cell Disease, it is essential to be working towards a diagnosis so that the infant may be identified and placed on antibiotics to prevent infection.

### Quality Assurance and Improvement Initiatives

- ☀ The Nebraska Newborn Screening Program continued its longstanding oversight and monitoring of multiple quality measures of hospital and laboratory performance while looking for ways to support hospitals in their QA/QI endeavors.
- ☀ One main focus was on improving “TIMELINESS” which is a national priority in the newborn screening field.
- ☀ Specimen quality was the other priority. Keeping unsatisfactory specimens to a minimum is essential for many reasons. 1) Unsatisfactory specimens result in delays obtaining reliable screen results because babies have to be brought back to the hospital for specimen recollection followed by shipping to the lab and testing of the new sample. 2) Babies have to receive another heel stick procedure, 3) Parent’s can be unhappy with having to make another trip and subject their newborn to another heelstick.

Twelve hospitals volunteered to participate in a DHHS NNSP sponsored quality improvement initiative aimed at reducing the number and percent of specimens deemed unacceptable due to “quantity not sufficient /QNS” or “blood spots not soaked through,” the two most common problems. The Program purchased and distributed to the 12 participating hospitals complimentary copies of the Clinical and Laboratory Standards Institute’s (CLSI) current Guideline on Collection of Dried Blood Spots for Newborn Screening and the blood spot collection training DVD. These facilities committed to using these materials to train all personnel involved with newborn specimen collection, and complete competency evaluations; update their procedures to quality control on all outgoing specimens; and investigate and report on any unacceptable specimens in these categories.

**Eight of the 12 completed all requirements and were awarded the Excellence in Newborn Screening Certificate:**



**Avera St. Anthony's Hospital, O'Neil:** (Pictured L to R); Jose Paulo Paraoan, Medical Technologist; Jan McNichols, Phlebotomist; Julie Carlson, Phlebotomist; Ella Gupana, Medical Technologist; Bianca Haboc (front) Medical Technologist; Keith Mansuet; Sarah Ward NNSP QA/Follow-up Specialist; Julie Luedtke NNSP Program Manager



**Gothenburg Health:** (Pictured L to R); Sarah Ward, NNSP QA/Follow up Specialist; Julie Luedtke, NNSP Manager; Deb Saum, Lab Supervisor; Danita Paul, Kimberly Russman and Nikki Stevens. Not pictured but part of the GH lab department are Justina Horkey, Rebecca Gronewold and Jessica Schneider.



**Lexington Regional Health Care:** Not pictured, Cathy Sarnes MLS, Laboratory Director; (Pictured L to R); Jim Hain, COO; Leslie March, CEO; Carleton Medallo, MT; Tracy Shafer, MLT; Katya Reiman, Phlebotomist; Paulette Favela, lab clerk; Amber Fox, MLT; Julie Luedtke, NE NNSP Program Manager; Sarah Ward, NNSP QA/Follow-up Specialist



**Filmore County Hospital Geneva:** (Pictured L to R); Sarah Ward, NNSP QA/Follow-up Specialist; Julie Luedtke NE NNSP NBS Program Manager; Jessica Jurgens, MLT (ASCP)<sup>CM</sup>; Dan Meyer, MLT (ASCP)<sup>CM</sup>; MLT (ASCP)<sup>CM</sup>; Alicia Disney, MLS (ASCP)<sup>CM</sup>; Shaundee Graham, MLT



**Thayer County Hospital, Hebron:** (Pictured L to R); Jackie Haller, MT; Natalie Waters, MLS; Destiny Utter, PBT; Susan Linton, PBT; Cody Pachta, MLS, TCHS Lab Manager; Julie Luedtke, NBS Program Manager; Sarah Ward, NNSP QA/Follow-up Specialist



**Community Medical Center, Falls City:** (Pictured L to R); Naresh Khadgi, MLS(ASCP); Heather Kirkendall, MLT(ASCP); Whitney Lippold, MLS(ASCP); Maechelle Rosales, MLS(ASCP); Jaypee Davidon, MLS(ASCP)





**Mary Lanning Healthcare:** (Pictured L to R); Mark Callahan, Chief Operating Officer; Adam Horn, MD, Laboratory Medical Director; Rochelle Nelson, Lead Clinical Lab Assistant; Gena Kile Lead Clinical Lab Assistant; Terri Brown, Laboratory Director; Julie Luedtke, NBS Program Manager; Sarah Ward, NNSP QA/Follow-up Specialist.



