August 27, 2014

Patrick O'Donnell, Clerk of the Legislature
State Capitol, Room 2018
P.O. Box 94604
Lincoln, NE 68509

Dear Mr. O'Donnell,

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.

This is the third year for which we are able to report the outstanding outcomes for 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 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.

I hope you will find the Annual Report useful.

Sincerely,

Joseph M. Acierno, M.D., J.D.
Chief Medical Officer
Director, Division of Public Health
Nebraska Department of Health and Human Services

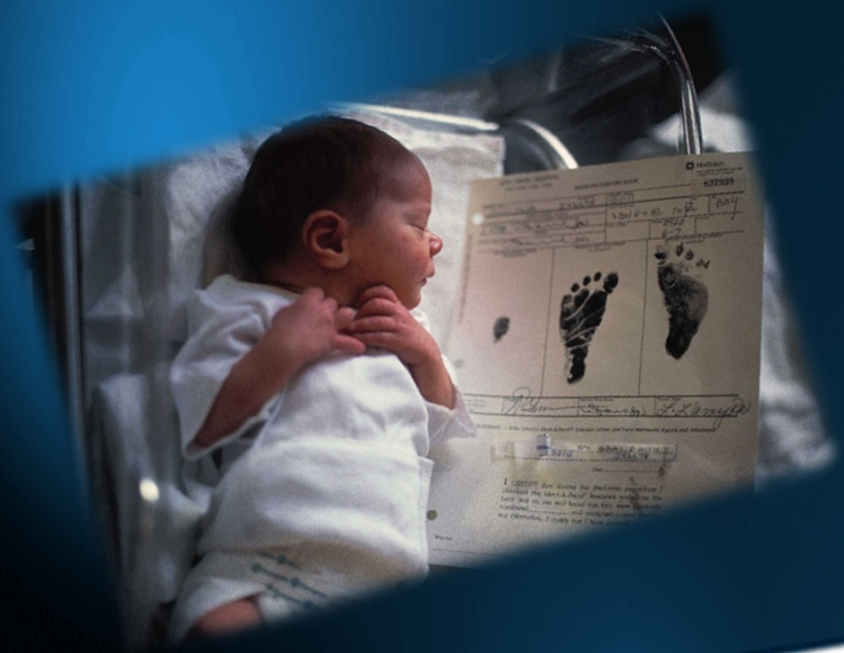
New shorter synopsis 2013

NEWBORN SCREENING IN NEBRASKA

Newborn Bloodspot Screening for Metabolic & Inherited Disorders

and

Early Hearing Detection & Intervention



2013 Annual Report

Department of Health & Human Services
DHHS
NEBRASKA

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NEBRASKA EARLY HEARING DETECTION AND INTERVENTION ANNUAL REPORT - 2013

Our Journey with Cystic Fibrosis…

My daughter, Ellie, has Cystic Fibrosis. As a result of the newborn screen that had recently added CF screening to the panel, she was the second child born in Nebraska to be diagnosed right after birth. While this diagnosis was completely devastating for us, I believe it gave us the ability to begin her treatment at 8 days old. Because of that, she is now 8 years old and doing unbelievably well.

Prior to Ellie's diagnosis my only awareness of the disease was that I knew my father's brother died from it at age 16, the year I was born. That was my reference point when I heard Ellie's diagnosis. I did not know the advances, the treatments, and the clinical teams that have been developed to keep kids as healthy as possible.

