Hemolytic uremic syndrome from Shiga toxin-producing E. coli (STEC-HUS)

What is hemolytic uremic syndrome (HUS)?
HUS stands for:
• Hemolytic – destroys red blood cells
• Uremic – a build up of waste products in the body because the kidneys are not working well
• Syndrome – a group of symptoms

STEC-HUS is the most common type of HUS. There are other types of HUS that are rarer. This teaching sheet will go over STEC-HUS.

What causes STEC-HUS?
STEC-HUS happens after a severe (very bad) bowel infection. The infection is most often caused by a bacteria (germ) called E. coli that makes a toxin called Shiga toxin. Other types of bacteria may also cause STEC-HUS. Most often, your child will have diarrhea (loose, watery stools) that may be bloody.

E. coli is a bacteria that normally lives in the intestines. Most often, it is harmless, but some types of E. coli can make you sick. These types of E. coli most often come from:
• Unwashed hands after using the bathroom
• Contaminated foods, such as:
  – Raw or undercooked meat
  – Dairy products and fruit juices (especially if they are not pasteurized)
• Contaminated pools or lakes
• Animals on a farm or petting zoo

What symptoms could my child have?
It may take up to 1 week for your child to start having diarrhea after they come in contact with E. coli. After the diarrhea starts, it can take another week to see symptoms of STEC-HUS. Your child may have 1 or more of these symptoms:
• Stomach pain, diarrhea or vomiting (throwing up)
• Fever (temperature of 100.4°F or higher)
• Bruising
• Pale skin
• Feeling tired, weak or moody
• Seizures or weakness of 1 part of the body
• Changes in behavior

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.
What symptoms could my child have if their kidneys are not working?
When the kidneys suddenly stop working, this is called acute kidney injury (AKI). If your child has AKI, they may have these symptoms:
- Less urine than normal or no urine at all (fewer or no wet diapers for babies)
- Blood in urine
- Not feel like eating
- Nausea and vomiting
- Swelling around the eyes, legs, stomach area or other body parts
- High blood pressure

Some children with AKI have no symptoms at all but blood tests will show that their kidneys are not working well.

What tests could my child have?
Some tests may include:
- Urine tests
- Blood tests
- Stool tests
- Ultrasound, CT or MRI scans. These are less common.

What is the treatment?
There is no specific treatment or medicine for STEC-HUS. Your child’s care team will treat the symptoms of STEC-HUS until it gets better with time. This may include:
- Frequent blood tests to watch:
  - Kidney function (how the kidneys are working)
  - Blood counts
  - Electrolytes
- Blood transfusions – red blood cells are given through an I.V.
- Medicines to control high blood pressure
- Medicines to decrease swelling (diuretics)
- Diet changes to help keep the level of salt, electrolytes and water normal inside the body
- In severe cases, your child may need dialysis (a treatment to clean the blood and remove fluid) until their kidneys get better.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.
How can I stop E. coli from spreading?

Follow these safety guidelines to help stop E. coli from spreading:

- Wash your hands well with soap and water for at least 20 seconds after you change a diaper or help your child use the bathroom. Also help your child to wash their hands well.
- Do not swim if you have diarrhea.
- Your child may not be allowed to return to school until they have a stool test that is negative for Shiga toxin-producing E. coli.

Some other ways to avoid E. coli infection are:

- Eat fully cooked meat.
- Do not leave frozen raw meats out on the counter to defrost. Defrost frozen meat in the microwave or refrigerator.
- Wash fruits and vegetables well before eating.
- Avoid swimming in water that could have feces (poop) in it.

What kind of follow-up care will my child need?

Most children with STEC-HUS get better. Some children may be left with high blood pressure or some permanent (lifelong) damage to their kidneys. After your child goes home, they may need:

- Regular checkups with a kidney doctor (nephrologist)
- Regular blood and urine tests

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.