



## FLORIDA NEWBORN SCREENING (NBS) NURSING STAFF

**Nurses are an important part of Florida's newborn screening process.** From the bedside collecting the blood spot specimens and performing critical congenital heart disease (CCHD) screenings, to working in critical roles within the NBS Follow-up Program. The NBS Nursing Unit is staffed by a nursing supervisor and eight registered nurse consultants. The NBS program director and marketing manager are also registered nurses. Prior to joining NBS, these nurses have clinical experience in mother baby, neonatal intensive care units (NICU), and pediatric hospital settings, which is beneficial in performing job duties within NBS.

The primary role of NBS nurse consultants is to review out-of-range results released by the Department's Bureau of Public Health Laboratories each day and confirm next steps in the plan of care for each baby with out-of-range results. If results are borderline out-of-range, a NBS nurse will contact the hospital or primary care provider to provide results and instructions for when to collect a repeat specimen. If results are critically out-of-range, the NBS nurse will refer the baby to a contracted NBS referral center for a diagnostic evaluation. NBS nurses also manage caseloads for each of the core conditions on the NBS panel, reviewing diagnostic information from the referral centers to ensure each baby has received timely evaluation, diagnosis, and treatment, if needed.

The NBS nurses also offer technical assistance visits to collection facilities across the state to improve the rate of satisfactory specimen collection, timely submission of specimens to BPHL-Jacksonville, and reporting of CCHD screening outcomes (See page 3). TA visits include communication with facility contacts, visiting facilities to provide educational presentations, and observe the NBS process from specimen collection to submission. The goal of this outreach is to promote the best possible health outcomes for every baby by ensuring that facilities submit high quality specimens in a timely manner.

## Florida's NBS Program Nurses

**Emily Reeves, BSN, RN, CPN:** *Follow-up Director*

**Kristin Barnette, RN:** *Nursing Supervisor*

*Registered Nurse Consultants*

- **Sandra Crump, BSN, RN**
- **Kirstie Gordon, RN**
- **Chantel Alfred, BSN, RN**
- **Stephane Crumbaker, RN**
- **Tori Davis, BSN, RN**
- **Amy Fritsch, IBCLC, RN**
- **Karli Clark, RN**
- **Gail Simpson, DNP, RN**

**Jessica Williams, BSN, RN:** *Marketing Specialist*



*"The NBS nurses are a phenomenal team whose dedication to the mission of NBS and serving Florida's smallest residents is evident in all they do."*

Kristin Barnette, RN  
Nursing Supervisor

NBS nurses are available Monday-Friday from 8 a.m.-5 p.m. by calling the toll-free nurse line at 866-804-9166. In addition, a NBS nurse is on call every Saturday to relay time critical results to the appropriate referral center.



# SPOTLIGHT: MPS I and MPS II

**Mucopolysaccharidosis type I and II** both are inherited conditions that affect many different parts of the body. They are considered lysosomal storage disorders because individuals affected have lysosomes (the recycling center of each cell) that cannot break down certain types of complex sugars. This causes undigested sugar molecules and other harmful substances to build up in cells throughout the body, resulting in a variety of symptoms.

## Mucopolysaccharidosis type I, (MPS I)

If a baby has MPS I, their body is missing or making non-working copies of an enzyme called **alpha-L-iduronidase (IDUA)**. When these enzymes are not working correctly, the baby's body cannot break down large sugar molecules called glycosaminoglycans (GAGs) into smaller components. This causes sugar molecules and other harmful substances to build up in cells throughout the body, resulting in the many signs and symptoms of MPS I.

MPS I comprises a wide spectrum of severity and individuals may be categorized anywhere from severe to attenuated (less severe). Along with age of onset, the symptoms and long-term outcome within the spectrum of disease vary widely. For some babies with MPS I, detecting the condition early and beginning proper treatment may help prevent or delay some of the severe health outcomes associated with the condition.

Babies with severe MPS I usually develop serious signs and symptoms in the first year of life and have a rapid disease progression. In the attenuated form of MPS I, symptoms are generally milder and do not appear until later in childhood.

