Northwestern Medicine®
Center for Fertility and Reproductive Medicine

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Waiver of Genetic Carrier Screening of Other Genetic Testing

I, _____, (DOB: _____) and

☐ my spouse/partner, _____, (DOB: _____)

OR

☐ Not applicable (no partner)

have been informed by the clinical staff of the Northwestern Medicine (NM) Center for Fertility & Reproductive Medicine ("NM FRM") that genetic carrier screening or another genetic test has been recommended for me/us.

I/We understand the following:

- Genetic carrier screening is a type of DNA test to determine whether someone is at increased risk to have a child with certain genetic diseases. The American College of Obstetricians and Gynecologists (ACOG) and the American College of Medical Genetics (ACMG) have set forth recommendations for routine carrier screening for certain genetic diseases, some of which are ethnicity dependent, for all individuals or couples who are planning to conceive. Consequently, NM FRM recommends genetic carrier screening for all patients.
- It is common for individuals to be a carrier for one or more genetic conditions. As carriers are typically asymptomatic, a negative family history (including healthy children from previous pregnancies) cannot exclude an individual from being a carrier for a genetic condition. Genetic carrier screening may include, but is not limited to, testing for cystic fibrosis, spinal muscular atrophy, Fragile X syndrome (females only), alpha thalassemia, beta hemoglobinopathies, Tay-Sachs disease, Canavan disease, and familial dysautonomia.
- When both the individual contributing the egg AND the individual contributing the sperm are carriers of the same autosomal recessive condition, there is a high risk (25%) of having an affected child with each pregnancy. In this case, certain reproductive options may be available to reduce the chance of having an affected child.
- When a female is a carrier of an X-linked condition, there may be a high risk of having an affected child, regardless of the male partner or sperm donor's genetic status. In this case, certain reproductive options may be available to reduce the chance of having an affected child.
- Individuals with a family history of a specific genetic condition may require specialized genetic testing (such as targeted variant analysis) to determine if he/she is at risk to have a child with the same condition.
- **Without genetic carrier screening, it cannot be determined whether there is an increased risk of having a pregnancy/child affected with a genetic condition.**

My/our physician and staff have explained the risks, potential benefits of, and alternatives to genetic testing to me/us. I/We understand the explanation that has been given to me/us. I/We have had the opportunity to ask any questions I/we might have and those questions have been answered to my/our satisfaction. Any future questions I/we have may be addressed to my/our treating physician or genetic counselor (312-695-7269)

I/We understand the recommendation for genetic testing and have been informed about the potential risks for genetic condition(s) affecting my/our pregnancy and child. By my/our signature(s) below, I/We acknowledge the information provided but decline the following genetic testing against the medical advice of my/our physician:

- ☐ **Genetic carrier screening**
- ☐ **Carrier screening for ethnically-relevant diseases**
- ☐ **Other:** _____

Patient Name – Please PRINT	Patient Signature	Date of Birth	Date

Partner Name (If Applicable) – Please PRINT	Partner Signature	Date of Birth	Date