NORTH DAKOTA
DEPARTMENT of HEALTH

BABY'S FIRST TEST

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North Dakota
Newborn Screening Program

Objectives

- Understand the importance of newborn screening education, collection and timeliness
- Identify partners involved with the newborn screening process in North Dakota
- Identify good and poor quality specimens
- Discuss specimen transportation

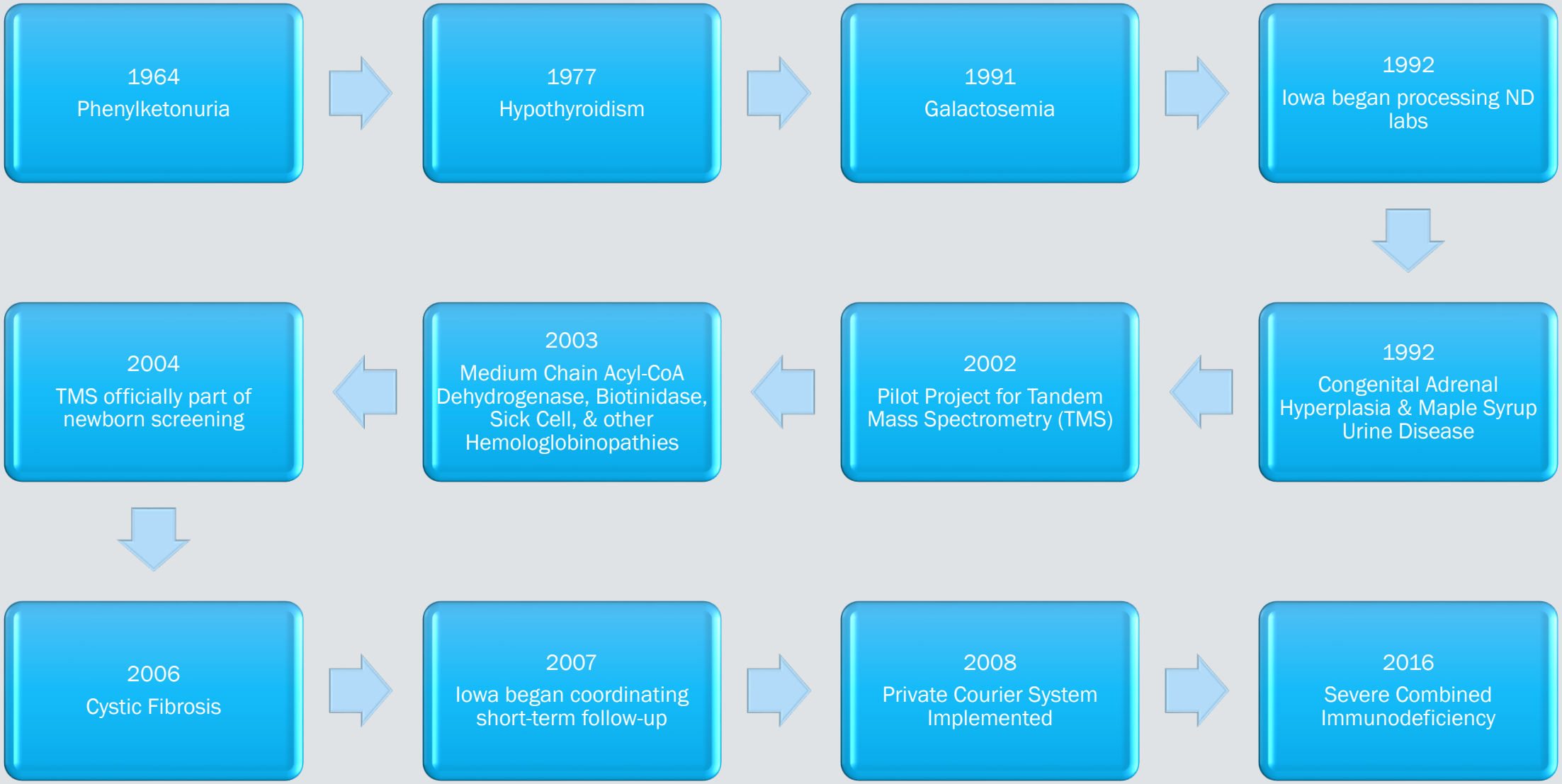

POPULATION – BASED SCREENING
Slide credit - Michele Caggana

What is Newborn Screening?

- Public health service that began with PKU screening in 1960's – it can change a baby's life
- Screening identifies individuals in a population who may be at an increased risk for serious health conditions
- Detects life threatening medical conditions to prevent:
  - Abnormal metabolism
  - Developmental delays
  - Brain damage
  - Coma
  - Death
- Babies with disorders often look and act like healthy normal newborns
- *GOAL* – Screen before symptoms occur
  - *Early treatment and identification SAVES LIVES*
  - *Treatment is available for **ALL** disorders screened, although it may be life long treatment*


Newborn Screening:
Saves or Improves the Lives of Over
12,000
Babies a Year!
PARENT EDUCATION
Obstetrician explains newborn screening process to expectant parents.
HOSPITAL SCREENING
Hospital nurse tests baby's hearing and heart, and collects blood from baby's heel.
LAB SCREENING
State public health lab tests baby's blood for at least 29 genetic conditions.
NORMAL RESULTS
Pediatrician reviews test results with parents at baby's first wellness visit.
POSITIVE RESULTS
Health Department staff calls pediatrician/parents to request re-testing baby. Medical specialists perform tests and make diagnosis.
FOLLOW-UP
Medical specialists and pediatrician develop a treatment plan and guide parents in caring for baby.

History of ND Newborn Screening



Confirmed ND Newborn Screening Disorders

- 2011: 10,072 births (80 conditions detected by NBS)
- 2012: 11,503 births (87 conditions detected by NBS)
- 2013: 11,978 births (96 conditions detected by NBS)
- 2014: 12,840 births (115 conditions detected by NBS)
- 2015: 12,842 births (137 conditions detected by NBS)
- 2016: 13,027 births (156 conditions detected by NBS)

Statistics include traits identified through screening, not only disease

Most Common Disorders in ND ~ Past 5 Years

Congenital Hypothyroidism
42 cases

National Incidence:
1/3,000 to 1/4,000

Cystic Fibrosis
13 cases

National Incidence:
1/3,500 – Caucasians
1/17,000 – African Americans

Sickle Cell Anemia
9 cases

National Incidence:
1/375 African Americans

Congenital Adrenal Hyperplasia
6 cases

National Incidence:
1/15,000

Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
4 cases

National Incidence:
1/15,000

Classic Phenylketonuria (PKU)
3 cases

National Incidence:
1/10,000 to 1/15,000

Biotinidase Deficiency
3 cases

National Incidence:
1/60,000

When Did That Change?

THEN		NOW
Newborn Screening was called the “PKU Test” or “Metabolic Test” – 1960’s – 1990’s	⇒	Newborn Screening is no longer referred to as the “PKU Test” or “Metabolic Test” – Just call it Newborn Screening - PKU is *1* out of *49* conditions that are screened
Wait 3-4 days until specimen collection or before discharging baby	⇒	Collection between 24-48 hours, no later – the closer to 24 hrs the better (c-sections too)
Baby must be fed before specimen collection can occur	⇒	Most often babies will be fed before testing occurs, but baby’s no longer need to feed before screening
Restrict protein for babies who might have PKU	⇒	No longer recommended to restrict protein for babies that might have PKU – no restriction until diagnosis is confirmed

It Takes A Village

North Dakota Newborn Screening Program

NORTH DAKOTA DEPARTMENT of HEALTH

Newborn Screening Advisory Committee

FAMILY VOICES OF NORTH DAKOTA
Navigating Crossroads to Hope

NORTH DAKOTA DEPARTMENT of HEALTH
Children's Special Health Services

Family Resources & Assistant Programs

STATE HYGIENIC LABORATORY
Iowa's Environmental and Public Health Laboratory
EST. 1904
THE UNIVERSITY OF IOWA

Specimen Processing

Newborn & Family

Midwives & Doulas

University of Iowa Children's Hospital

Iowa Newborn Screening Program

Short-term Follow-up Services

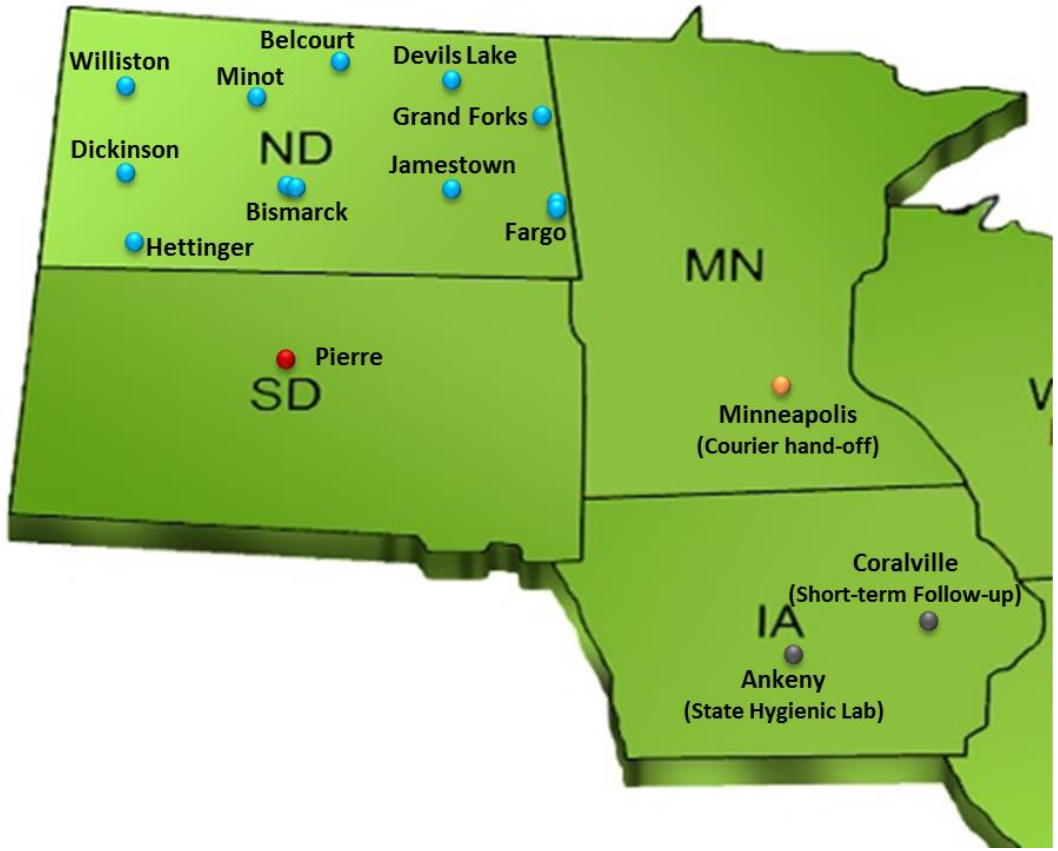
Health Care Providers

Hospitals, Clinics, & Labs

Newborn Screening Tri-state Collaborative

Partners include: ND, SD, and IA

- ND – estimated 13,000 births/year and 12 birthing hospitals
- SD - estimated 13,000 births/year and 26 birthing hospitals
- IA - estimated 40,000 births/year and 83 birthing hospitals



