

# NEWBORN SCREENING IN NEBRASKA

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



# 2018 Annual Report

**NEBRASKA**

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

# TABLE OF CONTENTS



## 2018 Annual Report Newborn Bloodspot Screening

### NEWBORN SCREENING FOR INBORN ERRORS OF METABOLISM AND INHERITED DISORDERS

Nebraska's Newborn Screening System Performs at the TOP of States Participating in Timeliness and Other Quality Measure Reporting	4
What it is and Why we do it	8
Newborns Identified in 2018	9
System Overview	10

### MAJOR INITIATIVES OF 2018

Implementing screening for three new disorders	11
Enhancing intra-agency collaboration for follow-up	11
Quality Assurance and Improvement Initiatives	12

### HIGHLIGHTS FROM SOME KEY ELEMENTS OF NEWBORN SCREENING

Follow-up	13
Advisory Committee	14
Financing Newborn Screening	15
Assurance of Treatment with Metabolic Foods & Formula	15
Intervention Data	16
Outcome Data	17

STAFF	34
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DISCLOSURES	35
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## **2018 ANNUAL REPORT EARLY HEARING DETECTION AND INTERVENTION**

<b>INTRODUCTION</b>	19
<b>NEWBORN HEARING SCREENING DATA REPORTED FOR 2018</b>	20
Birthing Facility Screening Programs	20
Hearing Screening at Birthing Facilities and Birthing Centers	20
Parent Education	20
Monitoring, Intervention, and Follow-up Care	21
Testing Status of 2018 births	21
Timeliness of Follow-up Screening/Evaluations/EDN Services	21
Lost to Follow-Up Progress over 12 years	22
<b>ACTIVITIES – 2018</b>	23
Funding	23
Advisory Committee	23
<b>PROJECTS</b>	25
Collaboration with HearU Nebraska/Children’s Hearing Aid Loaner Bank	25
Collaboration with Hands and Voices/Guide By Your Side	25
Family Support Events	26
Recipient of the NE-EHDI Parent Scholarship for the EHDI National Meeting	28
Learning Communities	28
Hospital Site Visits and Pediatric Audiology Meetings	29
Exhibits and Presentations	31
A 2018 Parent’s Story Sharing the Importance of Newborn Hearing Screening	31
<b>SUMMARY</b>	32
<b>STAFF</b>	34
<b>DISCLOSURES</b>	35



**Newborn Screening represents one of the best opportunities to prevent morbidity and mortality in newborns.**

**The goal of newborn blood spot screening is to identify newborns at risk for life threatening and debilitating conditions that would otherwise not be detected until damage has occurred, and for which intervention and/or treatment can improve the baby's outcome.**



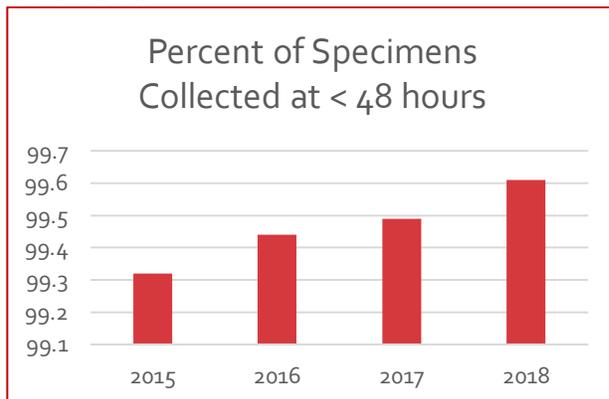
## NEWBORN SCREENING FOR INBORN ERRORS OF METABOLISM AND INHERITED DISORDERS

### Nebraska's Newborn Screening System Performs at the TOP on Multiple Measures of States Participating in Timeliness and Other Quality Measure Reporting.

Since 2015, Nebraska's Newborn Screening Program has participated in reporting of timeliness measures developed by the Association of Public Health Laboratories "NewSTEPS" Program. These measures were founded on goals established by the federal Advisory Committee on Heritable Diseases in Newborns and Children. The national attention to timeliness came on the heels of publicity about tragic "deadly delays" in collection, handling, shipping and testing of newborn screening specimens. During the first 4 years of participation, Nebraska has consistently ranked very high among participating states as shown below:

#### **MEASURE: Age at Collection (Goal < 48 hours)**

For the fourth year in a row Nebraska ranks # 1 of all NewSTEPS participating states for the highest percent of specimens collected at < 48 hours after birth. Each year continues to see incremental improvement. Regulations require collection at between 24 and 48 hours after birth.



To further clarify the adjacent data:

2015: 99.32% (12 states participating)  
2016: 99.44% (24 states participating)  
2017: 99.49% (25 states participating)  
2018: 99.61% (20 states participating)

(Source NewSTEPS Data Repository)

**"All of these performance measures are more than just numbers. They are a testament to the great effort by hospitals, Nebraska DHHS Newborn Screening Program, and PerkinElmer Genetics Laboratory personnel and clinicians, working hard to achieve the goal of the earliest identification, diagnosis and intervention or treatment possible for our newest Nebraskans!"**

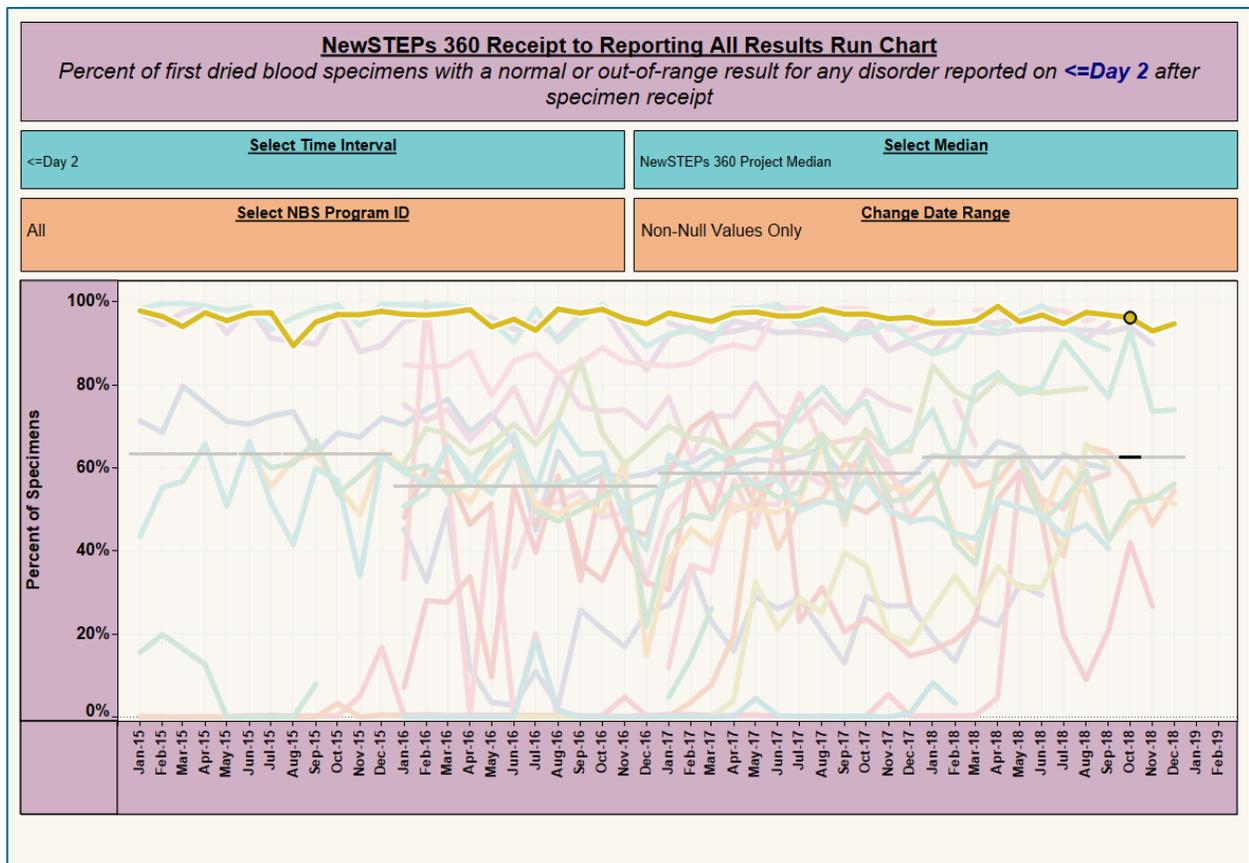
*Julie Luedtke, Nebraska Newborn Screening Program Manager*

