

Welcoming

your son or daughter into the world will bring joy to you and your family. Your baby will be just like other babies in most ways. He or she will play, enjoy life and like to learn new things. Like any parent, you may have some questions about your baby.

This brochure is a starting point for learning about Down syndrome, resources and support groups.

congratulations

answers

to questions you might have

What is Down syndrome?

There are about 350,000 people in the United States with Down syndrome, the most common genetic disorder.

Babies with Down syndrome are born with three copies of chromosome 21, instead of the usual two. The cause of this extra chromosome is unknown.

When a baby has Down syndrome, it can change the way he or she looks. These differences will not affect their health:

- skin folds at the inner corners of the eyes
- flat nose bridge
- low or small ears
- curved “pinky” fingers
- gap between the big and second toe



I thought my pregnancy was normal. What happened?

About 80% of children with Down syndrome are born to mothers under age 35. Mothers over 35 have a higher chance of having a baby with Down syndrome. It's not certain how or why this happens. Without specific medical tests, it is impossible to tell if an unborn child might have Down syndrome.

What will the future hold for my baby with Down syndrome?

People with Down syndrome have some level of intellectual disability, which can be anywhere from mild to severe. Most are somewhere in between. No one can look at any infant and know how intelligent, successful or independent he or she will be in the future.

Today, people with Down syndrome are achieving more with advances in health care and increased opportunities in education. With support, many can:

- move out of the family home
- take care of themselves
- hold regular jobs
- participate in leisure activities
- live rich and full lives

How might Down syndrome affect my baby's health?

Babies with Down syndrome might be affected by any of the following health conditions:

- difficulty breastfeeding
- low muscle tone
- heart defect
- digestive or feeding problems
- ear, nose or throat issues
- vision problems
- thyroid disease
- slow or delayed growth and development
- dental problems

All babies are different. It is important to talk with your baby's doctor to learn what to do if your baby has any of the above health concerns.

What if I want to have another baby?

If you are planning to have more children, ask your doctor about your chances for having another child with Down syndrome. You may be referred to a genetic counselor.

Where do I begin to help my baby?

- Love and enjoy your new baby.
- Stay in touch with your baby's doctor.
- Seek support from parent groups.
- Enroll your baby in early intervention (birth to 3 years old).
- Follow-up with recommended medical specialists.
- Find disability-related resources in your state.



Where can I find more information about Down syndrome?

Ask your doctor about important health screenings at different ages. Clinical guidelines can be found at the following medical professional association websites:

- **American Academy of Pediatrics** www.aap.org
- **American Academy of Family Physicians** www.familydoctor.org

The following organizations can answer many of your questions, offer support and refer you to resources:

- **National Down Syndrome Society** (NDSS) 800-221-4602 or www.ndss.org
- **National Down Syndrome Congress** (NDSC) 800-232-6372 or www.ndscenter.org

Many parents recommend the NDSS *Changing Lives Program* (contact NDSS). Health professionals often mention the book *Babies with Down Syndrome* (by Karen Stray-Gundersen) to new parents.

How can I find other parents of children with Down syndrome?

Many parents are happy to share their experiences and can:

- answer questions
- explain medical language, services and how specialists can help
- find resources (financial assistance, early intervention, health, social services, etc.)



To find parent support groups in your area, contact:

- NDSS at 800-221-4602 or www.ndss.org
- NDSC at 800-232-6372 or www.ndscenter.org
- Down Syndrome Newsgroup at www.downsyndrome.com

Additional resources in your area:

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Your Baby and Down Syndrome

Answers to Questions You Might Have

Q&A

From the office of: