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DEPT. OF HEALTH AND HUMAN SERVICES

NEWBORN SCREENING

Nebraska Department of Health and Human Services **January 2, 2024**

Essential Information for Practitioners

Newborn (bloodspot) screening is mandatory for every baby born in Nebraska, but every step of the process doesn't just magically happen. While the state system is in place to support you in your responsibilities, it is important for every healthcare provider who takes responsibility for the care of newborns to know what state law requires of them. Frequently, hospitalists who are seeing the baby during the obstetric stay, won't be caring for the baby post-discharge. So whose job is it anyway? How do we make sure no baby affected with a screened disorder goes unidentified? The law requires the attending physician to ensure the screen is done, and to follow-up and confirm results that need further action..

I ordered the screen but I'm not seeing the baby post-discharge. What's my responsibility?

Your first job is to educate the parents about the newborn screen. Materials are available from the Department of Health and Human Services (DHHS). The "Parent's Guide to Your Baby's Newborn Screening" explains how , why and which conditions will be screened. The guide also discusses the reasons why parents might be asked to bring their child in for repeat or confirmatory screening. Be sure your patients' parent(s) read this, and have an opportunity to ask questions. This is a good time for you to be sure they have identified a post-discharge healthcare provider for their baby. This is the name of the provider who should be on the filter paper sent to the screening lab. If you do not ensure that this is documented in the medical record any follow-up may become your responsibility as the attending practitioner.

Whose job is it anyway?

It is 2:00 am and you are calling me with a positive Congenital Adrenal Hyperplasia (CAH) on a baby I only saw in the hospital. What am I supposed to do next? Unless you know who the post-discharge physician is, you will need to contact the parents, evaluate the condition of the baby, consult with the pediatric endocrinologist on call, arrange for confirmatory testing and possibly readmit the baby for evaluation. Critical positive results for some conditions represent a neonatal emergency. CAH is just one of them. The NBS follow-up personnel will provide you with the recommended actions from the pediatric subspecialists, and the Nebraska Newborn Screening Program ACT Sheets for guidance.

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Newborn Screening, Saving Babies' Lives

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Is this really necessary?

The screen was collected too early, but only 10 minutes shy of the 24 hour mark. Do I really have to get a repeat?

Under Nebraska State Law you are responsible for ensuring the screen is completed. Specimens collected at less than 24 hours very frequently have false positive results for Cystic Fibrosis (CF), Congenital Adrenal Hyperplasia (CAH) and Congenital Primary Hypothyroidism (CPH), and CPH results are not considered reliable from specimens collected at less than 24 hours of age.

The screening lab no longer tests specimens collected at less than 24 hours for those conditions, (CF, CAH, MPS-1, Pompe, and CPH) so it is imperative to get the repeat so you have a complete screen.

Are Your Patient's Medical Records Complete?

Most clinics verify at the one or two week well-baby check-up that they have all of the newborn screening results (blood spot, hearing and critical congenital heart disease), per the recommendations of the American Academy of Pediatrics "Bright Futures". If you don't have a copy of the bloodspot screen results there are a number of options available to you. You may be able to potentially access them from the birth hospitals EMR or request them from medical records.

Alternatively, you can access the results for your patients directly from the Revvity Omics (Nebraska's contracted newborn screening laboratory) secure web portal. To get access contact Susan Felinczak at Revvity Omics at 866-463-6436 Ext. 2064887 or Susan.Felinczak@revvity.com You will be asked to complete and sign a form to access your patient's results, and to be set up for a secure account and establish a password. The web portal is simple and easy. You can print and scan or download your patients' bloodspot screen results into your own EMR.

Helping Parent's Understand

The "Parent's Guide" is available at no charge from DHHS, in English and Spanish.

A video that might be helpful produced by Baby's First Test: https://www.babysfirsttest.org/newborn-screening/your-babys-screening

The Heartland Genetics Network has a Spanish Language videos available on Newborn Screening and Genetic Clinic referrals: https://www.heartlandcollaborative.org/for-families/resources/

When to educate?

Ideally, provide this to expecting patients during the third trimester. If you are a family physician providing obstetric care, this will help you and the parents later. Some OB/GYN practices include the Parent's Guide and/or a one-page NBS intro (also available at no charge) to their patients.

