

Information for new Parents about their visit to Rainbow Babies and Children's Hospital Leroy W. Matthews Center for Cystic Fibrosis and The Center for Human Genetics.

Your pediatrician has explained to you that your baby's newborn screen came back positive for Cystic Fibrosis. You have been referred to Rainbow Babies & Children's Hospital Leroy W. Matthews Center for Cystic Fibrosis for a confirmatory test called a "sweat test."

How to make an appointment for testing at Rainbow.

To make an appointment please call (216) 844-3936 and inform the receptionist you would like to schedule a sweat test for cystic fibrosis newborn screening.

Sweat test appointments are scheduled on Fridays.

The test should be scheduled 2 – 4 weeks after the birth of your baby for the most accurate result.

How much time do I need for the appointment?

The actual sweat test will take approximately 60 minutes. See the section below "About the Sweat Test" for more information.

Your visit at Rainbow including meeting with a genetic counselor could take several hours in total. When you schedule your appointment you will be told how long the appointment will take.

Getting to Rainbow

Rainbow is located on Adelbert Road off 11100 Euclid Avenue in University Circle, Cleveland. It is part of University Hospitals Case Medical Center. Visit <http://rainbowbabies.org/AboutRainbow/Directions/tabid/344/Default.aspx> for directions.

Parking at Rainbow

Parking is available in the Adelbert Road Parking Garage about 100 yards up from Euclid Avenue on your left or the Cornell Road Parking Garage. Visit <http://www.uhhs.com/Facilities.aspx?ShowDetail=315&MID=99> to get a map of the campus. Complimentary Parking will be available. Please bring your parking ticket with you so it can be validated.

Getting to the Center for Human Genetics for testing

Your testing will take place at The Center for Human Genetics located in the Lakeside Building, 1st Floor, Suite 1500. For more information on this location – stop at any receptionist desk for assistance.

After checking in at the front desk of the Center for Human Genetics, you will meet with a genetic counselor that is familiar with cystic fibrosis.

Your baby will then have a sweat test to confirm whether he/she has cystic fibrosis.

About the Sweat Test

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 1 hour to perform.

Be our guest

Rainbow will provide a complimentary lunch voucher for use in the hospital cafeteria during your appointment.

You can also relax in the second floor Ronald McDonald Family Room – (216) 844-2350, located in Rainbow's Leonard & Joan Horvitz Tower.

Sweat Test result and follow-up with your pediatrician

You will return to The Center for Human Genetics in the early afternoon and be given the result of your baby's test.

If your baby does not have CF, you will meet again with the genetic counselor. This is because babies who do not have CF but who tested positive on the first newborn screening are carriers of CF. This means that although they are not diagnosed with CF, they might pass on the disease to their future children. It also means that either you or the other parent of the baby is definitely a carrier of CF. It is important to know this since other children you may have in the future may be born with CF, and other children you already have may be carriers.

If your baby has CF, you will meet with Rainbow Babies & Children's Hospital CF team for an introduction to the CF Center and our services. At our Center, we have a dedicated team of staff members to care for your child with the very newest and best treatments for CF.

If you have additional questions or concerns please contact us at (216) 844-3936.

The LeRoy W. Matthews Cystic Fibrosis Center at Rainbow Babies & Children's Hospital 11100 Euclid Avenue Cleveland, Ohio 44106

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 Centers' treatments become, that Rainbow recently opened a 10 room in-patient unit. This unit provides specialized care for its large population of adult CF patients who are among the oldest in the nation.



(216) 844-RAINBOW | www.rainbowbabies.org