# All About Your Options for Pregnancy & Prenatal Care



## What You Might Want to Know Before Embarking on Your Parenting Journey

Our heartiest wishes to you, mom to be! During this special phase of your life, you must be so excited and must be looking forward to meeting the youngest member of your family. But at the same time, many of you might have concerns about what is happening with you and your baby.

Today, medical advances offer new options for obtaining information about a baby's health before birth. Although more information sounds helpful, it often leads to information overload and confusion among patients. Many optional tests are not included in regular checkups, making it even more difficult for parents to decide on their own.

Our professional mission is to assist you in making the best informed choices. This leaflet includes an overview of your prenatal options, as well as a few resource suggestions to better meet your needs. Feel free to contact any of them if needed.

The following is a handy list of questions and answers that will help you learn the basic concepts regarding the prenatal options available to you.

## Q1. What are prenatal genetic tests?

These medical tests are used to obtain genetic information about unborn babies. Certain tests performed during prenatal check-ups are routine, and almost all pregnant women get them, while the prenatal testing we discuss here is completely optional. In this leaflet, we focus on fetal evaluation to identify specific chromosomal abnormalities. You can have a safe delivery without these tests, and it is up to you to choose whether or not to have them performed. It is becoming increasingly complicated to make decisions, given the greater number of options available to you. If you have any concerns about your baby, whether or not to undergo prenatal testing, please first consult your obstetrician where you are receiving your prenatal checkup. If necessary, we may refer you to a facility that offers more specialized genetic counseling.

# Q2. What are the common types of prenatal tests?

There are two types of prenatal tests: screening and diagnostic tests. The former includes NIPT, maternal serum tests, and special ultrasound examinations such as NT scans — none of which are definitive. When the screening test results show the presence of a possible problem, you might consider diagnostic tests — including amino or CVS tests — which carry a small chance of inducing a miscarriage. It is important to understand the characteristics of each test to decide whether or not to take it, and, if so, what kind of test to take.

# Q3. What is genetic counseling? Should every expectant mother obtain this information?

Genetic counseling helps people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. It includes specialists who identify families at risk, investigate the problem, interpret medical information, and review available options with the family. Anyone with unanswered questions about their baby should seek genetic counseling as it provides helpful information, education, support, and, often, peace of mind.

#### Q4. Are birth defects common? How much can a test find?

One in every 20~33 babies is born with a birth defect, and approximately 25% of them are affected by chromosomal abnormalities. It is impossible to detect everything about a fetus, but proper prenatal care helps ensure that things go right, as it enables the doctor to monitor the baby's health and to identify any problems before they become serious.

#### Q5. Does advanced maternal age increase the risk of a baby having a birth defect?



The word "risk" refers to the probability of something happening. Although the probability of many birth defects does not increase with advanced maternal age, the probability of some chromosomal disorders gradually increases with the age of the expectant mother. Although women over 35 years of age are sometimes referred to as an older pregnant woman, this does not mean that the probability of her baby having a congenital disease suddenly increases.

#### Q6. Is getting tested a common option?



Currently, approximately 10% of the expectant mothers in Japan undergo prenatal testing. The decision to pursue the tests is yours, with people choosing to have them conducted for various reasons. The decision must be made after a thorough discussion between you and your partner, along with genetics professionals.

#### Q7. What are my choices if the test results show problems?

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Depending on the type of illness, the baby in your tummy may need medical and welfare support after birth. A baby's future is highly individualized, and not everything can be known from the results of prenatal testing. Although there may be some uncertainty, one can still receive a detailed explanation of some of the prospects, post-delivery care, and support. Every baby is a blessing; even if the baby has a disability, it does not change this fact. Public welfare services offered by the government and advocacy services have been enhanced to create a society that recognizes and helps each other, including those with illness and disabilities. However, some people may find it difficult to continue with a pregnancy when they learn that their baby has some form of disease. In such cases, consultation services will work with you to determine what your options are.

#### Q8. Do family health problems affect the baby?



Only very few types of diseases can be passed on, and it is possible to inherit some types of genetic disorders. Estimating the chance of inheriting a condition can be complex. If you have specific concerns, please consult your obstetrician for a prenatal checkup.

## Q9. Does a disorder identified by a test mean the presence of another risk factor among family members?



The vast majority of families are not affected at all, but there are a few exceptions. When a genetic disorder is diagnosed, family members often want to know the likelihood that they, or their children, will develop the disorder. It is important to ask obstetricians for more information if a disease is detected in your baby.

## Q10. Where do I start for genetic counseling?



Consultations on prenatal testing is available from the obstetrician/gynecologist where you are receiving your prenatal checkups. Consultations are also available at the Maternal and Child Health Consultation Desk, Sexuality and Health Consultation Center (formerly the Women's Health Support Center), Child Rearing Generation Comprehensive Support Center, etc. — located at the municipal office. If more specialized consultations or genetic counseling are required, you may be referred to a specialized facility. \*Patients with limited Japanese proficiency are expected to bring an interpreter.

# Q11. When should I see a genetic professional?



Genetic counseling is helpful at any time during, or even before, pregnancy. You can obtain the support you need when you intend to start a family, when you're expecting, or after the baby is born.

# Q12. What can I discuss with my geneticist/genetic counselor?



In addition to prenatal testing, we can answer questions about your baby's illness, your own and your family's illnesses, and other concerns and worries related to pregnancy, delivery, and subsequent child-rearing. If you discover that your baby has a disease, then we can discuss the baby's subsequent development. Please feel free to consult with us not only about prenatal testing, but also when you have concerns, want detailed medical information, or feel that you would like to have a good discussion as a couple.

Steering Committee on Certification System for Prenatal Testing Website

"Let's think about what the prenatal testing means."

Please check our website for expectant mothers and their families. There is further information about various types of prenatal testing, and the places to consult. You can also read the experience of those who have/haven't undergone the testing, as well as the information on how the families live their lives with their children with congenital diseases, and what kind of welfare they are receiving.