### Early signs of MPS I:

- Soft out-pouching around the bellybutton or lower abdomen
- Large head
- Distinctive facial features that appear coarse
- Varying degrees of developmental delay and learning disabilities
- Swollen abdomen
- Clouding of the eye (corneal clouding)
- Hearing loss
- Frequent runny nose

## Mucopolysaccharidosis type II, (MPS II)

If a baby has MPS II, their body is missing or making non-working copies of an enzyme called **iduronate 2-sulfatase (I2S)**. When these enzymes are not working correctly, the baby's body cannot break down large sugar molecules called glycosaminoglycans (GAGs) into smaller components. This causes sugar molecules and other harmful substances to build up in cells throughout the body, resulting in the many signs and symptoms of MPS II.

There are two types of MPS II: the neuropathic form (more severe) and non-neuropathic form (less severe). MPS II occurs almost exclusively in males, however it has been reported in a few females.

Children will appear healthy at birth, with signs of severe MPS II usually beginning between ages two and four and progressing more rapidly than in attenuated MPS II. Individuals with the attenuated form of MPS II usually do not develop symptoms until later in childhood, or even adolescence.

### Early signs of MPS II:

- Full lips, rounded cheeks, broad nose, enlarged tongue, large head
- Enlarged vocal cords causing deep, hoarse voice
- Frequent upper respiratory infections
- Poor vision, sleep apnea, seizures
- Swollen abdomen, soft out-pouching around the bellybutton or lower abdomen (hernias)
- Thick, non-stretchy skin
- Pebble like white growths on back and upper arms
- Frequent ear infections and hearing loss
- Short stature, joint stiffness (contractures)
- Severe intellectual disabilities, loss of basic skills, functions, and intelligence



# TOP PERFORMING FACILITIES

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



## Performance Benchmark 1

Less than 1% of all specimens submitted are unsatisfactory for testing.

## Performance Benchmark 2

Specimens are received at BPHL-Jacksonville within three days of collection.

## Performance Benchmark 3

At least 90% of babies have critical congenital heart disease screening data reported.

# congratulations!

## TOP CONTINUOUS A+ FACILITIES IN 2024, QUARTER 3

### HOSPITALS

- AdventHealth Celebration
- AdventHealth Fish Memorial
- AdventHealth Waterman
- AdventHealth Winter Park
- Baptist Hospital Pensacola
- Baptist Medical Center Beaches
- Bayfront Health St. Petersburg
- Bethesda Hospital East
- Cleveland Clinic Martin North Hospital
- Cleveland Clinic Traditions Hospital
- HCA Florida St. Petersburg Hospital
- HCA Florida Trinity Hospital
- HCA Florida University Hospital
- Jackson Memorial Hospital
- Memorial Hospital West
- Sarasota Memorial Hospital
- Tampa General Hospital
- UF Health at Jacksonville
- UF Health Flagler Hospital
- UF Health Leesburg Hospital
- Winter Haven Women's Hospital

### MIDWIVES

- Jen Robert's Midwifery and Massage-  
West Palm Beach
- Mary Hamelin, LLC-Tampa

### PEDIATRICIANS

- Baycare Medical Group-Palm Harbor
- Baycare Medical Group-South Tampa
- Bayside Pediatrics-Tampa
- Broward Community Health Center-  
Pompano Beach
- Community Health of South Florida, Inc-  
Homestead
- East Lake Pediatrics-Trinity
- First Choice Kid Care-Cape Coral
- Halifax Family Practice Clinic-Daytona  
Beach
- Halifax Health Keech Center-Daytona  
Beach
- Ingram Pediatrics, PA-Plantation
- Internal Medicine & Pediatrics of Tampa  
Bay
- Jackson North Medical Plaza-North  
Miami Beach

### PEDIATRICIANS

- Kids Health Alliance-Ocala
- Lake Nona Pediatrics-Orlando
- Lee Physicians Group Associates in  
Pediatrics-Cape Coral
- Lee Physicians Group Pediatrics  
Coconut Point-Estero
- Martin Luther King Clinic-Homestead
- NCH Physicians Group Pediatrics-Naples
- North Pinellas CMC-New Port Richey
- Pediatrics Associates Riverview
- Pediatrics Healthcare Alliance, PA-  
Brandon
- Pediatrics Healthcare Alliance-Apollo  
Beach
- Pediatrics in Brevard-Viera
- PPC Pediatrics Cape Coral
- South Miami Health Center-South Miami
- Tallahassee Memorial Family Medicine-  
Blountstown
- U Health Pediatrics-Miami
- UF Health Millhopper-Gainesville
- UF Health Pediatrics, Magnolia Park-  
Gainesville
- Watson Clinic North Pediatrics-Lakeland