We started Ellie on manual chest percussion therapy, enzymes and vitamins right away. At 4 months she developed pseudomonas. Oral and nebulized antibiotics did not work. At 5 months she was hospitalized for IV antibiotics. This was fairly new to everyone, the doctors and us. The question of how to treat an infant was still out there. We spent nearly two weeks in the hospital, taking turns staying overnight as we had Ellie's 2-year-old brother, Leo, at home that still needed us. The time was difficult and frustrating. She needed to be sedated to get in a PICC line. This was the first time we had a child under sedation after watching the nurses try on multiple areas to insert the IV. We also had several different doctors including our CF doctors, the adult CF doctor, hospitalists and several residents talk to us over and over again about their uncertainties as to what to do next. While we had trust in them, it was reassuring and scary to realize that they also trusted us to help give input. We knew our daughter, they knew CF, so between all of us we came up with an approach. Unfortunately, a week and a half into this my grandmother passed away in Michigan. So, at that point we needed to decide how to proceed. It was incredibly important for me to get home for the funeral, but also make sure that Ellie received the entire dose of antibiotics. The team was amazing at that point. They taught us to do the antibiotics ourselves through the PICC line. So, we packed everything up and drove half way across the country. We gave her a dose every couple of hours as instructed, even waking up through the night trying to administer the doses without waking everyone up, especially Ellie. While it was a long couple of exhausting weeks, it worked. Ellie has been pseudomonas free since that time.

We have been blessed to be part of the Cystic Fibrosis Center since Ellie was a week old. They have watched her grow and have been very supportive. More than that, they have been always respectful of our opinions, our ideas and our fears. It is for these reasons that I am very honored to serve as the parent representative for families who have children with cystic fibrosis on the Newborn Screen Advisory Committee. I know the positive impact that early diagnosis can have on this disease and many others.

Jennifer Peter, PsyD
Ellie's mom

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 screened conditions can range from brain and nerve cell damage resulting in severe intellectual disability, to damage to the infant or child's heart, kidney, liver, spleen, eyes, or hearing. Problems with physical growth, stroke and even infant death can also occur.

Newborn Screening is a system 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

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

In 2013, newborn screening for 28 conditions, resulted in successfully identifying and treating 57 newborns affected with conditions in time to prevent problems associated with them.

- 6 babies with partial (treated) and 2 mild biotinidase deficiency (BIO) (1 not treated)
- 2 babies with congenital adrenal hyperplasia (CAH)
- 5 babies with congenital primary hypothyroidism (CPH), 7 congenital hypothyroidism (not primary), 3 hypothyroidism and 1 primary hypothyroidism
- 9 babies with cystic fibrosis and 1 with CF related metabolic syndrome (CRMS)
- 1 baby with galactosemia and 1 Duarte galactosemia (GAL, and DG)
- 8 babies with clinically significant hemoglobinopathies (3 sickle cell disease, 1 SC-disease, 3 hemoglobin C Disease, and 1 sickle beta thalassemia)
- 1 baby with hypermethioninemia
- 1 baby with isovaleric acidemia
- 2 babies with MCAD - medium chain acyl-coA dehydrogenase deficiency
- 1 baby with phenylketonuria (PKU) and 1 with hyperphenylalaninemia
- 1 baby with propionic acidemia
- 1 baby with Methylmalonic acidemia
- 1 baby with SCAD – short chain acyl-coA dehydrogenase deficiencey
- 5 transient tyrosinemia (4 treated till resolved, 1 not treated).

While individually each condition is rare, the collective incidence rate of screened conditions in Nebraska using the last 5 years of data was

1 in every 529 births

System Overview

In 2013, 56 birthing facilities in Nebraska shipped specimens overnight, for 26,343 babies Monday through Friday, to PerkinElmer Screening Laboratory. The larger birthing facilities had Saturday pick up available as well. The laboratory is under contract with the State of Nebraska to receive specimens and conduct testing Monday through Saturday for all of Nebraska's newborns. The Program, administered by the Department of Health and Human Services, also partnered with pediatric specialists in genetics, metabolism, endocrinology, hematology and pulmonology, to connect health care providers for babies who had positive screens with the appropriate subspecialty for diagnosis and treatment. An Advisory Committee with expertise in these subspecialties, laboratory, hospitals, pediatrics, neonatology, family practice, 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 healthcare provider for every newborn who requires additional testing, receives the necessary information to act accordingly. The Program 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 multiple contracts with metabolic food vendors for individuals with PKU and other inborn errors in metabolism who required the specially manufactured foods. (For more information about Nebraska's system, governing statute, regulations and other resources, visit our website at www.dhhs.ne.gov/nsp)

MAJOR INITIATIVES in NEBRASKA During 2013

Education

- The Nebraska Newborn Screening Program continued to track and distribute the "Parents Guide To Your Baby's Newborn Screening" to the 56 birthing facilities, Children's hospital and upon request to some Obstetric, Family Physician and Pediatric practices.