University of Iowa Laboratory & Short-term Follow-up Services

- Iowa laboratory is open 365 days/year and processes labs daily
- ND NBS fee supports the services Iowa provides
- Ordering health care provider on the form is notified if abnormal screening
- ***Only*** time critical disorders are called out on a weekend or holiday
- If provider is called on a weekend/holiday, the baby requires intervention ***that day*** – not next business day
- **Hours** make a difference in the outcome and health of baby

Cost for Newborn Screening

- ND Newborn Screening Fee is $75 per baby

- Billing Process
  - State Hygienic Laboratory (SHL) in Iowa bills the facilities ⟹ facility bills the insurance ⟹ facility bills remaining balance to the patient
  - SHL does not charge facilities for repeat testing

- Each state sets their own newborn screening fee
  - *Fees vary state to state*

Newborn Screening Process & Collection

DON'T FORGET:

Has someone educated the parents on the procedure and benefits to newborn screening *prior* to the collection?

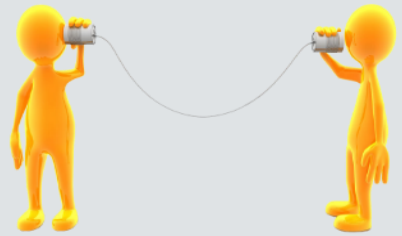
Collection of Newborn Screening

- Specimen collection should occur between 24 and 48 hours – ideally closer to 24 hours

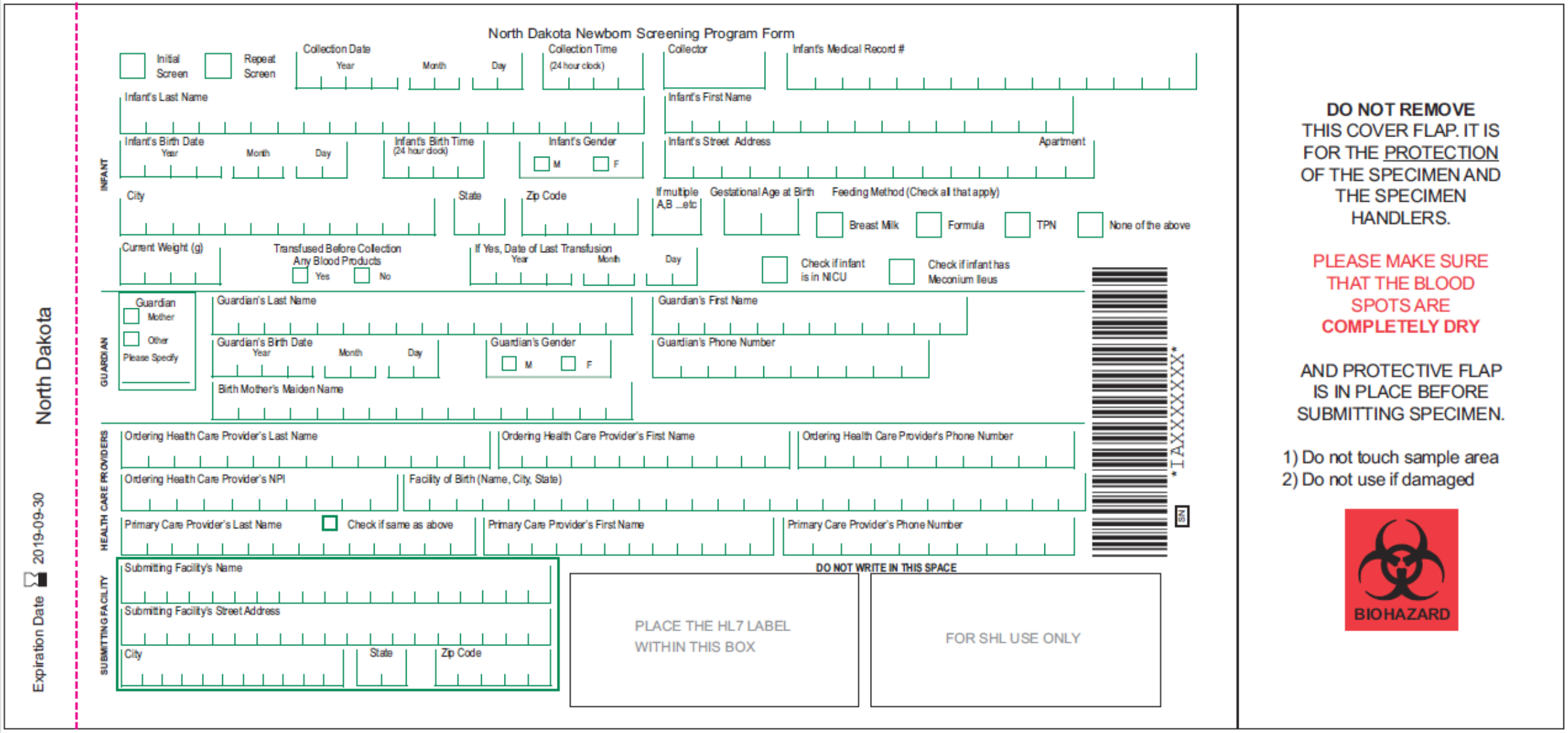
- Early Collection (<24 hrs) affects amino acid and endocrine results = invalid results
  - ***NOTE: even a minute early can cause an invalid result on some testing***
  - ***All*** *early collections need to be repeated after 24 hours*

- If baby is not doing well and needs to be transferred to a hospital, communicate a newborn screening has not been collected
  - *preference is for transferring facility to collect*

- **Communication** is ***Key***

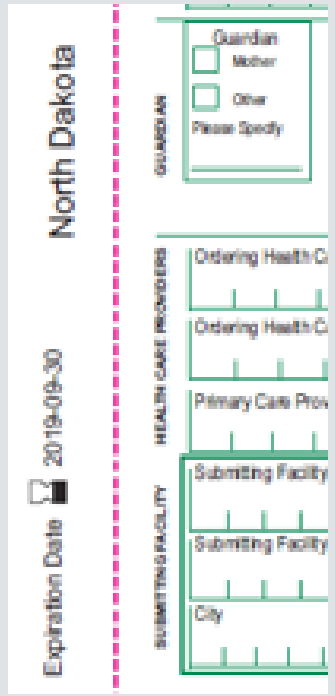


ND Blood Spot Card



Storage of Newborn Screening Dried Blood Spot Forms

- Clean and dry area
- Away from any direct sunlight
- Original wrapping
- Vertical position (avoids compression of the filter paper)
- Check the expiration date – shelf life 3 years



Every time you complete a newborn screening form you hold a baby's life in your hands.

Fill out the form:

- ✓ Accurately
- ✓ Completely
- ✓ Legibly

If the test comes back presumptive positive, the information you provide is essential to locate the baby. It can be a matter of life and death.

It's not just a form – it's a baby

Missing Information on the Form

- Early Collection (EC) or Unknown Information
  - *Birth date or collection date or time missing*
  - *No results for tests affected by EC*
- Unknown weight
  - *Congenital Adrenal Hyperplasia results not reported*
- Transfusion status
  - *Must be marked no, not assumed no if blank*
  - *Transfusions affect results of the following conditions:*
    - Biotinidase
    - Galactosemia
    - Cystic Fibrosis
    - Hemoglobin Disorders
- Gestational Age – need only completed weeks
  - *SCID testing*

Materials Needed for NBS Collection

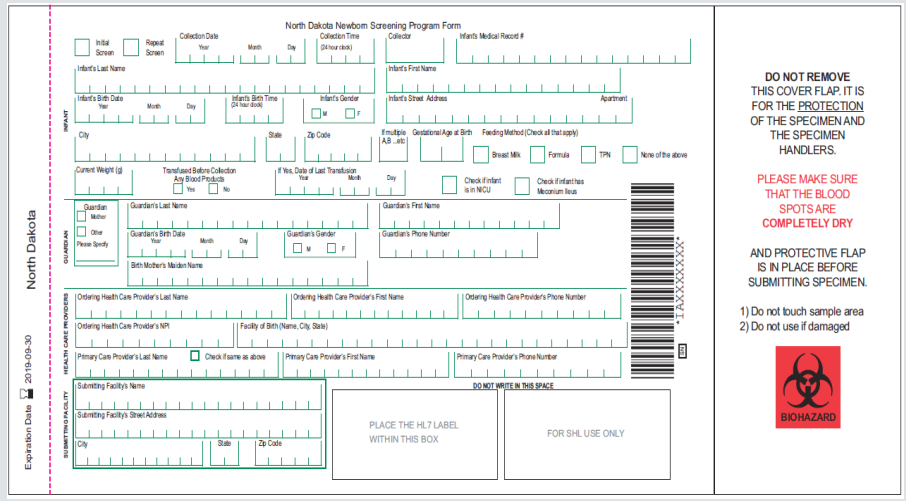
Heel Warmer – may also use warm wash cloth

70% Isopropyl Alcohol

Lancet Device – 1.0 mm deep by 2.5 mm long

Sterile Gauze – 2 X 2

Powder/Latex Free Gloves



Prepare for collection by…

- Confirm infant's identity
- Wash hands
- Wear powder/latex free gloves
- Follow safety precautions when handling and disposing of sharps

Preferred Method of Collection
Heel Stick

- Less invasive than blood draws and contains a mixture of arterial, venous and capillary blood along with interstitial and intracellular fluids from surrounding tissues
- Contains a higher proportion of arterial blood than venous because of the pressure in which the arterial blood enters the capillaries – the skin puncture blood more closely represents arterial blood than a venous puncture
- Venous samples have an increased risk of being contaminated by other substance being infused
  - *Venous blood collection is acceptable if that is the only way to get a sample - not preferred, but acceptable*
  - *NBS reference values have only been validated on blood spots presumed to be from heel sticks and no formal validation on known venous blood*
- Skin puncture blood differs in composition from regular venous blood, reference (normal) values for certain tests will be different for skin puncture blood
- Most notable differences are for glucose, which is higher in skin puncture blood; and total protein, calcium, and potassium, which are lower in skin puncture blood

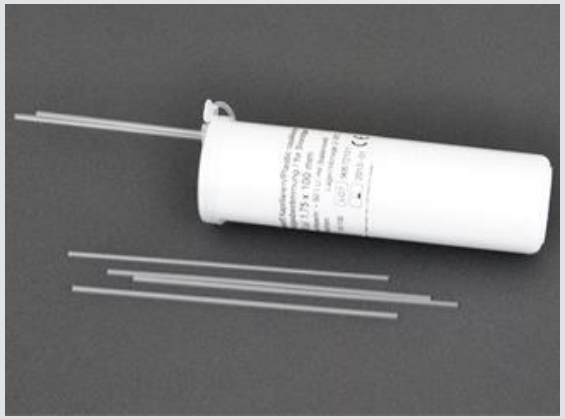
CLSI Guidelines Resources

Capillary Tubes

- Capillary tube collection is acceptable if excellent technique is used and no damage to the filter paper occurs and no clotting occurs – not preferred, but acceptable
  - *Can cause microscopic scratching of the paper if used incorrectly*

- Nothing can touch or scratch the surface of the filter paper
  - *the filter paper is considered a medical device that is calibrated to have certain concentrations of the analytes that are tested for in a punched disk from that filter paper*

- Increases the risk of clotted or layered specimens

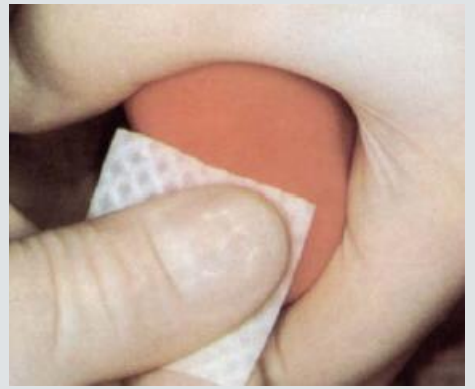


Site Preparation

- Warm the newborn's heel by using:
  - Heel warming device or soft cloth moistened with warm water up to 106˚F/41˚C for three to five minutes
  - *Never* use a microwave to warm a wash cloth – may cause severe burns

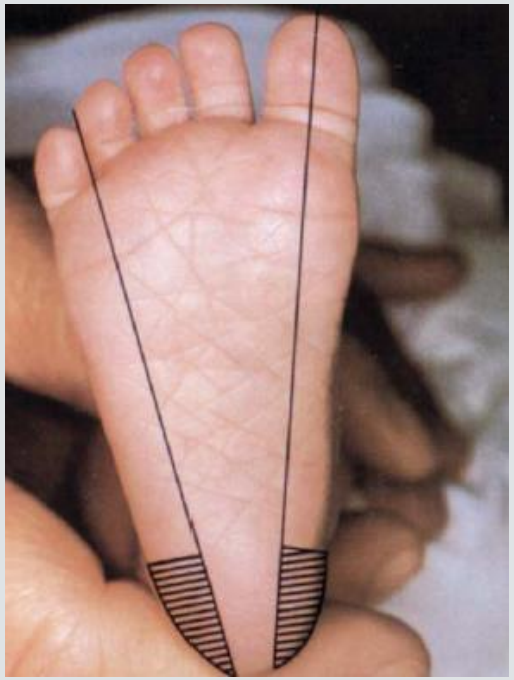
How to Position Baby

- Offer mother to breastfeed baby or encourage a parent to hold baby during the collection to keep them more comfortable
- Swaddle baby in a blanket leaving one leg out
- Infant's leg should be lower than the heart
- Increases venous pressure
- Wipe heel with 70% isopropyl alcohol
- Air dry
  - ***Note:*** *Let the alcohol dry* ***completely*** *before puncturing heel and applying blood to the filter paper otherwise specimen may become contaminated or diluted like image to right*



Contaminated/Diluted Specimen

Puncture and Collection Site



- Puncture in shaded area are safe
- Plantar surface of the heel
- Use sterile lancet - no scalpel blades or needles
- 1.0 mm deep by 2.5 mm long

Direct Application

- Wipe away first drop of blood with sterile gauze
- Allow a ***large*** drop to form (50-75 µL)
  - *If you are unable to obtain a large drop you may intermittently apply gentle pressure to the heel, but no excessive "milking" or squeezing*
- Touch paper to blood ***ONCE*** and let soak through
- Apply ***ONE*** drop on each circle to only ***ONE SIDE*** *of filter paper*
- Continue and fill ***ALL*** circles
- Do ***NOT*** touch the heel directly to the filter paper

Take care of puncture site

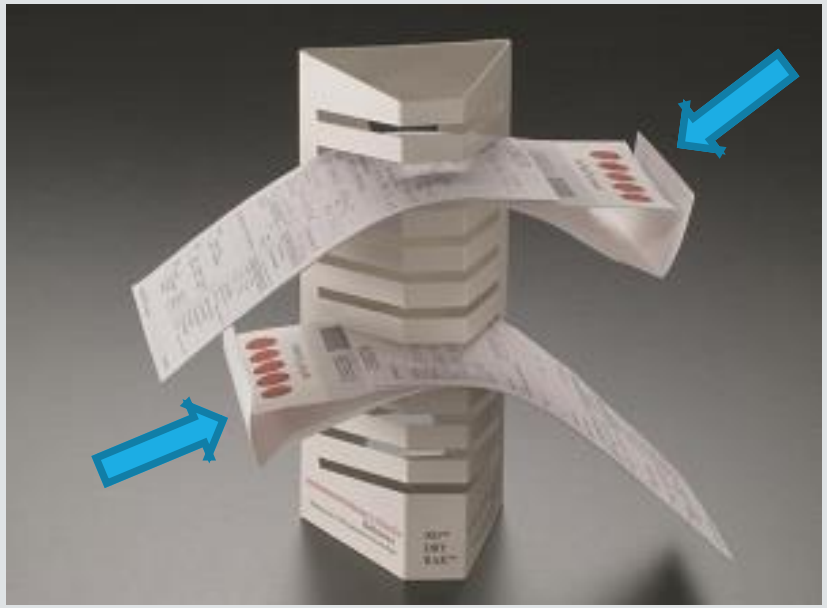
- Elevate foot above the body
- Hold gentle pressure with sterile gauze on puncture site until bleeding stops
- Do not apply bandages that may damage baby’s delicate skin

Quality Assurance

- Examine Blood Collection – take time to look at the specimen and determine if it is a good quality
- Verify blood has soaked through *both* sides of the filter paper
  - *If blood did not soak through – recollect on another card*
- Do ***not*** re-apply to same circle – this will cause layered or clotted specimen
- Blood can be applied outside of the circles if needed
  - *Blood still needs to be the same size of the circles*
- If specimen is not of good quality, recollect on another card at that time

Air Drying Specimens

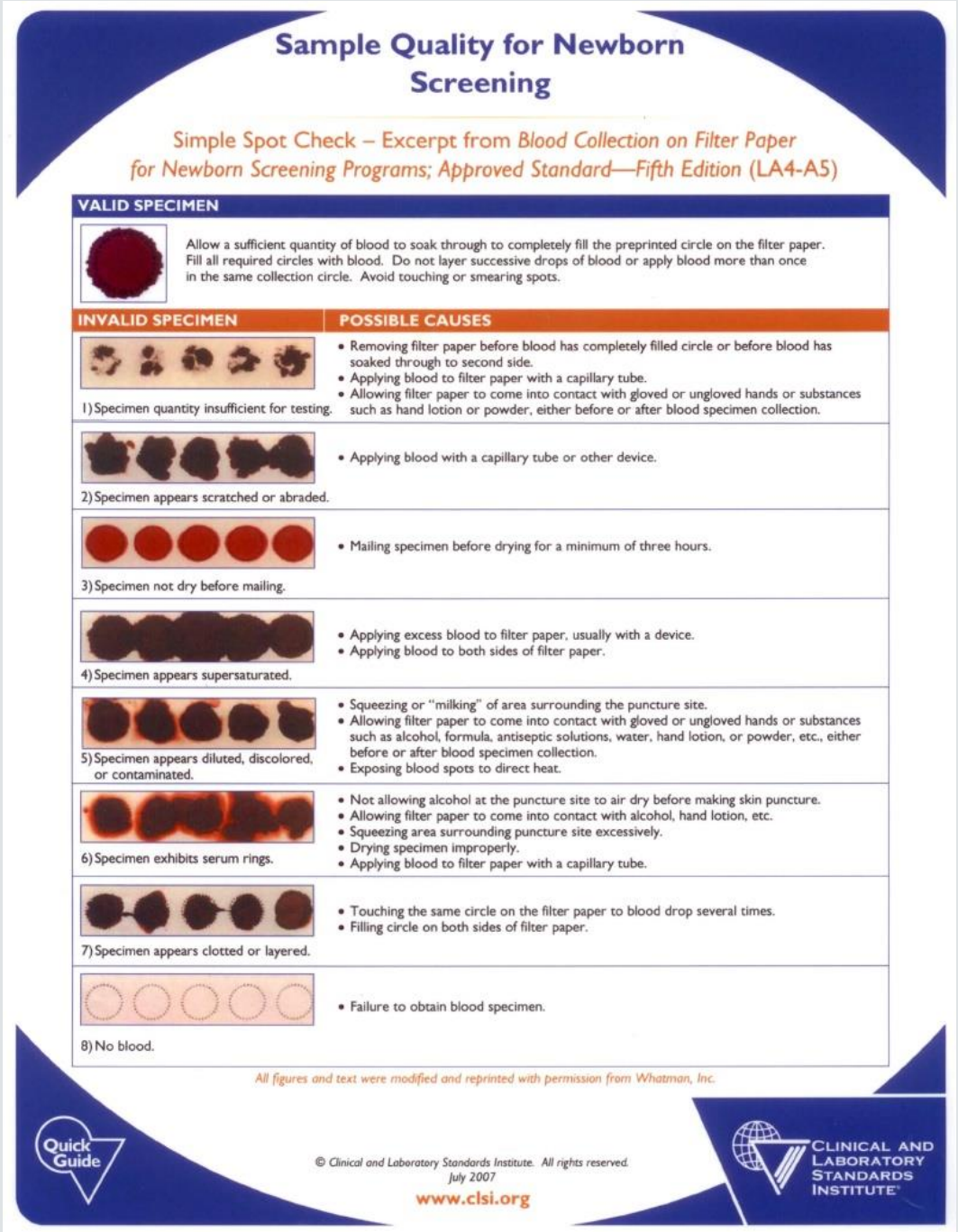
- Do not touch other blood spots
- Keep away from direct heat and humidity
- No direct sunlight
- Do not store specimens in vehicles – hot/cold/humidity can affect results
- Horizontal – actual blood spots
- Elevate off surface– the card can absorb anything on the countertops
- Dry at least ***3 hours*** at room temperature before placing in envelope
- To avoid contamination of the filter paper – wear gloves and make sure the flap is closed



Use this instead! We have drying racks on hand if you need some!

