

Down Syndrome



What is Down syndrome?

Down syndrome is a condition in which a baby is born with an extra chromosome. Chromosomes determine how a baby's body grows in the womb. Babies born with Down syndrome have an extra copy of one of these chromosomes. The extra copy changes the normal growth of the body and brain, causing mental and physical problems.

What types of problems occur with Down syndrome?

Babies born with Down syndrome may have a birth defect of the heart (50% risk), stomach and other digestive problems (10% risk), learning disabilities, mental retardation, eye problems (70% risk), thyroid problems, and skeletal problems.

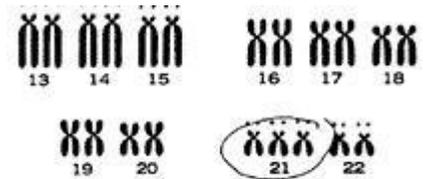
How common is Down syndrome?

There is about a 1% chance of a pregnancy resulting in Down syndrome. About 4,000 infants in the United States, or 13 of every 10,000 babies, are born with Down syndrome. About 9 in 10,000 babies are born in Kentucky with Down syndrome. The risk of Down syndrome increases with mother's age; however, 80% of babies born with Down syndrome have mothers who are younger than 35.

Some families have more than one person with Down syndrome. Down syndrome does not occur in a set pattern in these families. Parents of a child with Down syndrome, however, have a higher chance of having another child with Down syndrome (1 in 25). For families with two children with Down syndrome, the chance may be 1 in 10. A genetic counselor or geneticist can help you determine the risks for your family and situation.

What causes Down syndrome?

Approximately 95% of children born with Down syndrome are born into families with no family history of Down syndrome. The age of a mother is the only risk factor shown to increase the risk of having a baby with Down syndrome.



How is Down syndrome treated?

Early childhood intervention, screening for common problems, medical treatment where indicated, a conducive family environment, and vocational training can improve the overall development of children with Down syndrome. Although some of the physical genetic limitations of Down syndrome cannot be overcome, education and proper care will improve quality of life.

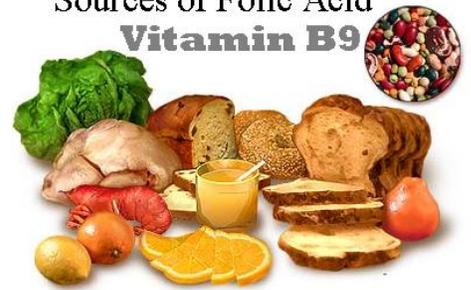
Babies and adults with Down syndrome can have physical problems, as well as intellectual disabilities. Every baby born with Down syndrome is different. In addition to the physical signs, some might have major birth defects or other medical problems. However, many people with Down syndrome live happy, productive lives well into adulthood.

What can I do to prevent Down syndrome?

There is no known way to prevent Down syndrome. However, infants and children with Down syndrome often will benefit from special programs that help to improve their physical and mental capacities. These include speech and occupational therapy along with exercises for physical coordination.

There are ways to maximize your chances of having a healthy pregnancy. Folic acid plays an important role during periods of rapid cell growth such as pregnancy. The most important time for women to have folic acid in their system is prior to pregnancy and during the first few weeks of pregnancy when the neural tube is forming. Most women do not even realize they are pregnant at this critical time. Therefore, the U.S. Public Health Service recommends that all women of childbearing age consume 400 micrograms of folic acid daily. This regimen will help ensure enough folic acid in a woman's system should she become pregnant.

Sources of Folic Acid Vitamin B9



Folic acid is a B vitamin that occurs naturally in foods such as leafy green vegetables (for example, romaine lettuce, broccoli, spinach, and asparagus). It can also be found in enriched and fortified foods, such as enriched grain products and fortified breakfast. However, to make sure that you're getting enough folic acid, a supplement or multivitamin that contains 400 micrograms of folic acid is recommended along with eating the fortified foods. In addition to taking folic acid, women can take steps before and during pregnancy to be healthy, including not smoking, taking illegal drugs, or drinking alcohol during pregnancy.

Where do I go from here?

This is a very stressful time for you. You may not know how to feel. Most parents feel denial, grief, and even anger. It's okay to feel that way and no one will blame you. You haven't done anything wrong, and you're not alone. Soon you will find other people and programs to help you through this. You may want to join a support group. Most importantly, take care of yourself. Be patient with yourself while you're grieving, and remind yourself that things will get better. We've provided some information below to help you.

Where can I go for more information about Down Syndrome?

Kentucky Resources

<http://dsack.org/> Down Syndrome Association of Central Kentucky (there are regional groups accessible through this website) (859) 494-7809

<http://chfs.ky.gov/ccshcn/parents.htm> KY Commission for Children with Special Health Care Needs – Parent Advocacy & Support (502) 595-4459 or toll-free 1-800-232-1160

http://mhmr.ky.gov/mhsas/ofl_supportgroups.asp Kentucky Parent Support Groups

National Resources

National Down Syndrome Society <http://www.ndss.org/>

National Association for Down Syndrome <http://www.nads.org/>