

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** (see discussion points below)
2. **Arrange confirmatory sweat testing** at the UAB/Children's of Alabama CF Foundation Accredited Care Center by calling 205-638-5262.

Family Discussion Points

RESULT:

- Newborn Screening identified one change in your baby's cystic fibrosis gene. This change is called a mutation.
- The result indicates the need for your baby to have a sweat test to rule out cystic fibrosis or CF. There is a **90% chance that the sweat test will be normal and your baby will just be a carrier.**
CF can occur in any baby regardless of race.

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 or rule out the diagnosis of cystic fibrosis.
- A CF team member will meet with you during this appointment to share more details and discuss treatment plans in case the diagnosis is confirmed.
- During the visit, the CF NBS Coordinator and other CF Team members are available to answer your questions.
- We have scheduled _____ for a sweat test at the Children's of Alabama CF Center
1600 7th Avenue South, Birmingham, AL 35233
- Date: _____ Time: _____ **Please arrive 30 minutes before your sweat test time.**
- **Please advise family to check in on the second floor at Referred Testing.** They will then be seen in Clinic 6 at 12:30 to receive results.
- The CF NBS Coordinator is Brianna Swope (205-638-5262). Feel free to share her number with the family.
- 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with CF, please visit the CF Foundation's website www.cff.org and avoid web searches that may provide inaccurate or outdated information.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
Brianna Swope, BSN, RN – 205-638-5262

MANAGING NEWBORN SCREENING RESULTS

-CYSTIC FIBROSIS (CF)-

Superhigh IRT level (No CF mutations identified)	Requires additional testing to rule out cystic fibrosis
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What should I do next?

3. **Notify the family** (see discussion points below)
4. **Arrange confirmatory sweat testing** at the UAB/Children's of Alabama CF Foundation Accredited Care Center by calling 205-638-5262.

Family Discussion Points

RESULT:

- Newborn Screening identified an elevated enzyme level (IRT).
- The result indicates 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.

CF can occur in any baby regardless of race.

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 or rule out the diagnosis of cystic fibrosis.
- A CF team member will meet with you during this appointment to share more details and discuss treatment plans in the case the diagnosis is confirmed.
- During the visit, the CF NBS Coordinator and other CF Team members are available to answer your questions.
- We have scheduled _____ for a sweat test at the Children's of Alabama CF Center
1600 7th Avenue South, Birmingham, AL 35233
- Date:_____ Time:_____ **Please arrive 30 minutes before your sweat test time.**
- **Please advise family to check in on the second floor at Referred Testing.** They will then be seen in Clinic 6 at 12:30 to receive results.
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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?

5. **Notify the family** within 24 hours. (see discussion points below)
6. **Arrange confirmatory sweat testing** at the UAB/Children's of Alabama CF Foundation Accredited Care Center by calling 205-638-5262.

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. A sweat test is needed to confirm the diagnosis.

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.

CF can occur in any baby regardless of race.

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 doctor who specializes in CF will meet with you during this appointment to share more details and discuss treatment plans.
- We have scheduled _____ for a sweat test at the Children's of Alabama CF Center
1600 7th Avenue South, Birmingham, AL 35233
- Date: _____ Time: _____ **Please arrive 30 minutes before your sweat test time.**
- **Please advise family to check in on the second floor at Referred Testing.** They will then be seen in Clinic 6 at 12:30 to receive results.
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