**Antelope Memorial Hospital in Neligh:** (pictured L-R); Sarah Ward, NNSP QA/Follow up specialist; Diane Carlin, AMH CEO; Julie Luedtke NNSP Program Manager; Mary Tomjack, MLS, (ASCP)<sup>CM</sup>, Laboratory Director; Tawnya Jensen, MLS (ASCP)<sup>CM</sup>; Jessica Dabalos, MLS (ASCP)<sup>CM</sup>; Casey Borgelt, MLS(ASCP)<sup>CM</sup>.

## Awards



**Krystal Baumert: NNSP Follow Coordinator**  
Photo Courtesy of: APHL

Krystal Baumert, NDHHS Follow Up Coordinator received the Association of Public Health Laboratory’s first “Everyday Lifesaver Award” at the National Newborn Screening Symposium in Chicago in 2019.

Krystal was honored with the inaugural award based on the more than 25 years of excellence she has contributed to newborn screening follow up. Krystal’s many accomplishments in the field of newborn screening include working to develop one of the first electronic match systems. Krystal is Nebraska’s first follow up coordinator, and the architect of the system in Nebraska. She is a master of relationship building, and has demonstrated that those relationships are the foundation for building successful timely follow-up. She has trained many other follow-up coordinators from other States and is continually called upon for her expertise, support, and ideas. She is the best at what she does, because she knows what is at stake and she truly, deeply cares.

# 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. Recently new educational materials were developed and distributed by our metabolic food specialist, Mamie Lush. The materials separated information about the program into smaller pieces with the goal of improving understanding of how the program works. The program continues to work with the metabolic clinic dietitian to improve the percent of people utilizing the metabolic foods program.



# Education And Outreach

A one page infographic featuring newborn screening on one side and Early Hearing Detection and Intervention (EHDI) on the other was developed and sent to all sent to all pediatricians and family physicians, physician assistants, advanced practice registered nurses, and residents. Each quarter any new practitioners in this group will also receive it. This is intended to be sure all practitioner's know the basic requirements in Nebraska for the NBS and EHDI programs.

# Advisory Committee

The Newborn Screening Advisory Committee conducted its annual review of quality assurance data of pre-analytical (e.g., unsatisfactory specimen rates and types), analytical (e.g., statistical performance of assays over time), and post-analytical (e.g., age at time of intervention, treatment for diagnosed patients, or long-term outcomes) performance measures for the system. Annually the committee also reviews the All-Hazards Contingency/Emergency Management Plan for newborn screening, as well as the program's education plan and strategies. The committee monitors national recommendations, trends, and reports, advising 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. Representatives from PerkinElmer Genetics Laboratory Inc., regularly provided input, presentations, and proposals to the advisory committee. 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. A special thanks to Dr. James Harper for chairing the committee along with Alina Sofronescu, PhD (UNMC) who served as Vice Chair in 2019.

# 2019 Newborn Screening Advisory Committee Members

|                                  |  |
|----------------------------------|--|
| Khalid Awad, MD                  | Methodist Women's Hospital - NICU                  |
| Lawrence Bausch, MD              | Nebraska Medical Assoc./Maternal & Child Health    |
| Angela Brennan, MD               | St. Paul, Family Medicine                          |
| Catherine Brooks, DO             | CHI St. Elizabeth Regional Medical Center-NICU     |
| John Colombo, MD                 | Children's Specialty Physicians Pulmonary Medicine |
| Jeanne Egger                     | Advocate   |
| Zoe González García, MD          | Children's Physicians, Pediatric Endocrinology     |
| James Harper, MD                 | UNMC, Pediatric Hematology                         |
| Kathryn Heldt, RD, LMNT, CDE     | Children's Hospital-Metabolic Management Clinic    |
| Mary Kisicki                     | Advocate   |
| Heather Leschinsky               | Nebraska Medicaid and Long Term Care, DHHS         |
| Richard Lutz, MD                 | UNMC, Munroe-Meyer Institute, Metabolic/Genetics   |
| Bev Morton                       | Advocate   |
| Hana Niebur MD                   | Children's Hospital - Pediatric Immunology         |
| Deborah Perry, MD                | Nebraska Methodist Hospital Pathology Center       |
| Samuel Pirruccello, MD           | University of Nebraska Medical Center              |
| Bob Rauner                       | Advocate, United Leukodystrophy Foundation         |
| William Rizzo, MD                | UNMC, Munroe-Meyer Institute, Metabolic/Genetics   |
| Kathy Rossiter, EJD, MSN, APRN   | JD/APRN /Medical Ethicist                          |
| Jill Skrabal, PhD, RD, LMNT, CDE | Metabolic Management Clinic UNMC                   |
| Alina-Gabriela Sofronescu, PhD   | Department of Pathology and Microbiology           |
| Margaret Woeppel, MSN, RN, CPHQ  | Nebraska Hospital Representative                   |



# 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



### **Inpatient Newborn Hearing Screening**

*Photo courtesy of: NCHA*

Approximately one to three in 1,000 babies are born with permanent hearing loss, making hearing loss one of the most common birth defects in America. Before newborn hearing screening, children who were deaf or hard of hearing (D/HH) sometimes were not identified until 2½ to 3 years of age. Left undetected, this 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 main 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 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 the identification of 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 the normal auditory, speech, and language developmental process in children. 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.