**MEASURE: Specimens received in 2 days from collection**

Despite having overnight shipping service from UPS 6 days a week from most facilities, factors that impact our performance on this measure include: no Sunday delivery, weather delays, mechanical (ground and air) problems, shipping specimens out of state to the laboratory, shipping company errors (e.g. missort) and hospital errors. **Over the 4 years Nebraska ranked 17<sup>th</sup> among 24 states with 72.99% of specimens received at the laboratory in 2 days or less.** Not our best measure, but fortunately it is compensated for by the other elements of the system (collection, testing and reporting).

**MEASURE: All results reported out by 4 days from receipt**

Over the 4 year period Nebraska ranks 1<sup>st</sup> of 19 reporting states, with 99.77% of all results reported out within 4 days of receipt.



In the graph above, the “bold gold” line represents Nebraska’s performance.

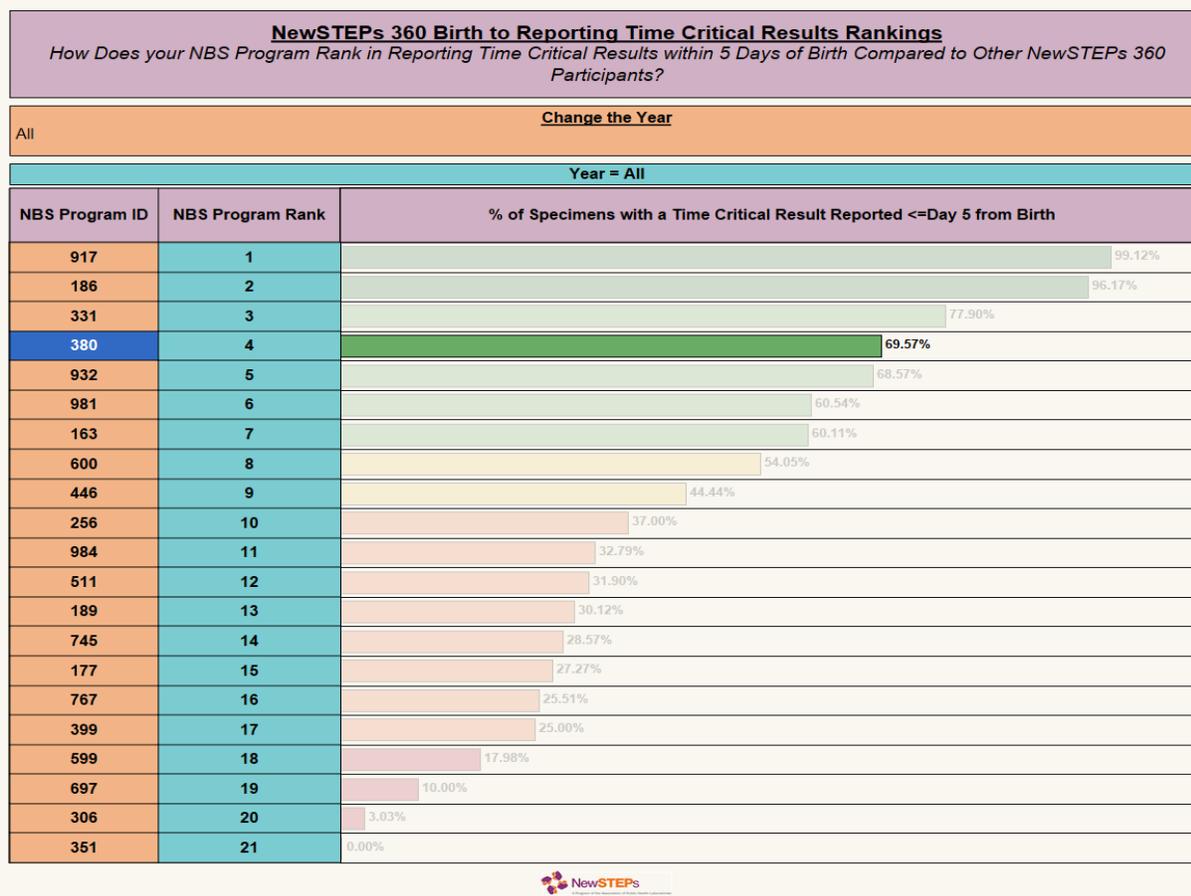
Source: NewSTEPS Data Repository

Note: For “next day” reporting, in 2018 the best performance was in May, when 81.43% were reported out the next day, and worst was in December when 58.69% were reported out the next day.

When looking at **percent reported out in 2 days** over the last 4 years, the best was 98.55% in April of 2018 and the lowest was 89.42% reported out in August of 2015.

**MEASURE: Time Critical Results Reported within 5 days of birth:**

For the 4 year overall ranking on this measure (2015-2018) Nebraska ranked 4<sup>th</sup> out of twenty-one states reporting at 69.57% .



Source: NewSTEPs Data Repository

Note: Time Critical Conditions screened have been defined as these conditions in the current NBS screening panel:

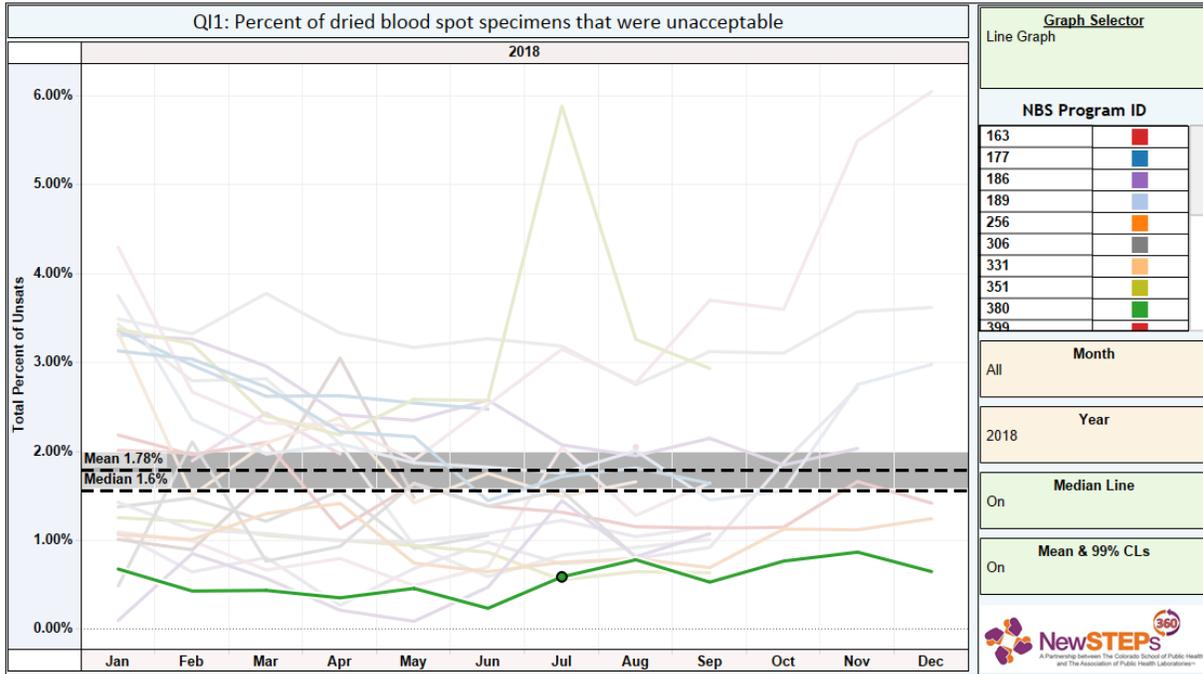
BKT CIT CAH GAL GA-I HMG IVA LCHAD 3-MCC 3-MGA LCHAD  
 MCAD MMA MSUD PA VLCAD \*

\*These abbreviations are for the conditions defined as "time critical". All are metabolic conditions with the exception of CAH (congenital adrenal hyperplasia) which is an endocrine disorder.

