

You are pregnant.

This information may be helpful to you and your family if:

1. You are considering getting tested to see if your baby has Down syndrome
2. You had a test and the results show your baby *may* have Down syndrome
3. You had a test and the results show your baby *does* have Down syndrome

Permission to test

By law, you do not have to be tested. You should not be tested unless you give permission. You should only consider giving such permission when you understand what the tests measure and any associated risks. A genetic counselor, another medical professional, and/or a spiritual adviser can help you understand the pros and cons of testing and the results of your test.



What is a “prenatal test” for Down syndrome?

Generally there are two types of tests (screening and diagnostic) you can have while you are pregnant to help determine if your baby has Down syndrome – these are called “prenatal tests”:

Screening tests – There are two types of screening tests – blood tests and ultrasounds. Maternal serum screening blood tests, such as the quad screening test, are usually administered between the 15th and 20th weeks of pregnancy, with an accuracy rate of between 69% and 81%.

New noninvasive blood tests (see details at www.downsyndrometest.org) can be administered as early as the 10th week of pregnancy and can be up to 99% accurate but only in “high risk” pregnancies. “High risk” is when a pregnant woman is of advanced maternal age, has had a different prenatal screening test showing the chance of having a baby with Down syndrome is increased, or has one or more relatives with Down syndrome. The new noninvasive blood tests are not recommended for women with low-risk pregnancies because their accuracy has not yet been demonstrated to the medical community.

There are no risks of miscarriage associated with screening tests. Screening tests cannot tell you for sure if your baby has Down syndrome, but if a screening test shows that chances are high, your doctor or medical advisers may offer a “diagnostic” test.

Diagnostic tests – There are two diagnostic tests that can tell you with almost 100% accuracy if your baby will have Down syndrome. The amniocentesis test (amnio for short) is usually performed after the 15th week of pregnancy. The Chorionic Villus Sampling (CVS for short) is usually performed between the 10th and 12th week of pregnancy. Both tests have a small but real risk of causing miscarriage.

Disclaimer: The information in this brochure is intended to serve only as an educational tool and is accurate to the best of the knowledge of the Global Down Syndrome Foundation and National Down Syndrome Congress. The reader should not rely on this brochure as medical advice. The reader is urged to seek competent medical advice from a licensed physician and other medical professionals who are knowledgeable about Down syndrome. The Global Down Syndrome Foundation and National Down Syndrome Congress disclaim any direct, indirect, consequential, special, exemplary, or other damages arising from any person following the information provided in this brochure with respect to any diagnosis, treatment, or action. The organizations do not endorse specific products or services, and any implications as such are unintentional.

What is Down syndrome?

Down syndrome, also known as Trisomy 21, is a condition where a person is born with three copies of chromosome 21 instead of two. In the United States, 1 in every 691 babies is born with the condition. There are hundreds of thousands of people with Down syndrome in the United States, and an estimated six million people with Down syndrome worldwide.

Why some babies have three copies of chromosome 21 instead of two is largely unknown. We do know that 98% of the time, Down syndrome is random and not hereditary (2% of the time the condition is inherited from a parent who passes along an extra chromosome 21). The chance of having a baby with Down syndrome increases with the mother's age; however, 80% of babies born with Down syndrome are born to mothers under 35 years old because more younger women are having babies.

It is important to note that Down syndrome has nothing to do with race, nationality, socioeconomic status, religion, or anything the mother or father did before or during pregnancy.



How will Down syndrome affect my baby?

There is no way to know what the future holds for any baby. In most ways, babies with Down syndrome are like other babies. All babies need to be cared for and loved. However, the healthcare and education needs of a person with Down syndrome can be different or more challenging than for a typical person. Below are some facts about people with Down syndrome that may be helpful to know.



General facts about people with Down syndrome in the USA:

- The average lifespan of a person with Down syndrome is 60 years, compared with 25 years as recently as 1983.
- There are physical and intellectual delays from birth, but there is a wide range of abilities in people with Down syndrome that are impossible to predict.
- By law, people with Down syndrome must be provided a free, appropriate education through their public school system.
- Most people with Down syndrome have IQs in the mild to moderate range of intellectual delay.
- Since the human and civil rights movements began in the 1960s, people with Down syndrome are increasingly recognized as an important part of society.
- People with Down syndrome participate in school, religious groups, sports teams, performing and visual arts programs, volunteer organizations, and the workplace.
- A growing number of people with Down syndrome live independently or semi-independently.
- A small but growing number of people with Down syndrome are choosing to get married.
- A small but growing number of people with Down syndrome are participating in post-secondary education programs.

Medical facts about people with Down syndrome in the USA:

- Up to 50% of babies with Down syndrome are born with a heart defect, and some will require surgery. The vast majority of these heart defects are correctable.
- The appropriate physical, speech and other therapies in the first five years (“Early Intervention”) can make a significant difference for a child with Down syndrome’s physical and intellectual development.
- Appropriate medical care for children and adults with Down syndrome is important and can strengthen their physical and intellectual abilities.
- People with Down syndrome have an increased risk for medical conditions such as respiratory issues, hearing problems, sleep apnea, thyroid conditions, and Alzheimer’s disease. However, many people with Down syndrome do not have these conditions, and since most of these are now treatable, the majority are able to lead healthy lives.
- People with Down syndrome rarely develop solid tumor cancers, or suffer from heart attacks or strokes.

For more information about Medical Care, please refer to the Resources section.



How will a baby with Down syndrome affect my family?

Many parents are concerned about how a child with Down syndrome will affect their family, including siblings.

It is natural to feel sad or worried if a test indicates your baby has or may have Down syndrome. A baby with special needs is not something people usually plan for, and there could be medical, educational, or financial challenges.

Every family is unique and may deal with the idea of, or the birth of, a baby with Down syndrome differently. Despite potential challenges, personal accounts and studies show most families that have a child with Down syndrome are stable, successful and happy, and that siblings often report having increased levels of compassion and empathy. One major study on marriages and Down syndrome shows that the divorce rate among parents of children with Down syndrome is lower than the national average.



What resources are there for pregnant women?

Every woman and every pregnancy is different. Family members, friends, spiritual advisers and others can assist a pregnant woman who is faced with a prenatal diagnosis of Down syndrome. Below is a short list of resources a pregnant woman may find helpful. For more detailed information please visit us at www.downsyndrometest.org.



Medical Care

- American Academy of Pediatrics Guidelines for Children with Down Syndrome: <http://pediatrics.aappublications.org/content/128/2/393.full.pdf>

New & Expectant Parents

- www.ndscenter.org/resources/new-and-expectant-parents
- www.downsyndromepregnancy.org
- Babies with Down Syndrome: A New Parents' Guide (book is available in English and Spanish)

Early Intervention, Educational and Emotional Supports

- Woodbine House Books on Down Syndrome
www.woodbinehouse.com/Down-Syndrome.29.0.0.2.htm

Adoption

Families may decide making an adoption plan is the right choice for their family. The National Down Syndrome Adoption Network (www.ndsan.org, 513-213-9615) can give you more information. There are more than 100 families across the country with completed home studies, hoping to adopt an infant with Down syndrome.

What resources are there for people with Down syndrome and their families?

In addition to non-profit organizations such as the National Down Syndrome Congress and the Global Down Syndrome Foundation, there are federal, state, and local government programs supporting people with Down syndrome and their families. Many, but not all, provide free or low-cost services. There are also an estimated 300 local Down syndrome organizations in the United States, so chances are there is one in your area.

If you have questions about your pregnancy or about Down syndrome, please call 1-888-960-1670 or visit us at www.downsyndrometest.org.



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