## 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 2019, there were 54 birthing facilities conducting hearing screenings.

### Hearing Screening at Birthing Facilities and Birthing Centers

#### Hearing screening/testing status of the 25,186 births for 2019:

|   |        |
|---|--------|
| Passed the screening <b>or</b> diagnostic testing (99% of thriving newborns)    | 24,902 |
| Expired (inpatient or outpatient)   | 105    |
| Pending final screening or diagnostic testing                                   | 66     |
| Diagnosed deaf or hard of hearing   | 47     |
| Parents refused screening and/or diagnostic testing                             | 34     |
| Unresponsive (did not complete protocol after communication with NE-EHDI staff) | 27     |
| Lost (no response to NE-EHDI letters and phone calls)                           | 3      |
| Moved out of Nebraska   | 2      |
| Late onset deaf or hard of hearing (passed initial screening)                   | 0      |

Inpatient hearing screenings were reported on 24,944 newborns or 99.7% of the 25,017 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 2019, 23,866 (95.7%) 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 or who do not receive 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 2019. 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 to 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.

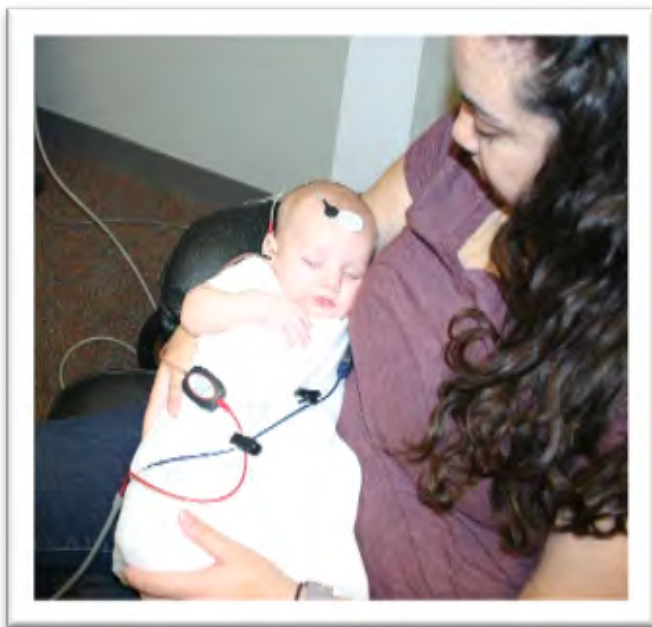
When an infant is identified as deaf or hard of hearing, parent(s) receive the Parent Resource Guide (PRG) from the audiologist, and a notification letter is sent to the primary health care provider. Hands & Voices (H&V)/Guide By Your Side (GBYS) Guides also discuss the PRG with families to provide support and stress the importance of starting early intervention as soon as possible. The PRG was developed by NE-EHDI shortly after the program started, with the collaboration of many partners and is available in print or online at <http://dhhs.ne.gov/EHDI-PRG>.

## 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 1,209 infants (2019 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.”*



**Outpatient Newborn Hearing Screening**

*Photo courtesy of: NE-EHDI*

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 97% of infants completed the inpatient/outpatient screening within one month of age. For the newborns who were recommended for an audiologic diagnosis, nearly 62% received the evaluation by 3 months of age according to individual data reported to the NE-EHDI Program by audiologists (as of May 2020). This percentage is preliminary and will likely decrease due to the number of infants having an initial diagnostic evaluation and needing a confirmatory evaluation.

*Note: Because 66 hearing records are still waiting for the final screening and diagnostic testing results, the “1-3-6” numbers above are preliminary as of May 2020 and will likely change.*

Records for the Early Development Network (EDN), Nebraska’s Part C Early Intervention Program, indicate that 81% 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 May 2020). It is projected that the final percentage for enrollment within 6 months will be less than 81%, since there are still 66 infants needing a confirmatory diagnosis and some will be referred to early intervention later than 6 months after the date of birth. The reasons for those infants not enrolled in EDN include: parents declined services, unable to contact the family, family moved out of state, and no indication of developmental delay (slight or mild hearing loss).