## Measure: Unsatisfactory Specimens

Nebraska has established its own benchmark that no more than 1% of specimens be unacceptable or unsatisfactory for testing of any or all of the conditions on the screening panel.

Q1: All Unsats	Q1a: Unsats Due to Collection Errors	Q1b: Unsats Due to Transport Errors	Q12: Specimens Missing Essential Info
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Nebraska remains pretty consistently amongst the best performers with the lowest unsatisfactory specimen rates.

Source: NewSTEPS Data Repository

**Nebraska's newborn screening panel targeted 32 core conditions but several more may be detected on the secondary panel. Three were added on July 1, 2018.**

**In 2018, this resulted in identifying and treating 50 newborns in time to prevent or reduce problems associated with identified conditions.**

\*Three babies with positive CF screens pending diagnosis. One of the three is in State and being followed.

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 even infant death can also occur. For these very good reasons, Nebraska's statute governing newborn screening ([Neb. Rev. Stat. §§71-519 through 71-524](#)) requires every baby born in Nebraska to receive the screening.

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.

Each of these components of the system requires ongoing monitoring to ensure quality.

**The 50 Nebraska Newborns diagnosed in 2018 following screening had these conditions:**

- 2 with Classical Galactosemia (GAL)
- 1 with Classical Phenylketonuria (PKU)
- 13 with Congenital Hypothyroidism (CH)
- 4 with Congenital Primary Hypothyroidism (CPH)
- 7 with Cystic Fibrosis (CF)
- 1 with Glutaric Acidemia Type I (GA I)
- 1 with Hemoglobin E Disease
- 1 with Hypermethionemia
- 1 with Hypothyroidism
- 1 with Hypothyroidism, Possibly Transient
- 1 with Long Chain Hydroxy Acyl-CoA Dehydrogenase Deficiency (LCHAD)
- 1 with Malonic Aciduria
- 1 with Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
- 1 with Partial Biotinidase Deficiency
- 1 with Pompe (Late Onset) (PD)
- 1 with Severe Combined Immune Deficiency (SCID)
- 1 with Sickle Beta Thalassemia
- 2 with Sickle Cell Disease
- 2 with Sickle Hemoglobin C-Disease
- 1 with Transient Congenital Hypothyroidism
- 3 with Transient Tyrosinemia
- 1 with Very Long Chain Acyl-CoA Dehydrogenase Deficiency (VLCAD)
- 1 with X-linked Adrenoleukodystrophy (XALD)
- 1 with X-linked Adrenoleukodystrophy Heterozygote diagnosis

*While each condition is individually rare, collectively 1 out of every 500-600 babies in Nebraska is identified each year with one of the diseases.*



## System Overview

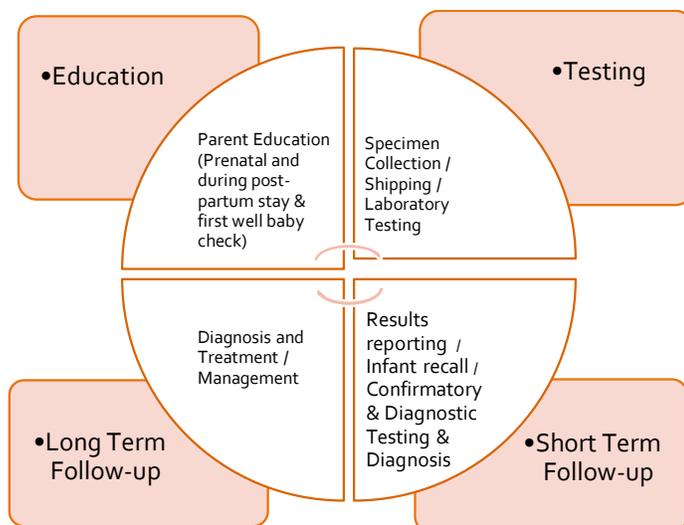


In 2018, fifty-six birthing facilities in Nebraska shipped specimens overnight for 25,842 babies Monday through Saturday to PerkinElmer Screening Laboratory (all but eight hospitals had Saturday pick-up available to them).

The program, administered by the DHHS, also partnered with pediatric specialists in genetics, metabolism, endocrinology, hematology, pulmonology, and immunology to connect primary health care providers for babies who had positive screens with the appropriate subspecialist for diagnosis and treatment.

An advisory committee made up of experts from these subspecialties plus pathology, chemistry, pediatrics, neonatology, family practice, as well as the Nebraska Hospital Association, Nebraska Medical Association, Medicaid and family representatives advised the program on technical and policy issues, monitoring quality, and professional and parent education through their quarterly meetings.

The follow-up staff ensured that the health care provider for every newborn who required additional testing received the necessary information to act accordingly and continued to follow-up with calls, faxed letters and information until diagnosis was made or ruled out. The program conducted ongoing evaluation and quality assurance activities throughout the year. To ensure access to treatment, the program administered a contract for the ordering and distribution of metabolic formula, as well as the reimbursement system for metabolic foods for eligible individuals with PKU and other inborn errors in metabolism who require the specially manufactured foods.



## MAJOR INITIATIVES IN NEBRASKA DURING 2018

### ❖ SUCCESSFUL IMPLEMENTATION of THREE NEW CONDITIONS

The 2-year grant received from the Association of Public Health Laboratories to facilitate activities necessary to add the three new conditions, concluded in 2018 with completion of all goals and objectives, and **implementation of screening for the three diseases MPS-I, Pompe Disease and X-ALD** began July 1, 2018. Major achievements included:

- Provision of physician and provider education via Grand Rounds, and development and distribution of "Update" newsletters. Pediatric Grand rounds held at Children's Hospital included Dr. Madhuri Hegde speaking on integrating sequencing into newborn screening, and Dr. William Rizzo presenting on the three new conditions of MPS-I, Pompe and X-ALD. Awareness was increased via the Nebraska Nurses Association Newsletter, a posting in the E-newsletters of the Nebraska Medical Association and Nebraska Hospital Association (NHA) and a full-page article in the NHA's quarterly magazine.
- Completed development of: customized laboratory report comments, notification letters to physicians, the "Parent's Guide to Your Baby's Newborn Screening" (and translations in multiple languages), Parent Fact Sheets and Physician ACT sheets faxed with positive screen results, the "Practitioner's Manual" and new and edited electronic tracking reports and follow-up procedures.
- Newborn Screening Laboratory data system updates were rolled out to the hospitals with the bi-directional laboratory interface, and a successful transition was achieved.

### ❖ ENHANCING INTRA-AGENCY COLLABORATION ON BEHALF OF BABIES

In recent years, more and more conditions have been added to newborn screening panels across the country, resulting in increased demand for follow-up. Nebraska's Newborn Screening Law is mandatory so every baby born here must be completely screened. When a parent refuses, the Department is compelled by law to report them to the County Attorney.

However, recently the program experienced more passive refusal, or failure to follow through by parents for babies who needed screening completed, or some tests repeated or confirmed. To address this, the program worked with other divisions in the Department of Health and Human Services throughout 2018. As a result protocols were established on communication standards and guidelines for referring these situations to Children and Family Services and to the Medicaid Managed Care Provider if the child was covered under Medicaid. This experience proved to be successful in several cases in 2018, where parental resources were insufficient to comply with the law, and the correct assistance made all the difference in the world.

