



# Newborn Screening

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Newborn Screening Program Director

# No Disclosures

# Objectives

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1. Identify the different parts of newborn screening.

2

2. Recognize resources available for children diagnosed with a condition.



1964





# NEWBORN SCREENING

## *The Three Parts to Newborn Screening*

*Did you know?*

All babies in the United States receive newborn screening.



### **Blood test or heel stick**

A small blood sample is taken from your baby's heel and placed on a newborn screening card. This card is mailed to a state laboratory for analysis.



### **Hearing screen**

One of two tests may be used to screen for hearing loss in your baby. Both tests are simple and safe and can be done while your baby is asleep.



### **Pulse oximetry**

Pulse oximetry is a test that measures the amount of oxygen in your baby's blood and can detect some heart problems called Critical Congenital Heart Disease (CCHD).





# What Screenings Are Mandated in ND?



Blood Spot Screening ✓



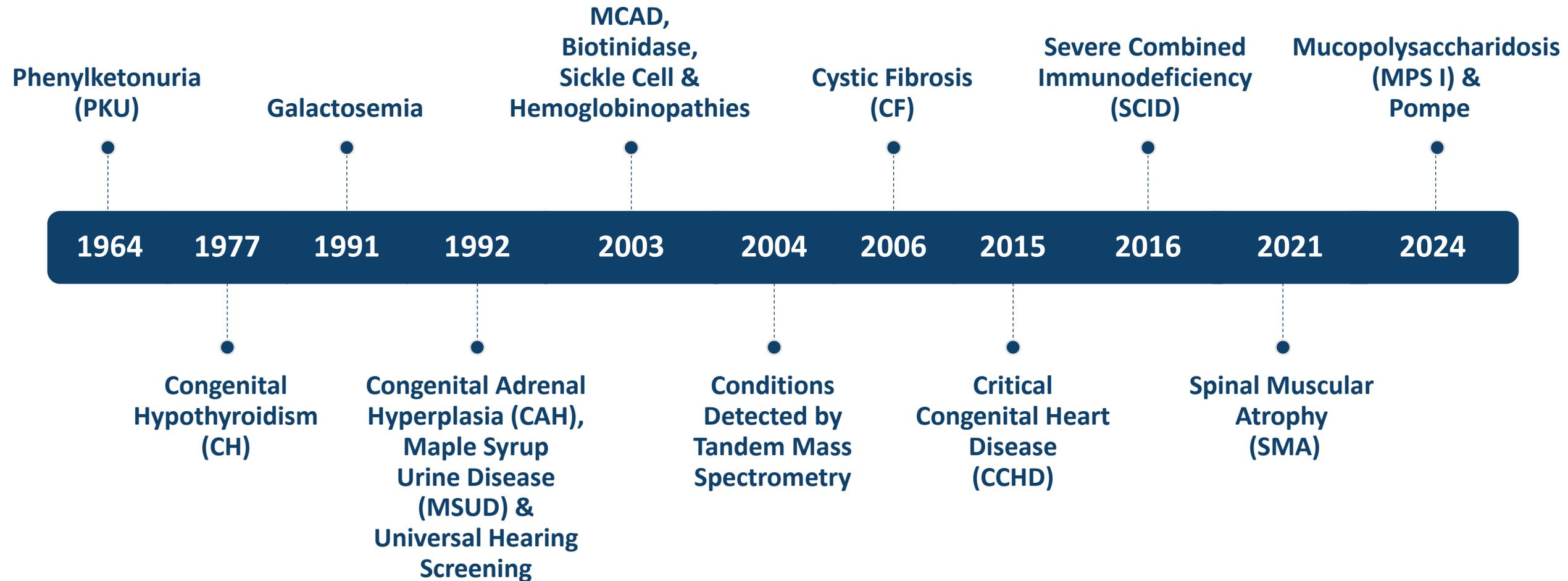
Hearing Screening



Pulse Oximetry Screening ✓



# Newborn Screening Condition Timeline in North Dakota





Recommended Uniform  
Screening Panel (RUSP)



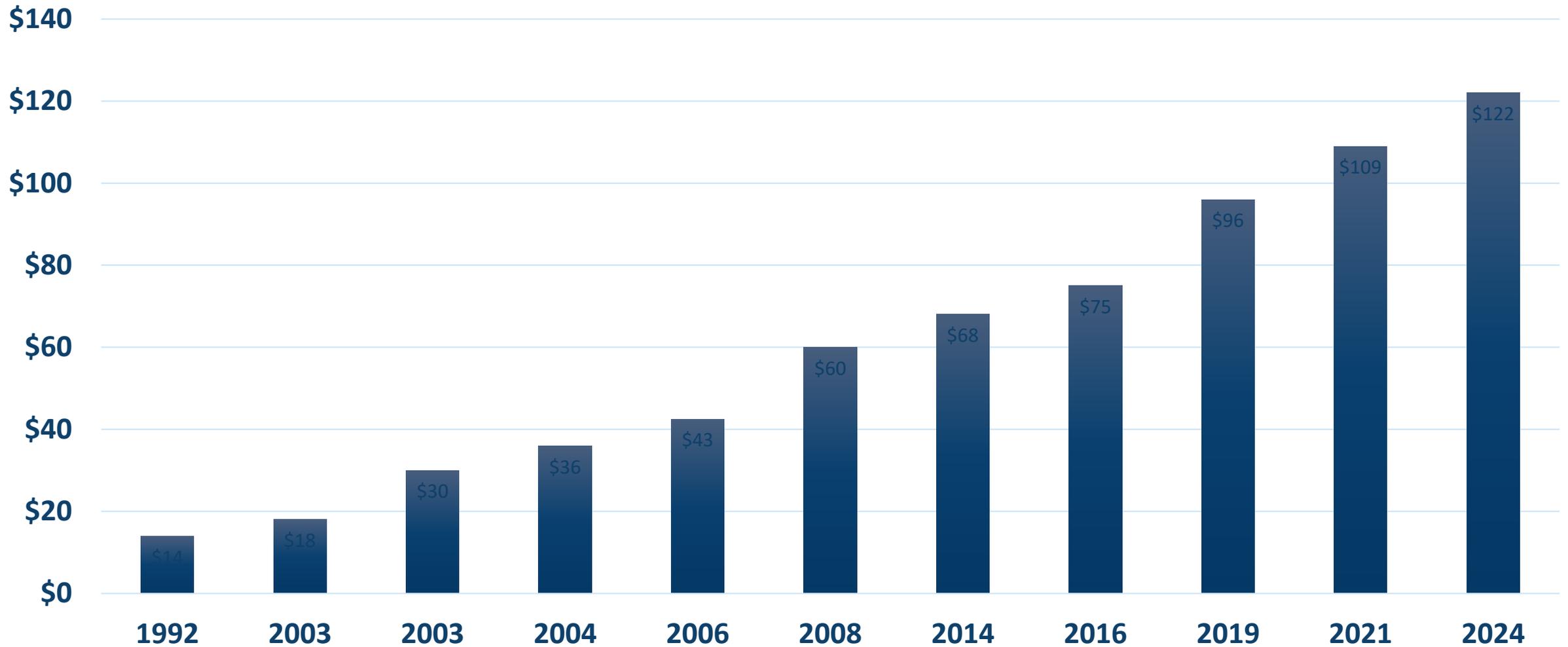
Advisory Committee on  
Heritable Disorders in  
Newborns & Children  
(ACHDNC)

