

My baby has...

Down Syndrome

You and your baby are not alone. Each year, about 66 babies in Kentucky and about 6,037 babies in the United States are born with Down syndrome.

What is Down syndrome?

Your baby has a genetic disorder caused by a defect in his or her chromosomes. Chromosomes carry the genetic information that makes each baby unique. Humans usually have 46 chromosomes arranged in 23 pairs, but babies who have Down syndrome have three copies of Chromosome 21. Down syndrome will affect your baby physically and mentally throughout his or her life.

How did this happen?

Older mothers are at a higher risk of having a baby with Down syndrome. However, your baby's birth defect is *not* your fault. There is no known way to prevent Down syndrome. Talk to your doctor about whether you should get genetic counseling for any future pregnancies.

Common physical features of babies with Down syndrome:

- A flattened face
- Almond-shaped eyes that slant up
- A short neck
- Small ears
- A tongue that tends to stick out of the mouth
- Tiny white spots on the eye
- Small hands and feet
- A single line across the palm
- Poor muscle tone or loose joints

What's next for my baby?

Each child with Down syndrome is unique, and all have different personalities, abilities, and needs. Your health care professional will refer you to services that will help meet your child's needs. Connecting with other families who have children with Down syndrome can also help reduce stress and feelings of loneliness.

How can I help my baby?

Babies born with Down syndrome have a higher risk for developmental delays, heart defects, stomach and digestive problems, eye problems, hypothyroidism, ear infections, and hearing loss. Keep a close eye on your baby, and go to your doctor if you have any concerns about his or her development. With love and support from their families, children born with Down syndrome are able to thrive.



Caleb's Story—Written by his mom, Stacy

There are many different emotions a mother and father go through when their child is born with a disability, but the emotion that most often gets stymied in the midst of tests and uncertainties is the simple beautiful joy of having a baby. Our son Caleb was born with Down syndrome a few months ago, and I did not wish to hide or ignore the diagnosis, but I found it difficult to celebrate as countless tests and pending results kept knocking at the door. Each time I looked at my baby boy, all I could see was a marvelous creation. He was not like any other baby—he was uniquely himself and he was altogether mine. Having a child with disabilities gives you a new cup by which to measure; a simple smile is no longer simple, it is a triumph and a glorious sight, and a common milestone on the doctor's chart becomes the very corner stone of great hopes. We do not know how far our children will go, but we do know the depth of our love. I cherish my little boy each day and don't waste the present worrying about the future.

To read more stories about families like yours, go to: <https://www.cdc.gov/ncbddd/birthdefects/stories/downsyndrome.html>

Available Resources

First Steps is a statewide early intervention system that provides services to children with developmental disabilities from birth to age 3, along with their families. Participating in early intervention can cause significant improvements in development and learning, which can reduce the need for special education programs later in life. You can receive services at the home, in a childcare center, or other community setting. <http://chfs.ky.gov/dph/firststeps.htm>

In Kentucky, there are several different organizations that support families and individuals with Down syndrome.

- **The Down Syndrome Association of Central Kentucky** is based in Lexington and provides services to families in Central and Eastern Kentucky. <http://www.dsack.org/>
- **Down Syndrome of South Central Kentucky** is based in Bowling Green and provides services to families in South Central Kentucky. <http://www.dssky.org/>
- **Green River Area Down Syndrome Association** is based in Owensboro and covers western Kentucky. <http://www.gradsa.org/>
- **Down Syndrome of Louisville** is based in Louisville and covers counties surrounding Louisville and Elizabethtown. <http://www.downsyndromeoflouisville.org/>
- **The Down Syndrome Association of Greater Cincinnati** supports families in Northern Kentucky. <http://www.dsagc.com/>
- **The Council on Developmental Disabilities** is based in Louisville and provides statewide services to individuals with developmental disabilities. <http://www.councilondd.org/>

Additional Information

The Kentucky Birth Surveillance Registry (KBSR) is dedicated to preventing birth defects through ensuring timely, complete, and accurate birth defects surveillance; referring children with birth defects to appropriate services; providing data for research studies after appropriate review; and implementing birth defects prevention programs in Kentucky. You can contact Kentucky's Birth Surveillance Registry at kbsr@ky.gov.

For more information about Down syndrome, visit:

<http://chfs.ky.gov/dph/mch/ecd/DownSyndromeInformation.htm>

<https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>

<http://www.ndss.org/>

Information adapted from: <https://www.cdc.gov/ncbddd/birthdefects/types.html>



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