
INFORMATION FOR PARENTS/GUARDIANS: My Baby Has a Positive Cystic Fibrosis Newborn Screening Result

What is Newborn Screening?

These are routine tests done soon after birth on every baby born in Ontario. A small sample of blood is taken from your baby and is tested for rare, treatable diseases, like cystic fibrosis (CF).

What does it mean if my baby has a positive CF newborn screening result?

This result does **not** mean your baby has CF. It means that more testing is needed because your baby **might** have CF. Babies with CF can be healthier if treatment begins early, so it is important to have follow-up testing to find out if your baby truly has CF. You may feel worried about your baby's positive screening result. Many parents in this situation feel this way. Remember, we do not know for sure that your baby has CF until follow up testing has been done.

What is cystic fibrosis (CF)?

Cystic fibrosis is an inherited (genetic) disease that causes thick mucus to build up in the lungs, digestive system and other organs. This leads to problems like frequent lung infections and problems gaining weight and growing.

CF affects about 1 in every 3,600 babies born in Ontario. CF health problems can range from mild to serious.

How do I find out if my baby has CF?

A painless test, called a sweat test, is the best way of checking for CF. People with CF have a large amount of salt in their sweat, and measuring the amount of salt in the sweat can help determine whether or not your baby has CF. Some babies need other tests like blood tests.

How is the sweat test done?

A special machine causes a small part of your baby's arm or leg to sweat. The skin may feel warm and tingly for 5 minutes while the machine is on. Your baby may cry during this part of the test, but it is not painful. The sweat is collected on a piece of filter paper or a plastic coil and sent to the lab to be tested. It takes about one hour from start to finish.

When can my baby have the sweat test?

The sweat test is usually done when your baby is two weeks of age or older. The test will be done later if your baby was born premature or had a low birth weight.

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 on the day of the test (including moisturizing soaps). You can bring an extra blanket or sweater and a hat to keep your baby warm during the test.



What do the results of the sweat test mean?

Usually, parents get the sweat test results the day after the test. There are four possible results:

- **Negative result:** This means that it is **very unlikely** that your baby has CF because a normal amount of salt was found in your baby's sweat. It is very rare for a person to have CF if the sweat test is normal. No more testing is needed and your baby should have the same health care given to any other healthy baby.
- **Positive result:** A positive sweat test means that your baby most likely has CF because a higher amount of salt was found in your baby's sweat. This result can not tell us if your baby will have mild CF or serious CF. Your baby should see a doctor specializing in CF.
- **Borderline result:** This means the result was between the positive and negative range and we can't tell if your baby has CF or not. Your baby should see a doctor who specializes in CF and may need other tests.
- **Insufficient quantity:** This means there simply was not enough sweat collected to do the test. You will need to bring your baby back on another day to do the test again.

Why screen for CF?

Screening means that babies with CF can be treated early with diet, medications and chest physiotherapy. The goal is to help people with CF live longer, healthier lives.

How does a baby get CF?

CF is an inherited (genetic) disease. A baby with CF inherits two non-working copies of the CF gene, one from EACH parent. People who have one non-working copy of the CF gene are called "carriers." Carriers of CF are healthy and often unaware they carry a non-working CF gene.

Where can I get more information?

For more information on newborn screening, please visit the Parents section of our website at www.newbornscreening.on.ca or talk to your health care provider.

For more information on CF, please visit the Canadian Cystic Fibrosis Foundation website at www.cysticfibrosis.ca or call 1-800-378-CCFF(2233).

NOTE TO PARENTS/GUARDIANS: This information is for parents whose baby has had a positive newborn screening result for cystic fibrosis. Please remember that this fact sheet was written for information purposes only. The fact sheet should not replace professional medical advice, diagnosis or treatment.

My baby's sweat test appointment information:

Date: _____ Time: _____

Phone Number: _____

Place: _____