Primary  
Conditions

Secondary  
Conditions

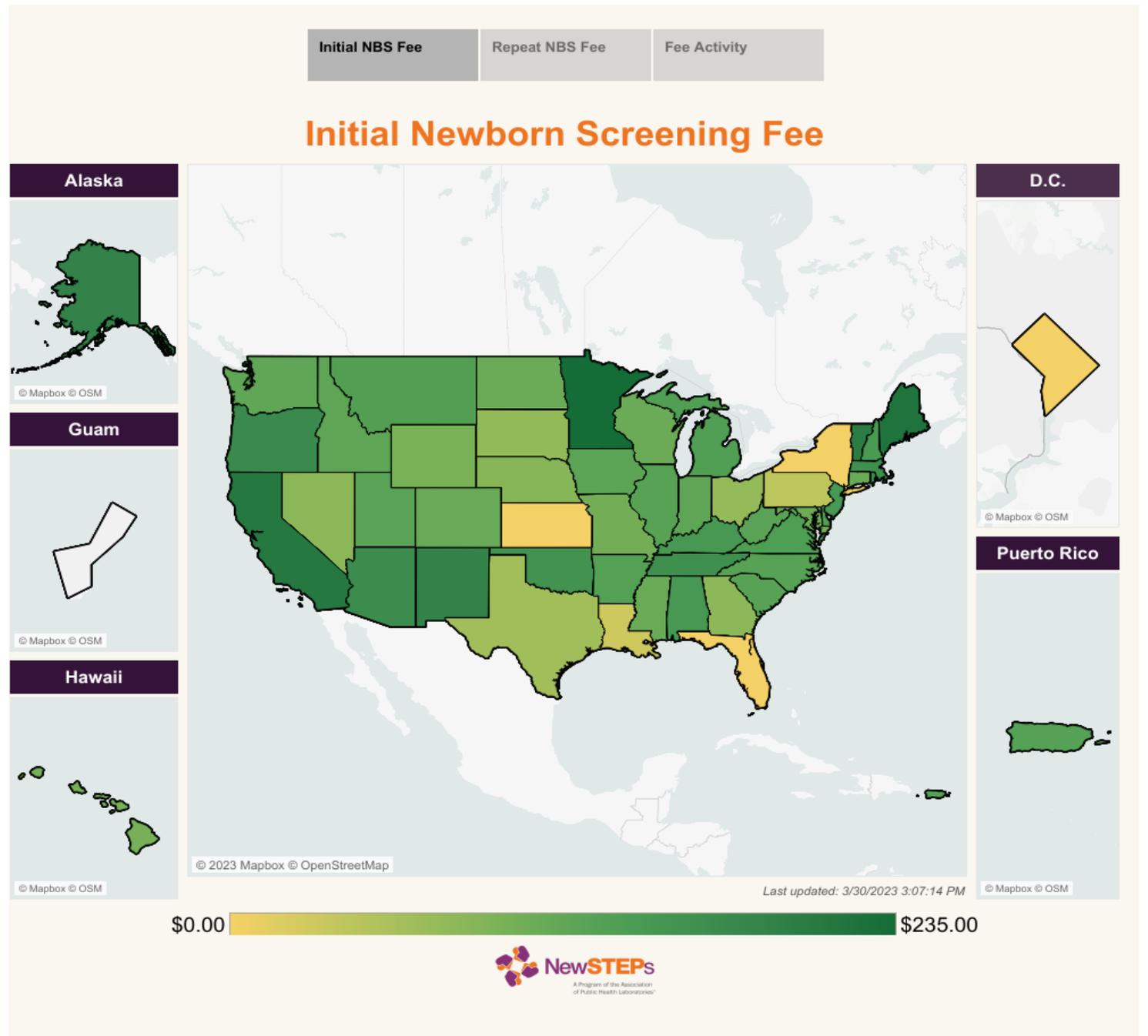


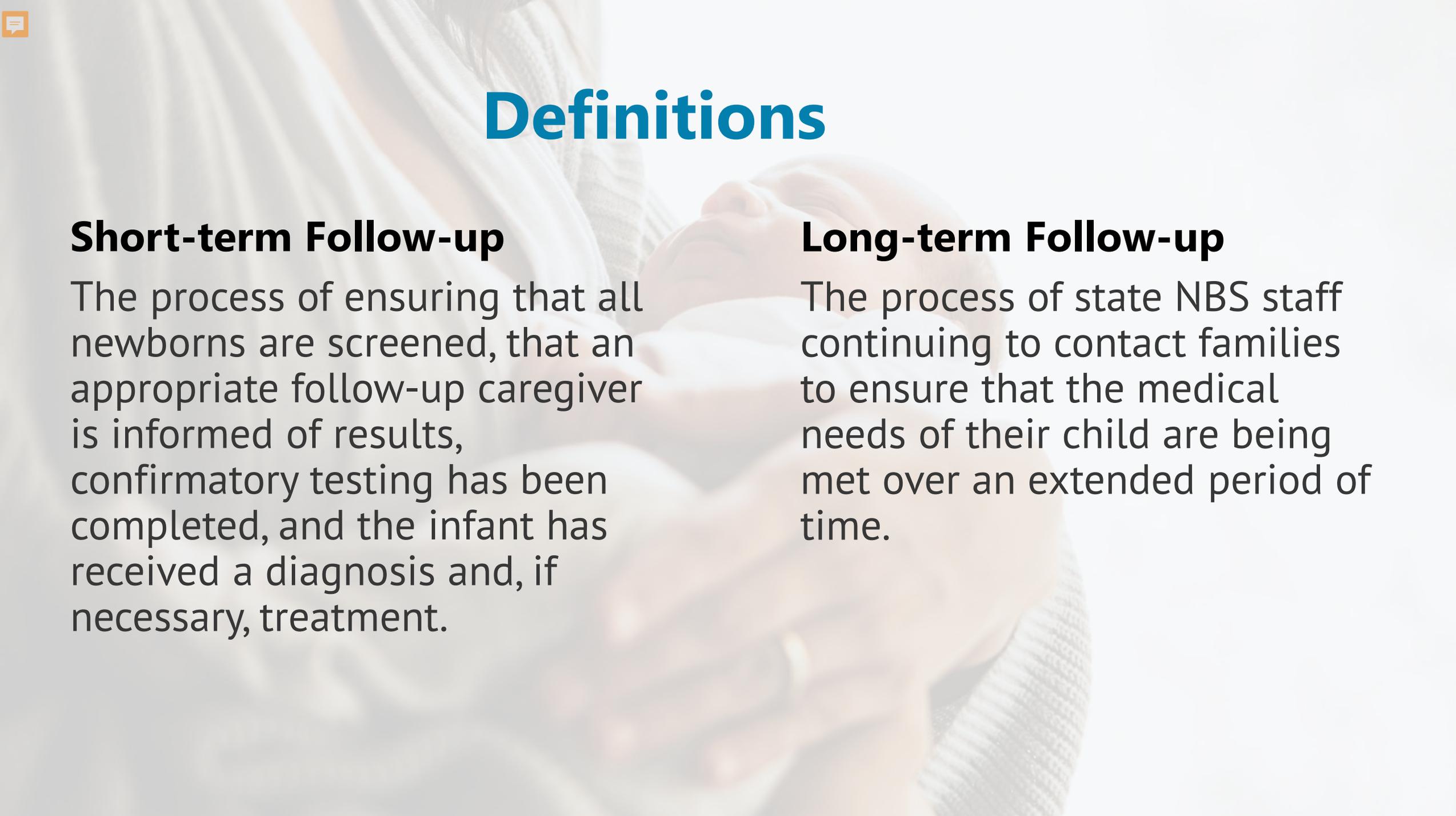
# Newborn Screening Fee History in ND



# How Does ND Compare?

- States in Yellow Have No NBS Fee
  - Kansas
  - Florida
  - New York
- States in Dark Green Have the Highest NBS Fee
  - Minnesota
  - Delaware
  - California



A soft-focus background image showing a person's hands gently cradling a baby. The person is wearing a light-colored, possibly white, long-sleeved shirt. The baby is wrapped in a light-colored blanket. The overall tone is warm and caring.

# Definitions

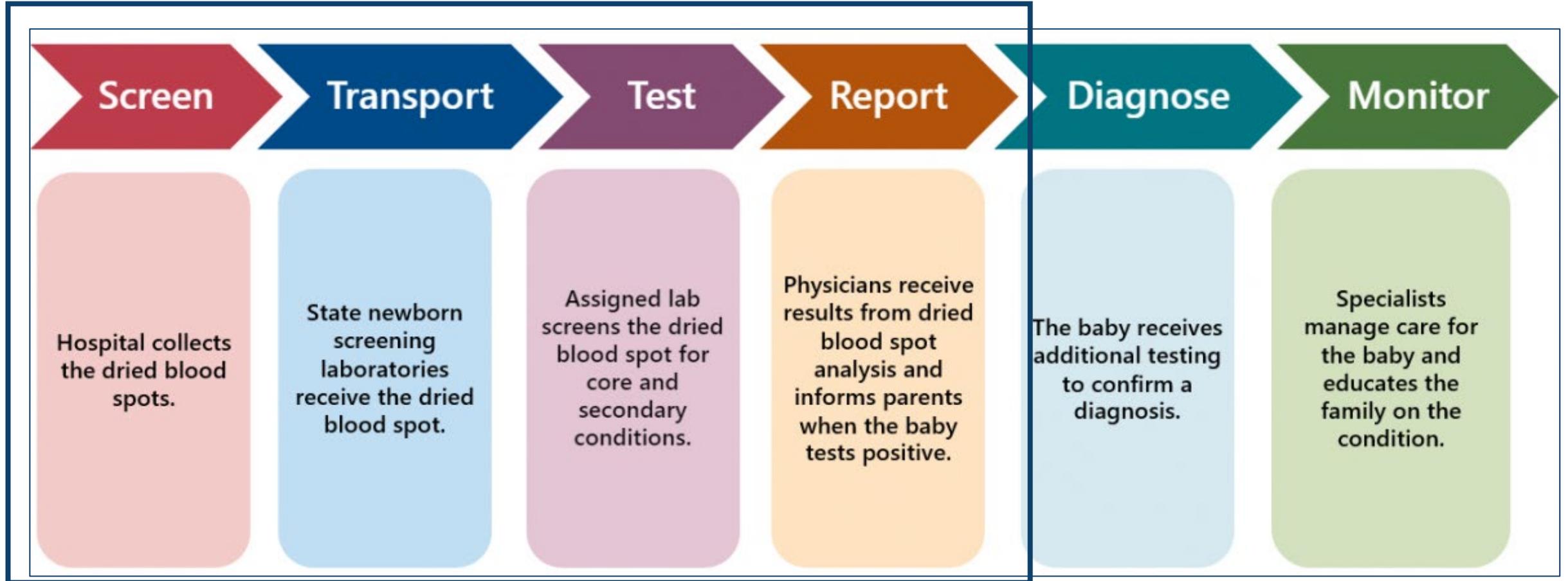
## **Short-term Follow-up**

The process of ensuring that all newborns are screened, that an appropriate follow-up caregiver is informed of results, confirmatory testing has been completed, and the infant has received a diagnosis and, if necessary, treatment.

## **Long-term Follow-up**

The process of state NBS staff continuing to contact families to ensure that the medical needs of their child are being met over an extended period of time.