CLSI Spot Check Card

- Excellent resource
- Display for your staff to allow them to compare the quality of their specimen
- This visual can help keep poor quality specimens to a minimal
- We have spot check cards on hand!



Sample Quality for Newborn Screening

Simple Spot Check – Excerpt from *Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard—Fifth Edition (LA4-A5)*

VALID SPECIMEN

Allow a sufficient quantity of blood to soak through to completely fill the preprinted circle on the filter paper. Fill all required circles with blood. Do not layer successive drops of blood or apply blood more than once in the same collection circle. Avoid touching or smearing spots.

INVALID SPECIMEN	POSSIBLE CAUSES
1) Specimen quantity insufficient for testing.	• Removing filter paper before blood has completely filled circle or before blood has soaked through to second side. • Applying blood to filter paper with a capillary tube. • Allowing filter paper to come into contact with gloved or ungloved hands or substances such as hand lotion or powder, either before or after blood specimen collection.
2) Specimen appears scratched or abraded.	• Applying blood with a capillary tube or other device.
3) Specimen not dry before mailing.	• Mailing specimen before drying for a minimum of three hours.
4) Specimen appears supersaturated.	• Applying excess blood to filter paper, usually with a device. • Applying blood to both sides of filter paper.
5) Specimen appears diluted, discolored, or contaminated.	• Squeezing or "milking" of area surrounding the puncture site. • Allowing filter paper to come into contact with gloved or ungloved hands or substances such as alcohol, formula, antiseptic solutions, water, hand lotion, or powder, etc., either before or after blood specimen collection. • Exposing blood spots to direct heat.
6) Specimen exhibits serum rings.	• Not allowing alcohol at the puncture site to air dry before making skin puncture. • Allowing filter paper to come into contact with alcohol, hand lotion, etc. • Squeezing area surrounding puncture site excessively. • Drying specimen improperly. • Applying blood to filter paper with a capillary tube.
7) Specimen appears clotted or layered.	• Touching the same circle on the filter paper to blood drop several times. • Filling circle on both sides of filter paper.
8) No blood.	• Failure to obtain blood specimen.

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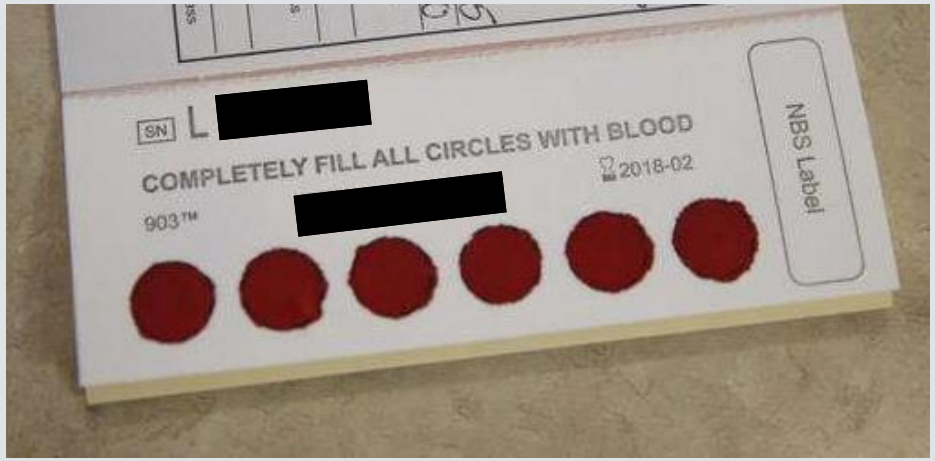
Quick Guide

July 2007
www.clsi.org

CLINICAL AND LABORATORY STANDARDS INSTITUTE

Good Quality Specimen

- After collection, determine whether or not the specimen is acceptable
- Double check quality of your specimen once dried
- If unacceptable, recollect at that time on a new filter paper



Poor Quality Specimen ⟹ Recollection

Collecting a good quality specimen the first time reduces the chance of having to recollect

Endocrine disorders

Greta's story

Our daughter, Greta, was born with congenital hypothyroidism, which was first detected by her newborn screen. I can't possibly put into words what it means to us that she will be given the best possible chance of growing up strong and healthy.

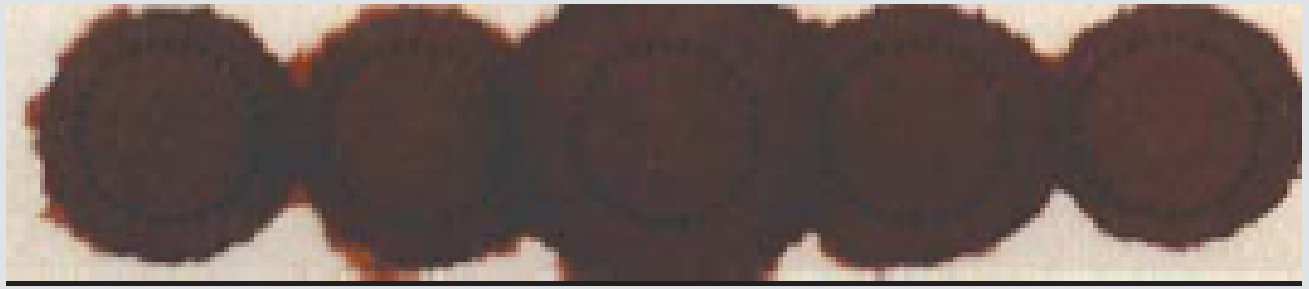
Read Greta's full story.

Credits:
Minnesota Department of Health
http://www.health.state.mn.us/divs/phl/newborn/families/stories/greta.html

My specimen was rejected… Why?

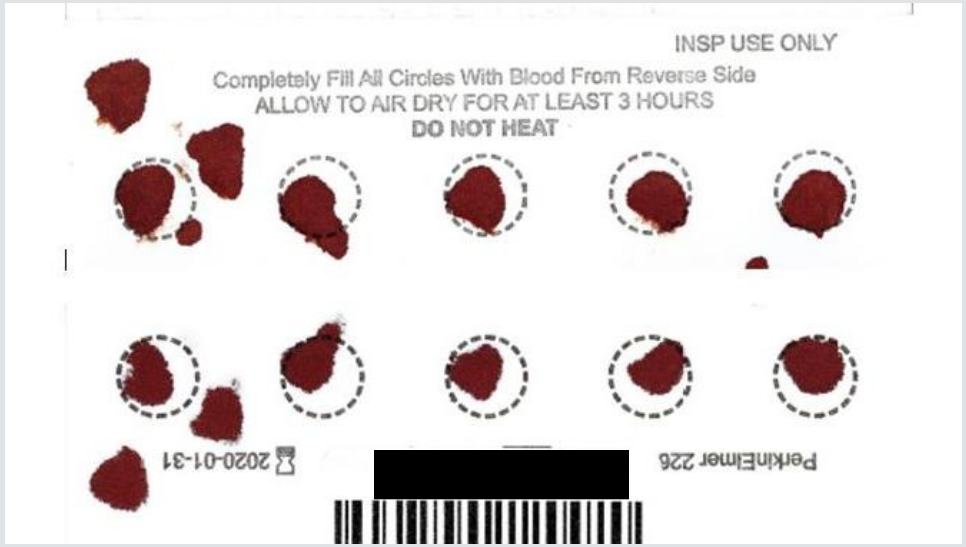
- The laboratory will reject a sample if it is poor quality
  - *Insufficient amount of blood*
  - *Contaminated sample*
  - *Blood didn't soak through filter paper*
  - *Layered/clotted specimen*
  - *Serum separation*
  - *Expired collection form*
  - *Paper scratched (capillary tube?)*
- All samples are tested even if rejected
- Facilities designate personnel to receive an image of every poor quality specimen
  - *Why? To provide timely education to staff to ultimately decrease time that it may take to save or positively impact a baby's life*

