

# Reproductive Care Center

## Cystic Fibrosis Information and Consent

Cystic fibrosis (CF) is a life-long illness that is usually diagnosed in the first few years of life. The disorder causes problems with digestion and breathing. CF does not affect intelligence or appearance. Recent advances in genetics have resulted in the recommendation that couples be offered testing for CF. About 1 out of 30 white people in the USA is a carrier for CF, and if two of these carriers marry each other, the risk that any children from them will have CF is one out of four. One out of about every 2,500 babies born to parents with European Caucasian ancestry is born with the disease. Other ethnic groups have lower chances. Couples considering pregnancy can be tested to see if they are carriers, and pregnant women can have tests done on their fetus to see if it is affected. These tests are usually not covered by insurance but they can give helpful information for a couple deciding if they want to have a child together. There are more than 1,000 genetic alterations that can cause cystic fibrosis. The screening tests currently recommended detect 25-30 of the most common alterations. In some circumstances (such as one spouse is already a known carrier) it may be of benefit to test for a more extensive panel of 80-90 alterations. If both the husband and wife are carriers of CF, preimplantation genetic diagnosis can usually be performed to help prevent transmission of the disease (prior to implantation of the embryos). After conception has been achieved your obstetrician can perform or refer you for prenatal testing such as chorionic villi sampling or amniocentesis.

We understand that testing for cystic fibrosis is recommended for people with European Caucasian ancestry (higher chance of passing this disease on to their offspring), and offered to all couples contemplating conception or childbirth. We have had the opportunity to discuss this disease with our physician, and all of our questions have been addressed. It is our desire to:

- \_\_\_\_\_ Have basic (25-30 most common mutations) cystic fibrosis preconception screening, This is usually done through ARUP or ReproMedix. Recommended screening for Caucasian couples. (Least expensive option)
- \_\_\_\_\_ Have comprehensive (more than 90 of the more common mutations) cystic fibrosis preconception screening. This is usually done through Genzyme Genetics or ReproMedix. This is recommended if the spouse is a known carrier or if the husband has congenital absence of the vas deferens.
- \_\_\_\_\_ Have complete (gene sequencing) cystic fibrosis preconception screening.
- \_\_\_\_\_ Not have cystic fibrosis screening at this time.

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Wife's name spelled out

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Wife's signature

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Date

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Husband's name spelled out

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Husband's signature

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Date