



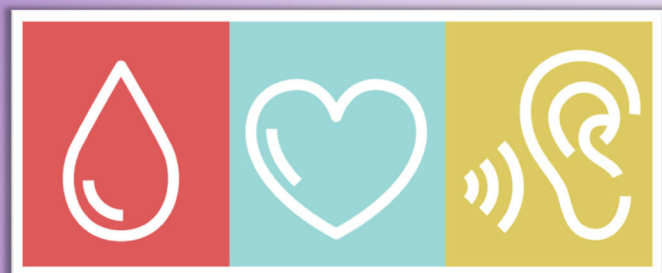
# FLORIDA NEWBORN SCREENING Newsletter

WINTER 2023

VOLUME 1: ISSUE 1

## WHAT IS NEWBORN SCREENING?

Newborn Screening (NBS) is a population-based public health program within the Florida Department of Health (DOH). NBS identifies certain rare conditions which may not be diagnosed before the onset of symptoms, which may, in some cases, be too late to prevent health issues. NBS programs are found in every state and in many countries throughout the world.



**Blood Spot Collection**   **Critical Congenital Heart Disease**   **Hearing Screening**

## WHAT IS THE PURPOSE OF NEWBORN SCREENING?

NBS **blood spot** testing can detect metabolic, endocrine, hemoglobin, pulmonary, and various other conditions. Infants born with these conditions may appear healthy at birth, and there may be no known family history. Early identification, along with timely and appropriate treatment, can be the difference between healthy development and potentially life-threatening problems.

**Pulse oximetry** testing is designed to detect some critical congenital heart diseases (CCHD). CCHDs affect the body's ability to maintain healthy oxygen levels and often require surgical correction. Screening is quick and painless and is a simple measurement of the oxygen saturation present in the infant's right hand and either foot.

**Hearing screening** provides early detection and intervention to improve communication, education, and overall social development for children who are deaf or hard of hearing.

## THE NEWBORN SCREENING SYSTEM

- Florida's NBS Program is a comprehensive system serving approximately 200,000 babies born each year.
- For the NBS system to work, partnerships are vital to the success of this public health program.
- NBS consists of Bureau of Public Health Laboratory (BPHL)-Jacksonville, NBS Follow-up Program, Newborn Hearing Screening Program and Early Hearing Detection and Intervention also within CMS in Tallahassee, Genetics and Newborn Screening Advisory Council, referral centers, birthing facilities, and health care providers.



## NBS: More Than Just PKU...

### THE BEGINNING OF NEWBORN SCREENING

Robert Guthrie, MD, PhD is considered the “father of newborn screening.” Dr. Guthrie’s son had an intellectual disability, and through his research efforts to try to determine the cause, he became a parent advocate. At the time, a metabolic condition called phenylketonuria (PKU) was a leading cause of intellectual disability each year.

Researchers found that a special diet could manage the progression of PKU, but frequent testing to monitor phenylalanine levels was needed. At the time, traditional testing methods were complicated and expensive.

Dr. Guthrie and his colleagues were tasked with developing a simpler and more cost-effective method of testing. A method of collecting drops of blood on a special filter paper was developed and became known as “Guthrie Cards.” Four states began using this testing method in 1963, followed by Florida in 1965, as a standard of care for all newborns.

### SPOTLIGHTING PKU

It is only fitting to spotlight PKU since this is where it all started. Classic PKU is a condition in which the body is unable to break down certain building blocks of proteins, known as amino acids. Individuals with PKU cannot break down the amino acid phenylalanine. If left untreated, PKU can cause brain damage or even death. However, if the condition is detected early and treated, individuals with PKU can lead healthy lives.

PKU is a condition with multiple forms, each with different treatments and outcomes. Classic PKU is the most severe form. Babies with PKU usually seem healthy at birth, but signs of the condition begin to appear around 6 months of age. Signs of PKU include irritability, seizures (epilepsy), dry and scaly skin (eczema), musty body odor, pale hair and skin, and developmental delays. Many of these signs may occur when a baby eats foods the body cannot break down.

Stay tuned for spotlights on NBS conditions in future newsletters.