## ❖ 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.

- The primary focus was on improving “TIMELINESS” which is a national priority in the newborn screening field. (see pages 4-7 for highlights)
- On request of the Program, PerkinElmer Genetics Inc. Laboratory worked with UPS to develop a report identifying parameters requested by the program, to determine which delayed specimens were due to a possible hospital error, vs. a shipping delay (weather, mechanical etc.). This was put into service, and substantially reduced the number of incidents the program was asking hospitals to respond to, since the program could determine which were due to circumstances beyond the hospital’s control.
- With the advice of the Newborn Screening Advisory Committee, the quarterly QA report sent to hospitals was revised to streamline the number of measures, maintaining the most meaningful ones and establishing benchmarks for those that previously didn’t have them. All new benchmarks were based on the goals of the federal Advisory Committee on Heritable Diseases in Newborns and Children, prior data and extensive discussion of the Committee.
- In the fall of 2018, to enhance hospitals access and ability to self-monitor, the program requested reports be developed as “on-demand reports” allowing hospitals to run or download themselves. By the end of 2018 these were available via the PerkinElmer secure web portal, and a power point was developed by PerkinElmer to explain how to get secure access, and how to run various reports. This was rolled out with an announcement in early January 2019.
- In December the program invited voluntary participation in a 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 12 participating hospitals received complimentary copies of the Clinical and Laboratory Standards Institute’s 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 as well as investigate and report on any unacceptable specimens in these categories.

## HIGHLIGHTS FROM SOME KEY ELEMENTS OF NBS



### ❖ FOLLOW-UP A “CRITICAL KEY” TO THE SUCCESS OF NEWBORN SCREENING

The two follow-up coordinators at the state program, Krystal Baumert and Karen Eveans, MD and QA/follow-up specialist Sarah Seberger track, monitor, and make sure babies’ health care providers know what needs to be done to follow-up on hundreds of babies each year. 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 2018 alone this was an essential function for more than 4,000 results or distinct reasons for follow-up. Approximately half of those were specimens collected early (NICU admissions) as required to avoid interference from parenteral nutrition and transfusions.

The NNSP follow-up personnel are highly collaborative. In today’s world with multiple baby name changes, and baby’s physicians changing due to parent choice or insurance coverage changes, the follow-up personnel perform an essential function to ensure the correct health care professional has all the appropriate information needed to follow-up. This means ensuring the right test at the right time occurs for every baby who needs it, and that appropriate consultation and referrals are made.

## ❖ 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 or treatment for diagnosed patients, as well as 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. In 2018 the committee began evaluating the evidence submitted to the federal ACHDNC and began deliberations about Nebraska's state of readiness and feasibility to add Spinal Muscular Atrophy to its required newborn screening panel.

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 provided 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 2018.

### 2018 NBS Advisory Committee Members

Khalid Awad, MD	Methodist Women's Hospital / Neonatology
Lawrence Bausch, MD	Nebraska Medical Association / Neonatology
Angela Brennan, MD	Howard County Medical Clinic / Family Practice
Catherine Brooks, DO	CHI Saint Elizabeth Regional Med Cntr/ Neonatology
John Colombo, MD	Children's Specialty Phys / Pulmonary Medicine
Jeanne Egger	Parent / Advocate Advisor
Zoe Gonzalez-Garcia, MD	Children's Specialty Phys / Pediatric Endocrinology
James Harper, MD	Nebraska Medicine / Children's, Pediatric Hematology
Kathryn Heldt, RD, LMNT, CDE	Children's Hospital / Metabolic Management Clinic
Mary Kisicki, RN, BSN	Parent / Advocate Advisor
Rose Kreikemeier, APRN	Children's Hospital / Metabolic Management Clinic
Richard Lutz, MD	Nebraska Medicine / Children's Metabolism/Genetics
Bev Morton	Parent / Advocate Advisor
Hana Niebur, MD	Children's Specialty Phys / Pediatric Immunology
Deborah Perry, MD	Nebraska Methodist Hospital / Pathology Center
Samuel Pirruccello, MD	Nebraska Medicine /Pathology
Robert Rauner	Adrenoleukodystrophy Foundation
William Rizzo, MD	Nebraska Medicine / Metabolism/Genetics
Kathy Rossiter, EJD, MSN, APRN	Medical Ethicist Advisor
Monica Seeland, RHIA	Nebraska Hospital Association
Jill Skrabal, MS, RD, LMNT, CDE	Metabolic Management Clinic Nebraska Medicine
Alina-Gabriela Sofronescu, PhD	Nebraska Medicine / Pathology and Microbiology
Lisa White, MD	Medicaid and Long Term Care Medical Director

## FINANCING NEWBORN SCREENING

The program uses state general funds, revenues from the newborn screening fee and Title V Maternal and Child Health Block Grant funds to support access to treatment for the metabolic foods and formula. The Title V Block Grant and revenue from the newborn screening fee also funded a large portion of the administrative aspects of the program in 2018 (education, follow-up, program management and quality assurance). In 2018 with the passage of legislation and regulations, the per-infant screened fee that is returned to the state for treatment and administration increased from \$10 to \$20.

## Treatment and Management of Inborn Errors in Metabolism



To fulfill the statutorily-required public health assurance role, NDHHS contracted with the metabolic clinic through Nebraska Medicine to provide nutrition counseling and monitoring, and distribution of the metabolic formula. The contract requires insurance to be billed first, before billing the cost of the formula to NDHHS. Nebraska Medicine and Children's Home Health partner to achieve the distribution and billing. NDHHS reimburses for the unrecovered costs to provide formula, after insurance billing is completed.

Program staff coordinated the day-to-day pharmaceutically manufactured metabolic foods program. Most individuals participated by being reimbursed for eligible foods. For individuals who met financial hardship waiver criteria, the Department purchased the foods directly for them. It has proven more cost effective both in terms of the amount of time and effort to administer the foods program, and in helping the food dollars go further.

## Intervention 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.

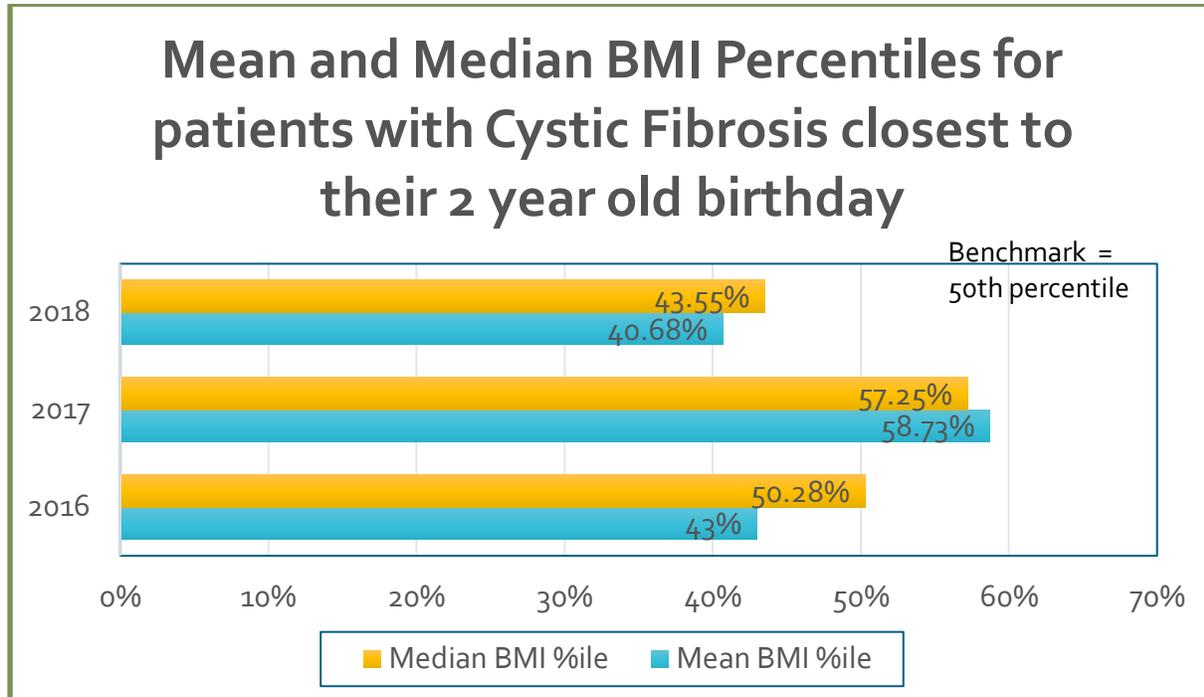
**In 2018 the average age of intervention for babies identified with each condition were:**

