

June 15, 2016

Memorandum

To: Nebraska State Legislators

From: Courtney N. Phillips, MPA
Chief Executive Officer
Department of Health and Human Services

As per Neb.Rev.Stat §71-4741 an annual report is to be submitted to the Legislature reporting on certain measures in the Infant Hearing Act. The Nebraska Department of Health and Human Services combines the annual reports of the Newborn (blood-spot) Screening and Early Hearing Detection and Intervention programs. These are among our most successful public health programs. Each year, screening saves babies' lives and prevents neurological damage, and other developmental disabilities. Early intervention for babies identified with hearing loss maximizes language and cognitive development.

We continue to report the successful outcomes of people with metabolic conditions. The success of these individuals is rooted in Nebraska's law requiring newborn screening and treatment, and the combined financial support from State appropriations and Title V Maternal and Child Health Block Grant allocations that help ensure patients receive the necessary treatment for their condition. So we'd like to take this opportunity to thank you and recognize your continued support of this important program.

The report can be found on the Newborn Screening homepage at www.dhhs.ne.gov/nsp. I hope you will find the annual report useful.

NEWBORN SCREENING IN NEBRASKA

Newborn Bloodspot Screening for
Metabolic and Inherited Disorders

and

Early Hearing Detection & Intervention



2015
Annual Report

Department of Health & Human Services

DHHS
NEBRASKA

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2015 ANNUAL REPORT
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2015 ANNUAL REPORT
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NEWBORN SCREENING FOR INBORN ERRORS OF METABOLISM AND INHERITED DISORDERS



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.

If not detected and treated in time, the 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. Problems with physical growth, stroke and even infant death can also occur. For these very good reasons Nebraska's statute governing newborn screening §§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 Newborn Screening Program collaborating with hospitals, laboratory, health care professionals and families and involving 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.
- ❖ Assuring access to needed specialized services and treatment.
- ❖ Evaluation and Quality Assurance/Quality Improvement efforts.

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

In 2015, newborn screening for 29 conditions, resulted in identifying and treating 58 Nebraska newborns affected with conditions in time to prevent or reduce problems associated with them.

Newborns were diagnosed with these conditions from screening in 2015:

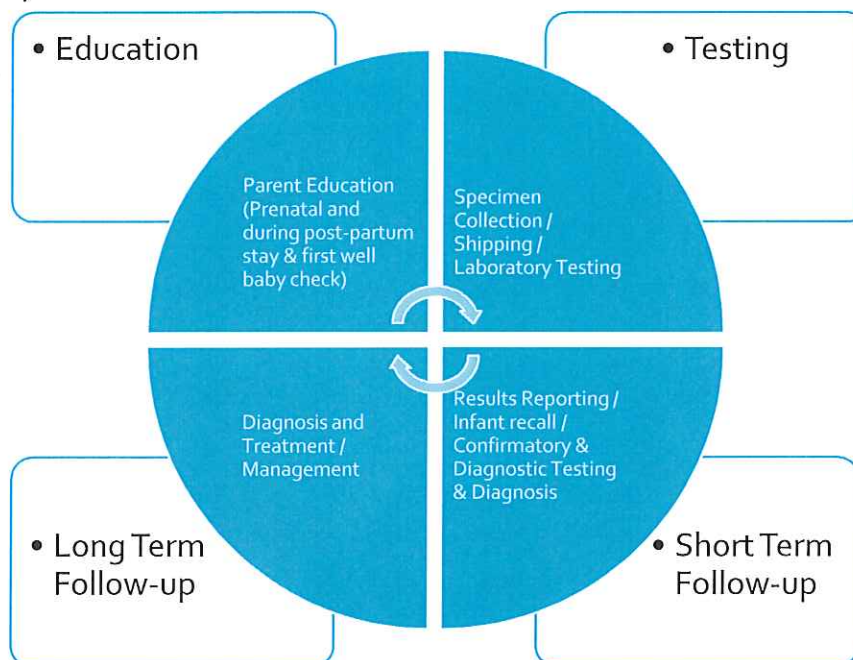
- 1 baby with Profound Biotinidase Deficiency (BIO)
- 1 baby with Partial Biotinidase Deficiency
- 3 babies with Congenital Adrenal Hyperplasia
- 8 babies with Congenital Primary Hypothyroidism (CPH)
- 3 babies with Congenital Hypothyroidism
- 1 baby with Hypothyroidism
- 1 baby with Primary Hypothyroidism
- 12 babies with Cystic Fibrosis (CF)
- 2 babies with CF Related Metabolic Syndrome (CRMS)
- 3 babies with Medium Chain Acyl Co-A Dehydrogenase Deficiency (MCAD)*
- 4 babies with Phenylketonuria (classical PKU)
- 2 baby's with Short Chain Acyl Co-A Dehydrogenase Deficiency (SCAD treated)
- 4 babies with Sickle Cell Disease
- 2 babies with Sickle Hemoglobin C Disease
- 1 baby with Sickle Cell Beta Thalassemia
- 1 baby with Beta Thalassemia Major
- 1 baby with Hemoglobin D Beta Thalassemia
- 1 baby with 3-MCC Deficiency
- 4 babies with Transient Tyrosinemia (treated)
- 1 baby with partial DiGeorge Syndrome (from SCID screen)
- 1 baby with CHARGE syndrome (from SCID screen)
- 1 baby with idiopathic T-Cell lymphopenia (from SCID screen)
- 1 baby with 22q11.2 deletion
- (1 Hemoglobin E disease pending at time of publication)
- (*Tragically one baby was affected so early and severely that even with screen results available by 3.5 days of age, the baby succumbed to the disease.)