# 2017-2019 - Not Completed Cases

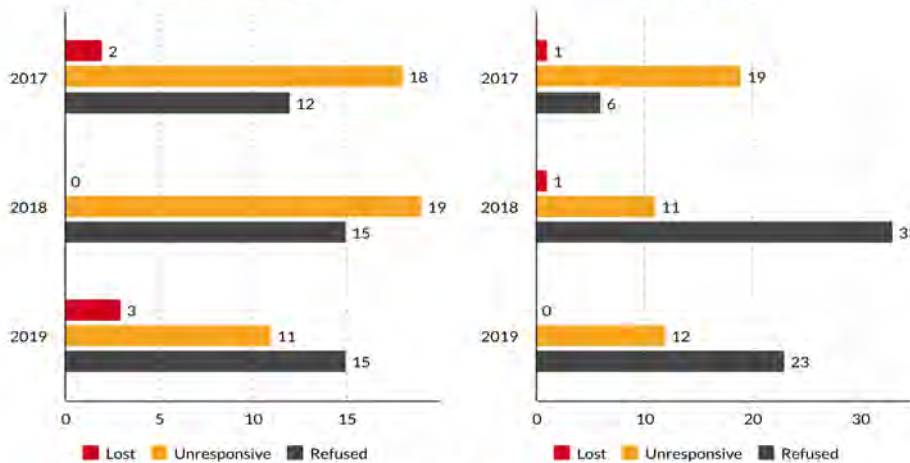
Lost - Unresponsive - Refused



Hospital Births



Home Births



## Combined Totals by Year

2017 (58 Total)

2018 (79 Total)

2019\* (64 Total)



Home Births (44.83%)  
Hospital Births (55.17%)



Home Births (56.96%)  
Hospital Births (43.04%)



Home Births (54.69%)  
Hospital Births (45.31%)

\*Preliminary data-numbers may change.

## 2019 Activities

### Funding

The NE-EHDI Program continued to receive only federal funding in 2019. 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. 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.



# Advisory Committee

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 and advising on the goals for the NE-EHDI Program.
- ☀ Advising on the improvement of 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 the expanding 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.

The NE-EHDI Advisory Committee voted and passed in 2019 to change the number of voting members of no more than 20 voting members to no more than 30 voting members. Two Advisory Committee meetings were held in 2019 and were open to the public. Minutes are posted on the NE-EHDI public website.

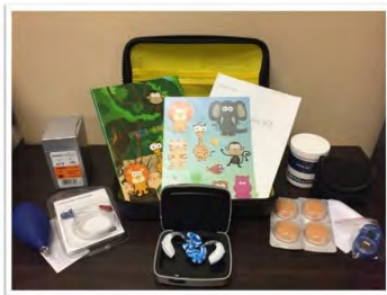
## 2019 Newborn Screening Advisory Committee Members

|                                 |  |
|---------------------------------|--|
| 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  |
| 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  |
| Nancy Hengelfelt, BSN, RN       | OB Director, York General Hospital   |
| Jayden Jensen                   | Deaf/Hard of Hearing Advocate/Advisor  |
| Kristin Jolkowski, Au.D., CCC-A | Educational Audiologist, Lincoln Public Schools  |

|                               |   |
|-------------------------------|---|
| Heather Gomes, M.D.           | AAP Chapter Champion/Otolaryngologist, Boys Town Research Hospital  |
| Cole Johnson                  | Special Education Office, Nebraska Department of Education  |
| 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 (NCDHH)  |
| Joan Luebbers                 | Head Start State Collaboration Office, Nebraska Department of Education   |
| Johnna Lygrisse               | Parent/Advocate Advisor - Moved out of state after May 2019 Advisory Meeting  |
| 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/Doctor of Audiology/Nebraska Hearing Aid Banks Director, Special Education & Communication Disorders, University of Nebraska - Lincoln/Parent |
| Colleen Richart               | Parent/Hard of Hearing Advocate/Hands &Voices   |
| Karen Rolf, Ph.D.             | College of Public Affairs and Community Service, Grace Abbott School of Social Work, University of Nebraska - Omaha   |
| Pete Seiler, Ph.D.            | Nebraska Association of the Deaf (NeAD)/Deaf Advocate/Advisor - Moved out of state after May 2019 Advisory Meeting  |
| Merry Spratford, Au.D., CCC-A | Research Audiologist, Boys Town and National Research Hospital  |
| Jana Wiblishouser             | Parent/Advocate Advisor - Joined Nov 2019   |
| Pam Zegers, M.D.              | Pediatrician, Complete Children's Health  |

# 2019 Projects

## HearU Nebraska



**HearU Care Kit**

*Photo Courtesy of: Hear U*

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 criteria was implemented January 1, 2018. The NE-EHDI Program continued to provide funds for administration of the program and to help purchase loaner hearing aids in 2019. In 2019 there were 59 hearing aids provided and fitted for 38 children (age range of 1 month to 18 years) with "free" hearing aids provided by HearU Nebraska. From 2008-2019, 771 hearing aids were provided and fitted on 459 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 May 1, 2017. NE-EHDI has collaborated for several years with GBYS to assist connecting families with family support. The current sub-award agreement involves a 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 gives families an opportunity to connect with a GBYS Parent Guide with their first EHDI contact and allows the guide to share experiences and knowledge as appropriate.