- The "QI Hints" newsletter was sent with each hospital's quality assurance reports quarterly.

- A Healthcare Providers update, in response to educational needs about screening newborns for critical congenital heart disease was distributed to all birthing facilities, pediatricians and family physicians. The "Parent's Guide" was revised to add Critical Congenital Heart Disease screening information. Publication is pending in consideration of fiscal responsibility, due to additional revisions expected for adding Severe Combined Immune Deficiency (SCID) to the newborn screening blood spot panel.

Policy

- 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 SCID sub-committee with Program personnel further developed screening protocols for the population of newborns in the NICU expected to have higher rates of abnormal screens for SCID. This was in preparation for the possible addition of Severe Combined Immune Deficiency (SCID). SCID has been part of the Secretary of HHS's endorsement to be included in the Recommended Universal Screening Panel since 2010.

- 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). The state general fund appropriation has stayed the same since 1997, and the Title V Block Grant appropriation to the state is below 1997 levels. The program continued to work with the metabolic clinic and look for creative ways to make shrinking funds go further as costs increase and the program used a higher percent of the Title V Block grant.

- Legislation (LB 225) requiring hospitals to screen all newborns for Critical Congenital Heart Disease passed and was implemented in September of 2013. Recommendations from an expert subcommittee of the NBS Advisory Committee were taken into consideration for the legislation. The legislation required the Department (DHHS) to provide parent

education materials (available on the newborn screening website until the next version of the "Parent's Guide" is published). It also required that the Department develop the method for screening. A protocol (adapted by the expert advisory committee), from the American Academy of Pediatrics for pulse oximetry screening was shared with all birthing facilities and neonatal intensive care units. A physician's update also provided education about the protocol and follow-up recommendations. Regulations adopting the protocol were in the promulgation process during 2013. While development of these protocols and educational materials was assigned to the newborn screening program, unlike blood spot screening, the program does not have oversight authority for follow up or a role with quality assurance monitoring.

Quality Assurance

- In 2013 quality assurance reports were sent to each birthing facility and Children's Hospital in Omaha. These reports included the individual hospital's quarterly measures compared to statewide averages for: specimens drawn early, unsatisfactory specimens, specimens collected post transfusion, and turnaround times for specimen collection for birth to collection, collection to receipt at the lab, in-lab processing time, and overall average time from birth to report of results.

- Nationally and in Nebraska, a great deal of attention was focused on newborn screening turnaround times. System evaluation and solutions continue to be explored including operating hours and days of the laboratory, transport services and follow up. In 2013 PerkinElmer Laboratory expanded its contract with UPS (and in some communities FedEx) to ensure Saturday specimen pick up availability to all birthing facilities in Nebraska. The lab also offered training to every birthing facility in Nebraska to ensure they understood all send-out requirements. The program is developing new quality assurance measures to better reflect hospital and laboratory performance based on benchmarks instead of averages. For example hospitals will receive information about what percent of their specimens arrive at the lab in 24 hours, or 48 hrs, vs. what the average shipping and handling time is.

SPECIAL THANKS to the Newborn Screening Advisory Committee

- A huge debt of gratitude is owed to the dedicated members of the Newborn Screening Advisory Committee who commit their time and expertise to the Nebraska Newborn Screening Program. Much of Nebraska's success can be directly tied to their 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. 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.

Assurance of Treatment and Management for 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 distribute the metabolic formula. The program coordinated the day-to-day metabolic foods program helping families understand the program and stay connected, and monitored vendors with which the Department contracted and processed payments for family orders. Families received a tracking log for their use in monitoring their orders and expenses and they received an annual spending report. The program worked closely with the metabolic clinic to ensure timely contract amendments of appropriate metabolically altered food products as manufacturers continue to expand their offerings.

