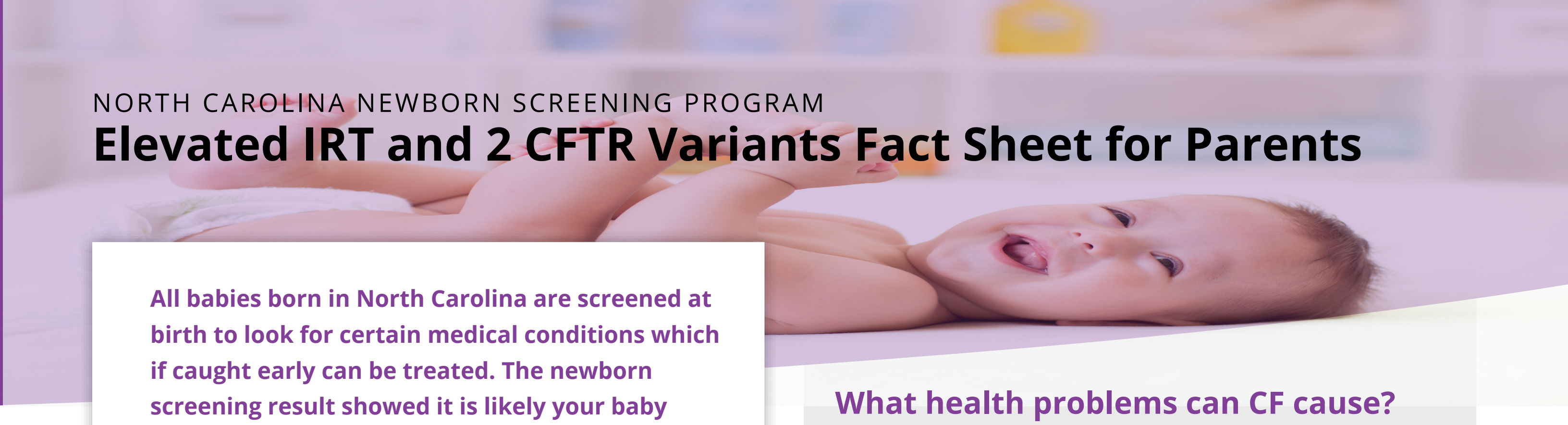

NORTH CAROLINA NEWBORN SCREENING PROGRAM

Elevated IRT and 2 CFTR Variants Fact Sheet for Parents

All babies born in North Carolina are screened at birth to look for certain medical conditions which if caught early can be treated. The newborn screening result showed it is likely your baby has cystic fibrosis (CF) or a related disorder. Your baby will be referred to a specialist for additional testing to know for sure.

What was found on the newborn screen?

The newborn screen that was collected at birth found that your baby has a high IRT level. IRT which stands for “immunoreactive trypsinogen” is a protein made by the pancreas. IRT can be elevated for several reasons, including cystic fibrosis (CF). Because the IRT was elevated, your baby’s blood spots were tested for the 139 most common changes (variants) to the gene that causes CF (CFTR gene). Your baby was found to have two disease-causing changes in the cystic fibrosis gene.

What does this mean?

It is very likely that your baby has CF or a related disorder.

What is cystic fibrosis (CF)?

CF is a genetic disease that causes thick, sticky mucus to build up. This mucus can lead to problems with breathing and lung infections. This mucus can also make it harder for the body to break down food.

What happens next?

Your baby’s doctor will help arrange for more testing at a cystic fibrosis center with specialists familiar with CF. The specialists will want to see your child as soon as possible to start treatment. They will arrange for a sweat test to confirm your child has CF.

What health problems can CF cause?

CF is different for each child. CF is a lifelong disease that may result in serious health problems. Children with CF can develop:

- Poor weight gain
- Greasy or oily bowel movements
- Poor growth
- Coughing and wheezing
- Lung infections

Children with CF can benefit from prompt and careful treatment.

How is this condition managed?

Although CF cannot be cured, the symptoms can be treated. Possible treatments can include:

- Prescription enzymes to help absorb food better
- Healthy, high-calorie diet
- Vitamins
- Medications to prevent infections and help with breathing
- Ways to help clear mucus from the lungs

Children with CF should see their regular doctor and a doctor who specializes in CF at an accredited CF center.

Where do I go for more information?

Use your phone’s camera to scan the QR code below.

Cystic Fibrosis Foundation: https://www.cff.org/

NC DEPARTMENT OF
HEALTH AND HUMAN SERVICES

State of North Carolina Department of Health and Human Services

www.ncdhhs.gov

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