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 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.
• Educate your baby in early intervention (birth to 3 years old).
• Seek support from parent groups.
• Love and enjoy your new baby.

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

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.

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

Today, all babies are different.

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Genetic counselor:

With Down syndrome, you may be referred to a genetic counselor to learn more about your chances for having another child with Down syndrome. Your doctor will give you the name of your child’s genetic counselor.

How might Down syndrome affect my baby’s health?

Babies with Down syndrome might be affected by any of the following health conditions:
- slow or delayed growth and development
- weak or small muscles
- hearing or vision problems
- heart or lung defects
- respiratory or feeding problems
- low muscle tone
- difficulty breathing

What might I do next?

• Live a rich and full life.
• Participate in physical activities.
• Find regular jobs.
• Take care of themselves.
• Move out of the family home.

With support, many can:
- Increase opportunities in education.
- Improve health care and services.
- Achieve more independence.

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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) 800-222-1662 or www.ndsc.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 your questions
- Help you understand medical language
- Explain medical services and how they work
- Help you find resources
- Connect you with parent support groups in your area, or direct you to other organizations

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.ndsccenter.org
- Down Syndrome Newsgroup at www.downsyndrome.com

Additional resources in your area:

- National Down Syndrome Congress (NDSC) 800-222-1662 or www.ndsc.org
- National Down Syndrome Society (NDSS) 800-221-4602 or www.ndss.org
- From the office of: Your Baby and Down Syndrome Q&A

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