Cystic Fibrosis (CF) Newborn Screening Fact Sheet for Parents

Before your baby came home from the hospital, a small amount of blood was taken for newborn screening (NBS). NBS is a statewide program to identify babies who may have certain health problems. Babies are screened for these problems because the earlier a child is diagnosed and treated, the healthier the child will be.

WHY did my baby's CF newborn screening test indicate more testing was needed?
Your baby's test showed a change in one or both of the CFTR genes meaning your baby *might* have CF. Everyone has 2 CFTR genes-1 gene comes from mom and 1 gene comes from dad. Only if the baby inherits abnormal versions of this gene from each parent, will he or she have CF.

WHAT does this mean?
Most babies with this test result will be **healthy** and **NOT** have CF. However, more testing is needed because some babies with this test result will have CF.

WHAT is CF?
Cystic fibrosis is a medical condition that mainly affects the lungs (*breathing problems and lung infections*) and digestion (*poor weight gain, loose stools*). CF does NOT affect intelligence.

HOW do I find out if my baby has CF?
Another test, called a sweat test, is needed to help determine if your baby has CF. To learn about this test, please see the enclosed sweat testing fact sheet.

WHEN can my baby have the sweat test?
Your health care provider will arrange for your baby to have the sweat test at the Newborn Screening Sweat Testing Center closest to you (Arkansas Children's Hospital). In most cases, the sweat test can be done within a week.

WHAT could cause the newborn screening result to be abnormal if the sweat test shows my baby does NOT have CF?
The newborn screening test also identifies *carriers* for CF. Carriers for CF have no health problems from being a carrier and will NEVER develop CF.

WHAT is the difference between being a carrier for CF and having CF?
Carriers for CF have a change in only **1** of the 2 CFTR genes. This change causes that gene not to work correctly, but the other gene works fine so the person does NOT have CF. Someone who has CF has changes in *both* CFTR genes causing *both* CFTR genes not to work. Newborn screening identifies babies who have changes in one or both CFTR genes. Therefore further testing is required to identify whether the baby is a carrier or has CF.

HOW could my baby have CF if the test found a change in only 1 of the CFTR genes?
The test does not detect all changes in the CFTR genes. There are over 1200 different gene changes that cause CF. This is why it is important to have the sweat test to determine if your baby has CF or is a carrier for CF.

WHEN a baby is a carrier for CF, are the parents also carriers?
One or both parents can be carriers for CF when their child is a carrier. Other family members such as your parents, sisters and brothers could also be carriers for CF. The newborn screening coordinator (NBSC) you meet with will explain more about the chances of CF in your family and further testing you and you family might consider.

WHEN is the meeting with the NBSC?
You will meet with the NBSC after your baby has the sweat test. The NBSC will explain in detail the results of your baby's tests and what they mean for you and your baby. Ask your baby's health care provider about details of the appointment for the sweat test.

For more information or assistance, call the UAMS/ACH Newborn Screening Coordinator at 501-364-1100.

Information adapted from Oklahoma CF Screening Program