

Down Syndrome Facts for New and Expectant Parents

What is Down Syndrome?

Down syndrome is genetic, but does not run in families. People with Down syndrome have different abilities, traits, and health problems. These cannot be fully known before they are born. Causes:

- It is usually caused by an extra copy of the 21st chromosome.
- It is not caused by anything a parent did or did not do.
- As a woman gets older, she has a higher chance of having a baby with Down syndrome.

How Common is It?

About 250,000 people in the United States have Down syndrome.¹ One in 800 babies are born with it.²

What is a Baby with Down Syndrome Like?³

Raising a child with Down syndrome takes more time than raising other children. But, in general, they:

- Are more like other children than different.
- Have learning problems (usually not severe).
- Develop slowly. Physical, occupational, and speech therapy early in life can help them stay on track.
- Have hypotonia (low muscle tone) from birth. This gets better with time and physical therapy.
- Are more likely to have a problem with:
 - Feeding and digestion
 - Snoring
 - Hearing
 - Sleep apnea
 - Sight
- Frequent congestion

What is the Health of People with Down Syndrome?

People with Down syndrome have better health than in the past. They usually live for 60 years.⁴ This is from progress in health care, education, and public attitudes.

Half of them have health problems:

- About 5 out of 10 have a heart condition.
- About 1 out of 10 have a stomach problem that might need surgery.
- Some have lung infections.
- Some have sleep disorders, such as obstructive sleep apnea.
- Some have hypothyroidism.

This information was created and reviewed through a partnership with the UAMS Patient and Family Advisory Councils and the UAMS Center for Health Literacy.

What is Education Like for a Down Syndrome Child?

There are programs that help them reach their full abilities:

- Individualized education program (IEP)
- Special education (learning in a small group or the regular classroom)
- More than 250 college programs for people with mental disability

What is Adult Life Like for a Person with Down Syndrome?

Many are thriving, with active lives. Research finds that most are happy with their lives.⁵ This is because the public now values them as members of the community. People with Down syndrome can:

- Be in sports
- Take part in school and social activities
- Have a job
- Live on their own or in a group home
- Have friends and close relationships

Need Support?

A genetic counselor can help. Ask your nurse or baby's doctor if you would like a referral for one here in Central Arkansas. Or, you can go to www.nsgc.org to search for a genetic counselor on your own. They can provide info on:

- Types of pre-natal (pre-birth) screening tests – their accuracy and limits
- Your choices (keep the baby, adoption, or abortion)
- Your chance of having another baby with Down syndrome
- Genetics of Down syndrome
- Connecting with local resources (support groups or other Down syndrome families)

There are many Facebook groups you can join for additional support. Two great ones are:

- “Central Arkansas Buddy Talk”
- “Arkansas Down Syndrome Network”

Other Resources:

- Arkansas Down Syndrome Association (<http://ardownsyndrome.org/>)
- National Association for Down Syndrome (<http://www.nads.org/>)

The information in this fact sheet was pulled from a fact sheet on the National Society of Genetic Counselors website (<http://www.nsgc.org>). The National Society of Genetic Counselors Down Syndrome Information Act Working Group reviewed the information. The National Center for Prenatal and Postnatal Down Syndrome Resources assisted.

References

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2. de Graaf G, Buckley F, Skotko BG. (2015). Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States. *Am J Med Genet Part A* 167A:756–767.
3. Sheets KB et al. (2011). Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: recommendations of the national society of genetic counselors. *J Genet Couns*. 20(5):432-41.
4. Glasson, E.J., Sullivan, S.G., Petterson, B.A., Montgomery, P.D., Bittles, A.H. (2002). The changing survival profile of people with Down syndrome: implications for genetic counselling. *Clinical Genetics*, 62:390-393.
5. Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Self-perceptions from People with Down Syndrome. *American Journal of Medical Genetics, Part A*: 155:2360-2369. See more research at brianskotko.com.

Recommended Resources for Parents

To Learn About Down Syndrome

- Understanding a Down Syndrome Diagnosis (lettercase.org)
- Diagnosis to Delivery: a Pregnant Mother’s Guide to Down Syndrome (downsyndromepregnancy.org)
- Facts about Down Syndrome (Center for Disease Control and Prevention – cdc.gov)
- Babies with Down Syndrome (woodbinehouse.com)

From Parents of Children with Down Syndrome (Downloadable Books for New Parents)

- Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives (woodbinehouse.com)
- What Parents Wish They’d Known: Reflections on Parenting a Child with Down Syndrome (woodbinehouse.com)

To Help With Decision Making

- A Time to Decide, a Time to Heal (pineapplepress.org)
- A Heartbreaking Choice (aheartbreakingchoice.com)
- Planning for a Loving Future (ndsan.org)
- A Loving Choice: Making an Adoption Plan (ndsan.org)
- Brighter Tomorrows (brightertomorrows.org)

About Health Care and Treatment

- Health Care Information for Families of Children with Down Syndrome, American Academy of Pediatrics (healthychildren.org)

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About Prenatal Screening Tests

- Understanding prenatal screening and testing for chromosome conditions (lettercase.org)
- A Patient's Guide to Understanding Non-Invasive Prenatal Testing (nsgc.org)

To Find a Down Syndrome Organization

- National Down Syndrome Society (ndss.org)
- National Down Syndrome Congress (ndscenter.org)
- International Mosaic Down Syndrome Association (imdsa.org)

Focused on Adoption

- National Down Syndrome Adoption Network (ndsan.org)

Focused on Education

- Down Syndrome Education USA (dseusa.org)

Focused on Research

Research can greatly improve outcomes for people with Down syndrome. DS-Connect, sponsored by the National Institutes of Health (NIH), is a voluntary registry for families who want to take part in research, receive updates on research projects, and share their data about Down syndrome.

- DS-Connect (dsconnect.nih.gov)
- Jerome Lejeune Foundation (lejeuneusa.org)
- Global Down Syndrome Foundation (globaldownsyndrome.org)
- Lumind Foundation (lumindfoundation.org)

Professional Genetics Organizations

- National Society of Genetic Counselors (nsgc.org)
- American College of Genetics and Genomics (acmg.net)

National Disability Organizations

- American Association of People with Disabilities (aapd.com)
- ARC (thearc.org)
- Association of University Centers on Disability (aucd.org)
- March of Dimes (marchofdimes.org)
- Special Olympics International (specialolympics.org)

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