While each condition is individually rare, in Nebraska 1 in every 500-600 babies born is affected with one of them.

System Overview



In 2015, 54 birthing facilities in Nebraska shipped specimens overnight, for 27,039 babies Monday through Saturday, to PerkinElmer Screening Laboratory. Perkin Elmer Genetics (Nebraska's contracted screening laboratory) has successfully coordinated UPS or Fed Ex pick up on Saturday at almost all Nebraska hospitals (3 communities do not receive any Saturday service). The program, administered by the Department of Health and Human Services, 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 with experts from these subspecialties, laboratory, hospitals, pediatrics, neonatology, family practice, as well as 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 requires additional testing, received the necessary information to act accordingly. The program expanded and completed ongoing evaluation and quality assurance activities throughout the year. To assure access to treatment, the program administered a contract for the ordering and distribution of metabolic formula, as well as reimbursement system for metabolic foods for eligible individuals with PKU and other inborn errors in metabolism who require the specially manufactured foods.



Quality assurance activities in all of these areas help assure a successful newborn screening system.

MAJOR INITIATIVES IN NEBRASKA DURING 2016

❖ EDUCATIONAL INITIATIVES

- Jessy Davis the Program's staff assistant, conducted a project to improve the distribution of parent education materials on newborn screening by obstetric and pediatric care providers. She developed an on-line ordering system through which providers can order the materials (available in 12 languages); demonstrated that orders increase when postcard mailers are followed up with personal phone calls to providers; found that despite no prior orders for the Arabic language, this was still identified as a need, and, learned the demand for Spanish language materials has shifted to different communities since 2013.
- All birthing facility laboratory directors were provided with a special mailer regarding appropriate confirmatory laboratory testing in an effort to address problems experienced with getting the correct follow-up testing to facilitate timely diagnosis of babies with positive screen results.

❖ QUALITY ASSURANCE AND IMPROVEMENT INITIATIVES

The 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 has become a national emphasis in the newborn screening field.
- Stakeholder efforts from 2014 (hospital representatives, Newborn Screening Advisory Committee and program personnel) to revise the quarterly hospital QA report measures, came to fruition in 2015.
 - Hospitals get specific data on unsatisfactory specimens in the QA report.
 - Quarterly reports are accompanied with a count of the # of incidents of batching and late specimen collection in the last quarter, as well as the number of incidents of any babies who were discharged without a screen in the prior year.
 - Emphasis is now on the percent of baby's specimens that meet certain quality and timeliness benchmarks rather than the facility's "average" performance.
- Later in 2015 more measures were added to be consistent with timeliness measures clarified from the Secretary's Advisory Committee on Heritable Diseases in Newborns and Children. Emphasis is on the percent of "critical positive" screen results reported by 5 days of age, and percent of all results reported out by 7 days of age.