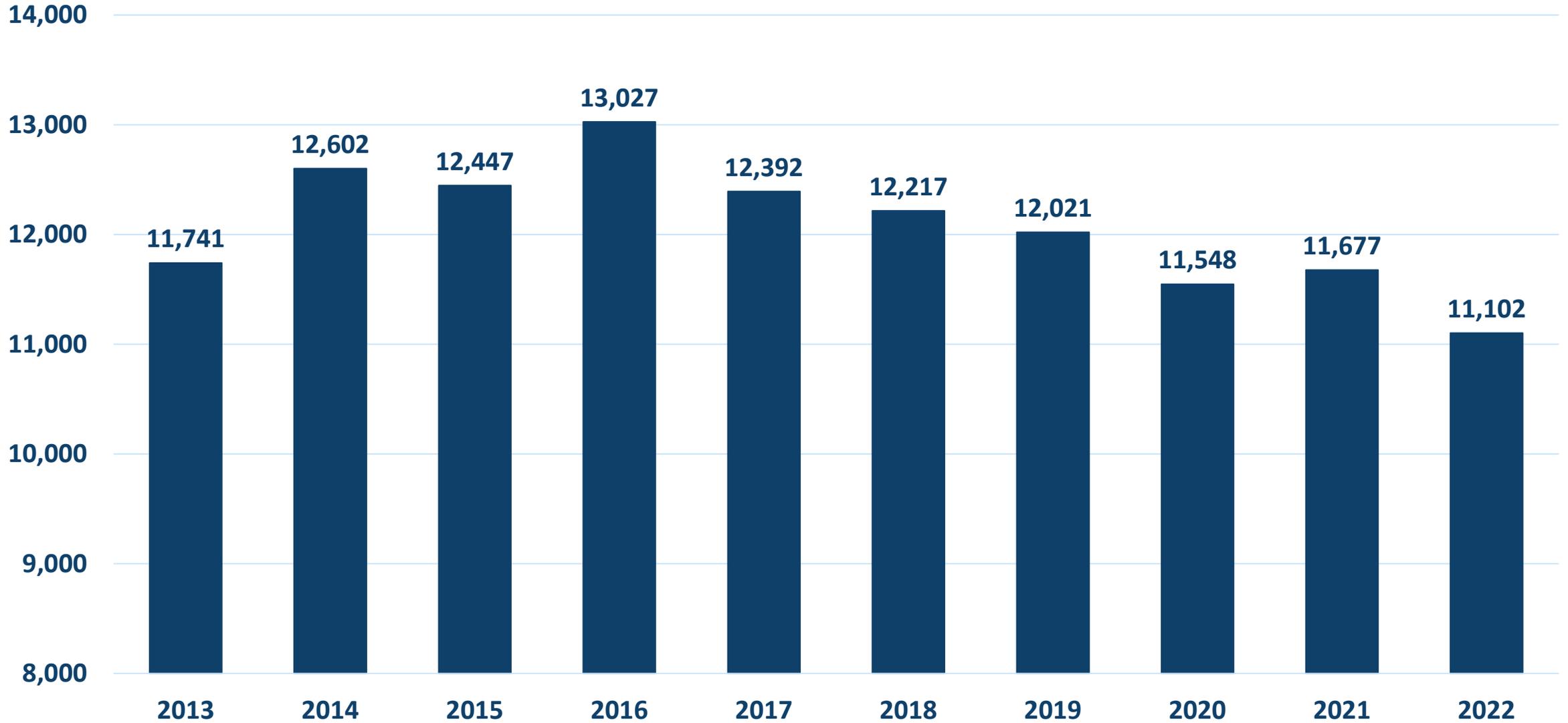
# Newborn Screening Process



**(Short-term Follow-up)**



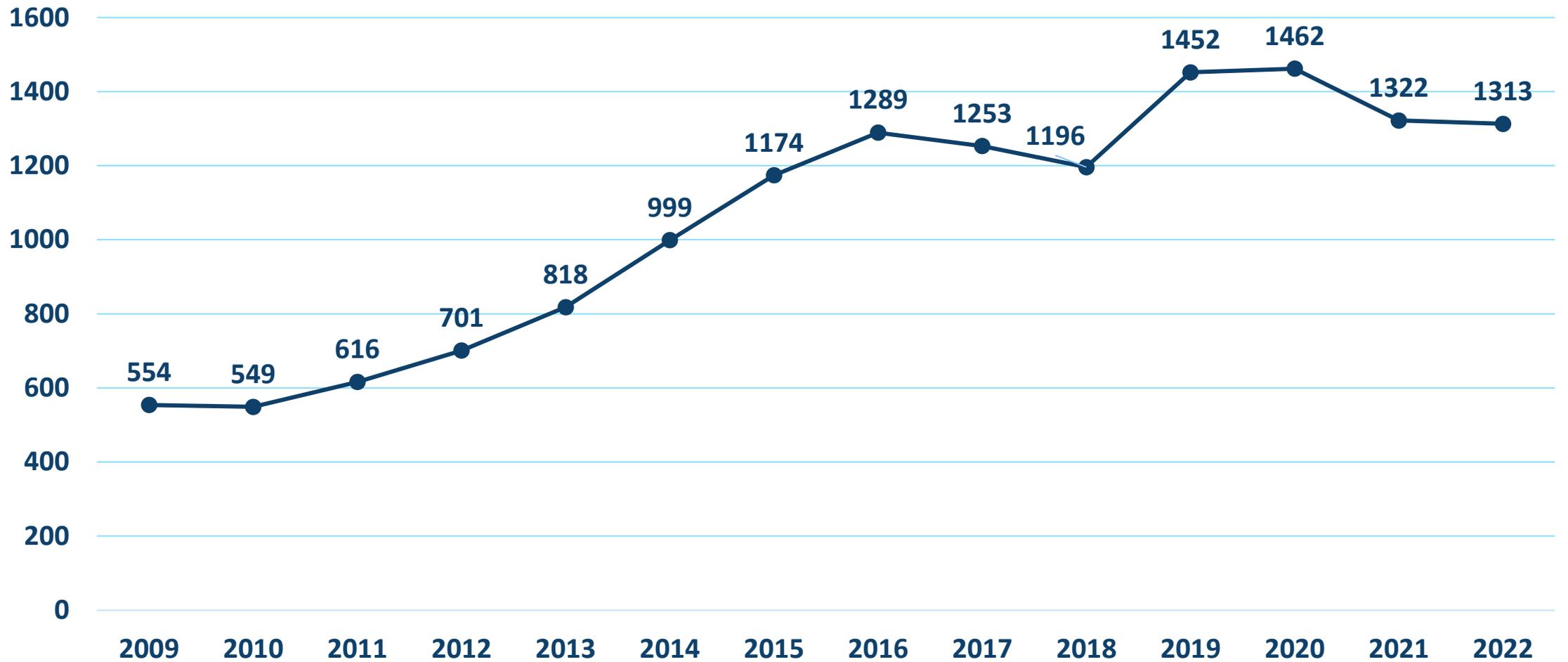
# ND Occurrent Birth Rate





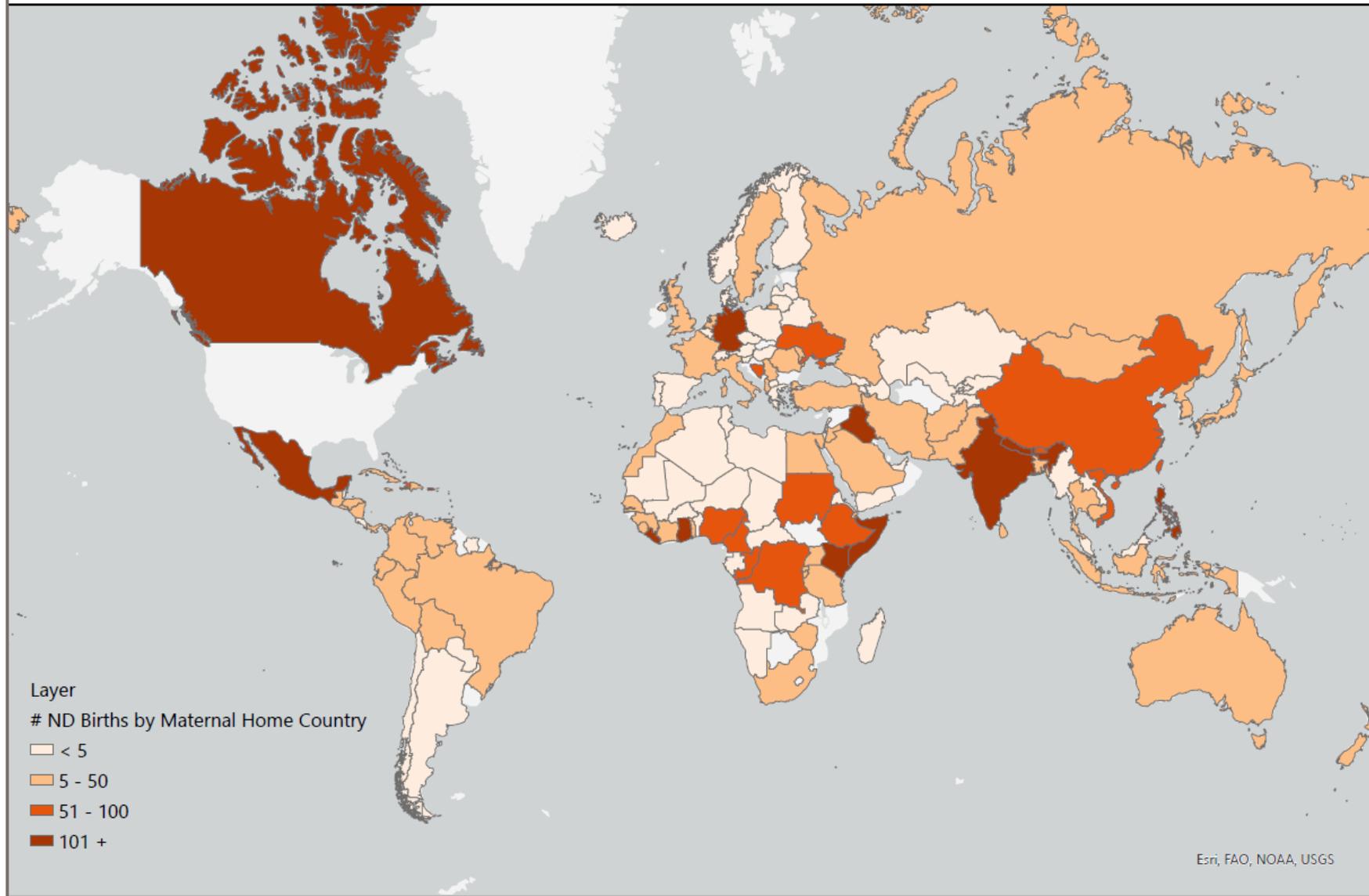
# Increasing Diversity in North Dakota

## Number of Births to Foreign-born North Dakota Resident Women, 2009 - 2022



\*Data source: ND Vital Records

# Number of North Dakota Resident Births by Mother's Home Country, 2019 - 2023\*





# Deadly Delays

The nation's newborn screening programs depend on speed and science to save babies from rare diseases. But thousands of hospitals fall short, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer.



*Kristyna Wentz-Graff/Journal Sentinel*

**Delays at hospitals across the country undermine newborn screening programs, putting babies at risk of disability and death**

*By Ellen Gabler of the Journal Sentinel staff*

*Milwaukee Journal Sentinel released on November 16, 2013*

National  
Push for  
Timeliness  
in NBS

# Time Critical Disorders

## Organic Acid Conditions

- Propionic Acidemia
- Methylmalonic Acidemia (methylmalonyl-CoA mutase)
- Isovaleric Acidemia
- 3-Hydroxy-3-Methylglutaric Aciduria
- Holocarboxylase Synthase Deficiency
- Beta-Ketothiolase Deficiency
- Glutaric Acidemia, Type I

## Fatty Acid Oxidation Disorders

- Medium-chain acyl-CoA Dehydrogenase Deficiency
- Very long-chain acyl-CoA Dehydrogenase Deficiency
- Long-chain L-3 Hydroxyacyl-CoA Dehydrogenase Deficiency
- Trifunctional Protein Deficiency
- Glutaric Acidemia, Type II
- Carnitine Acylcarnitine Translocase Deficiency
- Carnitine Palmitoyltransferase Type II Deficiency