The GBYS Parent Guides are a parent of a deaf or hard of hearing (D/HH) child who has been 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 2019, 14 trained Parent Guides provided family support throughout Nebraska.

The H&V/GBYS staff through the sub-award agreement with NE-EHDI, worked with 861 families for EHDI follow-up during 2019. As of December 31, 2019, GBYS Guides were actively serving 152 families, and 95 of those families were referred by NE-EHDI (63%). The percentage of infants with a diagnostic evaluation completed within 3 months reported by NE-EHDI improved from 59% for 2016 births to 63% for 2017 births, to 65% for 2018 births, and then slightly decreased to 62% for 2019 births. This 2019 percent may decrease since it is based on preliminary data.

## Quotes From Families Served

*“The guide by your side program have made life better for us. Learning and sharing with other parents that ‘get it’ has made such a difference for us. Thank you so much!”*

*“When you find out you have a child with hearing loss/deaf difference I had no clue what to do next. Out of the blue I got a call from my parent guide and I was like oh wow, how did you know? You want to help me go through all this???? And I was like oh thank you!!! I had no clue what to do so it was nice to sit down with someone who knows what I am going through and helped point me in the right directions. Without my parent guide, I probably would still be sitting here spinning. I get emails of advice and events and whenever I have a question or thought I just call or email her and I know I will get the best advice without any judging.”*

*“Our guide is there exactly how much we need her and it’s tailored to our needs which is great. We don’t feel overwhelmed but we have it there when things get tough! I met another mom through the program with the same guide and she and I became fast friends and I love that!”*

*“The Newborn Screening is a godsend! I’m glad they set up perimeters that ensure follow up and early intervention to children detected with hearing loss or other disorders that could cause delays in development.”*

## 2019 Family Support Events

NE-EHDI collaborated with H&V/GBYS for many family support events in 2019.

**Parent Night Out Event for parents of D/HH children (January 2019 Hastings)** - Facilitator had topics with questions for families to discuss, which started the dialogue. It was an opportunity for parents to connect with other parents who have D/HH children.

**Hands & Voices Social Emotional Workshop (Jan 2019 Hastings) and (Feb 2019 Omaha)** - Presentation on social emotional wellness for families with children who are deaf or hard of hearing. This workshop was for parents who have children (under the age of 21) who are D/HH. This workshop focused on issues that come with raising a child who is D/HH. Part of this workshop was a lecture, and the other part was a panel and open discussion about issues that parents may be dealing with. This was a great opportunity to learn from professionals who specialize in Deafness as well as other parents.

**Hands & Voices Winter Family Bash (February 2019 Omaha)** - Replaced the Fall Bash that was cancelled due to a winter storm. 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.

**Moms Night Inn (February 2019 - Lincoln)** - An opportunity for moms to share experiences and provide support to each other. Topics included – self-advocacy, empowerment, literacy, socialization, communication & more.



**Mom's Night Inn 2019**

*Photo courtesy of: Nebraska Hands & Voices*  
Photo courtesy of: Nebraska Hands & Voices

### **Sizzling Summer Educational Zoom Series (Weekly Zoom meetings during August)**

- ☀ August 4, 2019 - Nebraska Educational Resources - Families learned about various educational resources in Nebraska. This included the equipment available through Nebraska Commission for the Deaf and Hard of Hearing (NCDHH) to promote independence for your child.
- ☀ August 11, 2019 - Transitioning and Fostering Independence - Families learned what to expect as their child transitions from 0-3 to 3-5 for education services; rule 51 & 52; understanding of the common acronyms such as individualized family service plan (IFSP), individualized education plan (IEP), multidisciplinary evaluation team (MDT), etc.; tips on how to navigate the IEP process; and where to go for educational support.
- ☀ August 18, 2019 - Preparing Your Child for Self-Advocacy - Families learned about strategies to help their child be more independent; how to help their child be more involved in their IEP; and books available to introduce their child with a hearing difference to the classroom.
- ☀ August 25, 2019 - PowerPoints are Powerful! - Families learned from other experienced parents their perspective on how self-advocacy has helped their child; self-advocacy in action from a middle school and college student; understanding why it's important to start teaching self-advocacy at a young age; and sharing the child's individual needs with the professionals working with your child.