- Weekly “batching/specimen shipping delay” reports and “late specimen collection” reports are run by the program manager and reported to hospital QA contacts. This gives quicker feedback to hospitals and allows a more rapid response to systematically correct any problems.
- As a supportive function, the program applied for and was granted a 3 year \$120,000 sub-contract with NewSTEPS 360 to address timeliness. The funds will be pass-through to hospitals on a competitive sub-contract basis to assist them in obtaining the electronic HL7-compatible interface with the screening lab for electronic ordering and reporting of newborn screening results.

HIGHLIGHTS FROM SOME KEY ELEMENTS OF NBS



❖ FOLLOW-UP

The two follow-up coordinators at the state program (Krystal Baumert and Karen Eveans MD) 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 until either a satisfactory screen has been completed, an inconclusive result has had a repeat screen, or a positive result has received confirmatory testing and a diagnosis is either made or ruled out. In 2015 alone this was an essential function for more than 4300 results or distinct reasons for follow-up.

Many things are known to conspire to complicate and delay follow-up, for example, the baby’s doctor identified on the filter paper (and to the follow-up program) is incorrect, and when notified, that provider doesn’t always let the program know quickly that they are not the provider, and who the actual provider is. Other things complicate follow-up such that any one baby can have multiple reasons follow-up needs to get done. Babies admitted to the neonatal intensive care unit (approximately 9% of all births) are especially prone to having complications with their newborn screen. For example, a baby can have an initial unsatisfactory specimen followed by a repeat specimen collected too close to the time of the last transfusion, followed by a result of multiple amino acid elevations consistent with

hyperalimentation, or an inconclusive result for cystic fibrosis, all of which require monitoring and follow-up to ensure an acceptable screen for all diseases is completed.

The two professional follow-up coordinators are highly collaborative. In today's world with multiple baby name changes, and baby's physician's being changed due to parent choice or insurance coverage changes, the follow-up coordinators perform an essential function to ensure the correct health care professional has all the appropriate information to follow up. This means ensuring the right test at the right time occurs for every baby who needs it, and 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, and 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! (Refer to the "contacts" page at www.dhhs.ne.gov/nsp for the list of fantastic advisors who provided technical expertise and policy guidance to the Nebraska Newborn Screening Program).

Members committed at least a half day every three months to advise the state program (collectively over 250 hours). Representatives from PerkinElmer Genetics Laboratory Inc. regularly provided input, presentations and proposals to the advisory committee. Several members provide extensive review and consultation beyond the committee meetings to help the program meet the recommendations of the larger committee.

❖ FINANCING NEWBORN SCREENING

The program uses state general funds, the newborn screening fee (\$10/infant) 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 also funds the administrative aspects of the program (education, follow up, program management and quality assurance).

Assurance of Treatment and Management of Inborn Errors in Metabolism



To fulfill the statutorily-required public health assurance role, the Program contracted with the metabolic clinic through the University of Nebraska Medical Center to provide nutritional counseling and monitoring, and distribution of the metabolic formula. In 2015 negotiations began for the requirement to bill insurance first, before billing the cost of the formula to the Department. Beginning in January of 2016, DHHS will reimburse for the unrecovered costs to provide formula, after insurance billing is completed.