## Amino Acid Disorders

- Argininosuccinic Aciduria
- Citrullinemia, Type I
- Maple Syrup Urine Disease

## Other Disorders

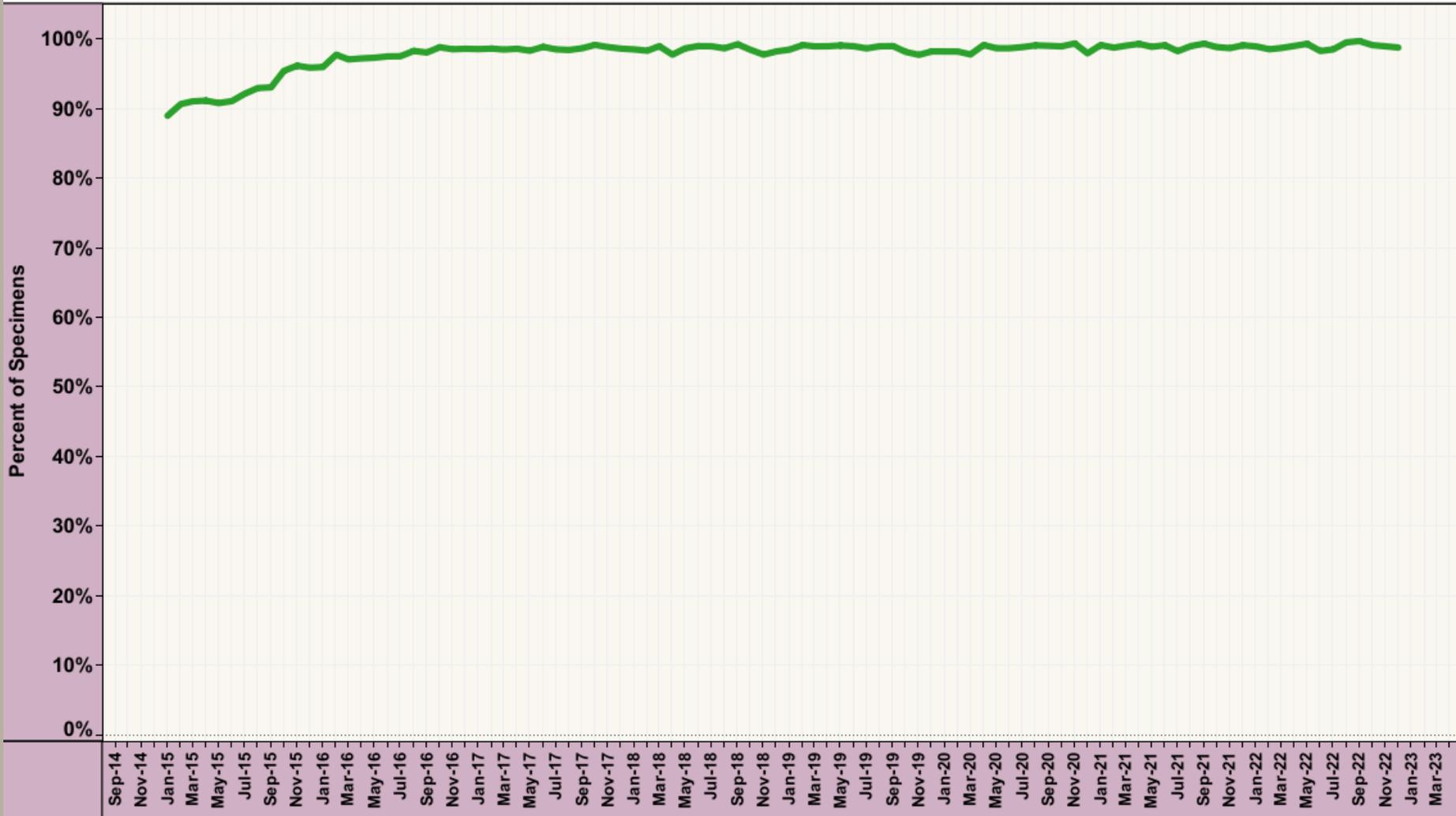
- Congenital Adrenal Hyperplasia
- Classic Galactosemia
- Pompe \* Not considered time critical in ND.
- Congenital Hypothyroidism \* Time sensitive in ND and providers notified if result is presumptive positive \*



# Timely Specimen Collection Run Chart

Percent of first dried blood spot specimens collected in **<=48 Hours** from birth

<p><b>Select Time Interval</b></p> <p>&lt;=48 Hours</p>	<p><b>Select Median</b></p> <p>No Median</p>
<p><b>Select NBS Program ID</b></p> <p>186</p>	<p><b>Change Date Range</b></p> <p>Jan 2015 to Dec 2022</p>





### Birth to Reporting Time Critical Results Run Chart

Percent of specimens with a time critical result reported on **<=Day 5** after birth

<=Day 5

Select Time Interval

No Median

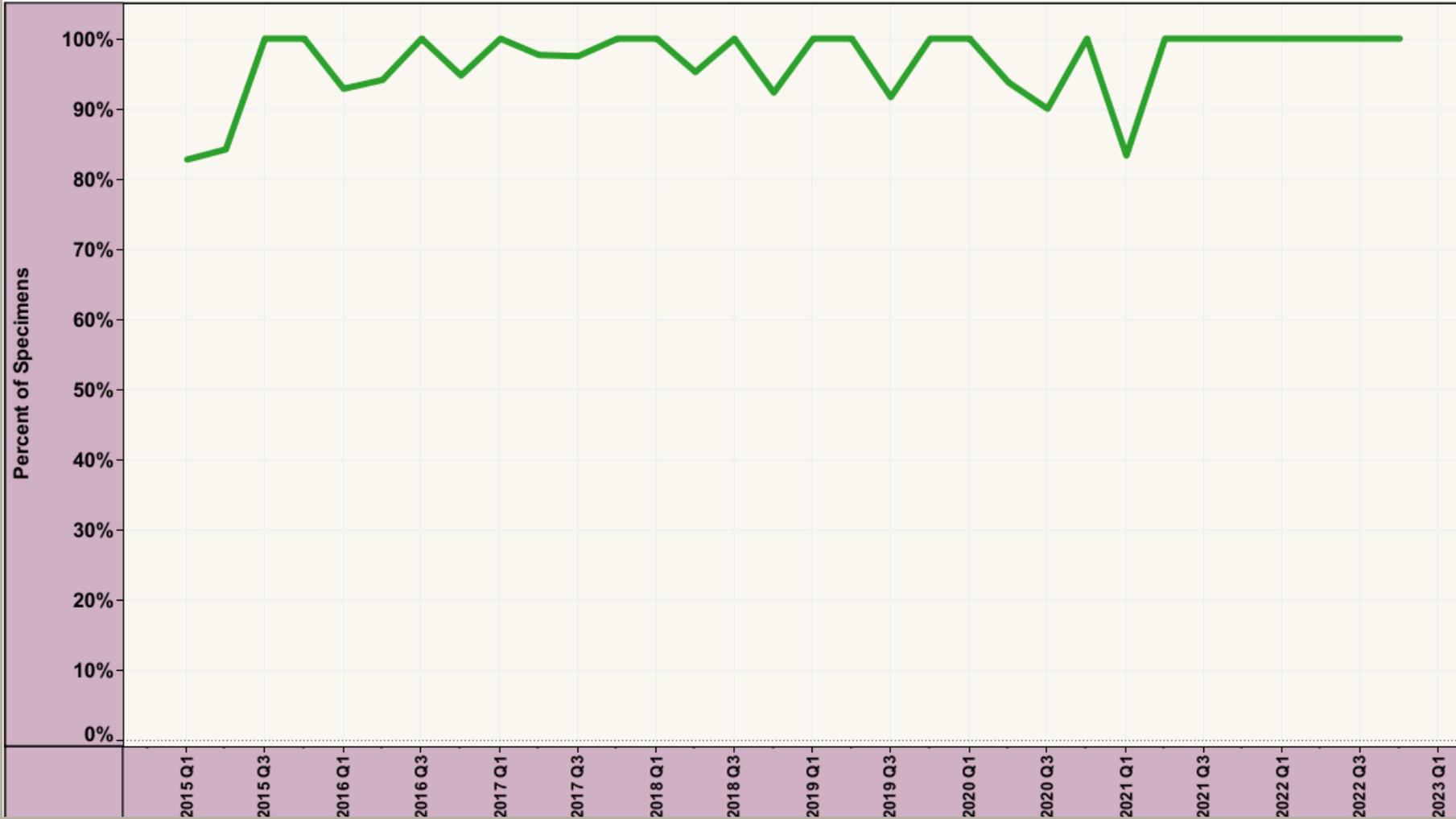
Select Median

186

Select NBS Program ID

2015 Q1 to 2022 Q4

Change Date Range



# Communicating Newborn Screening Results To Parents



**“Communicating NBS results is a delicate task and should be carefully and appropriately crafted to prepare for a range of outcomes, which could vary considerably given the wide range of clinical profiles of positive cases.”**

## PRESUMPTIVE POSITIVE RESULT: Cystic Fibrosis (CF)

### Sweat testing is expected to confirm diagnosis

Date

PCP/Facility:

Re:

DOB:

Initial Collected:

Lab #:

#### Newborn Screen Result:

Immunoreactive Trypsinogen (IRT): < > ng/ml (Normal value <58 ng/ml)

Cystic fibrosis transmembrane conductance regulator (CFTR) Variant Analysis: **2 pathogenic variants detected** (Normal: No variants)

➤ Variants found: < >

#### ACTIONS REQUIRED:

- Inform parent/guardian of results and review education provided.
- As soon as possible, refer infant for a coordinated sweat test and genetic counseling appointment at an accredited Cystic Fibrosis Center **for the first available appointment**. Please advise the newborn screening program about where referral was made within 24-48 business hours.
- The contact information for accredited state CF centers:
  - CHI St. Alexius Heart and Lung Clinic (Bismarck, ND)
    - Phone 701-530-7591 (MUST CALL BEFORE FAXING REFERRAL)
    - Fax 701-530-7435
  - Sanford Health Coordinated Treatment Center (Fargo, ND)
    - Phone 701-234-6602 (MUST CALL BEFORE FAXING REFERRAL)
    - Fax 701-234-7453
- Referral to an accredited CF center will help to ensure reliability of results and the provision of genetic counseling.
- Please fax a copy of this letter to the selected CF center.
- The 2017 Cystic Fibrosis Foundation Consensus Guidelines recommend that “testing should occur if at all **possible by the time the infant is 4 weeks old** because malnutrition and other risks such as potentially fatal hyponatremic dehydration may occur even in the first few weeks of life” if the child does have cystic fibrosis. Risks cannot be addressed until sweat testing is completed.
- If you are not this infant’s primary care provider, please contact our office **immediately**.
- Contact the newborn screening program with questions Monday through Friday at the telephone number listed on enclosed information page.

#### Newborn screening

A short time after your baby’s birth, a newborn screen was performed to look for certain medical conditions. This test involved a small sample of blood taken from your baby’s heel. The goal of newborn screening is to identify conditions which, if caught early, can be treated and improve the health of babies.

#### Your baby’s results: 2 variants detected

Your baby’s newborn screen was abnormal (out-of-range) for a condition called cystic fibrosis (CF). This screen involves looking for specific differences (variants) in the gene for CF. Infants with two genetic variants found on newborn screening are expected to have CF. A sweat test is needed when one or more genetic variants are identified to find out if a baby has CF. Your baby’s provider has been given a list of these CF centers in or near the state of Iowa. Someone at your provider’s office or one of the CF centers can help you schedule this appointment.

**Instructions for sweat test:** Feed, bathe, and care for your baby as usual. **DO NOT** apply creams or lotions **24 hours PRIOR** to the sweat test appointment.

**About the sweat test:** Small areas of your baby’s arm and/or leg will be made to sweat. The sweat is collected on a small piece of filter paper or in plastic tubing. The amount of salt is measured by the laboratory. Results are usually available the same day or the next day.

#### What is cystic fibrosis?

Cystic fibrosis is an inherited disorder that occurs when the body has a build-up of thick, sticky mucus that can damage many of the body’s organs. Babies may have problems with digestion, malnutrition, poor growth, weight loss. In addition, the mucus can clog the airways, leading to severe breathing problems and bacterial infections in the lungs.

#### Additional information

Genetic counseling is often scheduled with the sweat test appointment and is also available by phone through the Iowa Newborn Screening Program. Your child’s newborn screen result may have important reproductive implications for parents and other family members. Carrier screening could be considered.

Please call 319-384-5097 or toll free 866-890-5965 with questions Monday through Friday.

