PARENTS' RESOURCE GUIDE

Gastroschisis

What is gastroschisis (gas-tro-SKEE-sis)?

A prenatal ultrasound around 14 to 24 weeks by the obstetrician has found that your baby's intestines are located outside of the abdomen and floating free in the amniotic fluid. See Figure A. Around 12 weeks of development the abdominal wall has completely closed. In Gastroschisis the abdominal wall did not close properly.

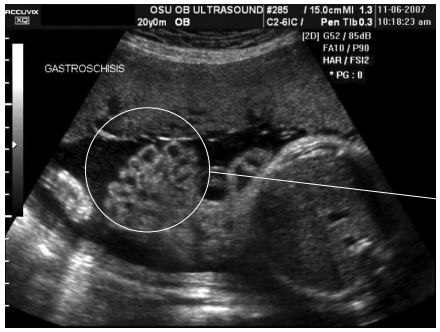

Figure A
Fetal ultrasound showing bowel protruding from abdominal wall defect. (Slide courtesy of the Department of Maternal Fetal Medicine at The Ohio State University)

Gastroschisis is the most common of the abdominal wall defects. The stomach, small bowel, and large intestine have come through a small opening to the right of the umbilical cord. See Figure B. Because the bowels have been exposed to the amniotic fluid, the intestines may be swollen and covered with a thick film. Sometimes the ovaries in girls and undescended testicles in boys are found outside also.

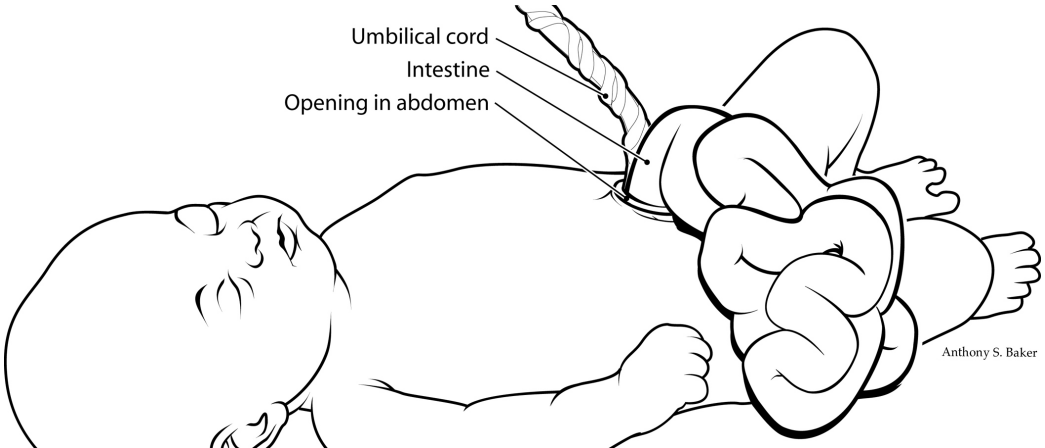

Figure B:
Illustration of baby with gastroschisis

Causes

The exact cause of gastroschisis is not known.
Gastroschisis affects both males and females in equal numbers. Most babies with gastroschisis are born to young mothers in their first pregnancy. Usually, the condition is not inherited, and future pregnancies are not affected.

What happens after your baby is born?

As soon as your baby is born, a sterile plastic bag called a bowel bag will be placed over the bowel to protect it. This bag helps to prevent infection by keeping germs from getting to the intestines. It also helps your baby stay warm and prevents dehydration (getting "dried out"). Your baby will need to keep this bag on until he or she has surgery.

A tube will be put into your baby's nose or mouth. It will be either an NG tube (nasogastric) or an OG tube (orogastric). This tube goes into your baby's stomach and helps to keep the stomach empty. The tube will stay in place until your baby is ready to be fed by the bottle.

An intravenous line (IV) will be started in your baby's arm, hand, foot or scalp. The IV provides fluids and antibiotics to prevent dehydration and infection. Next, your baby will be transported to Nationwide Children's Hospital,
Neonatal Intensive Care Unit.

Treatment of gastroschisis

Your baby will have surgery a few hours after delivery where the surgeon will carefully inspect the intestines. The surgeon may need to stretch the hole in the abdomen so the intestines can be put back into the abdomen. See Figure C.