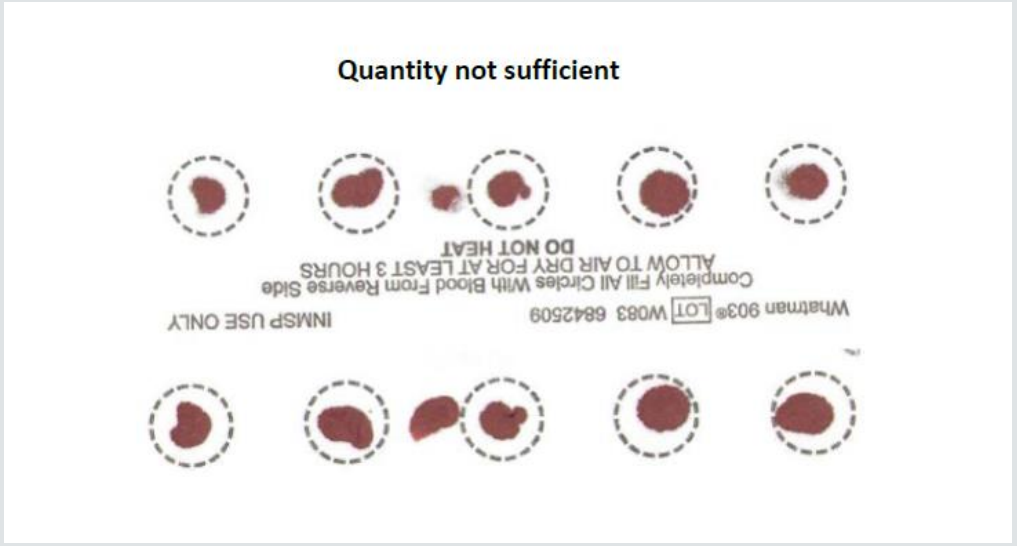
Oversaturation



Insufficient blood

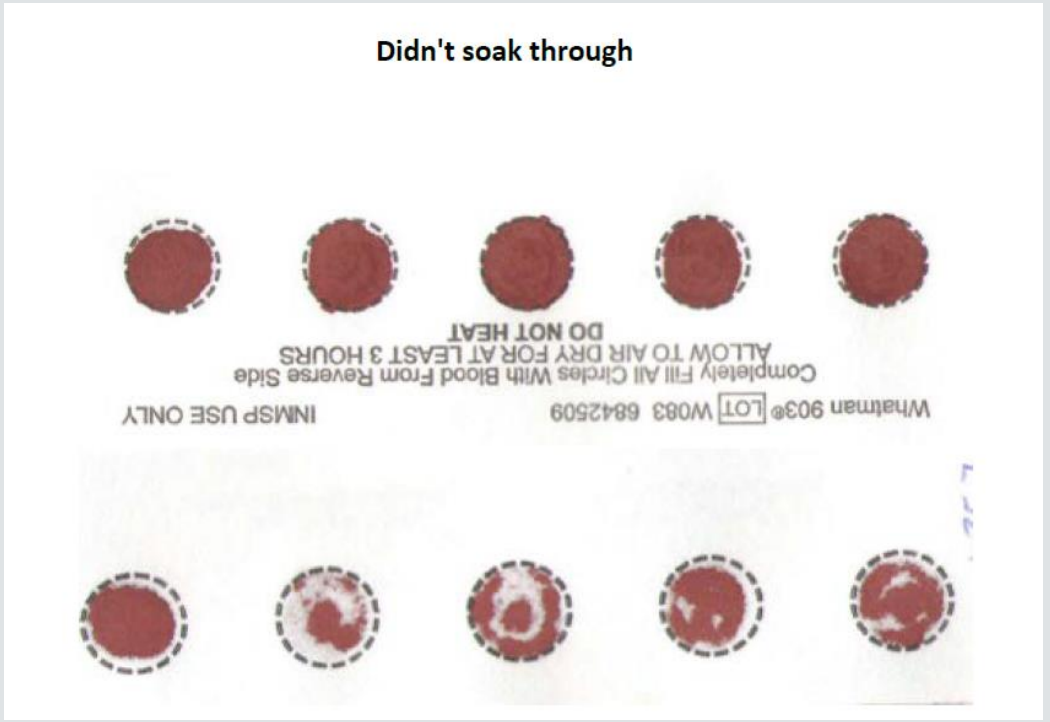
- Applying drops that are too small
- Removing filter paper before blood has soaked through to the other side

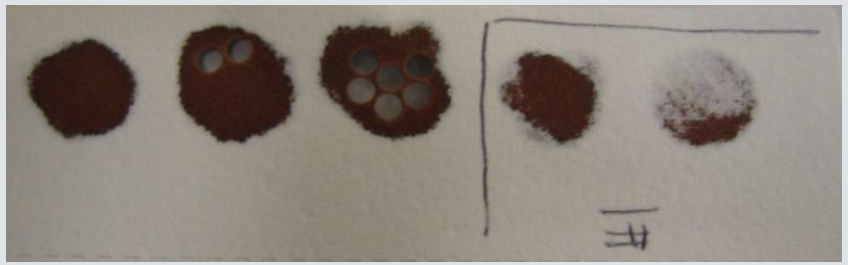




Uneven saturation

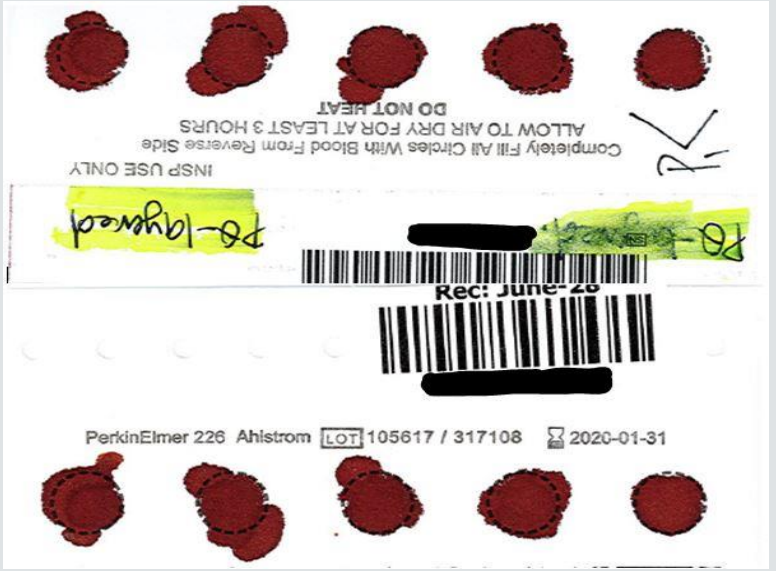
- Insufficient quantity so blood did not soak through
- Spreading the blood drop over the surface of the circle, contributing to uneven absorption.
- Improperly applying blood to the filter paper with a device.

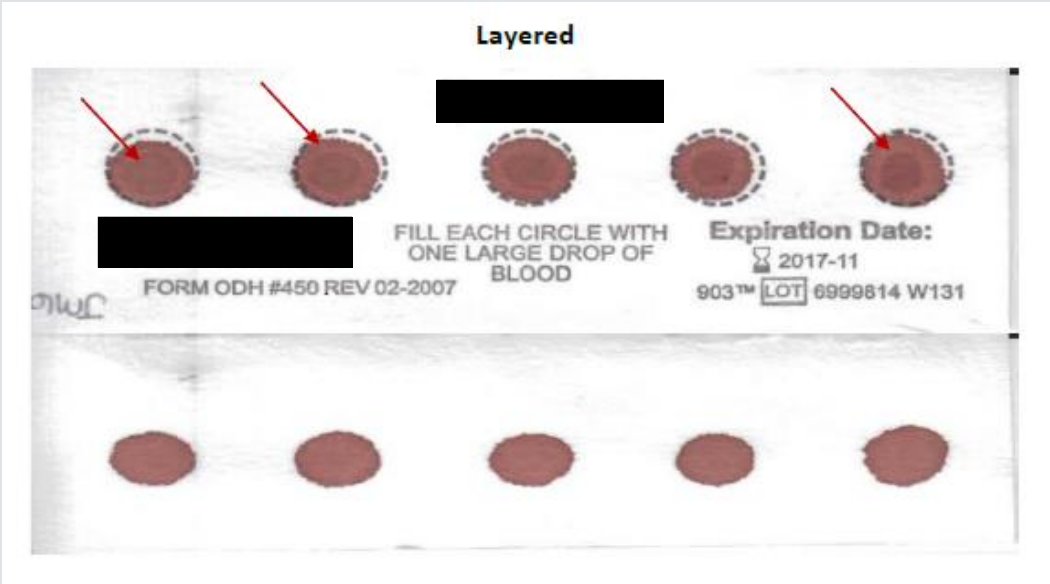




Layering

- Multiple drops added to each circle
- Non-uniform concentrations
- Analyte concentrations are not consistent





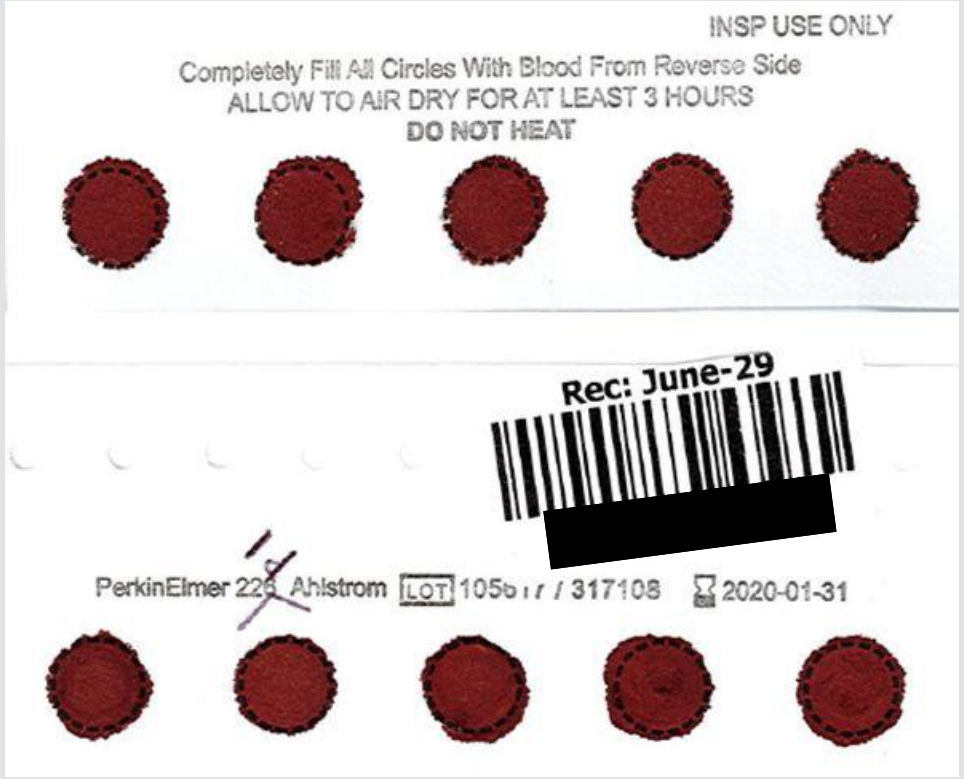
Contamination or dilution

- Alcohol not dried on baby's heel
  - *Other fluid/substances*
- Substances on bench top
- Not always this noticeable
- May affect analysis