#### For additional information about cystic fibrosis, please visit the following websites:

<https://www.babysfirsttest.org/newborn-screening/conditions/cvstic-fibrosis-cf> For your convenience, please scan the QR code:



<https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/> For your convenience, please scan the QR code:



# Communication Guide for Primary Care Providers

**S**hare the specific [positive]\* newborn screening result and associated condition(s) with the family.

**C**omprehension: Assess the family's understanding of newborn screening.

**R**eiterate what screening is and is not.

**E**ngage with the family and provide information at their desired level and pace.

**E**xplore the family's emotions.

**N**ext steps: Discuss a shared plan and provide resources.



## Communication Guide

**THIS GUIDE WILL HELP YOU EFFECTIVELY COMMUNICATE [POSITIVE]\* NEWBORN SCREENING RESULTS TO PARENTS.**



Because this type of communication is not a routine activity for the primary care provider, the information below may be used to help frame the discussion with families to improve understanding of the screening result, adherence to follow-up recommendations, and the family's overall experience with newborn screening.

Families who have had [positive]\* newborn screening results have suggested that the following key points are important in helping families cope with the uncertainty of a [positive]\* newborn screening result and understand the next steps needed to gain certainty.

**S**hare the specific [positive]\* newborn screening result and associated condition(s) with the family.

- Help the family understand that a [positive]\* newborn screening result is serious, but that you are there to help guide them through the next steps.

**C**omprehension: Assess the family's understanding of newborn screening.

- Assess if the family recalls and understands the process of newborn screening.

**R**eiterate what screening is and is not.

- Remind the family about the purpose of newborn screening and that it is not a diagnostic test, so it is important that timely follow-up confirmatory testing be done.

**E**ngage with the family and provide information at their desired level and pace.

- Offer to provide the family additional result-specific information provided by the state newborn screening program.
- Discuss information using non-medical terms, at the family's pace and desired level of detail.

**E**xplore the family's emotions.

- Explore with the family how they might use their support system or other support resources now and as they go through the diagnostic process.
- Remember there is a wide spectrum of how families may cope with this result (anxiety to denial). Tailor your discussion to help the family hear and retain the information discussed.

**N**ext steps: Discuss a shared plan and provide resources.

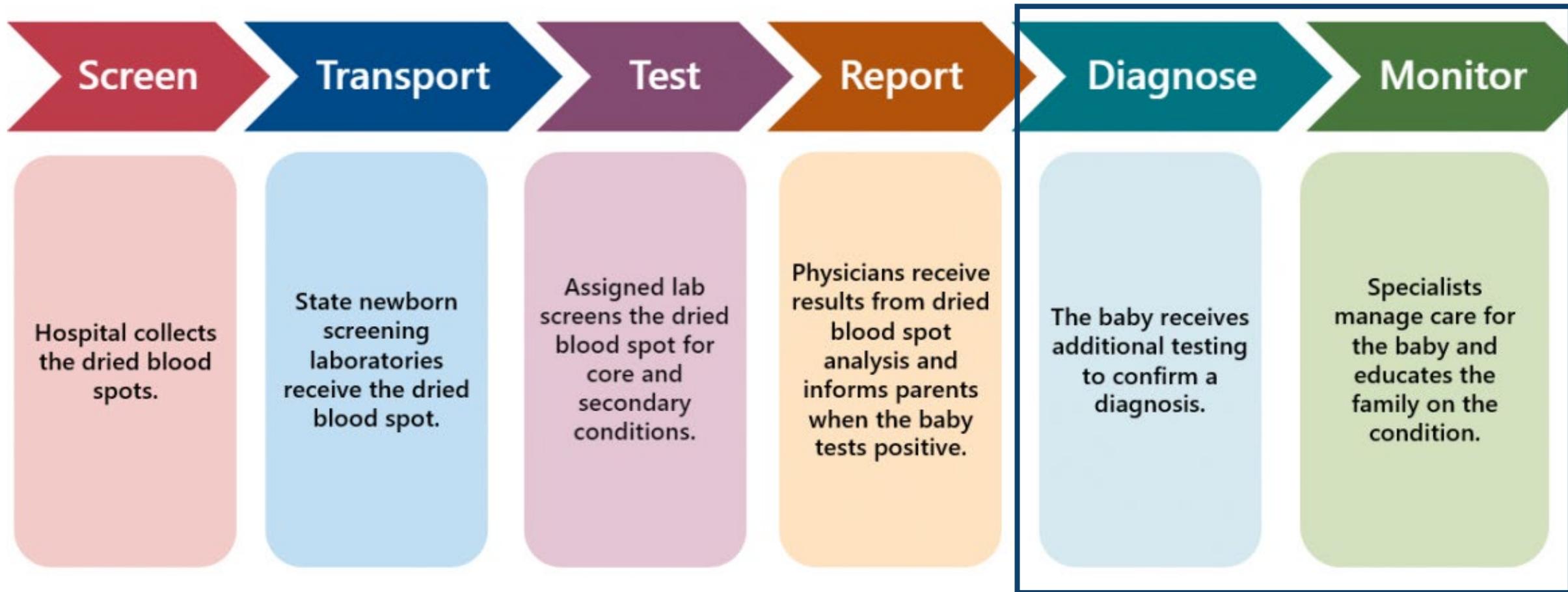
- Discuss with the family a shared plan that is concrete, specific, and includes the following:
  - Where, when, and with whom is the next appointment?
  - What testing will be considered and/or done?
  - What should they watch for in their child while they wait?
  - Who can they contact if they have additional questions or concerns?
- Assess the family's understanding of the visit and information provided using teach-back methods, and provide valid websites for them to get more information.

\*A positive newborn screening result can also be referred to as an abnormal result, an out-of-range result, or presumptive positive result.

For more information about the Advisory Committee on Heritable Disorders in Newborns and Children, please visit <https://www.hrsa.gov/advisory-committees/heritable-disorders>