Practitioners must provide the information at a minimum during pre-admission registration of the obstetric in-patient stay. Hospitals usually support the ordering physician by providing the "Parent's Guide" with the information packet. Hospitalists may wish to work with nursing personnel to be sure the education is completed.

Where are the Best Resources for Practitioners?

The Nebraska Newborn Screening Program has information on it's website for practitioners and links to reputable associations and organizations with expertise in those conditions. You'll also find publications, reports, the state law and regulations governing newborn screening on our page. Subscribers receive email notices when updates are made to the web page. Go to: https://service.govdelivery.com/accounts/NESTATE/subscriber/new?qsp=2931

Marginalizing Newborn Screening- a Deadly Risk

It can be a deadly mistake to dismiss the importance of newborn screening. These conditions are rare, and while we do have false positives that is the nature of screening. These conditions appear in asymptomatic children and have been selected for screening in infancy with the utmost balance between conditions which have treatments, have reliable testing, and generally have an onset in the immediate newborn period.

Newborn Screening professionals are well aware that we cannot save every baby affected by the screening panel's diseases. Sometimes even with the earliest feasible notification, things still go wrong, and babies die. This has even happened here in Nebraska.

Because of the urgent need to identify these babies, we continually try to optimize screening.

Every year in Nebraska alone, about 1 in every 450 babies are found to have a disease through the dried bloodspot screening process. Because of early diagnosis, these babies can be entered into treatment, optimizing their growth and development.

Newborn Screening, Saving Babies' Lives

Neb. Rev. Stat. §§ 71-558-71-560 -Congenital Cytomegalovirus Education Bill

The Early Hearing Detection and Intervention (EHDI) Program is required under Nebraska revised statute §§71-558-71-560 to produce and publish informational materials for pregnant women and women who may become pregnant regarding the incidence, transmission to pregnant women, birth defects, methods of diagnosis, preventative measures, as well as interventions, treatments services for children diagnosed with congenital cytomegalovirus. These materials are available for child care facilities, school nurses, hospitals, birthing facilities, and health care providers offering care to pregnant women or infants. Materials are available for download or distribution at the EHDI website: https://dhhs.ne.gov/Pages/Hearing-Detection-and-Intervention.aspx

As apart of this bill, birthing facilities may offer testing information to families if a newborn fails their initial hearing screening. The Nebraska Newborn Screening Program recommends providers wishing to pursue cCMV testing consult with their hospital's pathologist, a pediatric infectious disease expert, or https://www.cdc.gov/cmv/clinical/lab-tests.html.

For additional questions, you may also call Jillian Chance, DNP,RN, at the Nebraska Newborn Screening Program at (402) 471-6733.

Early Intervention Services may also be offered by the birthing facilities if a newborn fails their initial hearing screen. To refer an infant to Early Intervention Services: https://edn.ne.gov/cms/

CCHD Screening is Mandatory

Per Nebraska revised Statute §71-556 and Chapter 10 Title 181, all Newborns shall be screed for Critical Congenital Heart Disease. Healthcare providers caring for infants are responsible for ensuring that every newborn in their care has had a screen for CCHD. If they are the discharging provider, they must provide the results documented in the medical record before discharge or transfer. Providers also must provide in the case of a failed screen that they assess the infant, or-der an echo, or refer for echo and/or neonatology or cardiology referral. Per regulations, providers of expecting parents are responsible for educating their patients on the screening, how it is completed, and that the test is mandatory for all newborns whether they are born in the hospital or not. https://www.nebraska.gov/rules-and-regs/regsearch/Rules/

Nebraska Newborn Screening Program

The mission of the Nebraska Newborn Screening Program is to prevent or minimize morbidity and mortality through newborn screening. The staff of the program are here to assist you with any questions:

24/7 Phone: (402) 471-0374

Fax: (402) 742-2332

Parent Education resources:
402 471-9731 or order online at:
http://dhhs.ne.gov/publichealth/Pages/OrderLiterature.aspx

Program Staff:

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Send your email address to us at : Dhhs.newbornscreening@nebraska.gov and we will skip paper copies in the future!

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