Biotinidase Deficiency (Partial) – 20 days	MCAD – at birth
Congenital Primary Hypothyroidism – 12.5	Phenylketonuria – 2 days
Congenital Hypothyroidism – 14.7 days	Pompe Disease – 11 days
Cystic Fibrosis – 15 days	Severe Combined Immune Deficiency – 6
Galactosemia – 4 days	Sickle Beta Thalassemia – 9 days
Glutaric Acidemia Type I – 11 days	Sickle Cell Disease – 20.5 days
Hemoglobin E Disease – 12 days	Sickle Hemoglobin C Disease – 7.5 days
Hypermethioninemia – 24 days	Transient Hypothyroidism -22 days
Hypothyroidism – 74 days	Transient Tyrosinemia – 15 days
LCHAD – 4 days	Very Long Chain Acyl-CoA Dehydrogenase 4
Malonic Aciduria – 5 days	X-linked Adrenoleukodystrophy - 34

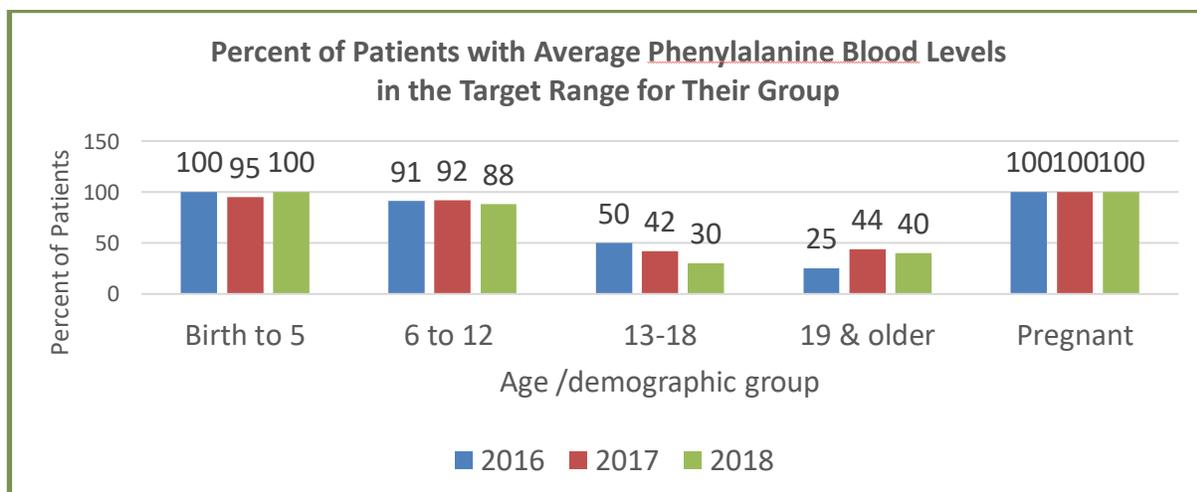


## Outcome Data

Measures to evaluate patient outcomes are important for evaluating the effectiveness of the newborn screening system. These measures vary widely from disorder to disorder. For example, physical growth measures such as body mass index or BMI (weight/inch) can be critical indicators for good outcomes in patients with Cystic Fibrosis. That is because children with CF are at risk for poor nutrition and slow growth due to malabsorption of nutrients. Measuring BMI for CF patients is a CF Foundation targeted outcome. For patients with PKU, phenylalanine blood levels (indicating phenylalanine control) and academic achievement are better indicators of outcomes.



Close monitoring and ensuring access to the metabolic formula and foods are essential elements to the success of our Nebraskans affected with inborn errors in metabolism.



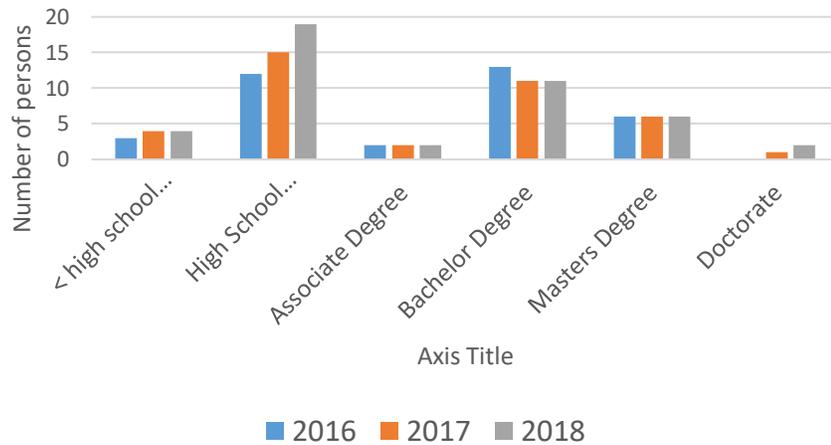
**Developmental Measures:**

Since reporting of long-term outcomes began in 2011, through 2018, 100% of children with PKU age 0-12 receiving services in Nebraska were assessed by the pediatric metabolic specialists as meeting all developmental milestones.

Outcome measures of educational achievement demonstrate the success of families and individuals who get early treatment for their metabolic conditions, which was made possible initially because of newborn screening.



**Educational Attainment of PKU Persons  
Age 18 and Older Served in Nebraska**



# NEBRASKA EARLY HEARING DETECTION AND INTERVENTION ANNUAL REPORT - 2018

*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



Hands & Voices Family Event  
Photo courtesy of: Nebraska Hands & Voices

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 impacts 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 a 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.

## **2018 NEWBORN HEARING SCREENING DATA REPORTED FOR NEBRASKA BIRTHS**

### **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 2018, there were 56 birthing facilities conducting hearing screenings.

### **Hearing Screening at Birthing Facilities and Birthing Centers**

In 2018, inpatient hearing screenings were reported on 25,645 newborns or 99.5% of the 25,770 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.



Inpatient Newborn Hearing Screening  
Photo courtesy of: NCHAM

In 2018, 24,696 (96.3%) 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 2018. 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.

### Monitoring, Intervention and Follow-up Care

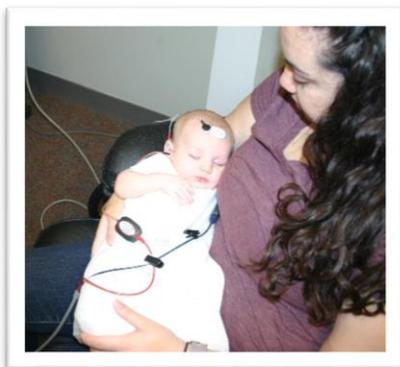
The NE-EHDI Program’s tracking and follow-up processes are conducted for each baby reported as not passing the hearing screening during birth admission and for infants not receiving the inpatient hearing screening. In 2018, a total of 1,066 infants (hospital and non-hospital births) were tracked by the NE-EHDI Program to encourage parents to have the infant receive an outpatient hearing screening or audiologic diagnostic evaluation.

