

UNDERSTANDING GASTROSCHISIS

CARMEN AND JOHN THAIN CENTER FOR PRENATAL PEDIATRICS

What is gastroschisis?

Gastroschisis is a birth defect in the abdomen, and is often referred to as a “ventral wall defect.” Babies with gastroschisis are born with portions of their small and large intestines exposed outside the body through a small opening generally found to the right of the belly button. The protruding bowel has no protective covering, and so it is exposed to amniotic fluid and can become swollen and damaged. The image on the right depicts the intestines freely floating as they would in the amniotic fluid and the repair after surgery.

Gastroschisis generally occurs as an isolated birth defect, so babies with this condition are not likely to have a chromosomal abnormality or other birth defects. Around 10% of babies with gastroschisis will also have a blockage in their intestines.

How common is gastroschisis and what causes it?

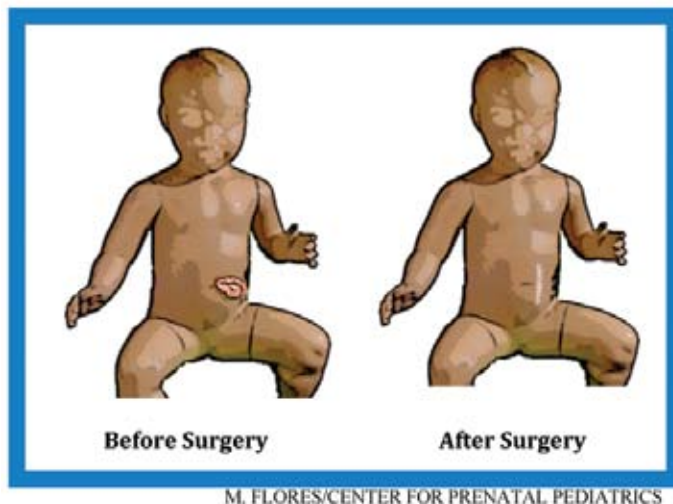
Gastroschisis is seen in approximately 1 in 5000 births, and is more common in mothers under 20 years old. Women who smoke during pregnancy may also have a higher chance to have a baby with gastroschisis.

No specific cause is known for gastroschisis, but it results from the incomplete formation of the abdominal wall in the first trimester of pregnancy.

How is gastroschisis detected during pregnancy?

Gastroschisis is usually identified during pregnancy through prenatal ultrasound in the second trimester. Careful ultrasound examination can distinguish it from other types of ventral wall defects. Gastroschisis can not be detected in the first few months of pregnancy because the abdominal contents are within the umbilical cord as a normal part of their development.

Gastroschisis may also be suspected due to results of a screening test, known as the ‘AFP test’, performed in the second trimester. This test can indicate if the baby is likely to have gastroschisis or other ventral wall defects, as well as a birth defect of the spinal cord called spina bifida. If the results are positive (meaning a higher chance for these birth defects has been identified) a prenatal ultrasound is performed to closely examine the baby’s development.



How will my pregnancy be managed now that gastroschisis has been detected?

Regardless of where the gastroschisis was first detected during your pregnancy, you will still have another thorough ultrasound to examine the anatomy and development of the baby through the Center’s ultrasound unit. Your prenatal care will be handled by an MFM specialist, an Obstetrician with special training and expertise in high-risk pregnancy. Once the diagnosis of gastroschisis is confirmed, you will have an opportunity to meet with a variety of pediatric subspecialists who routinely see patients with this diagnosis and who work together as a team to best manage your pregnancy and prepare for the birth of your baby. Your clinical care coordinator will make appointments for you to meet the following subspecialists:

- A **Pediatric Surgeon** who will thoroughly discuss with you the general surgical approach taken with gastroschisis, and what you might expect for your baby after birth. The same pediatric surgeon you meet during your pregnancy will likely be the one to operate on the baby after birth.
- A **Geneticist** or a **Genetic Counselor**, who are experts in fetal development and inheritance.
- A **Neonatologist**, a pediatrician specializing in newborns that need extra attention in the Neonatal Intensive Care Unit (NICU). You will have an opportunity to tour the Labor floor and the NICU with a Neonatologist, learn what to expect in the days after you give birth, and become familiar with the facilities and the philosophy of care. *(continued on next page)*