Blood didn’t soak through

Make sure to check the blood has soaked through on both sides

Clotted Specimens

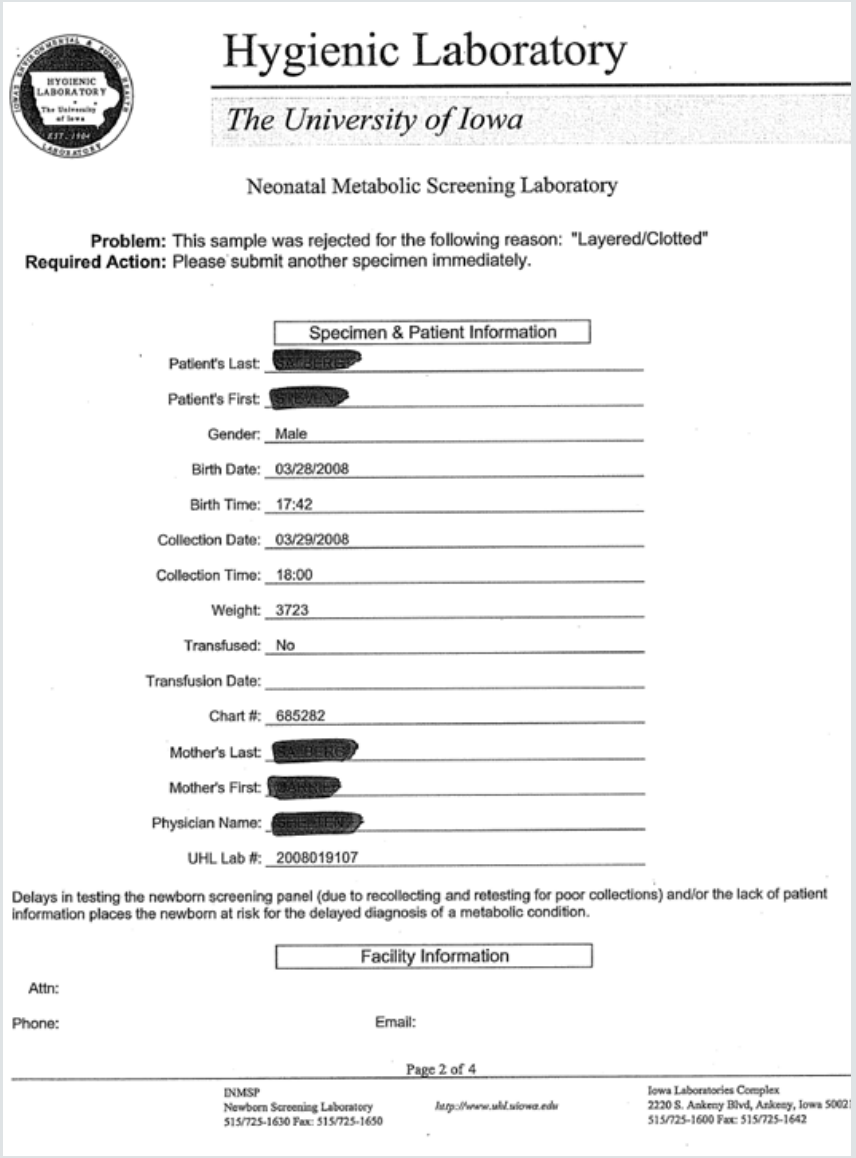


Serum separation

- Serum rings
  - *Squeezing or milking the heel causes hemolysis*
  - *RBCs have settled in capillary tube*
  - *Use gentle pressure to avoid this*

Quality Assurance

- Daily fax sent from lab to collectors for missing information or poor quality specimens
- Must be a secure fax line
- Complete necessary information and fax back immediately



Hygienic Laboratory

The University of Iowa

Neonatal Metabolic Screening Laboratory

Problem: This sample was rejected for the following reason: "Layered/Clotted"
Required Action: Please submit another specimen immediately.

Specimen & Patient Information

Patient's Last: [redacted]
Patient's First: [redacted]
Gender: Male
Birth Date: 03/28/2008
Birth Time: 17:42
Collection Date: 03/29/2008
Collection Time: 18:00
Weight: 3723
Transfused: No
Transfusion Date:
Chart #: 685282
Mother's Last: [redacted]
Mother's First: [redacted]
Physician Name: [redacted]
UHL Lab #: 2008019107

Delays in testing the newborn screening panel (due to recollecting and retesting for poor collections) and/or the lack of patient information places the newborn at risk for the delayed diagnosis of a metabolic condition.

Facility Information

Attn:
Phone: Email:

Page 2 of 4

INMSP
Newborn Screening Laboratory
515/725-1630 Fax: 515/725-1650
http://www.uhl.uiowa.edu
Iowa Laboratories Complex
2220 S. Ankeny Blvd, Ankeny, Iowa 5002
515/725-1600 Fax: 515/725-1642

Reminder – Newborn ***Screening*** Test

- Not a diagnostic test
  - *Abnormal results always need confirmatory testing*
  - *Important to follow the recommendations given by follow-up staff to confirm diagnosis*
- There may be false positives/false negatives
  - *Continuous quality improvement to decrease false positives and false negatives*
- Continuously improving and evolving practice and testing

What?... It's a *screening* test?!?

Sending Specimens to the Lab

- Send specimens with a shipping manifest to ensure the lab receives all specimens that are sent

- Birthing facilities use a courier service for specimen transport to the lab – at no cost to the facilities
  - *Meadowlark Logistics LLC – https://www.meadowlarklogistics.net/contact-us.html*
    - David Lawson – 701.361.7666 or David.Lawson@MeadowlarkLogistics.net

- ***Never*** place a specimen in the regular USPS mail – this may delay testing by 5-7 days

Courier Services for NBS

- Iowa coordinates the courier via contract with Meadowlark
- Courier transports initial and repeat specimens
- *Weekdays* – Monday through Friday – every birthing facility and select clinics in ND have courier services available (scheduled or on call)
  - *Contact your lab send outs for your specific time. Most pick ups are around 1500.*
- *Saturdays* – 7 birthing facilities have a scheduled Saturday pick up and many clinics have on call services for earlier in the day
- *Sundays* – currently no courier services available for any facilities
  - *Working to expand this*

Every baby deserves the same opportunity for a healthy life regardless of which day they are born

Newborn Screening Results

Normal Results

- PCP will notify parents at the first well child visit (should be within the first few weeks of life)
  - ***Educate parents to ask about results***
    - No news is not always good news
- Facilities may access State Hygienic Laboratory web portal for results.
- Most facilities are still receiving paper results

Out of Range (Abnormal) Results

- Borderline/Presumptive Positive Results
  - *Reported to Health Care Provider listed on the card*
- Lab notifies short-term follow-up of abnormal results
- Short-term follow-up contacts PCP typically in less than an hour and they inform them of recommendations for confirmatory testing. A fax is also sent to provider with written information on the possible disorder.
- Recommendations vary depending on severity of each disorder:
  - *Repeat screening*
  - *Diagnostic/confirmatory testing*
  - *Examine baby urgently (ER or office)*
  - *Hospitalization locally or transfer to a tertiary health facility may be necessary*

Follow-up on baby with possible or confirmed disorder

- Staff from Special Health Services contacts family a few weeks after testing
  - *Offers support services and resources:*
    - Family to Family Partnerships
    - Family Voices
    - Financial assistance for confirmatory testing

- If baby has a confirmed disorder
  - *Additional services may be available that are **not** income based*

- For additional information on available services and resources visit: http://www.ndhealth.gov/cshs/ or call 701.328.2436

Newborn Screening Report

State Hygienic Laboratory

The University of Iowa

NURSERY SUPERVISOR	For Questions About Resubmission and Result Interpretation Contact Medical Consultants
	For Questions about resubmission and results, referrals, and newborn screening procedures, contact the North Dakota Health Department, Joyal Meyer 701-328-4534.

Newborn Screening Report

Patient		Birth Date	
Chart Number		Date Collected	
Mother's Name		Date Received	
Physician		Early Collection	
Laboratory No.		Transfused	
Test		Weight at Collection	
Date Reported		Gender	

Disorder	Substance(s) Measured	Result Interpretation
Congenital Adrenal Hyperplasia	17-Hydroxy Progesterone	Within Normal Limits
Hypothyroidism	Thyroid Stimulating Hormone	Within Normal Limits
Biotinidase Deficiency	Biotinidase	Within Normal Limits
Galactosemia	Gal-1-Phosphate Uridyl Transferase	Within Normal Limits
Hemoglobinopathies	Hemoglobin Phenotype	Within Normal Limits
Cystic Fibrosis	Immunoreactive Trypsinogen	Within Normal Limits
Expanded Screening Disorders	Amino Acids and Acylcarnitines	Within Normal Limits
Severe Combined Immunodeficiency	T-Cell Receptor Excision Circle	Within Normal Limits

Expanded Screening Disorders: Analytes Screened: Analytes refer to amino acids: (ARG) Arginine, (ASA) Argininosuccinic Acid, (CIT) Citrulline, (LEU) Leucine, (MAA) Multiple Amino Acids, (MET) Methionine, (PHE) Phenylalanine, (SA) Succinylacetone, (TYR) Tyrosine, (VAL) Valine and acylcarnitines: LOW C0, HI C0, C3, C3-DC, C4, C4-DC, C4-OH, C5, C5:1, C5-DC, C5-OH, C6, C6-DC, C8, C10, C10:1, C14, C14:1, C16, C16-OH, C16-OH/C16, C16:1-OH, C0/C16, C18:1, C18-OH, C18:1-OH, (MAC) multiple acylcarnitines.

This is a screening test and not indicated for stand-alone purposes; results should be used in conjunction with other available laboratory and clinical information. A false negative or a false positive result must always be considered when screening; therefore, clinical findings and status should be considered whenever interpreting laboratory results. Newborn reference values may not be applicable to older infants, thus screening results should be interpreted with caution in such cases. Disorder information is available in the Practitioners' Manual at www.idph.state.ia.us/genetics.