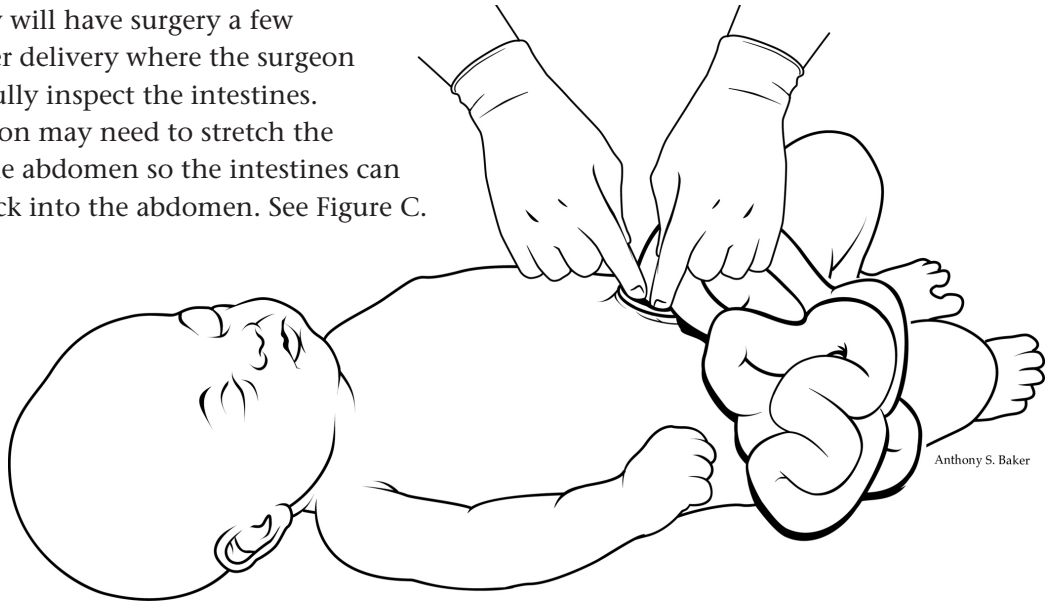

Figure C
Illustration showing surgeon stretching hole in abdomen so intestines can be put back.

A primary repair is when the surgeon is able to place all the intestines back into the abdomen and the opening is closed. This occurs about half of the time.

Sometimes the bowel is too swollen and inflamed and a staged procedure must be done. The first stage is when the surgeon is able to place some of the intestines back into place, but must leave a part of it out because it is too swollen. A primary repair cannot be done in this case because it would put too much pressure on the lungs, making it hard for your baby to breathe.

A surgical pouch called a silo is placed around the intestines. See Figure D. Your baby will be placed in an Isolette® so the silo can be suspended, and your baby's surroundings kept as clean as possible. Every day the surgeon will gently push part of the intestines into the abdomen until everything is inside. It takes about a week for this to occur. Then your baby will go back to surgery to close the hole in the abdomen.

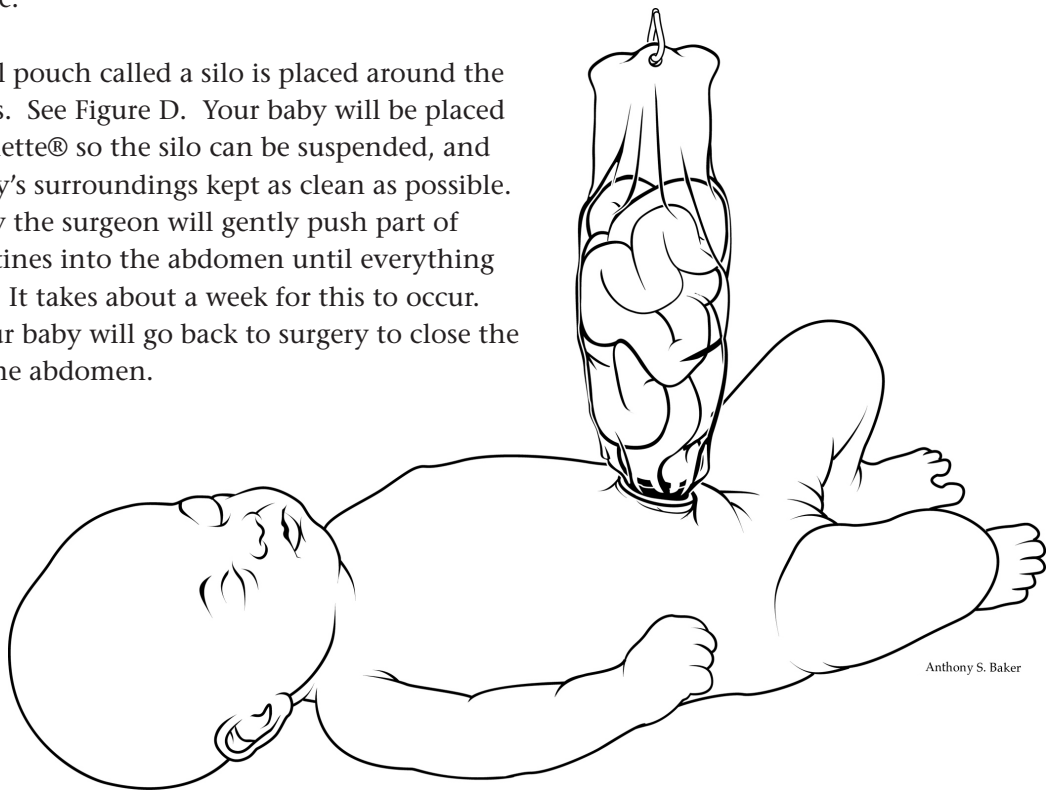

Figure D
Illustration with baby requiring a Silo

Preventing infection

Completely sterile (germ-free) linen will be used. Anyone who touches or handles your baby must wear sterile gloves to help prevent infection. Your baby will remain on antibiotics until the silo is removed.

