



HUS and Your Child

What is HUS?

HUS stands for hemolytic uremic syndrome. HUS is most often caused by an infection from bacteria called E. coli O157:H7. About one in 10 children who are infected with E. coli O157:H7 develop HUS.

HUS is an illness that affects the blood cells and blood vessels. It destroys red blood cells, causes swelling of tiny blood vessel walls and causes clotting in small vessels. When the vessels in the kidney that filter blood become clogged, they cannot clean the blood as well. This can lead to kidney failure in some children.

What are the signs of HUS?

The signs of HUS vary from child to child. Most children with HUS have recently had bloody diarrhea, but some have had non-bloody diarrhea or no diarrhea at all. Children who develop HUS look pale and act tired and irritable. It usually takes 4 to 9 days after the diarrhea starts for HUS to happen. A child with HUS may also have small bruises that are caused by damage to the blood-clotting cells (platelets) and swelling of the face, hands and feet.

What problems can happen with HUS?

Some children have mild problems and no treatment is needed. Yet HUS can cause more serious problems. It can cause the blood disorder called anemia, which may require blood transfusions. It can also lead to kidney failure, which requires kidney dialysis. HUS can also affect your child's nervous system, causing them to become irritable, restless and may cause seizures. Their blood pressure can go up, and the pancreas or other organs may be affected.

How serious is HUS to my child?

HUS can be a very serious disorder. It is important to bring all of your questions and concerns to your child's doctors and nurses so that you know what is happening.

With prompt treatment, chances for recovery are good. Your child will need close follow up after treatment to watch for possible problems. There are studies being done to find out how children are doing years after becoming ill with HUS.

How long does the diarrhea last?

This varies from child to child. It may last as long as 7 to 10 days.

What type of treatment should I expect for my child?

If symptoms are mild, no treatment is needed. Sometimes, children with HUS have to stay in the hospital. The average length of a hospital stay is about 14 days, but can be as short as a few days or as long as a few months. While in the hospital, we will do blood tests often to check on how your child's kidneys are working. If HUS develops, your child may be put on a low-salt diet to help lower high blood pressure. Some children cannot eat, and we will give them nutrition through a needle in the vein (IV).

Medicines:

Antibiotics are not used to treat the E. coli bacteria or HUS. Your child may be given medicines to treat high blood pressure or to help with stomachaches. Other infections can happen, which might need antibiotics.

Blood transfusion:

Children often develop very low blood counts due to the destroyed blood cells. They sometimes need a blood transfusion. Your doctor will discuss this with you.

Dialysis:

About half the children with HUS need kidney dialysis for a few days to a few weeks. When the kidneys are damaged, dialysis does the work of the kidneys to remove waste products.

How do you decide to put my child on dialysis?

The doctors are watching your child's lab results and how much they go pee.

The lab results they watch are:

- Blood Urea Nitrogen (BUN) – Normal is less than 8 to 10.
- Potassium (K) – Normal range is 3.5 to 5.0.
- Creatinine (Cr) – Normal range is less than 1.0, but varies with age and diet. Ask your doctor what level is normal for your child.

You will hear repeated reports on these three levels. These are products normally removed by the kidneys. If these numbers rise higher than normal and your child stops peeing, the doctor will discuss starting dialysis.

How do you know when my child no longer needs dialysis?

When your child starts peeing more and the BUN and creatinine levels decrease, we know the kidneys are working better. Sometimes, your child will still need dialysis a few times a week until their kidneys fully take over on their own again. The average length of dialysis for HUS is 2 weeks. Permanent dialysis (for the rest of a child's life) is uncommon.

To Learn More

- Nephrology
206-987-2524
- Gastroenterology
206-987-2521
- Ask your child's nurse
or doctor
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

How will I know my child is getting better?

When your child is getting better, their blood platelet count begins to return to normal and they start to pee.

Can my child get this again?

Repeat infections with E. coli are rare, but can happen. Always prepare food using safe cleaning, thawing and heating methods. Have everyone in your family wash hands with soap and warm water after going to the bathroom and before touching food to prevent risk of infection.

What are the long-term problems after HUS?

- Some children develop gallstones. If your child is having stomach pain, call your doctor. They may order an ultrasound to find out if your child has gallstones.
- Some children who have had HUS develop a narrowing of their colon (intestines). This usually happens while in the hospital or within a few weeks after going home. Surgery is needed to fix this.
- Sometimes, children get frequent stomach pain, constipation or diarrhea. First, your child's doctor will make sure your child does not have gallstones or colon narrowing. Then the doctor will look at other common problems, like lactose or fructose intolerance, irritable bowel syndrome or constipation. Also, a germ called Clostridium difficile can sometimes cause diarrhea after children have had HUS. Usually, these problems can be treated quite easily once they are found.

What's next? Will my child need any follow-up care?

It is important for your child who has had HUS to be checked once a year by a children's kidney doctor (pediatric nephrologist). They will check for signs of high blood pressure or kidney problems.