<https://www.hrsa.gov/advisory-committees/heritable-disorders>

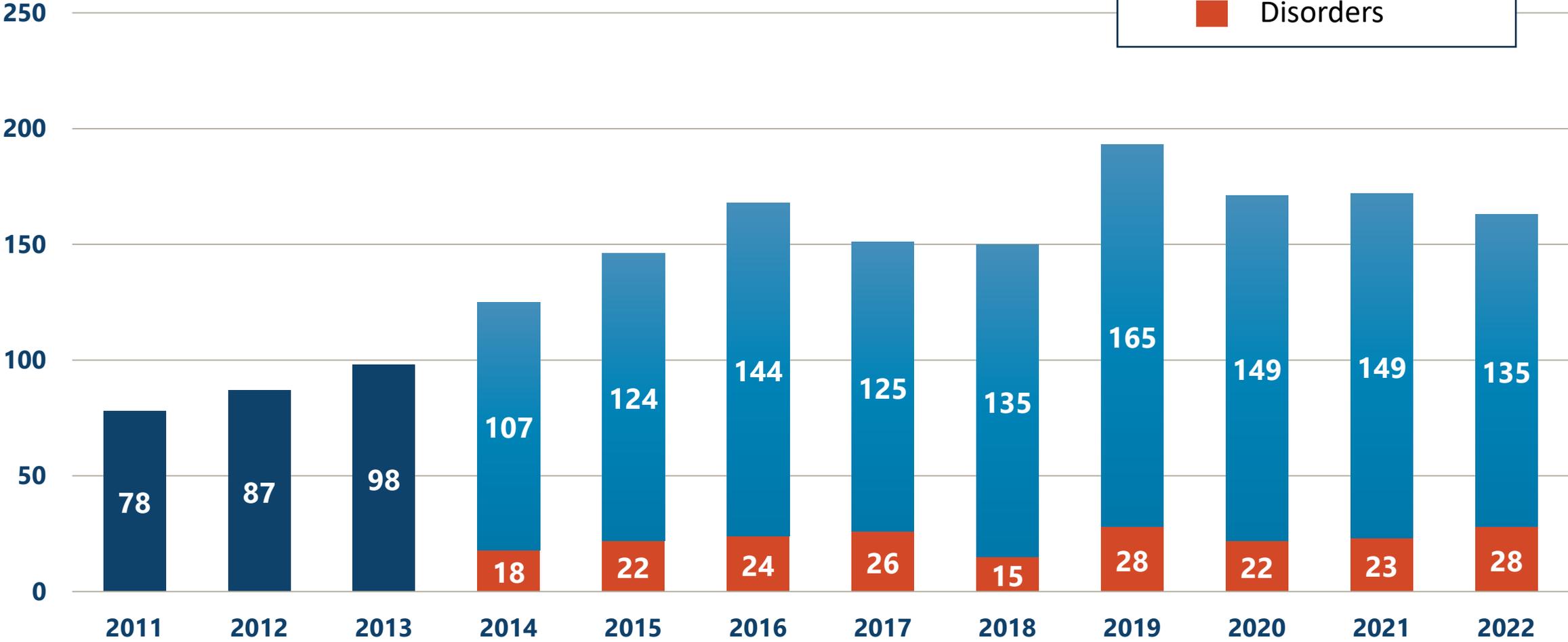
# Newborn Screening Process



**(Long-term Follow-up)**

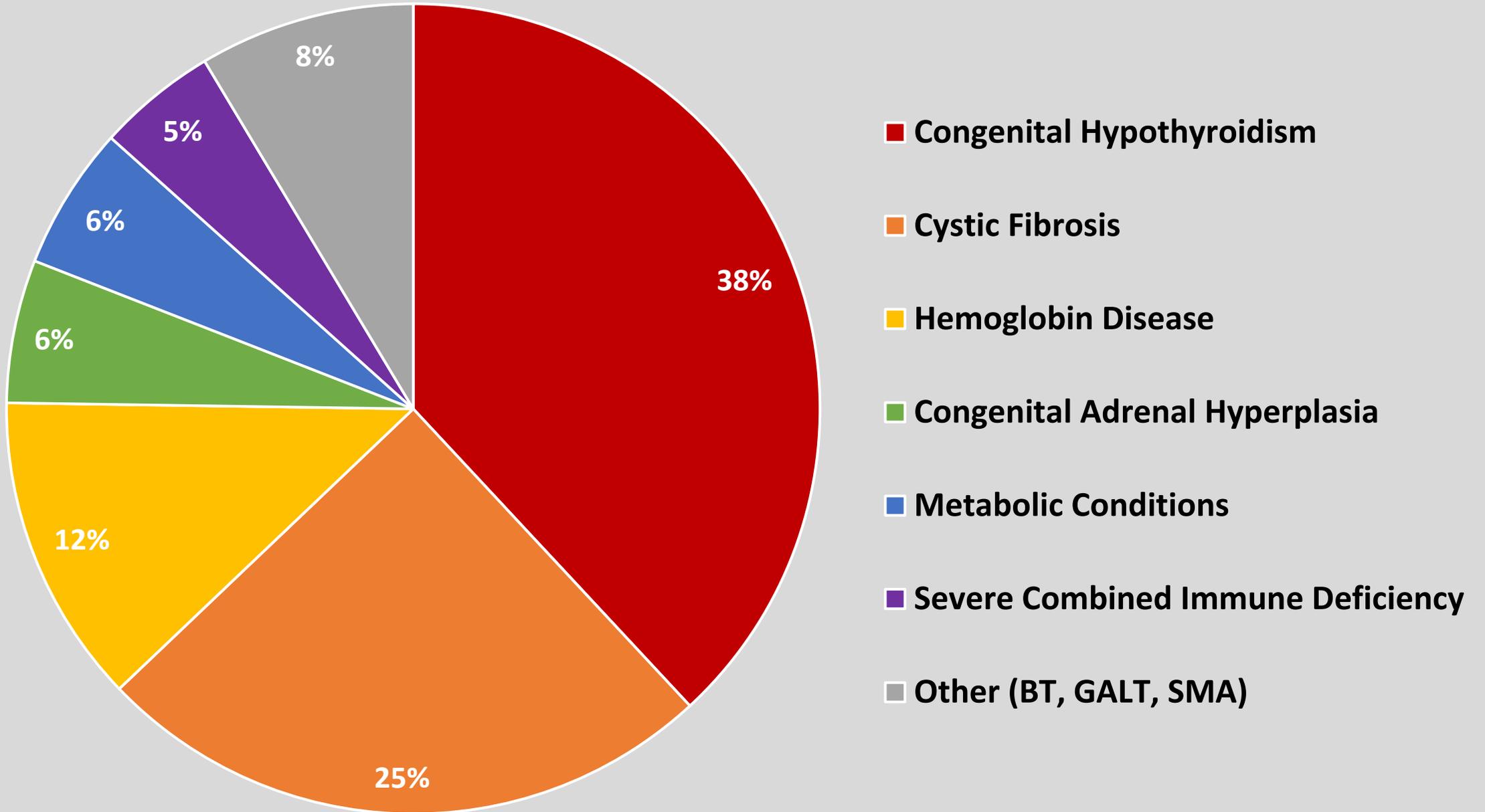


# Confirmed Newborn Blood Spot Screening Cases



\*Data Source: Newborn Screening Case Log

# 2019-2023 Newborn Blood Spot Confirmed Conditions



# Universal Newborn Hearing Screening

## Early Hearing Detection and Intervention (EHDI)

### Patient Checklist for Pediatric Medical Home Providers

Birth	<b>Hospital-based Inpatient Screening Results (OAE/AABR)</b> <small>(also Home Births)</small>	DATE: ___/___/___
	Left ear: <input type="checkbox"/> Missed <input type="checkbox"/> Incomplete <input type="checkbox"/> <b>Failed</b> Screen <sup>a, c</sup> <input type="checkbox"/> Pass Right ear: <input type="checkbox"/> Missed <input type="checkbox"/> Incomplete <input type="checkbox"/> <b>Failed</b> Screen <sup>a, c</sup> <input type="checkbox"/> Pass	
Before 1 month	<b>Outpatient Screening Results (OAE/AABR)</b>	___/___/___
	Left ear: <input type="checkbox"/> <b>Incomplete</b> <input type="checkbox"/> Failed Re-Screen <sup>a, c</sup> <input type="checkbox"/> Pass Right ear: <input type="checkbox"/> <b>Incomplete</b> <input type="checkbox"/> Failed Re-Screen <sup>a, c</sup> <input type="checkbox"/> Pass	
Before 3 months	<input type="checkbox"/> <b>Pediatric Audiology Evaluation<sup>b</sup></b>	___/___/___
	<input type="checkbox"/> Hearing Loss <input type="checkbox"/> Normal Hearing  <input type="checkbox"/> Document child and family auditory history <input type="checkbox"/> Report to State EHDI Program results of diagnostic evaluation <input type="checkbox"/> Refer to Early Intervention (IDEA, Part C) <input type="checkbox"/> Advise family about communication options and assistive listening devices (hearing aids, cochlear implants, etc.) <input type="checkbox"/> Medical & Otologic Evaluations to recommend treatment and provide clearance for hearing aid fitting <input type="checkbox"/> Pediatric Audiology for hearing aid fitting and monitoring	___/___/___ ___/___/___ ___/___/___ ___/___/___ ___/___/___
Before 6 months	<input type="checkbox"/> <b>Enrollment in Early Intervention (IDEA, Part C)</b> <small>(transition to Part B at 3 years of age)</small>	___/___/___
	<input type="checkbox"/> Medical Evaluations to determine etiology and identify related conditions <input type="checkbox"/> Otolaryngology (required) <input type="checkbox"/> Ophthalmologist (recommended) <input type="checkbox"/> Geneticist (recommended) <input type="checkbox"/> Developmental pediatrics, neurology, cardiology, and nephrology (as needed)	___/___/___ ___/___/___ ___/___/___ ___/___/___
	<input type="checkbox"/> Ongoing Pediatric Audiology Services	___/___/___

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiology Evaluation. Likewise, infants at higher risk for hearing loss (or loss to follow-up) also may be referred directly to Pediatric Audiology.

(b) Part C of IDEA<sup>®</sup> may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Even infants who fail screening in only one ear should be referred for further testing of both ears.

(d) Includes infants whose parents refused initial or follow-up hearingscreening.

OAE = Otoacoustic Emissions  
 AABR = Automated Auditory Brainstem Response  
 ABR = Auditory Brainstem Response  
 IDEA = Individuals with Disabilities Education Act  
 EHDI = Early Hearing Detection & Intervention

Patient Name: \_\_\_\_\_

Date of Birth: \_\_\_/\_\_\_/\_\_\_

#### Ongoing Care of All Infants<sup>d</sup>

- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Vision screening and referral as needed
- Ongoing developmental surveillance/referral
- Risk indicators for delayed-onset hearing loss:

(If risk factors are present, refer for audiology evaluation at least once prior to age 30 months)

#### Service Provider Contact Information

Pediatric Audiologist:

Early Intervention Service Coordinator:

Other:

Other:

Other:

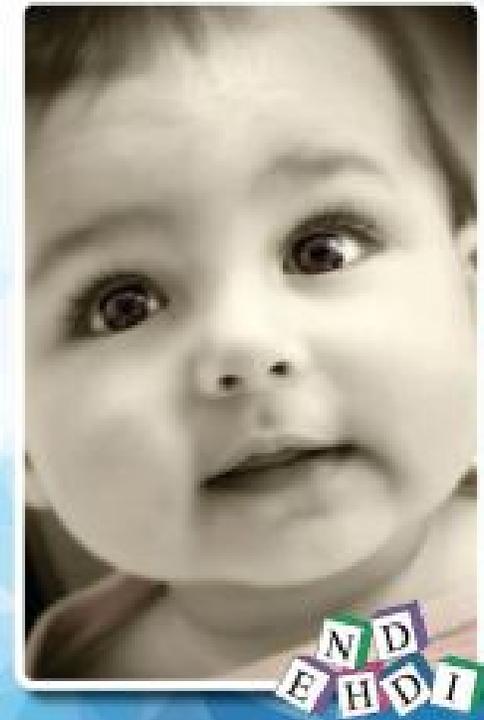
This project is funded by an educational grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services.



DEDICATED TO THE HEALTH OF ALL CHILDREN<sup>®</sup>



## Can Your Baby Hear?



North Dakota Early Hearing Detection and Intervention  
 www.ndehdi.org  
 1-800-233-1137

# North Dakota Infant Hearing Road Map

The ND Early Hearing Detection & Intervention Road Map is a quick reference on the "next steps" for complete hearing health care.

**Screen before 1 month**

1st hearing screen:  
Date: \_\_\_/\_\_\_/\_\_\_

**Hearing Screen Results:**

Left Ear	Right Ear
<input type="checkbox"/> Did not pass	<input type="checkbox"/> Did not pass
<input type="checkbox"/> Pass	<input type="checkbox"/> Pass

**Schedule** an outpatient screen, if your baby did not pass the birth screen.

**Outpatient Hearing Screen:**

Place: \_\_\_\_\_  
Date: \_\_\_/\_\_\_/\_\_\_

**Outpatient Hearing Screen Results:**

Left Ear	Right Ear
<input type="checkbox"/> Did not pass	<input type="checkbox"/> Did not pass
<input type="checkbox"/> Pass	<input type="checkbox"/> Pass

If your child **DID NOT PASS** the screen and/or re-screen, your baby will need to see an Audiologist for further testing. Continue to monitor Language/Communication Milestones.



If your baby passes her/his screening and/or evaluations while on the journey of hearing health care, followup care is complete. Continue to monitor milestones, and follow risk-factor care recommendations.

**By 4 Months of age:**

- Begins to babble
- Babbles with expression and copies sounds they hear

**Diagnostic Audiology Results:**

Left Ear	Right Ear
<input type="checkbox"/> Did not pass	<input type="checkbox"/> Did not pass
<input type="checkbox"/> Pass	<input type="checkbox"/> Pass

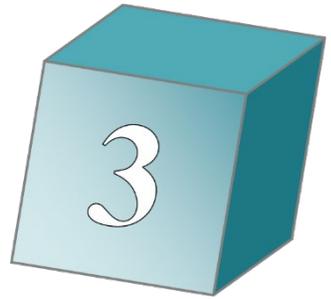
**Pediatric Audiology Appointment:**

Place: \_\_\_\_\_  
Audiologist: \_\_\_\_\_  
Date: \_\_\_/\_\_\_/\_\_\_

**Diagnose before 3 months**

**By 2 Months of age:**

- Coos, makes gurgling sounds
- Turns head toward sounds



**Early Intervention before 6 months**

- ~Part C Infant Development
- ~Parent Infant Program
- ~Tribal Early Childhood Tracking
- Other: \_\_\_\_\_

**Family Support Services** are available at any time during your family's journey

**By 6 Months of age:**

- Responds to sounds by making sounds
- Strings vowels together when babbling ("ah," "eh," "oh")
- Responds to own name

