

My baby has...

Gastroschisis

You and your baby are not alone. Each year, about 15 babies in Kentucky and about 1,871 babies in the United States are born with gastroschisis.

What is gastroschisis?

Gastroschisis is a birth defect that causes an opening in your baby's belly just to the right of the belly button. The opening can be small or large. Your baby's organs, such as the intestines, stomach or liver, might grow on the outside of your baby's body.

How did this happen?

Scientists think that a mix of genetic and environmental factors cause gastroschisis. They are trying to learn more about what causes this condition. Remember, your baby's birth defect is ***not*** your fault. There is no known way to prevent gastroschisis. For future pregnancies, doctors recommend having a healthy weight, eating well, taking prenatal vitamins, and not smoking or drinking, to have the best chance of a healthy pregnancy and baby.

What's next for my baby?

Shortly after you give birth, your baby will need surgery to repair the hole in his or her belly and move the intestines inside. Depending on how many of your baby's organs grew outside the body, your baby might need multiple surgeries to move all the organs inside. Ask your doctor about the treatment plan for your baby.

How can I help my baby?

After the repair, your baby might still have problems with feeding, digesting food, or absorbing nutrients. Keep a close eye on your baby and go to your doctor if you have any concerns. With love and support from their families, many children born with gastroschisis are able to live long and happy lives.



Ashley's Story—Written by her mom, Kayte

Ashley was born in 2005 with a condition called gastroschisis, which caused her intestines to be outside of her body. The beginning of her life was filled with surgeries and tests, setbacks and worry. She caught an infection in her central line that nearly killed her, and she needed a special transfusion and lots of strong antibiotics to keep her alive. It seemed so unfair that such a tiny person would have to endure so much,

but she was a fighter and soon was able to come home. I will never forget the way she looked at the sky with silent awe the first day she finally left the neonatal intensive care unit, or how scary it was at first to have her home without the constant beeping of machines to monitor her. She has always held a sense of wonder and curiosity about the world, and Ashley has a resiliency that other kids her age don't possess.

Seven years and a few more surgeries later, Ashley is doing really well. She is smaller than other children, which is normal for gastroschisis survivors. She will always be at risk of intestinal kinks and blockages, which makes every stomach bug or tummy ache a worry. She is also hearing impaired from an additional birth defect called microtia. Although her life was initially filled with challenges, Ashley is blossoming into a remarkable young girl who has inspired countless other gastroschisis families with her story.

To read more stories from families like yours, go to: www.cdc.gov/ncbddd/birthdefects/stories/gastroschisis.html

Available Resources

Avery's Angels Gastroschisis Foundation is a foundation dedicated to research, awareness, and support for patients and families affected by gastroschisis. <http://averysangels.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 gastroschisis, visit:

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

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



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