

Cystic Fibrosis Newborn Screening



FAST FACTS

~120

positive newborn screens
Cincinnati Children's CF
Center receives annually

~10

positive newborn screens
that result in a CF diagnosis
by our CF Center annually

>50%

of the CF population is
18 years old and above

>30,000

people living with CF in
the United States

If you have clinical questions
about the CF testing process,
email CFPULM@cchmc.org.

To learn more detailed information
about newborn screening, the
sweat testing process and other
provider reference material or to
watch the video referenced above,
use www.cincinnatichildrens.org/cf
and click on the Healthcare
Professionals button.

Cystic fibrosis (CF) is a rare genetic disorder affecting the lungs and digestive system that causes production of thick, sticky mucus that impacts lung function and prevents the normal breakdown of food in the body. Babies diagnosed with CF through newborn screening benefit from earlier management of symptoms, which can improve nutritional status, slow progression of lung damage, and improve quality of life.

Due to the importance of early management, all 50 states now perform newborn screening to test for CF. A confirmatory sweat test must be performed on any baby with a positive newborn CF screen. In Ohio and northern Kentucky, your state health department will fax newborn screen results to both you and the Cincinnati Children's CF Center.

POSITIVE NEWBORN SCREEN RESULTS *(See other side for complete process)*

If you receive a positive screen report on a patient, a Cincinnati Children's CF team member will contact you as soon as possible to discuss the results and next steps. They will also discuss a plan for contacting your patient's family.

PRIMARY CARE PROVIDER ROLE

You are in a unique position to guide parents through the diagnostic process in a manner that's informative and anxiety-reducing. **Families have told us they want accurate information, emotional support, and a clear understanding about what to expect next.** You can visit the CF center website (shown below) for a helpful video on how to discuss with families. It is important that the first call comes from you, the child's PCP, but a follow-up call will come from the CF team with more details.

As soon as possible, call the parents to:

- Share the newborn screen result and explain next steps *(see other side)*
- Explain that most babies with a "positive newborn screen" do not actually have CF
- Whenever possible, don't make this call on a Friday, as doing so could lead to unnecessary stress and anxiety for the family as they wait until Monday to schedule the test
- Let them know they can visit the Cincinnati Children's CF Center website, the CF Foundation website, or contact the Newborn Screen Coordinator for additional information

Because many parents want to know the symptoms of CF, share these:

- Difficulty growing or a need to consume extra calories to grow – most common
- Steatorrhea (fatty stools) or frequent, large, foul-smelling stools
- Other symptoms may include:
 - Salty-tasting skin
 - Shortness of breath
 - Daily, wet cough
 - Severe constipation

Prepare parents for the sweat test by informing them of the following:

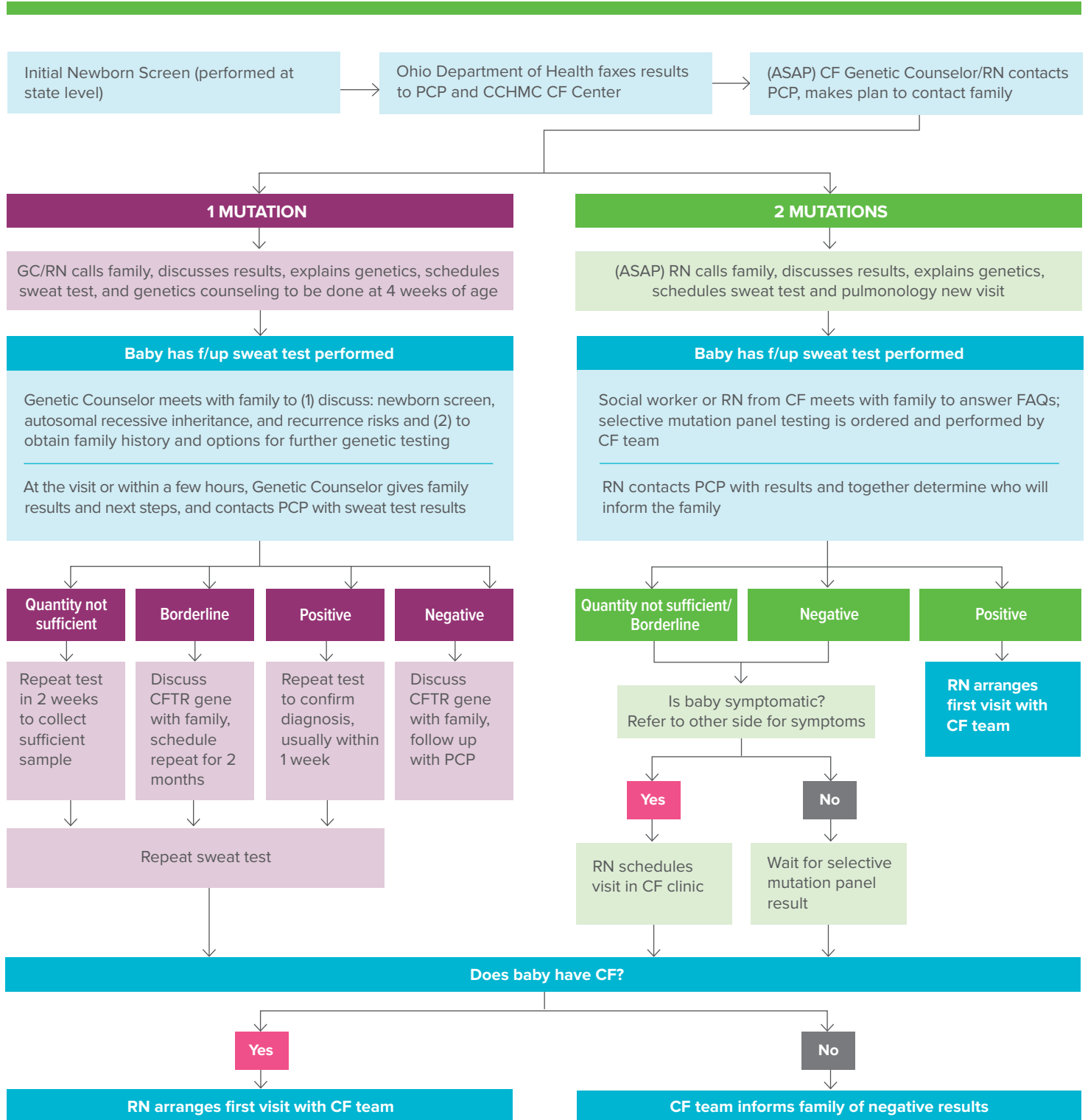
- Do not use any lotions or creams on the baby's skin 24 hours before the sweat test
- Continue regular feeding to ensure their baby is well hydrated for the test
- Dress their baby in warm clothing to increase the likelihood the baby will produce enough sweat for an accurate test
- Encourage them to visit the Cincinnati Children's CF Center website and watch "What to Expect" video

If you would like additional copies of this tool, or would like more information, please contact the Physician Outreach and Engagement team at Cincinnati Children's.

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Provider process following a positive newborn screen in Ohio

Communication of newborn screen results varies by state.



For urgent issues, call 513-636-6771 and ask to speak to the CF newborn screening coordinator.