**UNL Football Player, Todd Honas Event (September 2019 Lincoln)** - Interview with Todd Honas, a college junior Husker football player who is hard of hearing. Opportunity to also network with other parents who have children who are D/HH. This was one of the largest attended D/HH family events that Hands & Voices has organized. 137 people attended. Not all who attended were parents of a D/HH child, but they were involved with supporting D/HH individuals on some level. Attendees commented how they loved to hear the perspective of such a wonderful role model. Todd values literacy and is a very humble person.





**UNL Football Player, Todd Honas Event 2019**

*Photo courtesy of: NE-EHDI*

**Feedback from families about how the event made a difference for them:**

*“Hearing Todd talk about his life, similar to our daughters hearing loss.”*

*“Great role model for our deaf children to look up to.”*

*“Encouragement from an athlete that my son admires, letting him know he can aspire to do what he puts his mind to.”*

*“At the stadium with a Husker, once in a lifetime!”*

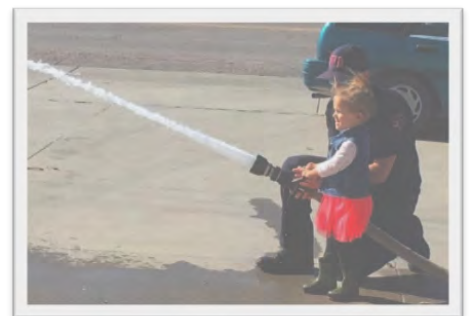
*“The positive atmosphere, the chance for my son to meet others like him.”*

*“Having the kids ask questions to the speaker. Gives them confidence.”*

*“Loved hearing Todd’s background and how he handled multiple situations.”*

*“Giving my son the opportunity to be around other people who are Deaf or Hard of Hearing.”*

**Fire Safety Event for families who have children ages 0-21 who are D/HH (Fall 2019 - McCook, Norfolk, Omaha, Bellevue, Kearney and Scottsbluff)** - Collaborating with NCDHH, NE EHDI, and fire departments to provide community education and resources to families with children who are D/HH or Deaf blind. NCDHH educated people about the Nebraska Specialized Telecommunications Equipment Program (NSTEP) resource. D/HH and Deaf blind needs were discussed with emergency plans. The emergency professionals educated about what families and individuals can do to help stay safe in an emergency.



**Fire Safety Event 2019**

*Photo courtesy of: Nebraska Hands & Voices*

**Rising Stars** - A Deaf & Hard of Hearing Youth Leadership Award Program was created in 2018 by Nebraska H&V/GBYS. 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 our youth to become positive role models in the D/HH community. They receive an award certificate, a \$10 gift certificate and are recognized on the Nebraska H&V Facebook.

## Parent Scholarship Recipient

NE-EHDI provides a 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 a parent 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.



**Jana Wiblishouser & Family**  
*Photo Courtesy of: Jana Wiblishouser*

The parent representative who attended the meeting in Chicago, March 2019 stated, “It was really exciting for me to be chosen to attend the EHDI Meeting this year. I learned so much, and still feel like I have so much more to learn. It was an amazing opportunity for networking. I met professionals and so many other parents that knew what I was going through, or were just starting to go through the process that I had completed. It was amazing to build relationships, and realize how much we had in common. The only two

disappointments were that I couldn’t attend all the sessions I wanted because there were so many to choose from, and I wish more parents could come. I feel like I benefitted immensely, and I think that a lot of parents would get a lot of good out of it. Attending the meeting has encouraged me to become more involved and to give back. I am so excited for the next EHDI meeting, and I plan to go to that one as well. It created an understanding of things behind the scenes. As a parent, I don’t think we get to see everything that goes into creating the resources we need and how many people are fighting for our children. It was amazing to see the faces and understand how much goes into it. I also got a better understanding of the community, and I see how it all ties together.”

## Learning Communities

### Parent Perspectives Hospital Training Video

Many parents expressed frustration and concern about how their infant’s newborn hearing screening results were communicated to them by hospital staff. Therefore, a work group consisting of two NE-EHDI staff, six parents of a child who is deaf or hard of hearing, and one labor & delivery nurse from a birthing hospital was formed. The goal was to focus on how our Nebraska partners can work together to ensure that each family has a positive and informative experience in the hospital when their baby does not pass the newborn hearing screening.



**MeLissa Butler presents St Francis Memorial Hospital - West Point with the first Newborn Hearing Hospital Champion Certificate on December 30, 2019.**

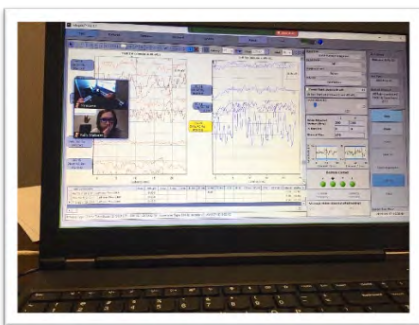
community, NE-EHDI Advisory Committee, and hospital personnel was gathered, and a revised video script was written.