INMSP
Newborn Screening Laboratory
515/725-1630 Fax: 515/725-1650

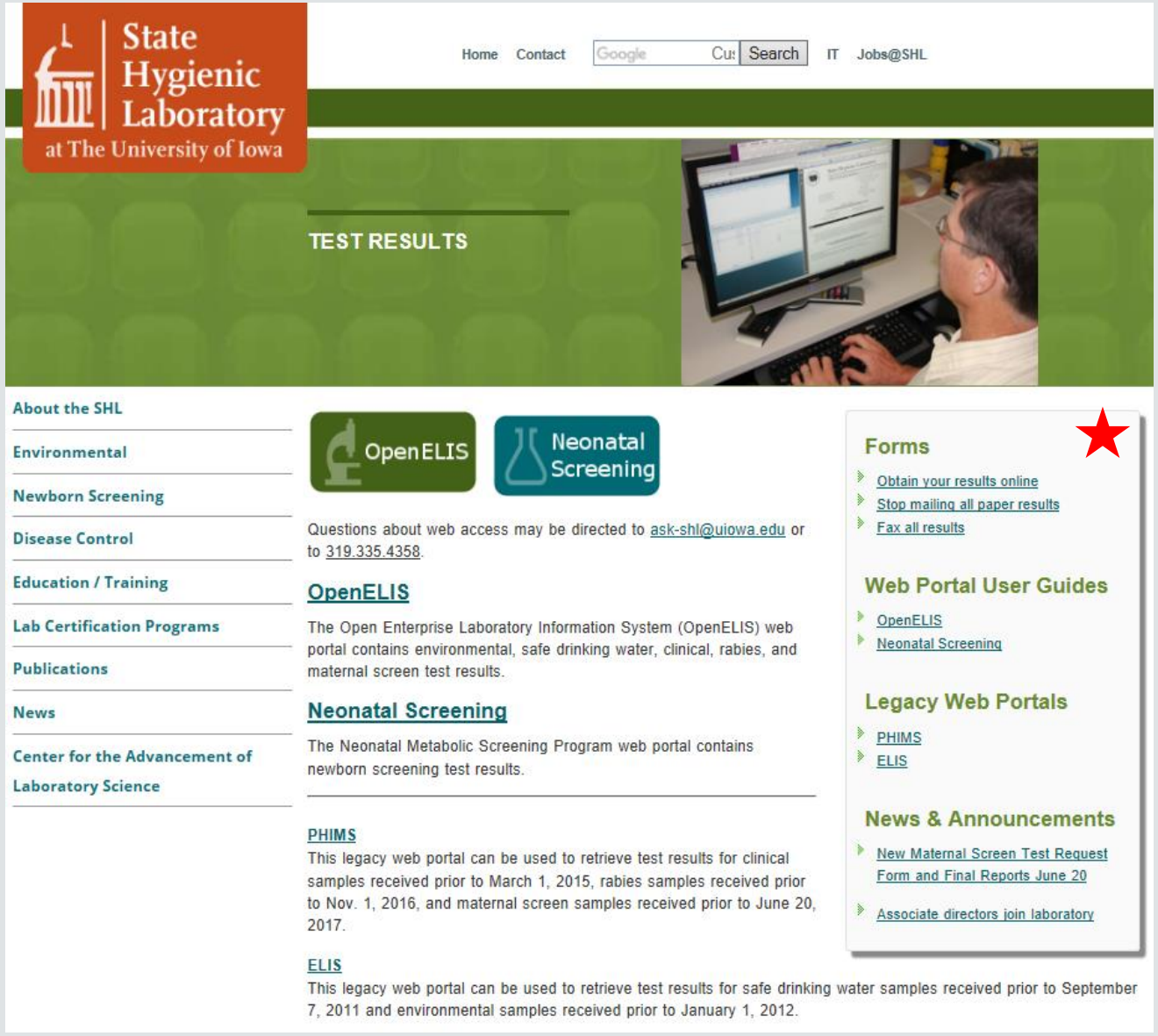
http://www.shl.uiowa.edu

Iowa Laboratories Complex
2220 S. Ankeny Blvd, Ankeny, Iowa 50021
515/725-1600 Fax: 515/725-1642

State Hygienic Laboratory (SHL) Database

Advantages of Database Web Access

- Download and print patient results
- Patient look-up online
- NBS reports available as soon as released by lab
- Reports available for your facility
  - *Quality control*
  - *Turnaround Statistics (ie. birth to collection, birth to reported etc.)*
  - *Facility Summary*
  - *Facility QA*
- Track unsatisfactory specimens back to collector
- www.shl.uiowa.edu



SHL Database Web Access

- Request permission for web access through your facility and complete this form
  - *http://www.shl.uiowa.edu/kitsquotesforms/webaccessformfillable.pdf*
- Send request to the State Hygienic Laboratory – contact info is on the request form
- Once approved, you will be given a unique user id and password
- Training via phone from Iowa IT on how to use web access (approximately 10 minutes)
- Login to access database:
  - *www.shl.uiowa.edu*

Critical Congenital Heart Defect Screening

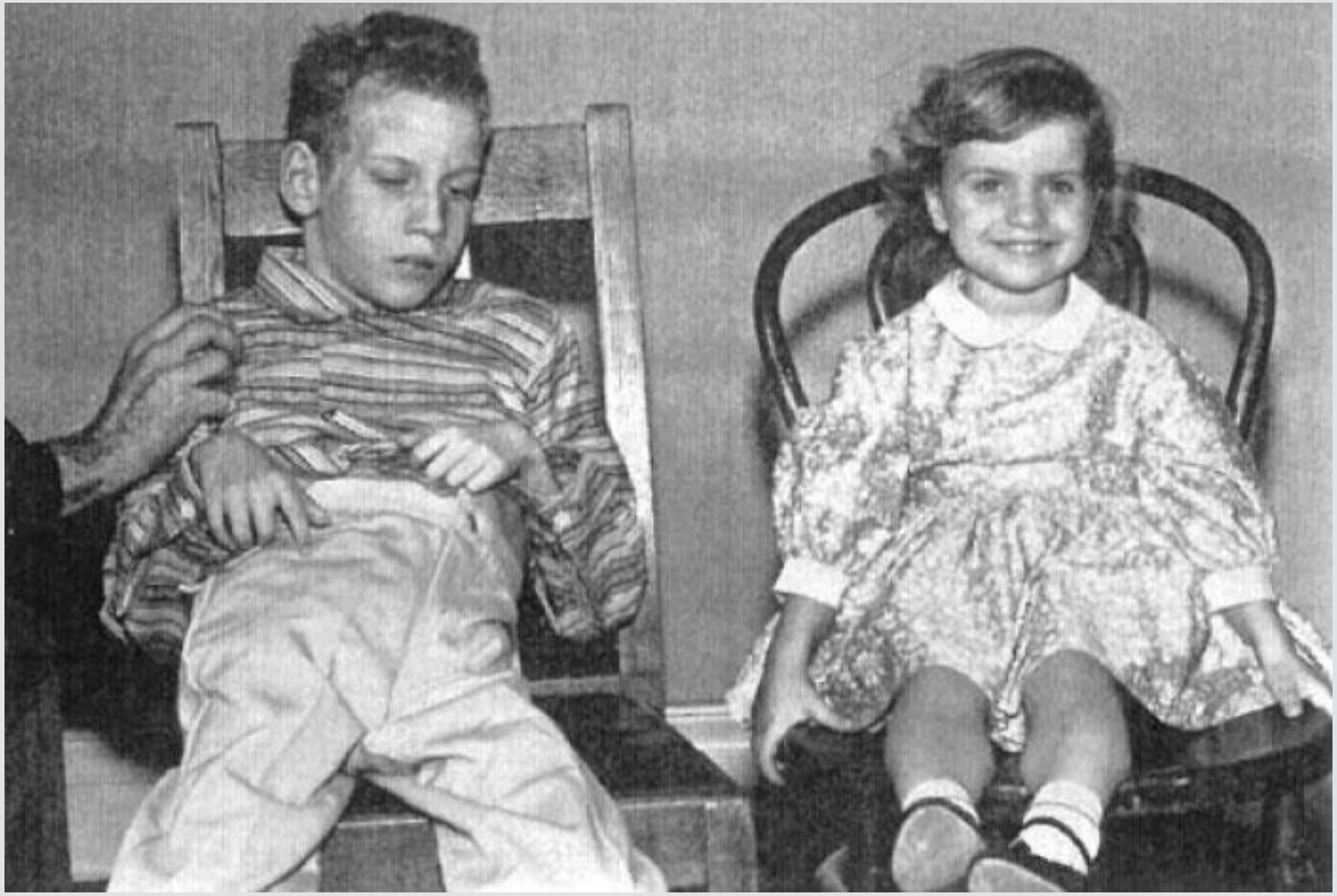
- Before Discharge all babies born in a ND birthing facility must receive CCHD screening , parents may object the screening

- Chapter 25-17-06. Pulse oximetry screening for critical congenital heart defects - Exception.

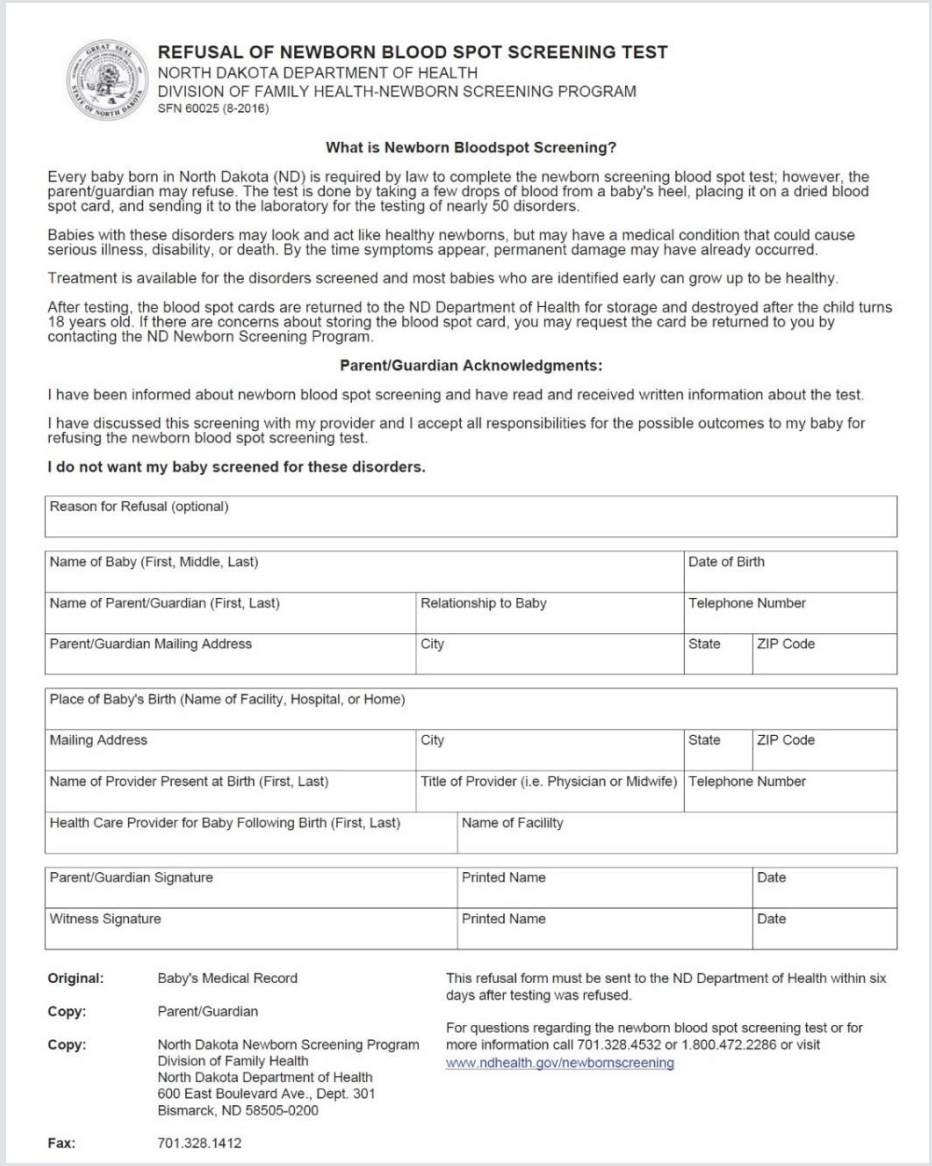
- Resources for CCHD Screening:
  - *Baby's First Test*
  - *American Academy of Pediatrics*
  - *Centers for Disease Control*
  - *American Heart Association*

- CCHD Protocol & Algorithm are currently under review by pediatric cardiologist
  - *Recommend to use protocol and algorithm that was provided when the mandate occurred in 2013 until the new drafts are approved*

PKU Before Newborn Screening



Newborn Screening Refusals



REFUSAL OF NEWBORN BLOOD SPOT SCREENING TEST
NORTH DAKOTA DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH-NEWBORN SCREENING PROGRAM
SFN 60025 (8-2016)

What is Newborn Bloodspot Screening?