See how Florida hospitals and non-hospital birth providers are performing by reviewing facility grades on [FloridaNewbornScreening.com](http://FloridaNewbornScreening.com).

# FLORIDA NEWBORN SCREENING: THE “WHY” BEHIND NEWBORN SCREENING BENCHMARKS.

## THE NBS BENCHMARKS (found on page 3 of the NBS newsletter)

- Created to give babies of Florida the best possible chance for early diagnosis and intervention.
- Identifies birthing facilities in need of assistance from a NBS nurse to identify areas of improvement to meet benchmarks.
- National standard for timely reporting of newborn screening results is within 5 days of birth.
- More than 20 conditions on Florida’s screening panel are time critical.
- Proper collection along with timely submission and processing of specimens allows for early identification and can prevent disability and death.

## WHY ACCURACY MATTERS

A full-term, well newborn was born at a large birthing hospital. The NBS card was completed but listed the date of birth as the date of collection.

- Results for **congenital hypothyroidism** were calculated as NORMAL based on the reported age at collection.
- At one month of age, the baby was referred by their primary care provider (PCP) to an endocrinologist at a NBS referral center. It was discovered that the specimen was **collected** on the day after delivery at **25 hours of age**.
  - Results of the NBS specimen **would have been** interpreted as **CRITICAL** if the initial collection date was correct.

**Diagnosis:**

**Congenital Primary Hypothyroidism**

## WHY TIMELINESS MATTERS

A full-term, well newborn was born at a large birthing hospital. The NBS specimen was collected at 50 hours of age (*recommended at 24 hours of age*) and the baby was routinely discharged home.

- **Day of Life (DOL) 3:** Initial NBS specimen collected.
- **DOL 9:** Baby was **admitted in crisis** to a NICU at a different hospital. NICU admission specimen was collected.
- **DOL 11:** NICU admission specimen received at the NBS Laboratory. **Galactosemia** results were **panic level**. Baby was referred to a genetic referral center.
- **DOL 14:** Initial specimen from birth hospital was received. Galactosemia results were also panic.

**Diagnosis:**  
**Galactosemia**

## WHY QUALITY MATTERS

A full-term, well newborn was born at a large birthing hospital. The NBS specimen was collected at 26 hours of age and the baby was routinely discharged home.

- The NBS specimen was **unsatisfactory** for incomplete saturation and quantity not sufficient.
- At two and a half months of age, a repeat NBS specimen was collected by the primary care provider.
- Results of the repeat NBS specimen had a **panic citrulline level**.
- Baby was immediately referred to a genetics referral center for assessment and diagnostic evaluation.

**Diagnosis:**  
**Citrullinemia, Type 1**



## YOUR FEEDBACK IS VALUABLE

How are we doing? The Newborn Screening Program created quarterly newsletters to introduce the NBS Program to healthcare providers throughout Florida. The goal is to increase awareness about the importance of newborn screening.

Please complete a short survey regarding the NBS newsletter and provide your contact information for a chance to win some awesome NBS merchandise. The winner will be announced in the Winter 2024 newsletter.



[SurveyMonkey.com/r/Z2QFPMH](https://www.surveymonkey.com/r/Z2QFPMH)

## FLORIDA DEPARTMENT OF HEALTH

Division of Children’s Medical Services  
Florida Newborn Screening Program  
850-245-4201 | [CMS.NBS@FLHealth.gov](mailto:CMS.NBS@FLHealth.gov)

**For additional information, visit**  
[FloridaNewbornScreening.com](https://www.FloridaNewbornScreening.com)

*Florida has a very broad public records law. Most written communications to or from state officials regarding state business are public records and will be available to the public and media upon request. Your email communications may be subject to public disclosure.*