Newborn Screening for Cystic Fibrosis

What You Need to Know

Your newborn has screened positive for cystic fibrosis. “Screened positive” means another test (sweat test) is needed to find out if your child has cystic fibrosis.

What is cystic fibrosis?

Cystic fibrosis (CF) is a disease that causes the body to make mucus that is thicker and stickier than normal. The mucus causes problems with the lungs and digestive system such as:

• lung infections
• trouble breathing
• problems digesting fat and protein
• poor nutrition and growth.

What are the treatments?

Treatments include:

• medicine to thin the mucus in the lungs
• antibiotic medicines for infection
• chest therapy to clear the lungs
• medicine to replace the enzymes (chemicals) that digest food
• a diet high in fat and protein.

How does a child get CF?

A child gets cystic fibrosis by inheriting certain genes from his or her parents. Genes are units that carry a code that tells our bodies how to look and act. All genes occur in pairs. A child inherits one gene from each parent to form a pair. A child with cystic fibrosis has received an altered gene from each parent.

What is a sweat test?

The sweat test will tell us if your child has CF. People with CF have higher amounts of salt in their sweat. The sweat test will measure the amount of salt in your child’s sweat. This test is very reliable.

If the sweat test comes back “normal,” your child is very unlikely to have CF.

What happens during a sweat test?

The sweat test takes about one hour. It is painless.

• First we put a chemical liquid on an arm or leg. This makes the skin sweat.
• Then we collect the sweat with a special paper.
• We measure the amount of salt in the lab.

We can often give you an unconfirmed result right after the test is done. Final results come back in one day.
After the sweat test, you will meet with the genetic counselor. You will discuss the results of the screening test and sweat test.

What happens if my child has CF?

If the sweat test shows your child has CF, we will likely do more genetic testing.

- We will take a blood sample. Testing the blood will tell us more about the gene that caused the CF. This test may give us an idea of how severe the disease will be.

- You will meet with a doctor, a genetic counselor and other members of the CF team. They will discuss treatments and your child’s care plan.

What happens if my child is a carrier?

If the sweat test results are “normal,” your child is most likely a carrier for CF. A carrier’s health is not affected. But the child has one altered and one normal gene.

You will meet with a genetic counselor. He or she will discuss family history, explain carrier testing and answer your questions.

Should I be tested to see if I’m a carrier?

The genetic counselor will discuss carrier testing for parents and other family members. Carrier testing is the only way to know if one parent is a carrier or if both parents are carriers. When both parents are carriers:

- There is a 1 in 4 (25%) chance their child will have cystic fibrosis.

- There is a 2 in 4 (50%) chance their child will be a carrier.

- There is a 1 in 4 (25%) chance their child will not have cystic fibrosis and will not be a carrier.

The drawing below shows the possible outcomes when two carriers have a child.

Where can I get more information?

For questions about cystic fibrosis, call:

The Minnesota Cystic Fibrosis Center, Discovery Clinic University of Minnesota Amplatz Children’s Hospital 2512 South 7th Street, Minneapolis, MN 55454
Phone: 612-624-0962, option #4
Web: www.med.umn.edu/peds/cfcenter

Genetic Counselor and Newborn Screening Coordinator Phone: 612-273-0694 or 612-889-6623

To learn more about research and treatments, go to:

Cystic Fibrosis Foundation: www.cff.org
Phone: 1-800-344-4823

March of Dimes: www.marchofdimes.com

The Minnesota Cystic Fibrosis Center is the only core care center in Minnesota certified by the Cystic Fibrosis Foundation (www.cff.org). Our affiliates include a center in Minneapolis and in Fargo, North Dakota.