### WHAT CONDITIONS ARE INCLUDED IN NBS?

In Florida, 55 conditions are screened using the Guthrie Card. These conditions include:

- **Metabolic Conditions:** The largest group of conditions which includes amino and organic acidemias, fatty oxidation disorders, enzyme conditions, and lysosomal storage disorders.
- **Endocrine Conditions:** Congenital Adrenal Hyperplasia (CAH), Congenital Hypothyroidism (CH).
- **Hemoglobin Conditions:** Sickle Cell (SC), related diseases, and traits.
- **Cystic Fibrosis (CF).**
- **Severe Combined Immune Deficiency (SCID).**
- **Spinal Muscular Atrophy (SMA).**

### What's in a NAME?



Newborn Screening



PKU, Infant Metabolic Screen

**Newborn screening encompasses more than just the PKU test. It is important to refer to the screen as “Newborn Screening” when educating families and other health care professionals. Calling the screen “the PKU test” or “the Infant Metabolic Screen” is inaccurate and can create confusion for families and physicians.**





## Top Performing Facilities



Florida hospitals and non-hospital birth providers receive quarterly grades based on each facility's performance in meeting the NBS performance benchmarks.

The three NBS performance benchmarks:

- 1 Less than 1% of all specimens submitted are unsatisfactory for testing.
- 2 Specimens are received at BPHL-Jacksonville within three days of collection.
- 3 At least 90% of infants have critical congenital heart disease (CCHD) screening data reported.

# CONGRATULATIONS!

Top straight A+ facilities for 2023, Quarter 4!

### HOSPITALS

- Baptist Medical Center Beaches
- Baptist Medical Center Jacksonville
- Bethesda Hospital East
- HCA Florida Gulf Coast
- HCA Florida St. Petersburg Hospital
- HCA Florida Trinity Hospital
- Holmes Regional Medical Center
- Memorial Hospital Miramar
- Memorial Regional Hospital-Hollywood
- Oviedo Medical Center
- Sacred Heart Hospital
- Sarasota Memorial Hospital
- St. Joseph's Hospital North
- St. Vincent's Medical Center Southside
- Studer Family Children's Hospital
- UF Health Flagler Hospital
- UF Health North
- Winter Haven Women's Hospital

### PEDIATRICIANS

- AdventHealth Medical Group Multispecialty at New Tampa
- AdventHealth Medical Group Pediatrics at Daytona Beach
- All About Kids Pediatrics
- Baycare Pediatrics
- Boca Raton Pediatrics
- C. L. Brumback Primary Care-Lantana Clinic
- Carrollwood Health Center
- Children's Care-Davis
- Children's Care-Heritage
- Children's Medical Center-Ormond Beach
- Clermont Pediatrics
- Cleveland Clinic Martin Health Pediatrics-Port St. Lucie
- Cleveland Clinic Martin Pediatrics-Stuart
- Community Health Centers of Pinellas-Lealman
- Community Health of South Florida, Inc.-Homestead
- Community Health of South Florida, Inc.-Miami
- Countryside Pediatric Care
- Doris Ison Community Center
- Ellis Pediatrics
- Halifax Health Keech Center
- Helgema and Liou Pediatrics
- Ingram Pediatrics, PA

### PEDIATRICIANS

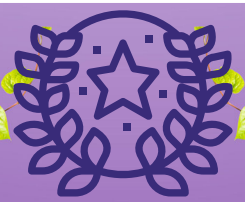
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- Jackson North Medical Plaza
- Just For Kids Pediatrics
- Lee Community Healthcare-Lehigh Acres
- Dr. Dario Lirman
- Middleton Pediatrics
- Nichols Pediatrics Center
- Pediatric Associates Bloomingdale
- Pediatric Associates Hialeah
- Pediatric Associates of Jacksonville-Ponte Vedra
- Pediatric Associates of St. John
- Pediatric Associates of Weston
- Pediatrics of Tampa Bay
- Premier Pediatrics
- South Miami Health Center
- Tallahassee Primary Care Associates
- Tampa General Medical Group, Inc.
- Turley Family Health Center
- U Health Pediatrics-Miami
- UF Health Millhopper
- UF Health Pediatrics-Magnolia Park
- Waldemere Medical Plaza
- Watson Clinic North Pediatrics
- Winter Garden Childrens HC

### MIDWIVES

- Stand and Deliver Midwifery, LLC
- Sweet Grace Midwifery
- Tampa Bay Midwives

See how Florida hospitals and non-hospital birth providers are performing by reviewing facility grades.



