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Gastroschisis (abdominal wall defect or hole)

Patient and family information, brought to you by the Education Committee of APSA

Overview - “What is it?”

Gastroschisis occurs as your baby is developing (fetus), and a hole in the muscle and skin of the belly (abdomen) forms. Most commonly this occurs just to the right of the umbilical cord. Because the abdominal wall keeps all of the abdominal organs contained, if there is a hole, then these organs may come out (Figure 1). As your baby is floating in amniotic fluid in the womb, the organs are in contact with this fluid and become irritated by it. It is not known why gastroschisis occurs.



Figure 1: Gastroschisis intestine of a baby after delivery.

Picture courtesy of MJArca 11/2016

Gastroschisis occurs in 3-4 per 10,000 births. There is an association between gastroschisis and a young mother (20 years or younger).

Signs and Symptoms - “What symptoms will my child have?”

Early signs and symptoms: If you are getting ultrasounds during pregnancy, your doctor may see this problem before birth. It is important to know that your baby does not have pain from this. However, your doctors may be watching the thickness of the intestine wall during follow-up ultrasounds to make sure that the intestine is not being damaged.

Later signs and symptoms: Gastroschisis may be detected after your child is born. The most common organ that comes out of the hole is the intestines. Sometimes, other organs can also go through the hole.

Diagnosis - “What tests are done to find out what my child has?”

Labs and Tests: In most instances, gastroschisis will be detected with prenatal ultrasounds, so further tests are usually not necessary after birth.

Conditions that mimic this condition: The other abdominal wall hole that may look like gastroschisis is called omphalocele. Unlike gastroschisis, omphaloceles occur within the belly button (umbilicus), and the internal organs are covered by a thin sac.

Treatment - “What will be done to make my child better?”

A baby with gastroschisis should deliver in a hospital that has ready access to surgeons and specialists that can take care of the baby right away (usually a dedicated children’s hospital). Your obstetric doctor will discuss options about delivery. The best time for delivery is not known. Most doctors believe that a baby with gastroschisis should be born close to term. Vaginal delivery is a very safe option and a Caesarian section (C-section) is not needed. However, you and your doctor should discuss what is best for your individual situation. Ideally, the parents can meet with surgeons and infant specialists before the baby is born to get an idea where and how your child will be cared for.

Surgery:

Preoperative preparation: After delivery, your baby will have a tube passed into the stomach to make sure fluid and air are drained and so the bowels do not expand. Your baby will likely need an intravenous (IV) to get fluids as s/he may lose fluid from the exposed bowel. To keep the bowel from being injured, your baby will have the lower body placed into a plastic bag with moisture. Your child will be rapidly brought to the closest neonatal intensive care unit (NICU) for further care.

Operative Care: Surgeons will look at the hole in the abdominal wall to get an idea as to its size and whether the bowels can be put back inside. Based on the baby’s size and condition,

how much intestine is out, and the condition of the intestines, the surgeon may decide whether the closure can be done at the bedside in the NICU or the operating room. The surgeon will make a decision whether putting all the organs that are outside will fit inside the belly cavity right away. If all the abdominal contents can be placed back inside without compromising the blood supply to the internal organs, then the surgeon will close the hole. If the surgeon cannot get all the contents back into the abdomen, then the bowels will be put into a temporary bag (silo) and allow gravity to move the bowel back into the abdomen over a period few days, after which your surgeon will close the hole. The photo below shows a baby with gastroschisis, whose intestines are contained in a silo (see Figure 2).



Figure 2: Intestines contained in a silo
Image credit: Matias Bruzoni/pedsurglibrary.com

Informed consent: A consent form is a legal document that states the tests, treatments or procedures that your child may need and the doctor or practitioner that will perform them. Before surgery, your doctor should tell you what the operation is, the goal of the surgery and other possible treatment options that are available. Your doctor should explain the risks and benefits of the surgery. You give your permission when you sign the consent form. You can have someone sign this form for you if you are not able to sign it. You have the right to understand your child's medical care in words you know. Before you sign the consent form, make sure all of your questions are answered. It is important to know that during surgery, there are things that can happen that your doctor may have not predicted before going in. He or she will explain these to you after the surgery.

Postoperative care: Because the intestines were exposed while developing in the uterus, they do not function normally for several days to weeks. Your baby will need to have nutrition given through his/her veins. After the bowel starts working, feeding will start and slowly advance. You can expect your baby to stay in the hospital for about a month or longer depending on how long it takes to get to full feeds. Some babies may need to be on the ventilator (breathing machine) to help with breathing for a few days after birth, especially if s/he needed to go to the operating room.

Risks/Benefits

Benefits: Getting all of the organs back into the abdomen and the hole closed is important because the bowel may otherwise get injured.

Risks: If all of the intestines were placed in the abdomen and the space is too tight, blood supply to the intestines and the rest of the contents of the belly may be cut off. Other risks include wound infection and injury to the organs.

Associated Issues: Up to one-third of babies with gastroschisis may experience an intestinal infection called necrotizing enterocolitis. Care must be exercised when advancing feeding in gastroschisis babies. About 10-15% of babies with gastroschisis can have intestinal atresia, where the intestine is not in continuity. In a small fraction of this babies, there is massive loss of intestine while inside the uterus resulting in “short gut syndrome”. In cases of atresia, repair is done weeks after birth, prolonging the hospital stay. Babies with short gut syndrome require long-term and intensive medical and surgical care. Uncommonly, babies with gastroschisis can have problems with intestinal movement and ability to digest and absorb nutrients.

Home Care (“What do I need to do once my child goes home?”)

Diet: By the time your baby comes home, s/he should be on a full diet with no restrictions.

Activity: There will be no activity restrictions.

Wound care: Your surgeon will review with you details on the wound care, as it depends on the way that the hole was closed.

Medicines: There are usually no medicines that are needed for uncomplicated gastroschisis.

What to call the doctor for: If your baby is not keeping feeds down (throwing up), the incision or the belly button is red, please call your doctor.

Follow-up care: You will need to follow up with your surgeon for at least one wound check after discharge and with your pediatrician for normal baby visits, especially to follow weight gain.

Long-Term Outcomes (“Are there future conditions to worry about?”)

In majority of cases, you can expect to have your baby tolerate all feeds and not have any issues. However, in cases of babies with atresia, history of NEC, problems with motility or absorption, or short gut syndrome, care at home can be very complex.

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