NOVA GROUP FOR WOMEN

CYSTIC FIBROSIS SCREENING

The American College of Obstetrics and Gynecology has issued a recommendation that screening for cystic fibrosis be offered to all pregnant patients who have a family history of the disease, are of an ethnic group at risk for the disease (ie, Ashkenazi Jewish), or who are Caucasian.

Cystic fibrosis (CF) is a genetic disorder that causes life-long breathing and digestion problems. It is an incurable illness usually diagnosed in the first few years of life. CF does not affect intelligence. Some individuals have a mild form of the disease and live well into their 50's while others may die in childhood. In order to inherit CF, a person has to inherit an altered gene from each parent. The carrier rate of this altered gene in the general Caucasian population is 1 in 20. Those who are carriers of CF have no related health problems, and often report no family history of the disease. If both parents are carriers, there is a 25% chance with each pregnancy that the child will have CF. Testing involves a blood test done on one partner. If the result is positive the other partner is tested. Since CF is associated with over 800 gene mutations, testing has been difficult. Recent improvements have made available a blood test that will detect over 95% of the mutations, but the test is not 100% accurate.

Cystic fibrosis is not a curable disease, but there are treatments available. There are no treatments available before the baby is born. If it is discovered that the fetus has CF there are only two choices to make; either continue the pregnancy and prepare to care for a child with CF, or terminate. Please indicate your choice on whether to have the screening blood test by signing on the appropriate line below.

Please Print Name_____Date of Birth_____

_____ _____

I choose to have the cystic fibrosis blood screening test . Date

_____ _____

I decline the cystic fibrosis blood screening test. Date