

Cystic Fibrosis Newborn Screening Fact Sheet for Parents & Families

What is newborn screening for cystic fibrosis?

The State of Ohio now performs newborn screening for cystic fibrosis (CF). The screening test helps find babies who might have CF so that they may be treated early. Early treatment means that there is a better chance that a baby with CF will grow-up with fewer complications and an improved quality of life.

My baby had a positive newborn screen for cystic fibrosis. What does it mean?

A positive newborn screen does not mean that your baby has cystic fibrosis. If your baby has a positive newborn screen, special testing, called a sweat test, must be done to know for sure.

Your pediatrician will refer you to Rainbow's Cystic Fibrosis Center for a sweat test to determine if your baby has CF or is a carrier of CF.

Testing will take place 2 – 4 weeks after the birth of your baby for the most accurate result. To schedule a sweat test and genetic counseling call (216) 844-3936.

What is cystic fibrosis?

Cystic Fibrosis affects breathing and digestion. CF causes the body to make thick, sticky mucus that clogs the airways of the lungs, and it can prevent the pancreas from doing its job to help digest food. In people with CF, the sweat glands also make very salty sweat.

What causes cystic fibrosis?

Cystic fibrosis is inherited when both parents carry an altered CF gene and pass it on to their child. A person who has one altered CF gene is called a "carrier." Carriers usually do not have any health problems caused by CF. When two CF carriers have children together, each baby has a one in four (25%) chance of having CF. Most children with CF do not have a family history of the disease.

What is the treatment for cystic fibrosis?

Although presently there is no cure for CF, there have been many advances in treatment. Individuals with CF must eat a healthy high-calorie diet and take special vitamins. Most people must also take medication to get more nutrients from the food they eat. To breathe better, many people with CF need help clearing mucus from their lungs each day. Some medications can also prevent lung infections and help with breathing.

Why do I need to go to a Cystic Fibrosis Center for testing?

Cystic fibrosis centers provide a team of specialists who are experts in diagnosing and treating CF. The team includes pediatric specialists, nurses, dietitians, social workers and genetic counselors.

The LeRoy W. Matthews Cystic Fibrosis Center at Rainbow is the largest and most comprehensive Center in the State of Ohio. The Center is fully accredited with the highest possible rating by the Cystic Fibrosis Foundation.

I had a negative cystic fibrosis blood test when I was pregnant. Does my baby still need a sweat test?

Yes. Any baby whose newborn screening result is positive should have a sweat test. The testing you had during your pregnancy does not detect all of the gene alterations that cause CF. Sweat testing is the best way to diagnose CF.

How is the sweat test done?

Small areas of your baby's arms or legs will be stimulated to sweat. The sweat will be collected on a piece of gauze and sent to the laboratory for analysis. The testing will take approximately one hour to perform.

Do I need to do anything to prepare my baby for the sweat test?

Do not use any lotions or creams on your baby's arms or legs the day of the test. It is okay to breast or bottle feed your baby before, during, or after the test.

How will I know the result of the sweat test?

A genetic counselor will meet with you the same day as your appointment to explain the result and next steps.

When I have the result of my baby's sweat test, will I know if my baby has cystic fibrosis?

Most of the time the result of your baby's sweat test will clearly tell you whether your baby has CF or not. However, some babies may not make enough sweat for the test to be accurate and the sweat test will need to be repeated when your baby is bigger.

The LeRoy W. Matthews Cystic Fibrosis Center at Rainbow Babies & Children's Hospital

The LeRoy W. Matthews Cystic Fibrosis Center at Rainbow is world-renowned for its care of children and adults with CF, and is fully accredited with the highest possible rating by the CF Foundation. The model of care — a multidisciplinary team approach that includes pulmonary specialists, nurses, respiratory therapists, nutritionists, social workers and other specialists — was first developed by Dr. LeRoy Matthews in the 1950's, and adopted nationwide by CF Care Centers.

Scientists at Rainbow and its academic affiliate, Case School of Medicine, are among the world's most innovative researchers, developing new treatments and leading the search for a cure for CF. The Willard A. Bernbaum Cystic Fibrosis Research Center strives to understand the basic defect of the disease and its consequences, the reasons for the lung infection and inflammation in CF and how to treat it, and methods by which the corrective gene can be introduced into the lung. The fruits of these discoveries come to the patients via The LeRoy W. Matthews Cystic Fibrosis Center and the newly opened KC and Ginny Bryan Pulmonary Diagnostic Center. At these facilities, living a long life is the goal. So successful have the Center treatments become, that Rainbow recently opened a 10 room in-patient unit which provides specialized care for its large population of adult CF patients, who are among the oldest in the nation.

The LeRoy W. Matthews
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