Sustaining the obligation to ensure access to treatment:
The number of people with conditions requiring special formula and foods will always increase. The metabolic diets are required for life, so people do not "age-out" of the need for the special formulas or foods. State general funds have remained flat and federal allocations to Nebraska of Maternal and Child Health funds have been reduced or flat for several years. The Newborn Screening Program then requires a higher proportion of the MCH funds to help meet the statutory mandate. While a relatively new drug is available to which about 40% of patients with PKU are expected to respond positively, this medication is expensive as well. Therefore the program continues to look for sustainable ways to continue to assure access to needed services for people who have these conditions.

Nebraska's Newborn Screening Fees:
In 2013 the charge for newborn screening was $40.00. The laboratory testing fee was $30.00 and the state fee (per statute and regulation) was $10.00 per infant screened. (State fee used only to help pay for treatment services). These fees are billed to the hospital and then are part of the hospital's charges. Hospital charges are separate and not regulated by the program.

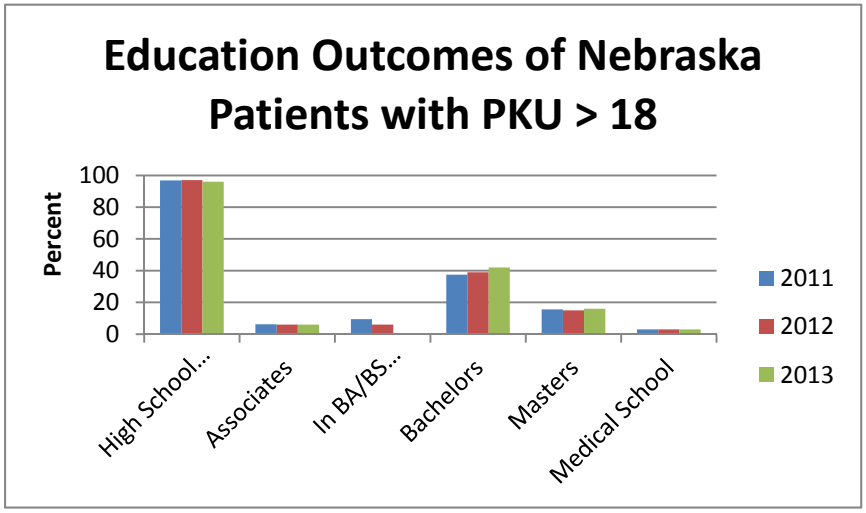


Intervention Data

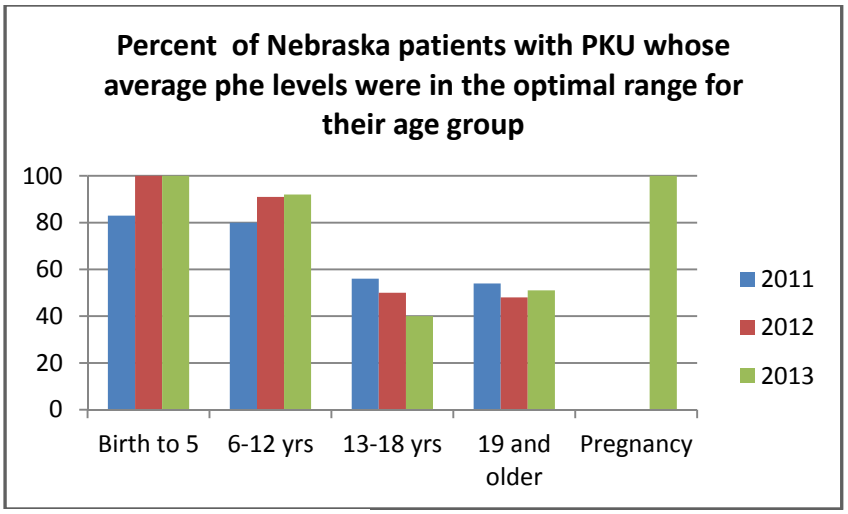
Several factors can conspire to create delays in treatment, so speed and persistence in follow up are essential. Some examples of these factors include babies with prolonged treatment in NICUs, parental resistance to confirmatory testing, problems in locating parents because contact information provided to the hospital or recorded on the filter paper collection cards was incorrect or no longer accurate.