Every baby born in North Dakota (ND) is required by law to complete the newborn screening blood spot test; however, the parent/guardian may refuse. The test is done by taking a few drops of blood from a baby's heel, placing it on a dried blood spot card, and sending it to the laboratory for the testing of nearly 50 disorders.

Babies with these disorders may look and act like healthy newborns, but may have a medical condition that could cause serious illness, disability, or death. By the time symptoms appear, permanent damage may have already occurred.

Treatment is available for the disorders screened and most babies who are identified early can grow up to be healthy.

After testing, the blood spot cards are returned to the ND Department of Health for storage and destroyed after the child turns 18 years old. If there are concerns about storing the blood spot card, you may request the card be returned to you by contacting the ND Newborn Screening Program.

Parent/Guardian Acknowledgments:

I have been informed about newborn blood spot screening and have read and received written information about the test.

I have discussed this screening with my provider and I accept all responsibilities for the possible outcomes to my baby for refusing the newborn blood spot screening test.

I do not want my baby screened for these disorders.

Reason for Refusal (optional)			
Name of Baby (First, Middle, Last)		Date of Birth	
Name of Parent/Guardian (First, Last)	Relationship to Baby	Telephone Number	
Parent/Guardian Mailing Address	City	State	ZIP Code
Place of Baby's Birth (Name of Facility, Hospital, or Home)			
Mailing Address	City	State	ZIP Code
Name of Provider Present at Birth (First, Last)	Title of Provider (i.e. Physician or Midwife)	Telephone Number	
Health Care Provider for Baby Following Birth (First, Last)	Name of Facility		
Parent/Guardian Signature	Printed Name	Date	
Witness Signature	Printed Name	Date	

Original: Baby's Medical Record

Copy: Parent/Guardian

Copy: North Dakota Newborn Screening Program
Division of Family Health
North Dakota Department of Health
600 East Boulevard Ave., Dept. 301
Bismarck, ND 58505-0200

Fax: 701.328.1412

This refusal form must be sent to the ND Department of Health within six days after testing was refused.

For questions regarding the newborn blood spot screening test or for more information call 701.328.4532 or 1.800.472.2286 or visit www.ndhealth.gov/newbornscreening

- Refusal form is available on the website
- Newborn screening is required by law in all 50 states; however, parents can object to testing
- "Written information" *must* be provided to the family before they can refuse
- Refusal form must completed, signed, and returned to the program within 6 days of refusing testing
- What are some reasons as to why some of your families refuse newborn screening?
- What can we do to help them understand the importance of testing and decrease home birth refusals?

Top 10 Things Parents Need to Know About NBS

1. Testing is required
2. Newborn screening saves lives
3. Babies with disorders may look healthy at birth
4. These disorders are not very common, happens in families with no history of diseases
5. Treatment is available for ALL the disorders screened
6. Just a few drops of blood
7. Dried blood spot card may be returned to parents
8. Discuss results with your health care provider
9. Retesting
10. Storage

Newborn Screening Family Stories: Evan's Story

Eighteen years ago, when I was only three days old, I became very sick. I couldn't communicate my problems beyond my cries, I did not have a voice of my own, so my parents did not know what was going on. My parents did not know the severity of my sickness. In the afternoon, my parents received a call from the hospital explaining that the reason for my sickness was my metabolic disorder called Galactosemia. Newborn screening caught me at just three days old to keep me healthy enough to live a normal life. Newborn screening acted as the voice that I didn't have at such a young age.

When I think back to that story of being diagnosed, I always wonder what would have happened if newborn screening did not catch that I have Galactosemia. I can imagine how hard it is for parents to deal with not knowing the problem that their child is facing. With all newborn babies it is hard to tell what is going on. The communication that these babies use is so limited that it is very possible to confuse the meaning of the cries that these babies use. For example my parents could have easily mistaken my cries and my sickness from my first three days as a sign that I needed more milk which would have likely resulted in death or in other harmful consequences. Luckily for me newborn screening saved my life and it saved my family from going through a difficult situation of losing their first born child.

Because of newborn screening I have a promising future ahead of me. I have made plans for next year to attend Marquette University. Newborn screening saves lives and families.

Credits:
Minnesota Department of Health
http://www.health.state.mn.us/divs/phl/newborn/families/stories/evan.html


find us on facebook
A BABY'S FIRST TEST -
THE ANSWERS MIGHT
SAVE A LIFE
Newborn Screening
is a test done before you leave the hospital using a few drops of blood from your baby's heel to screen for certain rare, but serious disorders. Babies with these disorders may look and act like healthy newborns, but may have a medical condition that could cause disability or even death. Most babies with these conditions who are identified within the first few days of life can receive treatment and grow up to be healthy and have normal development.
Ask your health care provider about newborn screening.
North Dakota
Newborn Screening Program
NORTH DAKOTA DEPARTMENT of HEALTH
OTW©2015

Contact Information

Mike Ramirez, Lab Supervisor, Iowa Laboratory

515.725.1630

Order supplies (DBS forms & drying racks)

515.725.1630

Questions on Specimen Transport – Ashley Comer

515.725.1630 or ashley-comer@uiowa.edu

Iowa State Hygienic Laboratory Database Issues (web access)

319.335.4358

University of Iowa Children's Hospital (patient short-term follow-up)

866.890.5965

Joyal Meyer, Newborn Screening Program Director, ND Department of Health

701.328.4534 or jbmeyer@nd.gov

Amy Burke, Newborn Screening Nurse Consultant, ND Department of Health

701.328.2784 or arburke@nd.gov

Kelsie Morris, Newborn Screening Administrative Assistant, ND Department of Health

701.328.4532 or kelsiemorris@nd.gov

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701.328.4534

Amy Burke, RN, BSN

Nurse Consultant & Long-term Follow-up
for ND Newborn Screening

arburke@nd.gov

701.328.2784

Follow ND Newborn Screening on Facebook and Instagram

Birth Certificate Worksheet Update

POTENTIAL RISK FACTORS

For Mother

Young Mother: Many factors make pregnancy more complicated for the young mother (under 19 years of age). Her physical and emotional development is incomplete and her support systems may be limited. Early, thorough prenatal care is the most critical factor for reducing risks in a young mother and her newborn.

Health Care (Doctor Visits) Started Late in Pregnancy: Lack of early and consistent prenatal care has been associated with prematurity, low-birth weight, and difficulties with pregnancy, labor and delivery.

Baby's Mother Diabetic Before or During Pregnancy: Poorly controlled diabetes before and during pregnancy increases the risk that the unborn child develops serious birth defects. Infants born to mothers with high blood sugars are more likely to be larger than normal causing birth trauma during delivery. These infants are also more likely to develop low blood sugar after birth. The diabetic mother is also at greater risk of high blood pressure and birth trauma due to excessive fetal growth. In addition, women with gestational diabetes and their children are at greater risk of developing diabetes later in life.

Use of Tobacco by Mother During Pregnancy: Use of tobacco during pregnancy has shown a greater likelihood of spontaneous abortions, tearing of the placenta, premature rupture of membranes, pre-term delivery, lower birth weight, respiratory distress, heart abnormalities and developmental delays. Infants exposed to second hand smoke are more likely to be hospitalized for pneumonia and bronchitis.

Use of Alcohol by Mother During Pregnancy: When mothers use alcohol during pregnancy, the baby can potentially develop Fetal Alcohol Syndrome (FAS). The major characteristics of FAS include: facial deformities, mental retardation, small head and body size, malformed organs and learning and behavioral difficulties. To be completely safe, no alcohol should be consumed during pregnancy.

Use of Illegal Drugs by Mother During Pregnancy: Taking illegal drugs during pregnancy increases a mother's risk for miscarriage, premature labor, anemia, infectious diseases and possible death. Almost every drug passes from the mother's bloodstream through the placenta to the baby. Babies that have been exposed to illegal drugs may be born too small or have withdrawal symptoms, birth defects, or learning and behavior problems.

R: 8-06

For Child

Baby's Weight Less Than 5.5 Pounds at Birth: Babies who are below the expected range of weight for gestational age may have growth delays because of intrauterine infection, maternal disease such as high blood pressure, maternal smoking, genetic disorders or other factors. Some growth delayed infants, whose poor growth is confined to weight, may recover. Those with poor growth parameters in head circumference and length, may have suffered permanent injury to the central nervous system.

Early Delivery of Baby or Prematurity: Prematurity is closely associated with low birth weight. With current technological advances and high quality neonatal intensive care, the larger premature infants often suffer few, if any, medical complications. The smaller and more premature an infant is, the greater the likelihood of further developmental abnormalities.

Twins, Triplets or Multiple Birth: During prenatal development, multiple-fetuses share a common environment and nutrient supply. A deficient environment and nutrient supply may affect health and developmental factors, including prematurity, low birth weight, and congenital problems.

Fetal Alcohol Syndrome (FAS): FAS is a pattern of mental, physical, and behavioral defects in infants born to some mothers who used alcohol during their pregnancy. Symptoms may include facial deformities, mental retardation, small head and body size, malformed organs and learning and behavioral difficulties.

Low Apgar score: The Apgar is a scoring system used to evaluate newborns at one minute and five minutes after delivery. The score is achieved by assessing skin color, breathing, heart rate, cry and muscle tone. Although not necessarily an indicator of long-term developmental delays, lower Apgar scores can reflect fetal distress prior to birth and may indicate a need for further assessment.

Baby Had Difficulty Breathing: Babies who need prolonged support to breathe may have too little oxygen in the blood and body tissues. This lack of oxygen places the child at risk for health problems such as developmental delays, hearing difficulties, cerebral palsy and blindness.

Baby Had Convulsions or Seizures: Seizures in the newborn period are most often the result of metabolic abnormalities, birth trauma, hypoxia (lack of oxygen), or developmental brain abnormalities. These may be isolated seizures which often do not require long term seizure medication. Seizures requiring medication are more likely to be seen in cerebral palsy, hydrocephalus and metabolic disorders.

Baby Had Abnormality Present at Birth: Various abnormalities that are present at birth may be associated with developmental delays, such as spina bifida, cleft lip/palate or Down Syndrome. There are other conditions that may not affect developmental milestones which include birthmarks, skin tags, extra fingers and toes, etc.

Factors Which May Affect Hearing Abilities: An increased risk for hearing loss exists if any of the following factors are present: referred from newborn hearing screening, low birth weight, jaundice, intrauterine infection, bacterial meningitis, and breathing difficulty.