KEY POINTS FOR BREAKING BAD NEWS

- Bad news is - any information that unfavorably affects the patient's view on their future
- Patients/Parents want the truth
- Breaking bad news can be difficult for providers because the diagnosis or prognosis may be unclear
- Mental rehearsal can be helpful when preparing for tasks that are stressful

A SAMPLE SCRIPT FOR DISCUSSING CYSTIC FIBROSIS (CF) POSITIVE NEWBORN SCREEN RESULTS

SPIKES COMMUNICATION

I am calling to speak with you about your child's newborn screen test that was done not long after your baby was born. Every baby in the state of Georgia has a heel prick blood test to check for 29 different health conditions.

S - SETTING

Setting up the converstaion for limited interruptions; don't be rushed; make sure its the right time and place to talk

Do you have a few minutes to talk? / Is this a good time that we can talk?
Are you comfortable discussing test results over the telephone or would you rather meet in person?
Would you like to plan for a time where I can speak with both parents or are there any other family members you would like to have available?

P - PERCEPTION

Assessing parent's perception; "before you tell, ask:" find out their understanding; open-ended questions; "tell me what you know"

Are you familiar with any of the conditions that are tested for on Georgia's newborn screen test?
One of these conditions is called Cystic Fibrosis. Have you ever heard of this condition before?

I - INVITATION

Obtain parent's invitation for details; determine how much information the parent desires

Would it be okay to go over the results with you right now?
Are you someone who likes to know a lot of details or would you like me to only focus on the most important details right now?

K - KNOWLEDGE

Giving information with simple words; avoid medical jargon; deliver a warning statement before the bad news; give information in small chunks

This is probably news that you were not planning to hear. Your baby's newborn screen test found that

ELEVATED IRT AND 1 CF MUTATION -NEEDS FURTHER TESTING

...your baby is a carrier of one Cystic Fibrosis gene. The next step for your baby is that he/she needs a test called a sweat test. This test will help to figure out if your baby is only a carrier or if your baby has the condition Cystic Fibrosis. This test is only done at a lab associated with a Cystic Fibrosis care center. It is important that your baby has this test done quickly.

OR

ELEVATED IRT AND 2 CF MUTATIONS - LIKELY POSITIVE

...your baby has two Cystic Fibrosis genes and likely has Cystic Fibrosis. The next step for your baby is that he/she needs to be seen very soon at a Cystic Fibrosis center to be evaluated by the specialized care team. The care team will order additional testing to confirm your baby's diagnosis.

I know this is a lot of information, what questions do you have so far?

E - EMOTION

·Pause to allow for emotion from the parent; address emotions with empathy; validate responses; provide support

I am sure that this is news you were not expecting to hear.
Do you have more questions?
What are your concerns?
As your baby's provider, I am here to help and support your family.

S - STRATEGY AND SUMMARY

Provide summary with simple and clear statements, explore goals for next steps; acknowledge what's coming next; acknowledge team approach to care

Let's talk about the next steps for your baby

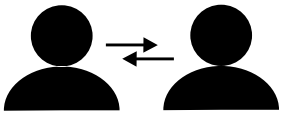
ELEVATED IRT AND 1 CF MUTATION

You will need to schedule a sweat test for your baby.
Augusta: 706-721-7881
Atlanta: 404-785-6014
The results will be available the same day. You may be contacted by the sweat test lab or by my office to go over the results.

OR

ELEVATED IRT AND 2 CF MUTATIONS

It is important to have your baby evaluated as soon as possible by the Cystic Fibrosis care team. You will be contacted within a few days to schedule the appointment.



Please be cautious if you look on the internet. There are a lot of websites that may not have the most up to date information. I suggest looking at the Cystic Fibrosis Foundation's website at cff.org to get some basic understanding before your baby's visit. I will be happy to work with the care team to make sure your baby has everything he/she needs.

WHEN THE PARENT ASKS: "WHAT IS CF? WHAT DOES THIS MEAN FOR MY CHILD?"

ELEVATED IRT AND 1 CF MUTATION

Cystic Fibrosis is a condition that happens when a CF gene is passed down from a baby's mother and father. Sometimes only one gene is passed down, and that person is known as a carrier. A carrier is not expected to have any symptoms and this test shows that your baby is <u>at least</u> a carrier. Georgia's newborn screen does not check for every type of CF gene and that is why your baby needs further testing. ***CF can occur in Hispanic and non-White infants and these groups are at higher risk of delayed diagnosis.*** The sooner we can find out if your baby is a carrier or has the condition, the better it will be for your baby. (Can also use the CF information in the next column ->)

ELEVATED IRT AND 2 CF MUTATIONS

Cystic Fibrosis is a condition that happens when a CF gene is passed down from a baby's mother and father. CF can occur in babies of every race and ethnicity. CF can affect the lungs, the digestive system, and other parts of the body. It causes mucus to build up in the lungs and damage to the pancreas makes it hard to digest food and gain weight. There are many treatments and medications for your baby. The CF care center team are the experts and I want to make sure your baby has the best care. That is why they are going to see your baby so soon and they will be able to answer all your questions.

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