

WHAT IS NEWBORN SCREENING?

Newborn screening (NBS) is the standard of care for all babies born in Florida. The process is comprised of three parts: blood spot specimen, pulse oximetry (oxygen), and hearing screenings.

The blood spot specimen is sent to the Florida Department of Health's laboratory to be screened for more than 55 conditions, including cystic fibrosis (CF). Screening includes evaluation for the presence of CF-causing variants.

WHAT IS A VARIANT?

Genes are the blueprints for our bodies. Every baby gets a copy of all genes from both of their parents. A variant is a part of a gene that doesn't work like it's supposed to.

WHAT IS CYSTIC FIBROSIS?

CF is an inherited condition which affects the lungs and can cause issues with digesting food. Lifelong medical treatment and monitoring is required. A person must have **two or more** CF-causing variants to be diagnosed with cystic fibrosis.

WHAT IS A CYSTIC FIBROSIS CARRIER?

Individuals with **one** CF-causing variant are a carrier. Florida's screening panel looks for all known CF-causing variants, so the odds of there being a second, undetected variant are very low.

CAN A CYSTIC FIBROSIS CARRIER DEVELOP THE DISEASE?

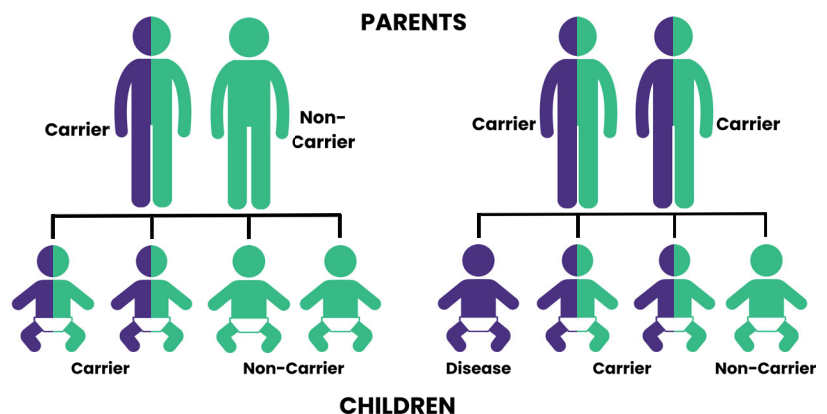
No. Individuals with a single variant should not expect any health concerns related to the variant, but it is important that this information be part of your baby's medical record.

WHAT HAPPENS NEXT?

- There is no additional testing required at this time.
- Consider talking to your primary care provider or a genetic counselor.
- Share this information with blood relatives, they may also be carriers.
- When your child is older, help them understand their carrier status so they can make informed choices when starting a family.

SHOULD PARENTS BE TESTED?

- It is a good idea for parents to know their CF carrier status as CF variants are inherited from biological parents.
- Speak with either your or your baby's primary care provider about testing and genetic counseling for planning of future children.
- If both parents are carriers, there is a chance of CF in each child they have.



See reverse for additional information.

BOTH PARENTS WERE TESTED FOR CYSTIC FIBROSIS AND NOTHING WAS FOUND.

If both parents were already tested for CF-causing variants but nothing was found, parents may wonder how their baby has a CF variant. CF screening performed through commercial laboratories is often limited to the most common CF-causing variants. Florida's screening panel includes all known CF-causing variants, so it is possible to detect a variant not included on the prenatal test.

WHERE CAN PARENTS GET MORE INFORMATION?

If you have questions or want to learn more about being a CF carrier:

- Contact either your health care provider or your child's pediatrician for a referral to a genetic counselor for a consultation, if desired.
- Visit the Cystic Fibrosis Foundation's website
 - [CFF.org/Intro-CF/Carrier-Testing-Cystic-Fibrosis](https://www.cff.org/Intro-CF/Carrier-Testing-Cystic-Fibrosis)
- Visit the Florida Newborn Screening Program website
 - [FloridaHealth.gov/NewbornScreening](https://www.floridahealth.gov/NewbornScreening)
- Contact the Florida Newborn Screening Program Nursing Unit
 - Call 866-804-9166