

## HUS and Your Child

### *Answers to common questions*

#### **What is HUS?**

HUS stands for hemolytic uremic syndrome. HUS is most often caused by an infection from bacteria called *E. coli* 0157:H7. About one in 10 children who are infected with *E. coli* 0157:H7 develop HUS. To learn more about *E. coli*, ask for Children's *E. coli* flyer or find it on the Web at [www.seattlechildrens.org](http://www.seattlechildrens.org).

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 filtering vessels of the kidney become clogged, their ability to remove products from the blood decreases. 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. HUS can cause the blood disorder called anemia and kidney failure, requiring a blood transfusion and/or kidney dialysis. HUS can also affect your child's

nervous system, causing them to become irritable, restless and easily upset. Their blood pressure can go up, and the pancreas or other organs may become involved.



#### **How serious is HUS to my child?**

HUS is a serious disorder that can scare your child and family. This illness can cause your family to go through the most stressful time that you can imagine. 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.

The chance of your child's complete recovery is high. About 95% of children will have no serious, lasting problems. Research studies are being done to look at how children are doing years after they had HUS. Fourteen years after

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the 1993 outbreak in the Seattle area, none of the children are on dialysis or required a kidney transplant

### **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 reduce high blood pressure. Some children cannot eat, and we will give them nutrition through a needle in the vein (IV).

### **Medicines:**

Antibiotics do not work in preventing or treating 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 require 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 require 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. Two types of dialysis can be used: hemodialysis and peritoneal dialysis. In hemodialysis, a

catheter is placed into one of your child's large veins; in peritoneal dialysis, a catheter is placed through the skin of your child's stomach area (abdomen).

### **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 can vary somewhat with age and diet.

You will hear repeated reports on these three levels. These are products normally removed by the kidneys. When 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 on days dialysis is not done, 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 two weeks. Permanent dialysis (for the rest of a child's life) is rarely needed after HUS.

### **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.

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## 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.

### TO LEARN MORE

- Nephrology (206) 987-2524
- Gastroenterology (206) 987-2521
- Your Child's Health-Care Provider

*Children's will make this information available in alternate formats upon request. Please call Marketing Communications at (206) 987-5205.*

*This handout has been reviewed by clinical staff at Children's Hospital. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's health-care provider.*