Condition & number of babies diagnosed	Average age (days) at intervention/tx.	Range in ages (days) at intervention/tx.
6 Biotinidase Deficiency (Partials) (2 mild)	13	3-30
2 Congenital Adrenal Hyperplasia	3.5	3-4
15 Congenital Primary Hypothyroidism (includes other forms of hypothyroidism)	11.5	1-33
9 Cystic Fibrosis	15.7	8-36
1 Classical Galactosemia 1 Duarte Galactosemia	8	5-11
1 Hypermethioninemia	Dx. @ 17 days	Not treated
1 Isovaleric Acidemia	8	8
2 MCAD	3	3
1 MMA (Methylmalonic Aciduria)	1	1 (prenatal dx. due to older sibling)
2 PKU	4.5	4-5
1 PA (Propionic Acidemia)	3	3
SCAD (Short Chain Acyl CoA Dehydrogenase)	91	91
8 Sickle Cell Disease & other hgb. diseases	14.5	7-26
5 Transient/probable transient tyrosinemia	34	13-76 (1 not treated)





Outcome Data



To compare to State & Nat'l averages from the most recent year (2011) Nat'l Center for Higher Education. (Nebr. PKU 2013 #'s)

Measure	State Average	US Avg
% age 18-24 with High school diploma	87.4 (Nebr. PKU 96%)	84.1
% age 25-64 with Associates degree or higher	30.4 (Nebr. PKU 6%)	30.1
% age 25-64 with Bachelors degree	30.4 (Nebr. PKU 42%)	40.1
% ages 25-64 Graduate or Professional Degree	9.5 (Nebr. PKU 16%)	10.8

Developmental Measures:

In 2011 through 2013 100% of children with PKU age 0-12 receiving services in Nebraska were assessed by the pediatric metabolic specialist as meeting developmental milestones.

Two children have been diagnosed with ADHD and are receiving treatment.

NEBRASKA EARLY HEARING DETECTION AND INTERVENTION ANNUAL REPORT - 2013

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 a child's speech and language, 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 2013

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 2013 there were 56 birthing facilities conducting hearing screenings.

Hearing Screening at Birthing Facilities and Birthing Centers

In 2013 inpatient hearing screenings were reported on 26,173 newborns, or 99.7% of the 26,246 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 Nebraska, 25,384 (96.9%) newborns passed the inpatient hearing screening in 2013. 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 test 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 2013. 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.

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 2013, a total of 923 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 26,417 births for 2013:

26,134 Passed outpatient screening and/or diagnostic testing (closed)
- 110 Expired (inpatient or outpatient)
- 54 Parents Refused screening and/or diagnostic testing
- 43 Diagnosed deaf or hard of hearing
- 41 Lost (no response to NE-EHDI letters and phone calls)
- 26 Middle-ear problems or inconclusive diagnostic testing (more testing needed)
- 6 Moved out of Nebraska
- 3 Pending diagnostic testing

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, established by the Joint Committee on Infant Hearing (JCIH) of "1-3-6" (hearing screening completed by 1 month, audiologic diagnostic evaluation completed by 3 months, early intervention initiated by 6 months), the timeliness of initiation and completion of follow-up activities is an important aspect of the quality of services. Over 99% of infants received an inpatient screening within one month of age. For the newborns who were recommended for an audiologic diagnosis, 48.8% received the evaluation by three months of age according to individual data received by the NE-EHDI Program from audiologists.