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How will my pregnancy be managed? (Continued):

Pregnancies with gastroschisis are very closely monitored during the third trimester due to the increased chance that the baby could have problems with growth, amniotic fluid volume (either too much or too little), or distress. In general, special ultrasounds and prenatal testing known as biophysical profiles (BPP) and non-stress tests (NST) are performed on a weekly basis to monitor the baby's well-being. As your delivery date approaches, your MFM and medical team will discuss with you the route of delivery for your baby; having a baby with gastroschisis does not mean that you have to have a cesarean section. Whether you undergo an induction of labor or a planned cesarean section, you will ideally have your baby when the whole medical team is ready and available. Ultimately, you and your medical team will decide what is best.

How will the gastroschisis be treated after birth?

Once you give birth, your baby will be examined carefully to check the gastroschisis and look for any other problems. A small tube is placed in the baby's mouth to the stomach to prevent the intestines from filling with air and fluid, and all nutrition is given to the baby intravenously (through an IV). Your pediatric surgeon will cover the exposed intestines in a sterile sheet known as a "silo," and the baby will go to the NICU. The exposed intestines will be gradually and carefully put back into the abdomen, making sure that the abdomen can expand enough to accommodate the intestines. When the silo is sufficiently reduced (usually over 5 to 10 days), the baby will have an operation where the abdomen is closed.

Once the intestines are in the abdomen, they take a little while to work well on their own. The baby will continue to receive all nutrition through the IV until the intestines start to function. When this happens, the baby will continue with the IV feeding, but can also take breast milk or formula through a naso-gastric drip (called an NG tube). Over time, feedings through the NG tube are increased, and when the baby is ready, feeding by mouth is started. When the baby has gained enough weight and is feeding well through the NG tube and by mouth, he or she is probably ready to go home. This whole process can take a few weeks, but before leaving the hospital you and your family will know how to care for your baby once you have left the hospital. You will continue to see your pediatric surgeon and other specialists as needed for regular check-ups to monitor the progress your baby has made since going home.

What is the long-term outlook for babies with gastroschisis?

Overall, children with gastroschisis are able to live very full, active, and productive lives. The length of stay in the hospital for babies after birth is directly related to the damage to the exposed intestines. In the minority of cases that have abdominal blockage, the affected portions of the intestines need to be removed, and can possibly result in a short gut. These children will need special feedings for much longer, sometimes indefinitely. Children with gastroschisis also have a higher chance of developing inguinal hernias (protrusions in the abdominal wall) later in life that need to be surgically repaired. However, for most children with gastroschisis there are no long-term health problems.

What are the chances I could have another baby with gastroschisis?

Gastroschisis does not appear to run in families, and the chances to have another affected baby are less than 5%. Future pregnancies should be monitored by prenatal ultrasound and AFP screening at 16 weeks gestation.

What can I expect from the specialists at Morgan Stanley Children's Hospital?

The well-being of you and your baby are extremely important to everyone involved in your care. NewYork-Presbyterian Morgan Stanley Children's Hospital/Columbia University Medical Center has consistently been ranked one of the best pediatric hospitals in the country: our pediatric surgeons have extensive experience with gastroschisis, and our MFM team is among the largest and most experienced anywhere. Our NICU is one of the most advanced in the United States, and has been cited several times for its excellence and dedication to patient care.

The well-being of you and your baby are extremely important to everyone involved in your care. Together we are all dedicated to giving you the best pregnancy and healthiest outlook for your child.

About the Carmen and John Thain Center for Prenatal Pediatrics

Complex pregnancies receive better care when specialists collaborate. The Carmen and John Thain Center for Prenatal Pediatrics is dedicated to helping pregnant women and their families when a birth defect or genetic syndrome is detected before the baby is born. The Center offers sensitive, complete, up-to-date information and testing, and an integrated approach to care that begins in the prenatal period and continues after birth with pediatric follow-up. A collaborative, coordinated program of care is created among specialists in perinatology, neonatology, genetics, pediatric cardiology, pediatric surgery and all pediatric subspecialties.