The following shows the hearing screening/testing status of the 25,915 births for 2018:

25,614	Passed the screening <u>or</u> diagnostic testing (99% of thriving newborns)
119	Expired (inpatient or outpatient)
48	Pending final screening or diagnostic testing
55	Diagnosed deaf or hard of hearing
44	Parents refused screening and/or diagnostic testing
23	Unresponsive (did not complete protocol after communication with NE-EHDI staff)
1	Lost (no response to NE-EHDI letters and phone calls)
7	Moved out of Nebraska
4	Late onset deaf or hard of hearing (passed initial screening)

### Timeliness of Follow-up Screening / Evaluations / EDN Services

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.”



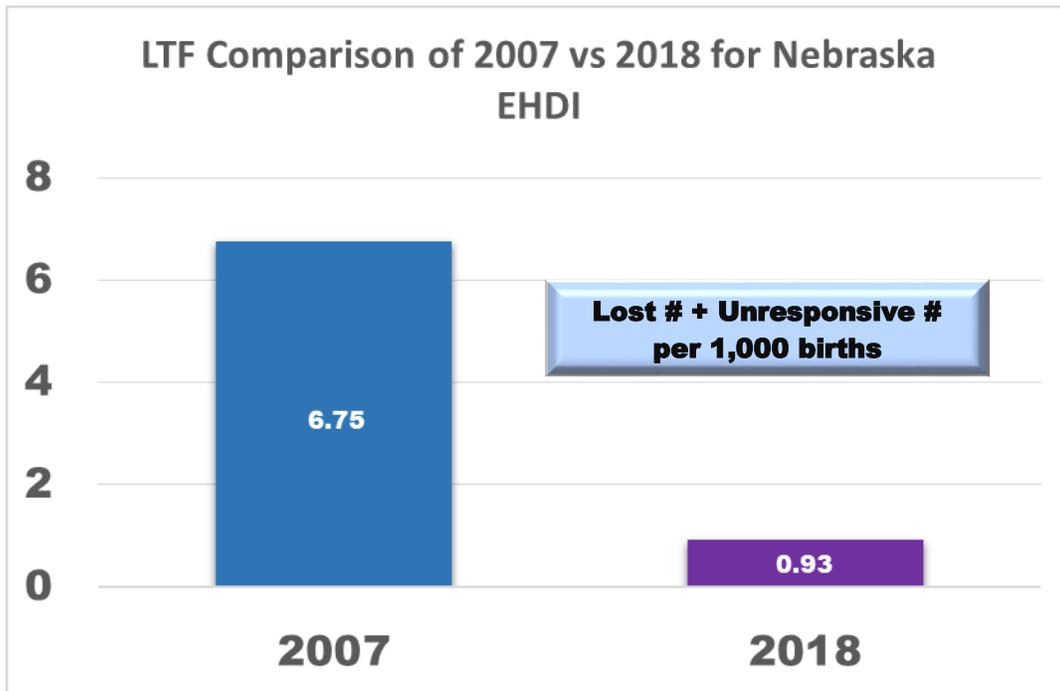
Outpatient Newborn Hearing Screening  
Photo courtesy of: NE-EHDI

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 70% received the evaluation by 3 months of age according to individual data reported to the NE-EHDI Program by audiologists (as of May 2019). 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 48 hearing records are still waiting for the final screening and diagnostic testing results, the "1-3-6" numbers above are preliminary as of May 2019 and will likely change.*

Records for the Early Development Network (EDN), Nebraska’s Part C Early Intervention Program, indicate that 87% of infants residing in Nebraska in 2018 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 2019). It is projected that the final percentage for enrollment within 6 months will be approximately 80%, since there are still 48 infants needing a confirmatory diagnosis and some will be referred to early intervention more 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).

**The following graph illustrates progress made in reducing the number of Lost and Unresponsive cases over the past 12 years:**



Birth Year	Lost # + Unresponsive # per 1,000 births	Births	Lost # + Unresponsive #	Factor (Lost + Unresponsive/Births)
2007	6.75	27,115	183	0.00675
2018	0.93	25,915	24	0.00093

## 2018 ACTIVITIES

### Funding

The NE-EHDI Program continued to receive only federal funding in 2018. 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 consists of no more than 20 voting members. Two Advisory Committee meetings were held in 2018 and were open to the public. Minutes are posted on the NE-EHDI public website.

#### 2018 NE-EHDI Advisory Committee Members:

Nina Baker	Health Information Coordinator (Infants, Toddlers, School Age and Young Adults) 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
Jenna Browning, Au.D., CCC-A	Clinical and Research Audiologist, Boys Town and National Research Hospital

Jenny Corum	Education Advocate, Nebraska Commission for the Deaf and Hard of Hearing (NCDHH)
Linsay Darnall, Jr.	Deaf Advocate/Advisor, Darnall Consulting LLC
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
Kim-Jae Kang	Family Support Advocate
Rick Kang, M.D.	AAP Chapter Champion/Otolaryngologist, Boys Town Research Hospital
Ashley Kaufman, Au.D., CCC-A	Clinical Audiologist, Boys Town and National Research Hospital
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
Pam Zegers, M.D.	Pediatrician, Complete Children’s Health

**2018 NE-EHDI Advisory Committee Liaisons:**

Amy Bunnell	Early Development Network, Nebraska Department of Education
Sue Czaplewski	Educational Service Unit #9, Nebraska Department of Education
Julie Docter	Early Development Network, Nebraska Department of Health and Human Services
Joan Luebbers	Head Start State Collaboration Office, Nebraska Department of Education
Cole Johnson	Special Education Office, Nebraska Department of Education
Laurie Miller	School Based Services/Early Development Network, Nebraska Department of Education
Sara Peterson	Educational Service Unit # 13, Nebraska Department of Education

## 2018 PROJECTS



HearU Care Kit  
Photo Courtesy of: HearU Nebraska

### Collaboration with 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 have 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 2018. In 2018 there were 52 hearing aids provided and fitted for 30 children (age range of 1 month to 18 years) with "free" hearing aids provided by HearU Nebraska. From 2008-2018, 696 hearing aids were provided and fitted on 411 children.

### Collaboration with Hands and Voices/Guide By Your Side

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 Guide is 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 2018, 15 trained Parent Guides provided family support throughout Nebraska.



Mom's Night Inn – 2018  
Photo Courtesy of: Nebraska Hands & Voices

The H&V/GBYS staff through the sub-award agreement with NE-EHDI, worked with 758 families for EHDI follow-up during 2018. As of December 31, 2018 GBYS Guides were actively serving 125 families, and 76 of those families were referred by NE-EHDI (61%). The percentage of infants with a diagnostic evaluation completed within 3 months reported by NE-EHDI improved from 58.7% for 2016 births to 62.8% for 2017 births and to 70% for 2018 births. The 2018 percentage may decrease since it is based on preliminary data. NE-EHDI attributes part of this improvement to H&V/GBYS staff assisting NE-EHDI with follow-up, and enrolling families sooner in the GBYS Program for family support.

### Quotes from families served by GBYS in 2018:

"Guide by your side has been the single most helpful connection I have made on this journey. In a matter of months, they have provided me with information that would have taken me years to figure out on my own. Connecting with other moms and children has also been an amazing experience."

"As a parent, you focus so much on the needs of your child(ren), and you don't realize how much your own emotional needs change and increase when you have a child with any sort of disability. GBYS has not only given me resources to help my child and help me better understand his needs and struggles, but has given me resources for my entire family. We have a whole community of parents that "just get it" and support each other no matter what. I never realized that I struggled until I had found a support system. So thank you, GBYS, for everything you have done for our family."

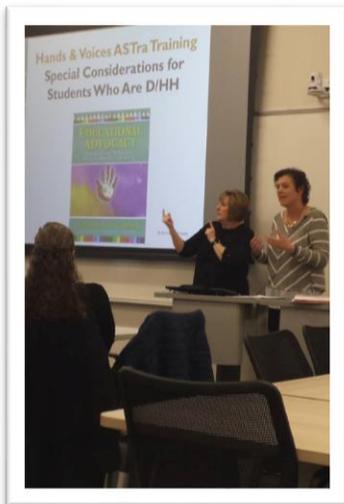
"The GBYS program was a welcoming surprise at a very confusing time with our new baby. The support I received in my first conversation with our Guide made me definitely feel I was not alone in our hearing challenges."

