

MANAGING NEWBORN SCREENING RESULTS -CYSTIC FIBROSIS (CF)-

1 MUTATION FOUND	CF Carrier Likely but additional testing is needed to rule out CF.
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What should I do next?

1. **Notify the family** within 24 hours. (see discussion points below)
2. **Arrange confirmatory sweat testing** at the UAB/Children's of Alabama CF Foundation Accredited Care Center by calling 205-638-5494.

Family Discussion Points

RESULT:

- Newborn Screening identified one change in your baby's cystic fibrosis gene. This change is called a mutation.
- The result indicate the need for your baby to have a sweat test to rule out cystic fibrosis or CF.

DISEASE:

- Cystic fibrosis is a genetic disease that primarily impacts breathing and how food is digested.
- Cystic fibrosis is a chronic disease that will require life-long treatment.

NEXT STEPS:

- Babies with cystic fibrosis do better if diagnosed and treated as early as possible.
- We need your baby to have a Sweat Test ASAP to confirm the diagnosis of cystic fibrosis.
- A pulmonologist will meet with you during this appointment to share more details and discuss treatment plans.
- We have scheduled your baby for a sweat test at the Children's of Alabama CF Center
Date: _____ Time: _____
- The CF NBS Coordinator is Staci Self (205-638-5494). She will be contacting you within 48 hours to answer any questions you may have.
- For **current** information on cystic fibrosis, living with CF, and caring for a child with CF, please visit the CF Foundation's website www.cff.org and avoid web searches that may provide inaccurate or outdated information.

Alabama's Cystic Fibrosis Foundation Accredited Care Center
University of Alabama at Birmingham/ Children's of Alabama CF Center
CF NBS Coordinator – Staci Self, LICSW – 205-638-5494

MANAGING NEWBORN SCREENING RESULTS -CYSTIC FIBROSIS (CF)-

2 MUTATIONS FOUND	CF Diagnosis Likely Additional testing needed to confirm diagnosis.
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What should I do next?

1. **Notify the family** within 24 hours. (see discussion points below)
2. **Arrange confirmatory sweat testing** at the UAB/Children's of Alabama CF Foundation Accredited Care Center by calling 205-638-5494.

Family Discussion Points

RESULT:

- Newborn Screening identified two changes in your baby's cystic fibrosis gene. These are called mutations.
- The result indicates it's very likely your baby has cystic fibrosis or CF.

DISEASE:

- Cystic fibrosis is a genetic disease that primarily impacts breathing and how food is digested.
- Cystic fibrosis is a chronic disease that will require life-long treatment.

NEXT STEPS:

- Babies with cystic fibrosis do better if diagnosed and treated as early as possible.
- We need your baby to have a Sweat Test ASAP to confirm the diagnosis of cystic fibrosis.
- A pulmonologist will meet with you during this appointment to share more details and discuss treatment plans.
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