EXPANDED CARRIER SCREENING: IS IT RIGHT FOR YOU?

I'm a carrier.

I wonder if I'm a carrier, too.

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One pamphlet was about a test called the **Expanded Carrier Screen**.

I had to ask my doctor about that one.
The carrier screen will let you know the likelihood that you'll pass on a serious genetic condition to your baby.

Oh, but I'm not sick.

The test is voluntary, but we offer it to everyone because anyone can be the carrier of a disease and not know it.

All parents pass on traits to their children. Will the baby have your eyes or Joe's funny toes?
Some traits are health-related, and knowing about them before birth -- or even before conception -- can be helpful.

Expanded carrier screening tests your blood to see if you "carry" certain disorders in your DNA, or genes.

Carriers are not sick. But they can pass on genetic disorders to their children.

Most genetic disorders are inherited from both parents. To determine risk for genetic problems both parents should be screened.

We can test for many serious conditions, but we can’t catch everything.

Talk about it with Joe and let me know.
I decided to have the carrier screen done, even though my insurance didn’t cover the cost.

There are enough uncertainties with having a baby.

I wanted to know as much as possible, so we could be prepared.
BUT THEN I GOT THE CALL FROM MY DOCTOR.

She said a lot of things, but all I heard was: “Your test shows you’re a carrier for cystic fibrosis.”

The first thing I did was Google cystic fibrosis.

What does this mean? Will my baby be OK? Will I get sick? What are my choices?!

Then I called my best friend.

You should talk to your doctor. I found out that I’m a carrier, too.

But Paul isn’t, so we didn’t need to do anything else, and our kids are fine.
Talking to my doctor did reassure me.

You’re still as healthy as you’ve ever been.

And the baby is growing normally.

But we should talk about testing your husband.

Every baby gets half of her genes from her mother and half from her father.

So the only way your baby could be born with the disease is if your husband is also a carrier.

If he is, there’s a 25% chance that you’ll pass on cystic fibrosis. Say you have four kids together. The odds are:

one would have cystic fibrosis...

...two would be carriers like you...

...one wouldn’t be a carrier or have the condition.
BUT WE WOULDN'T REALLY KNOW THE ODDS UNTIL JOE WAS SCREENED.

This says our insurance won't cover my test, either.

That's OK. We only need to do it this once.

WEEK 14 OF THE PREGNANCY

Can't you go in to have your blood drawn during your lunch break?

WEEK 15

The clinic is so far out of the way!

And you know I'm working extra hours so I can take time off once the baby's here.

WEEK 16

Even if I am a carrier...

...what would we do about it?
Even if you ARE both carriers, it doesn’t mean the baby will have C.F.

This test just tells us if Joe and I carry the genes that cause it.

We talked about it, and decided that Joe won’t be screened.

That’s OK. We can talk about testing the baby once he’s born, and I’ll give you some info about cystic fibrosis.

The best thing I can do now is to stay calm and healthy.
ONE YEAR LATER

THIS IS MY BEAUTIFUL BABY BOY.

AFTER HE WAS BORN, A NEWBORN SCREEN AND SWEAT TEST REVEALED THAT HE HAS CYSTIC FIBROSIS.

I REACTED TO THE NEWS MORE CALMLY THAN I THOUGHT I WOULD.

WE DO WANT MORE KIDS, BUT NOW THAT WE KNOW WE'RE BOTH CARRIERS, WE'RE CONSIDERING OUR OPTIONS.

THE END.
As with anything related to health and pregnancy, there’s a lot to think about. The more you know, the better decisions you can make for yourself. It is also helpful to find other people who have already gone through what you’re going through. Here are a few stories about couples who have had expanded carrier screening.

Rosa chose to have carrier screening done before she became pregnant, and learned that she is a carrier. Her partner, Gilberto, was also screened. He is not a carrier for that same condition, so their children will not have it and the parents don’t need to be screened again. But Rosa and Gilberto also understand that carrier screening does not check for every possible problem. This means that good news on the carrier screen is not a guarantee that their baby will be completely healthy.

Susie and Brian both decided to have expanded carrier screening after Susie got pregnant. They discovered that they are both carriers for the same serious genetic disease. The baby was tested in utero and was found to have the disease. After weighing all of their options, Susie and Brian decided to terminate the pregnancy.

Courtney was offered expanded carrier screening by her doctor while pregnant, and Phil agreed to be screened as well. They both are carriers for the same disease, but the baby was born without the condition. However, since they are both carriers, they decided to adopt their next child.
For more information about expanded carrier screening, please talk to your doctor or visit the following website:

https://www.acog.org/Patients/FAQs/Carrier-Screening

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