Let's Talk About ...

Prenatal Counseling: Gastroschisis

What is gastroschisis?

Gastroschisis [gas-tro-SKEE-sis] occurs when a developing baby's abdominal (belly) wall muscles don't form normally, causing a hole to form (usually near the umbilical cord). The belly organs, such as the stomach, intestines, ovaries or testicles, and bladder, are pushed outside the body through this hole.

Gastroschisis is a type of congenital (present at birth) abdominal wall defect. About 1 in every 2,500 to 3,000 babies are born with gastroschisis each year.

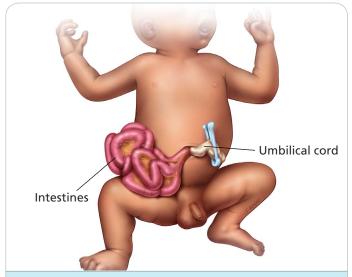
The **Utah Fetal Center team** will help you make the best possible decisions about your baby's gastroschisis. The team includes maternal-fetal medicine specialists for the pregnant mother, neonatologists who are specially trained to care for newborns, and pediatric specialists to help with your baby's needs before and after delivery.

What causes gastroschisis?

Doctors don't know exactly what causes gastroschisis. However, they know that it occurs early during fetal development. A baby is more likely to have gastroschisis if their mother:

- Is younger
- Had a urinary tract infection (UTI) just before becoming pregnant
- Drank alcohol or smoked while pregnant
- Has a low body mass index (BMI)

However, gastroschisis can also occur even if mothers do not have any of these risk factors.



Gastroschisis occurs when the belly organs are pushed outside the body.

How is gastroschisis diagnosed during pregnancy?

A healthcare provider usually finds gastroschisis during a pregnancy ultrasound about 20 weeks into the pregnancy, but they may see it as early as 14 weeks. After the provider diagnoses gastroschisis, they will recommend follow-up ultrasounds to monitor the baby's growth and watch for possible problems. Most babies with gastroschisis don't have other congenital disorders.

How does gastroschisis affect my baby?

Because the intestines sit in the amniotic fluid (liquid that protects the baby in the womb) during development, they can be damaged and not work well after birth.

Nine out of 10 babies diagnosed with gastroschisis have simple gastroschisis, meaning the intestine is normal. These babies can have surgery shortly after birth to fix the condition.

How is gastroschisis managed during pregnancy?

Once gastroschisis is diagnosed, your obstetrics (OB) provider should closely monitor your pregnancy. The fetal center will review your imaging and tell you more about gastroschisis, recommend ways to manage your pregnancy, and help you meet the pediatric specialists who will care for your baby after delivery.

You have a higher risk of miscarriage during the third trimester if your baby has gastroschisis. You should have weekly appointments to see how your baby is doing. If you notice any change, such as not feeling the baby move, go to your OB provider immediately. Most babies with gastroschisis will be born a few weeks early, around 36 to 37 weeks. Because these babies deliver early, your doctor may give you a course of steroids that will help your baby's lungs develop. This is given during the third trimester.

Where and how should I deliver my baby?

You should deliver your baby at a hospital where a pediatric surgeon can immediately evaluate your child in a neonatal intensive care unit (NICU) that specializes in caring for gastroschisis. Healthcare providers will help you decide where to deliver and coordinate this during your fetal center evaluation.

You can deliver your baby vaginally, but your OB provider may decide to perform a cesarean [sess-SAY-ree-un] section (C-section), depending on your baby's health. Gastroschisis does not determine the way you deliver your baby.

How is gastroschisis managed after delivery?

A neonatologist [NEE-oh-nay-TAHL-oh-jist], a specially trained pediatrician, will evaluate your baby and make sure their heart and lungs are working right. They will manage your baby's medicines, feeding, and daily needs in the NICU.

Your baby may need:

- An NG or OG tube. A healthcare provider inserts a nasogastric [NAY-zo-gas-trick], or NG, tube in your baby's nose or an orogastric [or-oh-GAS-trick], or OG, tube in your baby's mouth. The tube goes all the way to the stomach and sucks out any fluid. This prevents your baby from choking or breathing stomach contents into the lungs.
- A bowel bag. This plastic bag covers your baby's body below the armpits. It protects the bowel and keeps it warm and moist until the surgeon arrives.
- A silo. The bowel bag will be replaced by a silo, a soft plastic tube that holds your baby's intestines. A ring on one side of the silo fits into your child's belly, holding it in place. The intestines sit in the silo and slowly fall into the belly as more room becomes available. This usually takes 5 to 7 days.
- A PICC line. A peripherally [per-IF-er-uh-lee] inserted central catheter (PICC line) is a tiny tube inserted through the umbilical cord and then an arm or leg. Your baby will receive fluids, antibiotics, medicine, and nutrition through the PICC line.
- TPN: Your baby won't be allowed to eat at first, so they'll receive total parenteral [pah-REN-ter-ull] nutrition, or TPN, through the PICC line. TPN contains protein, fat, sugar, vitamins, and minerals and will meet all your baby's nutritional needs.

| Questions for my doctor | | | | |
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How is gastroschisis repaired?

Once your baby's organs are completely in the belly, they will have surgery to close the hole and muscle and create a belly button. The surgeon will look closely at your baby's intestines for any damage and remove the unhealthy parts. They will then stitch the opening in the belly wall back together.

When can my baby go home?

Most babies with gastroschisis stay in the hospital for 6 to 8 weeks. It usually takes several weeks for the intestines to work after surgery because they were injured from the amniotic fluid. Once your baby can eat by mouth (after they start pooping), it also takes several days for your baby to get enough nutrition to go home.

How is complicated gastroschisis managed?

One out of 10 babies born with gastroschisis have **complicated gastroschisis**, meaning the intestine is abnormal. They may need special care to fix:

- Abnormal tissue or belly wall. If the surgeon can't insert a silo because there is abnormal tissue or the hole is too small, they will put your baby's intestines back into the body shortly after birth. The surgeon may also open the hole and insert a silo so the intestines fall in over time.
- An intestinal atresia. Your baby will receive normal care in the NICU. However, if they still haven't pooped 6 weeks after surgery, they will have surgery to fix the atresia. The 6-week wait allows the bowel to heal so it can be repaired.

- An intestinal perforation (hole). Soon after your baby is born, they will go to the operating room (OR). The surgeon usually puts the intestine back into the abdomen, except for the perforation, which becomes an ostomy [0S-toh-mee]. This is an intestine opening at the skin of the belly, where it can drain into a bag. Your baby will have another surgery 6 weeks later to fix the perforation and put the bowel back together.
- Short-gut syndrome: A gastroenterologist [GAS-tro-en-ter-AHL-oh-jist], or doctor who specializes in stomach and digestive tract problems, will care for your baby in the hospital. Your baby may need months or years of TPN, even after going home. Fortunately, short-gut syndrome is rare.

What outcome can I expect after surgery?

The outcome for babies with gastroschisis is generally very good. Though a baby with gastroschisis is often smaler at birth, they tend to catch up with other children their age. Nine out of 10 babies with gastroschisis survive, and most only need normal follow-up with a pediatrician to monitor their growth and development.

For additional information

Utah Fetal Center

<u>intermountainhealthcare.org/locations/</u> <u>primary-childrens-hospital/medical-services/</u> <u>utah-fetal-center</u>

American Pediatric Surgical Association (APSA)

eapsa.org/parents/conditions/f-o/gastroschisis

Centers for Disease Control and Prevention (CDC)

cdc.gov/ncbddd/birthdefects/gastroschisis.html

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