**Family Support Services:**

**North Dakota Hands & Voices**  
(<http://www.ndhandsandvoices.org/>)

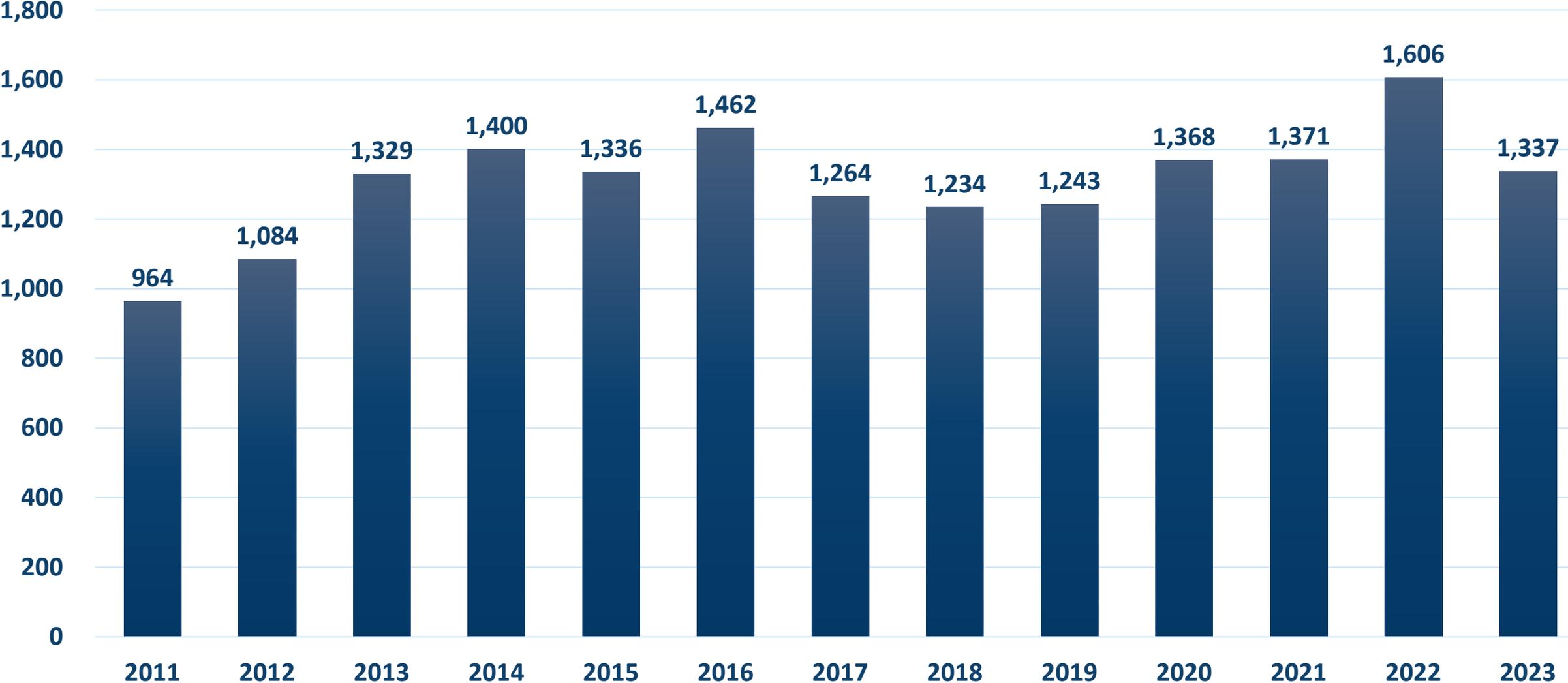
**Family Voices of North Dakota**  
(<http://fvnd.org/site/>)



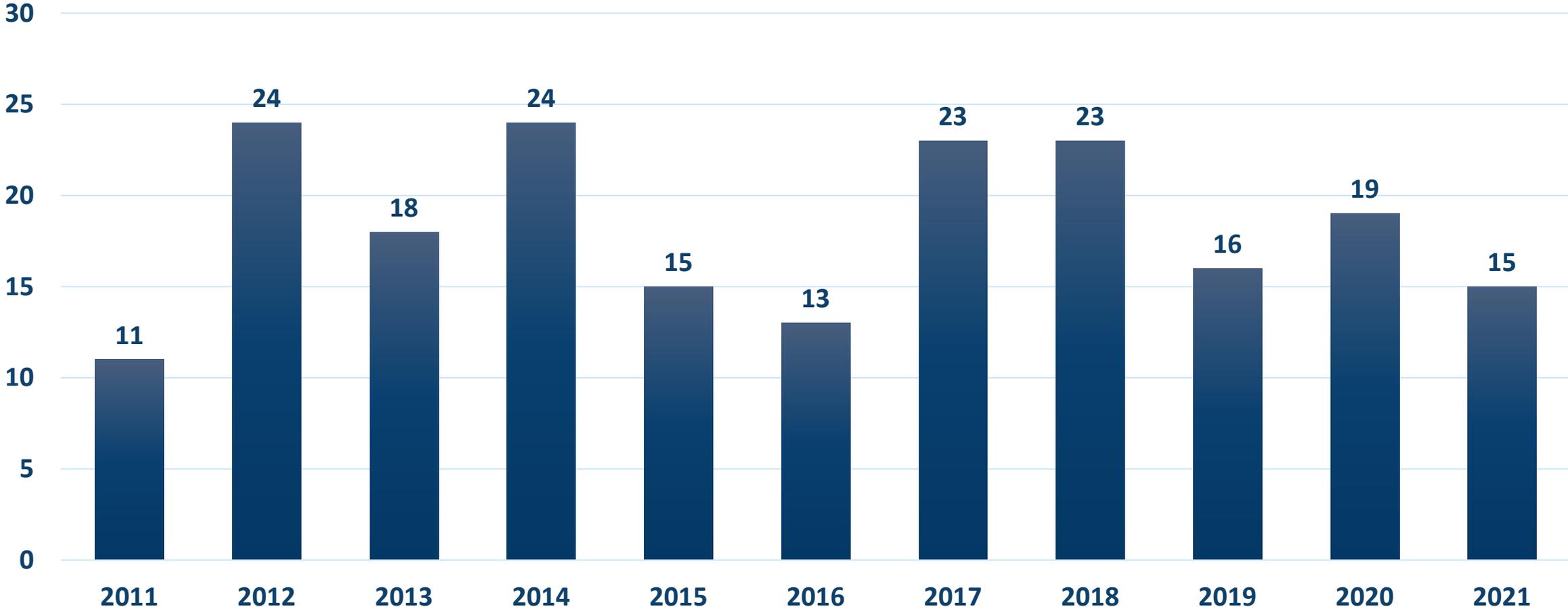
For further guidance with your child's hearing health journey or for a list of pediatric audiologists, contact ND EHDHI at 1.800.235.1737 or [www.ndcpd.org/ehdi](http://www.ndcpd.org/ehdi).



# Referred Birth Hearing Screening



# Confirmed Hearing Loss Cases





# NBS Long-term Follow-up



## North Dakota Long-term Follow-up

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- Initial contact with family within 2 weeks of diagnosis
- Quarterly contacts for the first year of life
- Annual contacts through age 6

# CONGRATULATIONS ON THE BIRTH OF YOUR BABY!

May your journey  
be filled with support,  
love, and warm cuddles.



## Congratulations on your new baby!

Through a blood test (called newborn screening) that was done at birth, your baby was found to have a condition that needs special treatment. We understand that you may not be aware of the many community supports that are available to help you and your baby. These supports can include (but are not limited to): Family Voices of ND, Right Track/ Early Intervention, WIC, and/or Medicaid.

We are here to help connect you with resources that can help your child and your family. In the next few weeks, a nurse will call from a Department of Health phone number and talk with you about this information and answer any questions you have.

If you have any questions before the nurse calls you or if you need interpreter services, please contact us at **1-800-755-2714** or **701-328-2436** or visit <https://nbs.health.nd.gov>.

We look forward to working with you to help your child grow up to be healthy.

Sincerely,



North Dakota Newborn Screening Staff

# NBS Welcome Card

**ENGLISH:** In order to best serve you, interpreter services are available upon request.

**SPANISH (LA):** A fin de servirte mejor, los servicios de interpretación están disponibles a solicitud.

**FRENCH:** Afin de mieux vous servir, des services d'interprétation sont disponibles sur demande.

**RUSSIAN:** По запросу доступны услуги переводчика в целях обеспечения наилучшего обслуживания.

**NEPALI:** तपाईंलाई सर्वोत्तम सेवा दिनको लागि, आग्रह अनुरूप दोभासे सेवाहरू पनि उपलब्ध छन्।

**SOMALI:** Si sida ugu fiican laguugu adeego, adeegyada turjubaanka ayaa la heli karaa markii la codsado.

**SWAHILI:** Ili kuwahudumia bora zaidi, huduma za ukalimani zinapatikana kwa ombi.

**ARABIC:** بلطالما دن ع ئي فو فغرا لما تم جرتالما تادمخ حاجت، ئىلئشم ئقو يربط لفتدمخ.

**BOSNIAN:** Kako bismo vam pružili najbolje usluge, usluge prevodenja će vam biti dostupne na zahtjev.

**KURDISH:** اواد رگهئ، ئار ئىگرمو ئىرازو گتەمژخ، ئىهكەب تەتەمژخ موئش ئىرئشراقەب هب ئىزئاوتەب ئهوهئ وەب هتسەدرەب ل، تەئزەكەب.

**FULANI:** Ngam huuwa neeki ma no woodata, kuude nantinoobe do waagi to dabbitida.

**HAITIAN CREOLE:** Pou sèvi-ou pi byen, sèvis entèprèt yo disponib sou demann.

**CHINESE:** 为了给您最好的服务，口译服务可按需提供。



# Car Seat Sticker



## CHILD EMERGENCY CONTACT

**MEDICAL ID CARD  
ENCLOSED**

NORTH  
**Dakota** Be Legendary.  
Health & Human Services

Please use this **EMERGENCY INFORMATION** card/adhesive pouch on your child's car seat. Be careful to not cover up any car seat safety instructions. Place the pouch either on the side or back of the car seat in an area free from car seat safety information. In emergencies, young children are transported to a medical facility in their car seat so this information is vital.

NAME	
NICKNAME	BIRTH DATE
PARENT/GUARDIAN	PHONE
EMERGENCY CONTACT	PHONE
MEDICAL PROVIDER	PHONE
ALLERGIES	
MEDICAL INFORMATION	

# NBS Care Coordination Pathway | Assessment

NBSPATIENT3, 2years11months SEX Male DOB Jan-04-2019 (3y 0m)



Amy BURKE

LOGOUT

Coordinate

Patient Summary

Medicines Viewer

Timeline

External Record

Pathway

Images

Circle of Care

Laboratory Results Flow Sheet

## Patient Tasks



### NBS Initial Assessment

Show

For

Group By

#### Today

There are no tasks to display.