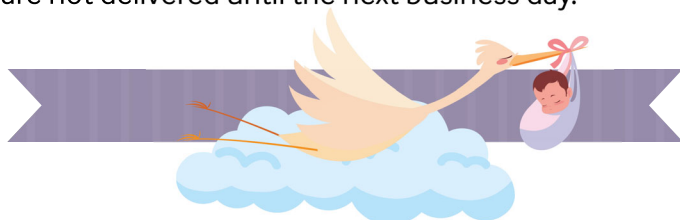
## CHECK THIS OUT

### Challenged by Transit Time?

- Facilities with exemplary transit rates send specimens as soon as possible after drying, sometimes on the day of collection, and ship packages Monday through Saturday.
- Collect specimens between 24-48 hours of age (the sooner the better).
- Collect specimens at least 4-5 hours before a scheduled courier pick-up to allow for ample drying time. Use overnight shipping rather than priority shipping; don't wait until the next day. Do not batch specimens, instead ship them daily.



- The BPHL-Jacksonville Laboratory is open to receive, and test specimens Monday through Saturday, except for state holidays.
- Specimens must be received at the laboratory by noon to be accessioned and begin testing the same day.
- Packages mailed on Fridays should be marked for Saturday morning delivery, otherwise the specimens are not delivered until the next business day.



I LIKE KNOWING WHAT HAPPENS NEXT

Recent conditions added to the screening panel and new conditions coming soon have increased the need for more blood to accurately complete screening for all conditions. Specimen cards with **seven collection circles** will be distributed to collection facilities in early 2024.

1) Do not touch sample area

PLEASE FILL IN THIS CARD USING CAPITAL LETTERS ONLY. ALL FIELDS MUST BE FILLED OUT COMPLETELY TO AVOID DELAY. ILLEGIBLE HANDWRITING AND INCOMPLETE INFORMATION WILL RESULT IN DELAYS. DARKEN ALL CIRCLES THAT APPLY:  REFUSED  INFORMATION ONLY | STATUS:  DECEASED  ADOPTION  NICU  MISCENIM LEUIS (continued on back)

INFANT'S INFORMATION: Infant's Last Name, Infant's First Name, Hospital of Birth, Infant's Birth Tracking Number, Infant's Birth Date, Transfusion Date, Time assumed

MOTHER'S/FATHER'S CONTACT: Mother's Last Name, Mother's First Name, Mother's Address, City, State, Zip Code, Mother's Date of Birth, Mother's or Contact's Telephone Number, Alternate Telephone Number

INSURANCE INFORMATION: Insurance Group, Relationship to insured, Name of Insurance Company

PRIMARY CARE / FOLLOW UP PHYSICIAN INFORMATION: Physician's Last Name, First Name, Physician's Telephone Number, NPI Number

ORDERING PHYSICIAN INFORMATION: Physician's Last Name, NPI Number

COLLECTION FACILITY INFORMATION: Collection Facility Name, Laboratory ID

MAIL TO (SUBMITTER INFORMATION): Facility Name (Hospital or Clinic), Address, City, State, Zip Code

STATE LAB USE ONLY: FLO0000000000, FLO0000000000

MAIL SPECIMENS TO: STATE OF FLORIDA-BUREAU OF PUBLIC HEALTH LABORATORIES 1217 N PEARL ST. JACKSONVILLE, FL 32202 (904) 791-1645

2) Do not use if damaged or after expiry date.



Florida Department of Health's  
 Division of Children's Medical Services  
 Florida Newborn Screening Program  
 850-245-4201  
 CMS.NBS@FLHealth.gov

For more info, visit: [FloridaNewbornScreening.com](http://FloridaNewbornScreening.com)