The program coordinated the day-to-day pharmaceutically manufactured metabolic foods program and made a significant structural change in 2016 by moving to a reimbursement system instead of contracting with a vendor from which families could order foods. This required a substantial amount of preparation and assistance to help families prepare for this change. 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 reporting out 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 these factors include babies with prolonged treatment in NICUs, parental resistance to confirmatory testing, problems in locating parents because contact information provided to the hospital or recorded on the filter paper collection cards was incorrect or no longer accurate. All parts of the system must work to reap the best benefits of early identification, treatment and intervention. In 2015 the average age of intervention for babies identified with each condition are listed below:

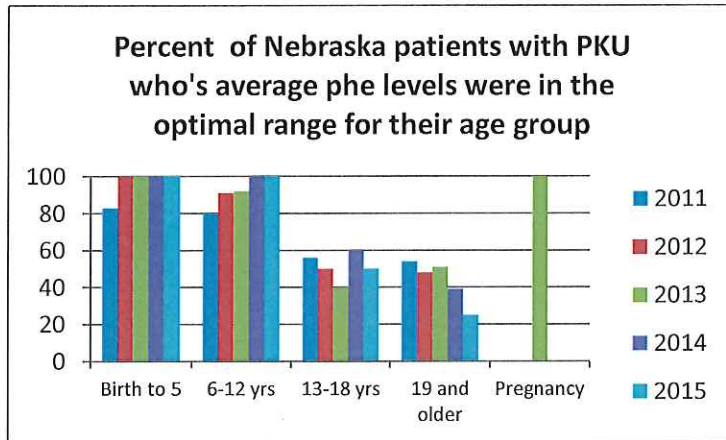
MCAD -- 3.5 days
Biotinidase Deficiency – 4 days
PKU -- 5 days
Congenital Adrenal Hyperplasia – 6 days
Sickle Beta Thalassemia – 9 days
Congenital Primary Hypothyroidism -- 16 days
Transient Tyrosinemia – 16 days
Cystic Fibrosis – 18 days
Hemoglobin D – Beta Thalassemia – 18 days
SCAD – 18 days

Sickle Cell Disease – 21 days
Sickle Hemoglobin C Diseases – 24 days
Hypothyroidism -30 days
Congenital Hypothyroidism -35 days
Primary Hypothyroidism – 55 days
3-MCC Deficiency – 57 days
Beta Thalassemia Major – 65 days
CRMS – 130 days

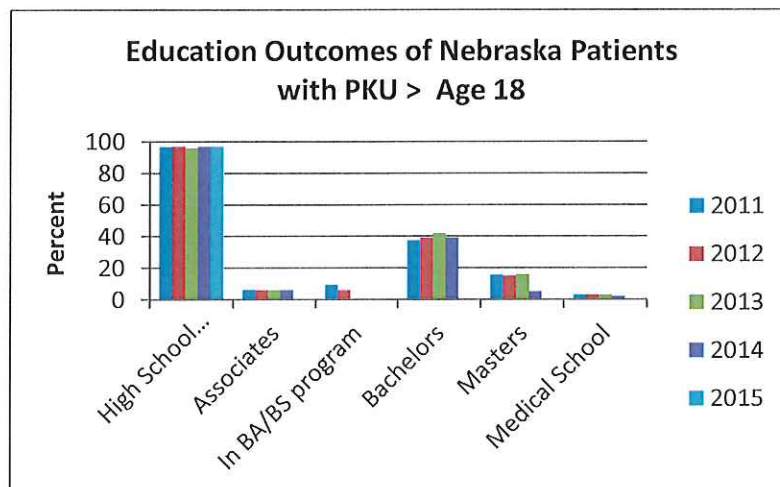


Outcome Data

Measures to evaluate patient outcomes are important for evaluating the effectiveness of the newborn screening system. Close monitoring, and ensuring access to the metabolic formula and foods are essential elements to the success of our Nebraskan's affected with inborn errors in metabolism.



Outcome measures of educational achievement demonstrate the success of the newborn screening system, and that of families, and individuals. In 2015 two had earned Associates, 13 Bachelor's and 5 Master's degrees. Two were attending medical school, and one was working towards a clinical doctorate in nursing.

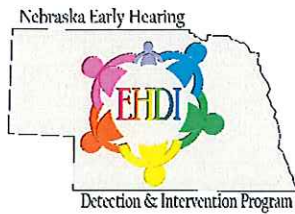


Developmental Measures:

Since reporting of long-term outcomes began in 2011, through 2014, 100% of children with PKU age 0-12 receiving services in Nebraska were assessed by the pediatric metabolic specialists as meeting developmental milestones.