#### Upcoming

NBS Initial Assessment  
Newborn Screening  
Due in 8 days

#### References

Add Document Upload

Enroll in Pathway

## NBS Initial Assessment

Show History

[Insurance](#) | [Maternal Profile](#) | [Family History](#) | [Newborn Screening History](#) | [Medications](#) | [Nutrition](#) | [Interventions and Treatments](#) | [Durable Medical Equipment](#) | [Recent Encounters](#) | [Development Milestones](#) | [Quality of Life](#) | [Transportation](#) | [Services](#) | [Patient Follow Up](#)

### Demographics

Alias Name

Family State of Residence at Birth

Gestational Age at Birth

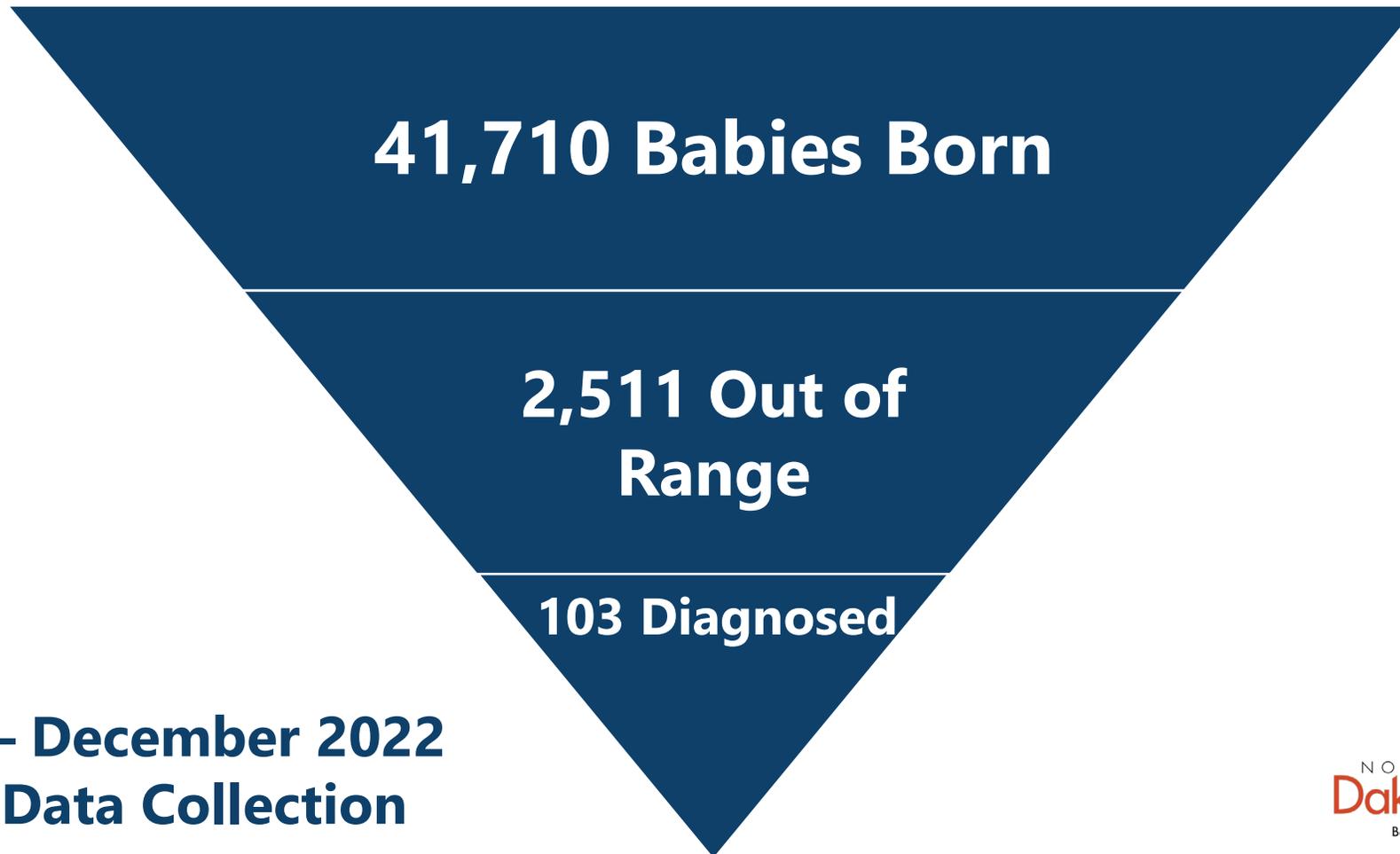
Family County of Residence at Birth

### Problems

Problems Reviewed Today

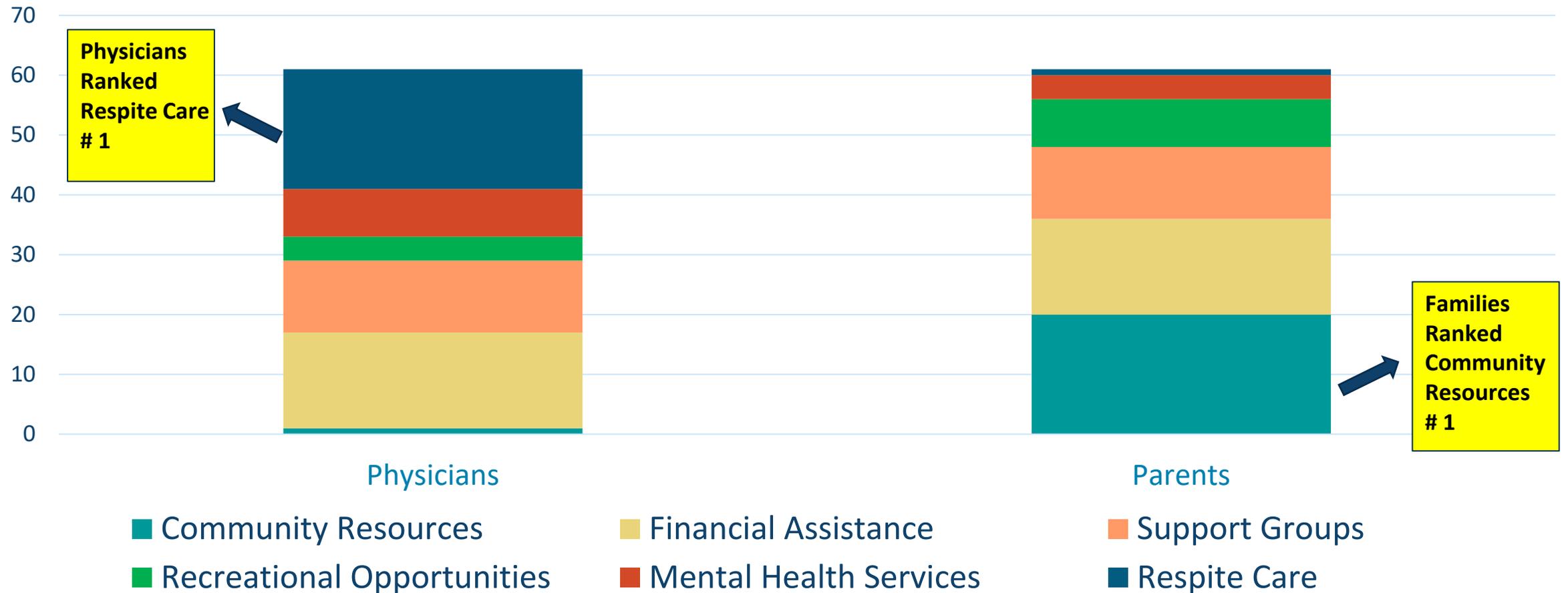
[Choose Problems](#)

# Referrals & Diagnoses Outcomes



**January 2019 – December 2022**  
**4 Years of Data Collection**

# Physician vs. Parent Ranking of Services





# Newborn Screening's Junior Ambassadors



**SPECIAL HEALTH SERVICES  
FINANCIAL COVERAGE  
PROGRAM**

**SPECIAL HEALTH SERVICES UNIT  
NORTH DAKOTA DEPARTMENT OF HEALTH & HUMAN SERVICES**



# FINANCIAL COVERAGE PROGRAM

- Helps families pay for medical services for eligible children, youth, and young adults who require specialty care to diagnose and treat their chronic health conditions
- Considered “payer of last resort”
  - Gap fill for eligible services after primary insurance
  - If child is uninsured, SHS will pick up covered expenses
- SHS covers child’s eligible condition, not the whole child



# DIAGNOSTIC SERVICES

- Promotes early diagnosis of SHS-eligible medical conditions
- Services can be covered until a diagnosis is confirmed or ruled out
  - If suspected condition is an eligible condition
- SHS provides coverage for eligible services only
- Diagnostic Program does require financial eligibility
- Once a diagnosis is confirmed – child can then apply for Treatment Services

# TREATMENT SERVICES

- Services are covered for children with confirmed eligible condition
- Families must meet medical and **financial eligibility** criteria at 185% of the federal poverty level
- If families are over income guidelines, they are still eligible, however they will have a cost-share (monthly spend down)
  - Families still benefit even if they do not see SHS pay a claim
    - Billed at the ND Medicaid rate



## Welcome to North Dakota's Newborn Screening Website!

Here you will find information and resources for parents and providers on Newborn Screening in North Dakota. Newborn screening is a state health service that reaches each of the nearly 4 million babies born in the United States each year. It ensures that all babies are screened for rare, but serious health conditions at birth. For babies identified with a health condition, early detection allows providers to start treatment before the baby becomes symptomatic and harmful effects happen.



### Newborn Blood Spot Screening

Newborn screening is a state public health service that reaches each of the nearly 4 million babies born in the United States each year.



### Newborn Hearing Screening

Early newborn hearing detection and intervention program.



### Pulse Oximetry Screening

Find helpful information and resources about critical congenital heart disease in newborns.

<https://www.hhs.nd.gov/cfs/newborn-screening>



## Information for Providers

This information will help guide your discussion with parents who have a child with an abnormal newborn screening result.



bitly



### Education

How to collect newborn bloodspot screening specimens and education modules.



### Order Forms and Materials

Order forms and materials.



### List of Conditions Screened in ND

Newborn screening list of disorders and fact sheets.



### Resources

Communicating results with your patients.



### Courier Services for Newborn Screening Specimens

Meadowlark Logistics offers daily courier services for newborn screening specimens for all the birthing facilities in North Dakota, as well as various clinics throughout the state.



### Newborn Screening Timeliness & Poor Quality Dashboard

Currently Under Construction.



### Newborn Screening in Home Birth Settings

Newborn screening videos for infants born at home.



### Reportable Newborn Screening Conditions

Report a newborn screening condition.



### Frequently Asked Questions for Providers

Additional information for providers.

## State NBS Forms

[Newborn Screening Brochure Order Form](#) +

[Newborn Screening Refusals](#) +

[Newborn Screening Return of Blood Spot Card Request](#) +

[Request Newborn Screening Results](#) +

[Car Seat Sticker](#) +

## State Hygienic Laboratory Forms

[Request Access to View Newborn Screening+ Results](#)

[Request Newborn Blood Spot Cards](#) +

# Medical Record

## Personal Details

Your first name and initial \_\_\_\_\_

Nationality \_\_\_\_\_

Address ( street and number), see instructions. \_\_\_\_\_

City, town, street and ZIP code, see instructions. \_\_\_\_\_

Phone Number \_\_\_\_\_

Last name \_\_\_\_\_

No. \_\_\_\_\_

Document No. 38520-1  
Number 1 \_\_\_\_\_  
Number 2 \_\_\_\_\_

*The number above is required.*

## Status

Check only one box.

- ▶ *Checking a box for confirmation (See instructions on page 12)*
- Single
- Married
- You  Spouse
- Divorced
- Others

## Income

1 It is a process to allow an organization to focus resources on

**NEED ACCESS TO  
NEWBORN BLOOD  
SPOT SCREENING  
RESULTS?**

**SEND REQUESTS TO  
[JBMeyer@nd.gov](mailto:JBMeyer@nd.gov)**

# QUESTIONS?

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**Newborn Screening:**  
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**701-328-4534**