"I love this program and feel like I'd be lost without having your support."

"It is nice to talk with someone who understands and can help understand my own feelings."

### 2018 Family Support Events

NE-EHDI collaborated with H&V/GBYS for many family support events in 2018.



ASTRA Training – 2018  
Photo courtesy of: Nebraska Hands & Voices

**ASTra Training** (January 12 Omaha & January 13 Lincoln 2018 – Zoomed statewide) – Also collaborated with Regional Programs for Students who are Deaf or Hard of Hearing (RPSDHH) for this event. This was a one-day training for any professional or parent who was interested in learning more about education and advocacy.

**Moms Night Inn** (February 2018 – Lincoln and November 2018 – Grand Island). NE-EHDI collaborated with H&V/GBYS and the RPSDHH. This was an opportunity for moms to share experiences and provide support to each other. Topics included – Self Advocacy, Empowerment, Literacy, Socialization and Communication.

**Back to School Workshop** (August 2018 - Omaha) – Collaborations with Parent Training and Information – Nebraska (PTI-NE) and RPSDHH. There were presentations on Individual Family Service Plans (IFSPs) and Individualized Education Programs (IEPs) and the Power of Self Advocacy. The workshop also included a student panel and parent panel.

**Dads Night Out Event** (October 2018 - Omaha) – Dads led the discussion. Questions discussed included, 1. Please introduce yourself and talk about your child who is Deaf/Hard of Hearing (D/HH). 2. Why did you come to this event? 3. What concerns, if any, do you have for your child who is D/HH? Dads really opened up and spoke about their concerns and fears. It was stressed the importance of dads being involved, especially in IEP meetings and doctor visits.

**Rising Stars** – A new Deaf & Hard of Hearing Youth Leadership Award Program was created in 2018 by 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 Nebraska Hands & Voices Facebook.

**Parent & Extended Family Workshop** (November 2018 - Omaha) – This workshop was for grandparents, aunts, uncles, parents and anyone else who has an extended family member (under the age of 21) who is D/HH. This workshop helped individuals understand how the child’s hearing difference can affect the entire family. They also learned of ways to help communicate with the family and the child who is D/HH. There was a parent and D/HH student panel.

**Couples Night Out Event for Parents of Deaf/Hard of Hearing (D/HH) Children** (December 2018 – Omaha) – Families met at a restaurant in a relaxed environment and shared their journey since their child has been identified as D/HH. They shared their joys, struggles and coping mechanisms. This was an opportunity to meet other families who are going through similar situations.



Couples Night Out – 2018  
Photo courtesy of: Nebraska Hands & Voices

**NE-EHDI contracted with The Boys Town National Research Hospital to help support their Roots and Wings Family Support Weekend** (February 2018) – The workshop provided education and networking opportunities for parents of young children with a hearing loss. This included a keynote speaker, plenary and roundtable sessions, lodging, meals, child care and social activities for the families.



Roots & Wings – 2018  
Photo courtesy of: NE-EHDI

Besides the benefits for families, the two sub-award agreements and one contract for family support events fulfill the federal HRSA grant award requirement that 25% of the funding has to be allocated to family support programs.

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

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.

The parent representative who attended the meeting in Denver, March 2018 stated, "When my daughter was first diagnosed at 1 1/2 years old, I made it my personal goal to work very hard at showing her that there isn't anything she can't do because of her hearing loss. I've always worked hard at bringing her to events for deaf/hard of hearing people and helping her to see that she isn't the only one out there going through this. Thank you so much for choosing me to be your parent representative at the 2018 EHDI annual meeting. My family and I learned so much, and my daughter really benefited from seeing so many people who are signing, and who are deaf and hard of hearing like she is."



EHDI Annual Meeting, Denver CO - 2018  
Photo courtesy of: Amber McLaughlin

## Learning Communities



Filming Parent Perspectives Video - 2018  
Photo courtesy of: NE-EHDI

A task force was created in 2014 to focus on how hearing screening results are presented to parents by the birthing facility staff when the baby does not pass the inpatient newborn hearing screening. The work group met intermittently through 2016. Work on the project continued through a Learning Community in 2017 and 2018. Options for funding and producing a training video were explored in depth. The stakeholders consist 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.

After receiving bids, a local video producer was selected to film and produce the video. Nebraska Hands & Voices provided funding for the video. Parents on the Learning Community finalized the video script, and the first draft of the video was filmed in July. Once the video was filmed and edited, the first draft was shared with the members of the Learning Community, Advisory Committee and the nursing staff at one hospital in Nebraska. After all of the feedback was collected and analyzed, the members of the Learning Community determined that the format and script of the video needed to be revised. Work on the revisions and re-filming are continuing in 2019.

Once the training video is available to hospitals, the NE-EHDI Program will survey hospital staff involved with the hearing screening process to assess the effectiveness of the training. Based on these survey results, NE-EHDI will develop additional training materials for staff responsible for educating parents about the results and next steps. As an incentive to incorporate the video into routine nurse trainings, a Hospital Champion incentive program will be implemented. This will give hospitals the opportunity to earn a certificate once their hearing screening protocols are revised and implemented.

In 2018, NE-EHDI continued to work with a Learning Community of Stakeholders interested in implementing tele-audiology services in western Nebraska. The purpose of this initiative is to address barriers to care and ensure that the quality of services available to families in western Nebraska are comparable to the metro areas of Nebraska. The stakeholders consist of two NE-EHDI staff; four audiologists based in Omaha/Lincoln; 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 has 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.

The Educational Service Unit (ESU) #13 that serves Scottsbluff, Chadron and Sidney will provide the remote site, and pediatric audiologists at the University of Nebraska-Lincoln (UNL) Barkley Speech Language and Hearing Clinic will serve as the originating site. In 2018, issues related to licensure, regulations and funding were addressed. Also, a baseline of the timeliness of the Joint Committee on Infant Hearing (JCIH) 1-3-6 goals were gathered by NE-EHDI for the target area of western Nebraska.

Funding options for acquiring the needed tele-audiology equipment were discussed throughout 2018. Options included borrowing equipment from a neighboring state, searching for rural outreach grants and determining if Maternal and Child Health (MCH) Title V funds could be utilized. Through the partnership with the Nebraska Department of Education (NDE), NE-EHDI was informed NDE could provide a grant to fund the tele-audiology equipment. UNL Barkley Speech Language and Hearing Clinic submitted an application to NDE for the grant to purchase the equipment. Purchasing the equipment and implementing the tele-audiology program will continue in 2019.

After the tele-audiology program has been implemented for one year, the same timeliness goals will be reviewed to evaluate effectiveness and quality improvement.

### **Hospital Site Visits and Pediatric Audiology Meetings**

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 Improvement 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 2018. The goal is to meet with every birthing facility during the three-year federal grants cycle from 2017 – 2020.

NE-EHDI e-mailed an online survey March 2018 to audiologists who see pediatric patients in Nebraska. This included a total of 23 clinics who see pediatric patients. The majority of them only see pediatric patients periodically. The 23 also include educational service units with the Nebraska Department of Education, as well as the Lincoln Public Schools and Omaha Public Schools.

The online survey requested feedback on their current understanding of EHDI:

1. Conducting timely diagnostic evaluations (within 3 months of age is the goal);
2. Reporting timely to EHDI;
3. Educating parents about the next steps if their child is identified as D/HH; and
4. Knowledge of steps for referral to Early Intervention (EI), in a timely manner (goal is within 3 months of age or as soon as diagnosed as D/HH).