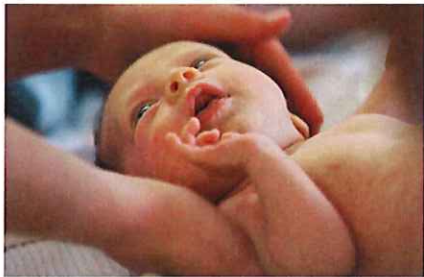
This data supports the need for continued funding to ensure access to the metabolic formula and foods required by patients identified with metabolic conditions via newborn screening.

NEBRASKA EARLY HEARING DETECTION AND INTERVENTION ANNUAL REPORT - 2015



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

Introduction



Approximately one to three in 1,000 babies are born with permanent hearing loss, making hearing loss one of the most common birth defects in America. Before newborn hearing screening, children who were deaf or hard of hearing 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 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 and 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 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 Reported for 2015 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 2015 there were 54 birthing facilities conducting hearing screenings.

Hearing Screening at Birthing Facilities and Birthing Centers



In 2015, inpatient hearing screenings were reported on 26,881 newborns or 99.7% of the 26,952 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 2015, of those who received a screening in Nebraska, 25,982 (96.7%) passed the inpatient screening. An outpatient 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 10 languages.

Birthing facilities reported educating over 99% of parents about newborn hearing screening, hearing loss, and normal speech and language development in 2015. 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.



Photo courtesy of: Cochlear Americas

Monitoring, Intervention, and Follow-up Care

The NE-EHDI Program's tracking and follow-up processes are followed for each baby who is reported as not passing the hearing screening during birth admission and for infants not receiving the inpatient hearing screening. In 2015, a total of 1,026 infants (hospital and non-

hospital births) were tracked by the Nebraska EHDI Program to encourage the parent(s) to have the infant receive an outpatient hearing screening or audiologic diagnostic evaluation.

The following shows the hearing screening/testing status of the 27,120 births for 2015:

26,834	Passed the screening or diagnostic testing (98.9% of births)
106	Expired (inpatient or outpatient)
57	Pending final screening or diagnostic testing
49	Diagnosed deaf or hard of hearing
42	Parents refused screening and/or diagnostic testing
13	Unresponsive (did not complete protocol after communication with NE-EHDI staff)
12	Lost (no response to NE-EHDI letters and phone calls)
7	Moved out of Nebraska

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."



To meet the state and national guidelines of "1-3-6" (hearing screening completed by **1** month, audiologic diagnostic evaluation completed by **3** months, early intervention initiated 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. Over 98% of infants received an inpatient screening within one month of age. For the newborns who were recommended for an audiologic diagnosis, 63% received the evaluation by three months of age according to individual data received by the NE-EHDI Program from audiologists.

Note: Because 57 hearing records are still pending the final screening and diagnostic testing results, the "1-3-6" numbers above are preliminary as of April 2016 and will most likely change.

Records for the Early Development Network (EDN), Nebraska's Part C Early Intervention Program, indicate that 63% of infants residing in Nebraska in 2015, diagnosed as deaf or hard of hearing with a developmental delay, were enrolled in EDN services by six months of age. The reasons for those infants not enrolling include: parents declining services, unable to contact the family, family moved out of state and no indication of developmental delay (slight or mild hard hearing loss).

ACTIVITIES – 2015

Funding

The NE-EHDI Program continued to receive funding from the Health Resources Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) and the Centers for Disease Control and Prevention (CDC). 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.



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:

- To discuss and advise on the goals for the NE-EHDI Program.
- To advise on the improvement of reporting, tracking, and follow-up protocols to effectively link the NE-EHDI Program and early intervention systems.
- To assist in increasing the program's responsiveness to the expanding cultural and linguistic communities in the state.
- To guide the long-term planning and evaluation of the NE-EHDI system in the state.
- To review the quarterly newborn screening statistics and make recommendations for program improvements.