The video was re-filmed in March 2019 using the new script. Editing and captioning of the video, as well as designing new education cards was completed in late summer 2019. The Parent Perspectives training video and education cards are key elements of the Nebraska Newborn Hearing Hospital Champion Campaign, which was piloted during October/November 2019.

Once the pilot hospital successfully completed the training protocol, the campaign was rolled out to all Nebraska birthing facilities in December 2019. 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. Full details about the Hospital Champion Program can be found on the NE-EHDI website.

## Tele-Audiology

NE-EHDI led a learning community from 2016-2019 which resulted in implementing tele-audiology services in Nebraska in 2019. The purpose of this initiative was to address barriers to care and ensure that the quality of services available to families in western Nebraska are comparable to the



**ABR performed via Tele-audiology**

*Photo Courtesy of: ESU13*

metro areas of Nebraska. The stakeholders consisted of two NE-EHDI staff; four audiologists; a deaf educator from western Nebraska; an Educational Services Unit (ESU) Services Coordinator from Scottsbluff, who is also the parent of a deaf child; an audiologist with the Minnesota Department of Health who successfully implemented a tele-audiology program; a Health Resources and Services Administration (HRSA) Project Coordinator with the North Carolina EHDI program; and a consultant with the Great Plains Telehealth Resource & Assistance Center (gpTrac) who helped Minnesota set up their tele-audiology program. Throughout the process, many barriers were encountered including finding the right partners, securing funding, and ensuring long term sustainability of the program.

The Educational Service Unit (ESU) #13 in Scottsbluff is the spoke site for western Nebraska and the University of Nebraska-Lincoln (UNL) Barkley Speech Language Hearing Clinic is the hub site in eastern Nebraska. The Nebraska Department of Education (NDE) provided funding through a grant to UNL to pay for the tele-audiology equipment. Customer satisfaction surveys are being utilized to monitor and make improvements as needed.

## Hospital Site Visits and Communication with Pediatric Audiologists

Site visits to hospitals determine what assistance the NE-EHDI Program can provide on lowering refer rates, offer an opportunity to discuss initiatives to reduce the number of children who are lost to follow-up, allow for time to discuss the Quality Assurance (QA) Reports and review newborn hearing screening protocols. These visits also establish relationships with the hospital staff, helping to ensure positive collaboration. NE-EHDI continued to complete hospital visits in 2019. The goal is to meet with every birthing facility during the three-year federal grants cycle from 2017 - 2020.

NE-EHDI e-mailed audiologists to inform them about NE-EHDI updates, reminders about reporting to NE-EHDI, and asked for program improvement feedback. The first annual Audiology QA reports were provided in 2019 to the main audiology clinics who see pediatric patients. NE-EHDI also communicates with the audiology clinics through e-mail, phone, and/or in person meetings if issues arise to discuss solutions.

## Exhibits and Presentations

NE-EHDI exhibited in 2019 at:

**Nebraska Young Child Institute** (June 26 & 27)

**DHHS Health Fair on the Mall** (September 10)

**March of Dimes Prematurity Summit** (September 20)

**Boys Town Newborn Exposition** (September 22)

**Association of Women's Health, Obstetric and Neonatal Nurses** (September 28)

**Nebraska Speech Language Hearing Association** (September 28)



**MeLissa Butler, NE-EHDI Community Health Educator, Sr., Jennifer Lee, NE-EHDI Community Health Educator** exhibiting at **DHHS Health Fair on the Mall**

*Photo courtesy of: NE-EHDI*

NE-EHDI presentations and partnerships with professionals for presentations in 2019: **Nebraska Speech Language Hearing Association (NSLHA) Conference** (October 3)

**NE-EHDI AAP Chapter Champion, Dr. Heather Gomes presented at the Nebraska Annual Otolaryngology Meeting** (October 4)



**NE-EHDI AAP Chapter Champion, Dr. Heather Gomes, ENT and Dr. Pam Zegers, pediatrician presented to a Pediatric Clinic (October 10)**

**Fall Newborn Expo at Boys Town National Research Hospital (October 12)**

**Recharge for Resilience Conference - Home visitors and early childhood professionals (October 30)**

## Educational Outreach for Professionals

A one page infographic featuring EHDI on one side and newborn screening (NBS) on the other side was developed and sent to all pediatricians and family physicians, MD, DO, PA, APRN, and Residents in the summer of 2019. The EHDI information is also posted on the NE-EHDI website on the primary care provider/pediatricians page. This is intended to be sure all practitioners know the basic requirements in Nebraska for the NBS and EHDI programs.