After the survey was completed, the data was analyzed and discussed with the NE-EHDI Advisory Committee. The NE-EHDI Team followed up with the five main pediatric audiology clinics in the state with meetings. These five clinics conduct about 95% of all the infant diagnostic evaluations in Nebraska. The other 18 pediatric audiologists/clinics mainly perform infant screenings. The meetings were very informative and productive, even though it was difficult to find a time to schedule with two of the smaller main audiology clinics. It was determined that it would be too difficult and not cost effective to schedule meetings with the audiologists who only see pediatric patients periodically. Therefore, we are communicating to them through a biannual e-mail and following-up when appropriate with individual e-mails and phone calls.

The following were implemented after analyzing survey data and the in-person meeting discussions:

- Revised the Audiologists page and Families page on the NE-EHDI website.
- Revised the NE-EHDI Audiologic Screening and Diagnostic Report form.
- Developed a NE-EHDI Summary and Reporting Guidelines for Audiologists document, which also includes referral guidelines for EI. EI in Nebraska is the Early Development Network (EDN).
- Developed a list of birthing facilities who use Auditory Brainstem Response (ABR) or Otoacoustic Emissions (OAE) for screening.
- Partnered with audiologists and utilized the Joint Committee on Infant Hearing (JCIH) recommendations to develop a risk factor document, which was e-mailed to birthing facilities with the link to the CDC risk factors poster. The risk factor document and CDC risk factor poster were also mailed to Primary Health Care Providers statewide and is included on the NE-EHDI website.
- E-mailed audiologists on September 2018 to inform them about all the updates and the new forms that NE-EHDI developed based on the feedback from Nebraska

audiologists. This was the first e-mail of the new series of biannual e-mails to audiologists who see pediatric patients. The e-mail provides NE-EHDI updates, reminders about reporting to NE-EHDI, and asks for program improvement feedback.

- Offered to provide in-service trainings for new audiologists and as a refresher for experienced audiologists. NE-EHDI provided three trainings to one of the main audiology clinics in October 2018.
- Developed an Audiology QA report draft that was shared with audiologists. Their input was incorporated to finalize the template. The first Audiology QA reports will be sent in 2019.

NE-EHDI also communicates with the audiology clinics through e-mail or phone if issues arise to discuss solutions.

### 2018 Exhibits and Presentations

#### NE-EHDI exhibited in 2018 at:

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

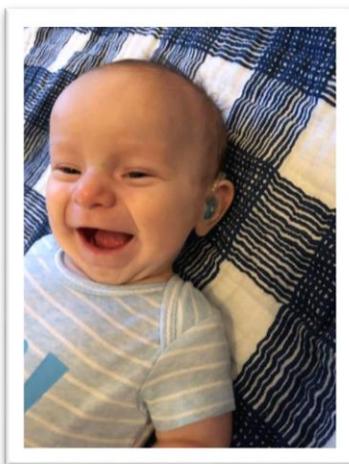


Boys Town Newborn Expo - 2018  
Photo courtesy of: NE-EHDI

#### NE-EHDI presented in 2018 at:

- Nebraska Nurses Association Conference (October 3)

### A 2018 Parent's Story Sharing the Importance of Newborn Hearing Screening



Hearing Aid Fitting Day for Ian  
Photo courtesy of: Abigail Barr

"Being able to identify my son as hard of hearing at such a young age has been a blessing. He failed his newborn screening and we were referred to Boys Town for an ABR. Three weeks after birth we learned he has mild/moderate hearing loss and that he was born with Congenital Cytomegalovirus (CMV). Without this early testing we would have never been able to identify CMV and start him on an important medication. This medicine can actually help save his hearing and prevent it from getting more severe, which is very common with CMV. We were able to get hearing aids at three months old. Being able to get him aided so early and start early intervention services has been extremely beneficial for him. He is able to hear all the important sounds he needs to develop his speech and it's nice to get him used to wearing his hearing aids. Knowing my son is able to hear what everyone around him can is a

relief. If we didn't have newborn hearing testing, I truly do not believe we would know he was born with hearing loss."

## 2018 SUMMARY

- All of the 56 birthing hospitals in Nebraska conducted newborn hearing screenings in 2018 prior to discharge from the hospital or birthing center.
- In 2018, birthing hospitals reported screening the hearing of 99% of newborns prior to discharge from the hospital.
- Over 99% of the 2018 infants passed an inpatient screening, an outpatient screening, or a diagnostic evaluation.
- Of the 1,066 infants (born in 2018) followed by the NE-EHDI Program, 89% have completed the recommended follow-up of outpatient screening/diagnostic testing and 4.5% are still in the process of completing the outpatient screening/diagnostic protocol in 2019.
- For 2018 births, there were confirmatory audiologic evaluations within 3 months of age for 70% of newborns when the newborn did not pass the inpatient/outpatient screening or did not receive an inpatient screening (preliminary percentage).
- There are 123 infants born in 2018 (as of May 2019) with unknown hearing status due to: **1)** parents refusing to follow the recommended hearing screening/testing protocol (n=68), **2)** medical conditions causing postponed final hearing testing (n=48), and/or **3)** families moving out of Nebraska (n=7).
- The incidence of Permanent Congenital Hearing Loss of 2.1 per thousand screened is within the anticipated range of one to three per thousand.
- 87% of the infants born in 2018 who were identified as deaf/hard of hearing and residing in Nebraska were enrolled in the Early Development Network and received special education services by 6 months of age when the parents accepted Part-C intervention services (preliminary percentage).
- NE-EHDI had a sub-award agreement with HearU Nebraska through the University of Nebraska-Lincoln for the loaner hearing aids program and had a sub-award agreement with 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 collaborated with seven family support events/programs during 2018 with H&V/GBYS.
- NE-EHDI provided a scholarship for a parent of a child who is deaf or hard of hearing to

attend the EHDI Annual National Meeting in Denver, CO.

- The work of the NE-EHDI Learning Communities 1) Parent Perspective Hospital Training and 2) Tele-Audiology work groups made great progress in 2018. Tele-audiology will be live in 2019 and the hospital training will be implemented in 2019.
- NE-EHDI continued to conduct hospital site visits, surveyed audiologists who see pediatric patients, and conducted audiology site visits with the main pediatric audiology clinics in Nebraska during 2018 to discuss quality improvement and build relationships.
- NE-EHDI exhibited at five conferences and presented at one conference during 2018.



Photo courtesy of: Angie Marie Photography

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

**Julie Luedtke, Newborn Screening/Genetics Program Manager (402) 471-6733**

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

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

Metabolic, endocrine and lysosomal storage condition,

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

Hemoglobinopathies, cystic fibrosis, SCID, X-ALD & transfusions

**Sarah Seberger, 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 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

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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

**Jennifer Lee, 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

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*This report was prepared and published by the Nebraska Department of Health and Human Services, Newborn Screening Program, and P.O. Box 95026, Lincoln, NE 68509-5026.*

*Filter Paper Blood spot photos courtesy of Whatman web site  
[www.whatman.com/repository/documents/s7/51684%20\(S9036-812\).pdf](http://www.whatman.com/repository/documents/s7/51684%20(S9036-812).pdf).*

*Laboratory photos courtesy of Perkin Elmer Genetics Screening Laboratory.*

*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.*

*Newborn Bloodspot Screening is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number B04MC29351 Title V/Maternal & Child Health Services Block Grant Program for \$656,069.42 in Federal Fiscal Year 16, with zero percent financed with nongovernmental sources. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.*

*The Nebraska Early Hearing Detection and Intervention Program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number H61MC00065, Universal Newborn Hearing Screening, and receives a \$250,000 award annually 4/1/2017 – 3/31/2020. The NE-EHDI Program is 100% financed with federal money and no funding is received by nongovernmental sources. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.*

*The Nebraska Early Hearing Detection and Intervention Program is also supported by the Centers for Disease Control and Prevention (CDC) under Cooperative Agreement Number 2NUR3DD000057, and receives \$150,000 award annually 7/1/2017 – 6/30/2020. The NE-EHDI Program is 100% financed with federal money and no funding is received by nongovernmental sources. This information and contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.*