What Happens after surgery?

After surgery, your baby will need to be on a ventilator to help him or her to breathe. It is hard for most babies to breathe after surgery because of the drugs given during surgery. Your baby's stomach will be tender and sore to touch. We will give pain medicine to reduce the pain and discomfort. The ventilator will be removed when your baby has recovered from surgery.

The NG or OG tube will stay in place until your baby's intestines begin to work properly. This may take several weeks. Your baby will not be able to eat until the intestines have healed. A special IV called a CVL (central venous catheter) will be used to provide IV nutrition. This IV catheter is placed during - or shortly after - the surgery. It will stay in place until IV nutrition is not needed anymore. The catheter will provide TPN (total parenteral nutrition) which has all of the calories and nourishment needed for your baby to grow.

When it is time to feed your baby his or her first bottle, the NG or OG tube will be removed. Your baby will be started off with small amounts of formula or breast milk, and the amount will be increased gradually over time. When your baby is taking enough formula or breast milk to grow and gain weight, the IV will be removed.

Frequently Asked Questions

What is the survival rate?
Gastroschisis has a survival rate of 95%.

When can my baby go home?
Your baby can go home when he or she is taking enough formula or breast milk to grow and gain weight.

How long will my baby have to stay in the hospital?
The average length of hospital stay is 6 to 8 weeks. A few babies will do especially well and go home earlier. Some babies may stay longer until their intestines are functioning properly.

What other tests are done on my baby?
The doctor is going to schedule an echocardiogram (scan) of the heart, kidneys and head. Also, your baby will have blood drawn to monitor lab values. The medical staff will talk with you regarding the results.

What are the complications involved with gastroschisis?

- **Infection**: Your baby will be on antibiotics at birth and for several days after surgery. The surgeon and staff will monitor your baby very closely for any signs of infection.
- **Twisting of the bowel causes bowel atresia (absence of a portion of the intestine) occurs 10% of cases.**
- **The bowel may have perforated (ruptured) in 5% of cases.**
- **Sometimes babies need a blood transfusion.** The surgeons will not give blood unless it is medically needed.
- **Feeding problems:** It takes the bowel several weeks to heal properly. Your baby will not be able to eat large amounts of formula or breast milk right away. This is one of the major reasons why your baby has to stay in the hospital for a long period of time.

Is it okay to have a vaginal delivery?
Most surgeons believe it is okay to have a vaginal delivery. It is not only safe for the baby, but the mother recovers from delivery faster than with a Caesarean delivery. Talk with your delivering doctor about this. If your obstetrician determines that you need to have a Caesarean delivery, the surgeon will agree.

Where do I need to deliver my baby?
Your high risk doctor will let you know the Columbus hospital where you will be delivering.

Will my baby have a belly button?
Yes, the surgeon knows this is very important and will make every effort to give your baby a bellly button.

When my baby has children, will this be passed on?
Usually there is not a family history of gastroschisis.

I live out of town. Where can I stay?
Nationwide Children's Hospital has a wonderful Ronald McDonald's House where families who live out of town may stay while their baby is in the hospital. Ask the Children's Hospital program coordinator if this can be arranged for you.

Am I at risk for delivering a premature baby?
On average, mothers deliver between 36 and 37 weeks. Your delivering doctor will discuss your delivery plans.

How will all of this get coordinated?
Nationwide Children's Hospital has a program coordinator to help with these arrangements. You may contact Becky Corbitt RN, BSN, at any time during your pregnancy for any questions or concerns. Phone: (614) 722-6520.

When can I hold my baby?
This is a difficult time for most parents. You will be able to hold your baby when the ventilator has been removed and your baby has recovered from surgery. Meanwhile, we encourage you to talk and touch your baby during this time.

How can I get involved with my baby's care?
The health care team at Nationwide Children's Hospital encourages family centered care. At any time you need to speak with any members of the team please ask. The staff is here for you and we want to help you to be involved with daily care.

Where do I follow up once my baby is discharged from the hospital?
You will want to find a local pediatrician to take care of all the routine checkups, immunizations and doctor's visits. The program coordinator can help if needed. The pediatric surgeon will follow up with your baby's surgical needs for as long as necessary.

References

American Pediatric Surgical Association @ wwww.eapsa.org/parents/resources
Helping Hands Patient/Family Education Program, Nationwide Childrens Hospital.

Notes

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