Records for the Early Development Network (EDN), Nebraska's Part C Early Intervention Program, indicate that 23 (65.7%) out of 35 infants residing in Nebraska in 2013, diagnosed as deaf or hard of hearing were verified for EDN services within six months. The remaining families opted not to enroll in EDN services.

ACTIVITIES – 2013

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 funds the development, implementation, and maintenance of the integrated electronic data reporting and tracking system.

Advisory Committee

The NE-EHDI Program was created based on the requirements identified in the Nebraska Infant Hearing Act of 2000 and the recommendations of the NE-EHDI Program Advisory Committee. 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

HearU Nebraska/Children's Hearing Aid Loaner Bank

The Nebraska Children's Hearing Aid Loaner Bank now known as 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 2013. At the end of 2013 there were 69 children (age range of 4 months – 15 years) with "free" hearing aids provided by HearU Nebraska.

Parent Workshops

The NE-EHDI Program worked with Hands and Voices and the Regional Programs for Students Who Are Deaf or Hard of Hearing to organize workshops for parents of children who are deaf or hard of hearing. In 2013, workshops were held in Scottsbluff and Mahoney State Park. The purpose of the workshops was to help parents build skills for effective parental advocacy for their child.

iEHDI CDC Contract

The NE-EHDI Program provided data to the Centers for Disease Control (CDC) as a partner in the iEHDI Data Project in 2013. The purpose of the contract was to "…obtain a limited set of existing, individual level data from a minimum of three states." This data will be used to determine ways to improve the quality and completeness of Early Hearing Detection and Intervention (EHDI) data at the national level and help address questions related to assessing progress towards national EHDI benchmarks. The information in the data set excludes direct identifiers, such as name of the individual or of relatives, employers, or household members of the individual. The iEHDI project has been extended through 2014 for the purpose of providing data on 2012 Nebraska births to the CDC so they can compare 2012 data with the data on 2010 births already provided.

Summary

- All the current birthing hospitals in Nebraska were conducting newborn hearing screening in 2013. All but one had conducted the hearing screenings prior to discharge from the hospital or birthing center.
- In 2013, birthing hospitals reported screening the hearing of over 99% of newborns prior to discharge from the hospital.
- The overall "refer" rate during 2013 for hearing screening during birth admission was 3.1%, with over 99% of all newborns/infants completing the hearing screening and any recommended follow-up screening/diagnostic testing.

- In 2013, audiologic evaluations were initiated within 3 months of age for almost 50% of newborns when the newborn did not pass the inpatient screening.
- There were 95 infants born in 2013 whose hearing status is unknown due to parents refusing to follow the recommended hearing screening/testing protocol or not reporting the screening/testing results.
- The incidence of Permanent Congenital Hearing Loss of 1.6 per thousand screened is within the anticipated range of one to three per thousand.
- Almost 70% of the infants identified deaf/hard of hearing and residing in Nebraska were verified for the Early Development Network and received special education services within six months of birth.

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
Susie Lyness, Administrative 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 Laboratory Vice President and General Manager, Bill Slimak 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, Early Hearing Detection & Intervention (NE-EHDI) Program Manager 402-471-6770
Program planning, evaluation and management, systems development

Jim Beavers, Business Analyst, NE-EHDI Program 402-471-1526
Data system planning and testing, development of reports, system security, training and technical assistance

MeLissa Butler, Community Health Educator, NE-EHDI Program 402-471-3579
Follow up, patient education materials distribution, data management

Debie Seiler, Community Outreach Coordinator, NE-EHDI Program 402-471-1440
Follow up, community outreach and education

Courtney Smejdir, Community Health Educator, NE-EHDI program 402-471-6746
Follow up, complex diagnostics, special projects

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. Laboratory photos courtesy of Perkin Elmer Genetics Screening Laboratory. Hearing screening photos courtesy of Natus Medical, SonaMed Corp, National Center for Hearing Assessment and Management. Any reference to specific commercial product in the Newborn Hearing Screening section does not constitute or imply an endorsement, recommendation or favoring by the Early Hearing Detection & Intervention Program.