The Advisory Committee of the NE-EHDI Program consists of no more than 20 voting members representing the following:

- Audiologists
- Deaf/Hard of Hearing community
- Early Intervention Services
- Ears, Nose and Throat Specialist/Otorhinolaryngologists or Otologist
- Family Support
- Hospitals (preferably hearing screening coordinator)
- Parents
- Pediatrics
- Public Health

Advisory Committee meetings are held four times a year and open to the public.

Projects - 2015

HearU Nebraska/Children's Hearing Aid Loaner Bank

Formerly known as the Nebraska Children's Hearing Aid Loaner Bank, HearU Nebraska began providing loaner hearing aids to young children in January 2008. The NE-EHDI Program continued to provide funds for administration of the program and to help purchase loaner hearing aids in 2015. In 2015 there were 88 hearing aids provided to 57 children (age range of two months to 18 years) with "free" hearing aids provided by HearU Nebraska. Since 2008 over 194 children have been provided with hearing aids.



Task Force

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 fails the inpatient newborn hearing screening. The Task Force continued to meet during 2015 and will be sending surveys in 2016 to mothers, over the age of 19, who have given birth to a child between July 1, 2015 and December 31, 2015. Results will be analyzed and a report issued on next steps.

Hospital Site Visits

During 2015, the Program Manager travelled Nebraska to visit 16 birthing facilities. The purpose of these visits was to determine what assistance the NE-EHDI Program could provide, how to lower refer rates, initiatives to reduce lost to follow-up rates, discuss the Quality Improvement Reports, review newborn hearings screening protocols, and to establish relationships with the hospitals.

Summary

- All of the 54 birthing hospitals in Nebraska were conducting newborn hearing screening in 2015. All but one had conducted the hearing screenings prior to discharge from the hospital or birthing center.
- In 2015, birthing hospitals reported screening the hearing of over 99% of newborns prior to discharge from the hospital.
- Over 99% of the infants passed an inpatient screening, an outpatient screening or a diagnostic evaluation.



- Of the 1,026 infants followed by the NE-EHDI Program, almost 92% of these infants have completed the recommended follow-up of outpatient screening/diagnostic testing and 5.7% are still in the process of completing the outpatient screening/diagnostic protocol in 2016.
- In 2015, there were confirmatory audiologic evaluations initiated within three months of age for 63% of newborns when the newborn did not pass the inpatient/outpatient screening or did not receive an inpatient screening.
- There were 131 infants born in 2015 whose hearing status is unknown due to: 1) parents refusing to follow the recommended hearing screening/testing protocol, 2) unreported results, 3) medical conditions causing postponed final hearing testing, and 4) families moving out of Nebraska.
- The incidence of Permanent Congenital Hearing Loss of 1.8 per thousand screened is within the anticipated range of one to three per thousand.
- Sixty-three percent of the infants identified deaf/hard of hearing and residing in Nebraska were verified for the Early Development Network and received special education services by six months of age.

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/publichealth/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 and endocrine conditions, transfusions, home births, drawn early specimens

Karen Eveans, NBS Follow up Specialist 402-471-6558

Hemoglobinopathies and cystic fibrosis, unsatisfactory specimens

Jessy Davis, Staff Assistant 402 471-9731

Metabolic foods, patient education materials, advisory committee and staff support

WEBPAGE: <http://dhhs.ne.gov/publichealth/Pages/nsp.aspx>

E-mail contact: dhhs.newbornscreening@nebraska.gov

E-FAX: 402-742-2332

Regular Fax: 402-471-1863

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

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

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

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

Kathy Northrop, Program Manager (Retired June 2016) 402-471-6770

Program planning, evaluation and management, 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, 402-471-3579

Follow-up, patient education materials distribution, data management

Courtney Smejdir, Community Health Educator, 402-471-6746

Follow-up, complex diagnostics, special projects

Marietta Mathis, Community Outreach Coordinator, 402-471-1440

Follow-up, community outreach, and education

Website: <http://dhhs.ne.gov/publichealth/EHDI/Pages/EHDIHome.aspx>

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

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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*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.

Hearing screening photos courtesy of National Center for Hearing Assessment and Management and Cochlear Americas. 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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