NE-EHDI developed a 1-3-6 EHDI Infographic in July, 2019 to share at conferences and meetings.

A one page education document was created in collaboration with the pediatrician on the NE-EHDI Advisory Committee for Pediatric Primary Care and Medical Home Providers. One side explains the Nebraska Newborn Hearing Screening Algorithm Guidelines, which aligns with the American Academy of Pediatrics and the other side lists the Joint Committee on Infant Hearing Risk Factors reporting check list. This was shared during the presentation with the pediatric clinic on October 10, 2019. This will continue to be shared during other presentations with pediatric clinics in Nebraska and is also posted on the NE-EHDI website on the primary care provider/pediatricians page.

**EARLY HEARING DETECTION & INTERVENTION**  
NEWBORN HEARING SCREENING

The goal of newborn hearing screening is to identify children who are deaf or hard of hearing (d/hh) so that they have access to hearing technology and early intervention at a young age. Early access to communication and intervention are important for developing children's social and academic potential.

**JCIH 1-3-6 Goals**  
The Joint Committee on Infant Hearing has established 1-3-6 goals for newborn hearing screening and follow-up.


- 1** All infants should receive a hearing screening by one month of age.
- 3** All infants who refer should receive a diagnostic evaluation prior to three months of age.
- 6** All infants who are identified as deaf or hard of hearing should begin receiving early intervention services by six months of age.

**Primary Care Provider's Role**

- Be familiar with the JCIH 1-3-6 goals.
- Update EHDI about a child's hearing status.
- Ensure timely and appropriate follow-up occurs.
- Provide ongoing monitoring of every child's hearing status, especially those with risk factors.
- Work with the audiologist to coordinate the evaluation and referral process.

**Visit our website to find out about:**

- Nebraska Law**  
Nebraska law requires birthing facilities to offer newborn hearing screening as the standard of care.
- Timely Follow-up**  
Find out why timely follow-up is important for infants who do not pass their newborn hearing screening.
- Next Steps**  
Determine what to do next when a baby does not pass the newborn hearing screening at birth.
- Ongoing Monitoring**  
Understand and identify risk factors for late onset hearing loss, and when ongoing monitoring is needed.
- Family Support**  
Learn the benefits of connecting families of d/hh children, and where parents can find support.
- Reporting & Referrals**  
Find out how to report results to EHDI, and when to make a referral to Early Development Network (EDN).

For more information visit:  
  
<http://d3.nba.ne.gov/EHDI>

Nebraska Early Hearing Detection & Intervention  
888-545-0935  
DHHS.NEEHD@nebraska.gov

**NEBRASKA**  
Good Life. Great Mission.  
DEPT OF HEALTH AND HUMAN SERVICES

NE-EHDI developed two educational videos posted on the NE-EHDI website called “CMV stops with ME!” and “Newborn Hearing Screening - Did You Know?”.



# Awards

MeLissa Butler, NE-EHDI Community Health Educator and Brenda Coufal, NE-EHDI Program Manager both received the DHHS Excellence in Leadership award.



*MeLissa Butler receiving the Excellence in Leadership award from Governor Pete Ricketts*

*Photo courtesy of: Nebraska Department of Administrative Services*



*Brenda Coufal receiving the Excellence in Leadership award from Governor Pete Ricketts*

*Photo courtesy of: Nebraska Department of Administrative Services*

*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>.*

# Program Staff

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

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

Program planning, evaluation and management, systems development, metabolic formula

**Krystal Baumert, NBS Follow up Coordinator (402) 471-0374**

Metabolic, endocrine and lysosomal storage conditions

**Karen Eveans, NBS Follow up Coordinator (402) 471-6558**

Hemoglobinopathies, cystic fibrosis (CF), Severe Combined Immunodeficiency (SCID), X-linked adrenoleukodystrophy (X-ALD), & transfusions

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

Drawn early and unsatisfactory specimens, hospital QA monitoring and home births

**Mamie Lush, Staff Assistant (402) 471-9731**

Patient education materials, advisory committee and staff support, metabolic foods and formula programs

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 Fax: (402) 471-1863

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

**PerkinElmer Genetics Screening Laboratory Director, Joseph Quashnock, PhD  
412-220-2300**

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

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# Program Staff, continued

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**

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

**Bailey Heaton, 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  
Department of Health and Human Services  
Division of Public Health  
Lifespan Health Services  
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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Cover Photo Courtesy of Chiến Phạm. <https://unsplash.com/photos/b1NsVYkIP6g>

Any reference to specific commercial product in the Newborn Hearing Screening section does not constitute or imply an endorsement, recommendation or favoring by the Nebraska Early Hearing Detection & Intervention Program.

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