

# VUR Patient Guide



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## Pediatric Health Committee

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## Addison's Story



Addison Parks was just 15 months old when she had her first urinary tract infection (UTI). Her doctor prescribed antibiotics. But two months later, Addison got a second UTI. That's when her doctor suggested her parents take her to a pediatric urologist. This doctor specializes in diseases of a child's urinary tract.

After having an x-ray of her bladder, Addison was diagnosed with vesicoureteral reflux (VUR). In normal kidney-bladder function, urine flows from the kidneys to the bladder. With VUR, urine flows backwards from the bladder up towards the kidneys. As a result, children with VUR develop urinary tract or kidney infections and have a higher chance for kidney damage.

One out of 100 children may get VUR, and are usually diagnosed around two or three years old. Luckily, many children outgrow VUR around age five or six, as their bladders and ureters develop. Three out of four children with VUR are girls, like Addison. VUR can be passed down from parent to child. If a mother has/had VUR, half of her children may also be born with the condition.

Addison's pediatric urologist said treating her VUR condition could mean more doctor visits, maybe medicines or even surgery. Her urologist said the goal of treatment is to treat current infections, prevent future urinary tract infections and avoid any possible kidney damage with the hope that Addison would outgrow the condition.

For now, Addison is taking daily, low-dose antibiotics. She gets bladder x-rays on a regular basis to check on her condition. "Every situation is a little different," says Sara, Addison's mother and a nurse. "As long as Addison's kidneys aren't damaged or hurt, and she remains relatively healthy, we'll keep re-evaluating her every six months." Sara says that they have learned to adjust to life with VUR. "Addison has no side effects. No one would ever know she had this condition unless we told them," she said.

*Story adapted from UrologyHealth Extra Winter 2014 issue.*

## Introduction: When Urine Goes the Wrong Way

We've all heard of acid reflux. It's when stomach acids move up, causing pain or a burning feeling in the chest area. This is not the only type of reflux the body can have. The bladder can also have reflux.

Reflux of the bladder is when urine moves up, rather than down. It is called vesicoureteral reflux (VUR) when urine flows backwards from the bladder up towards the kidney. If urine flows the wrong way to reach the kidneys, it can cause infections, kidney injury and scarring. If VUR and kidney infections are left untreated, it can cause long-term kidney damage.

About 1 in 100 children are diagnosed with VUR each year. Family history may be a factor. A parent who had VUR is more likely to have a child with it. And, about 1 in 3 siblings of a child with VUR can have it.

VUR can be found before a child is born. But it's commonly diagnosed when a young child develops a urinary tract infection. VUR is rare in older children and adults. About 3 out of every 4 children treated for VUR are girls.

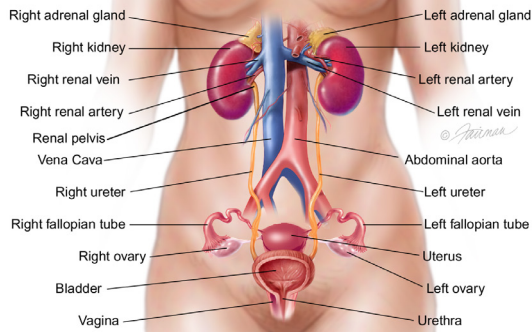
Treatment for VUR depends on your child's symptoms. The good news is that most children will outgrow VUR and have no lasting problems. In mild cases, no treatment or mild antibiotics are used to control infections. But, when kids have repeat infections and fevers from VUR, it can be a serious problem. In those cases, surgery may be a good choice.

This guide is here to help parents and caregivers manage their child's VUR diagnosis. We hope this information assists you when working with your child's doctor to determine the best care for your child.

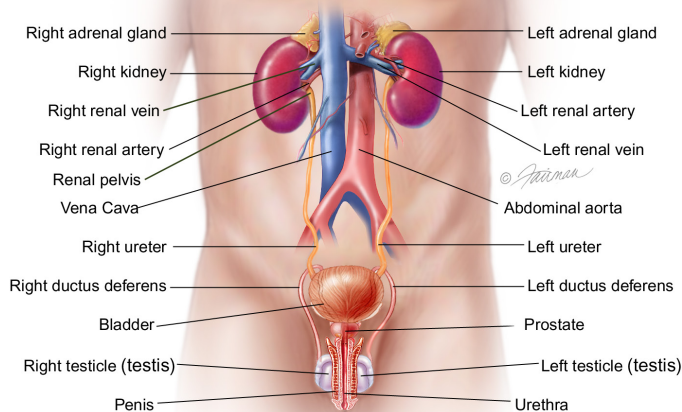


## How Does the Urinary Tract Work?

### FEMALE URINARY TRACT



### MALE URINARY TRACT



The **urinary tract** is made up of two **kidneys**, two **ureters**, one **bladder** and one **urethra**.

- The kidneys make urine. Urine drains down through thin tubes called ureters into the bladder. The kidneys are two fist-sized, bean-shaped organs that sit on both sides of the lower back. The job of the kidneys is to clean our

blood and remove waste (urine). They also serve as our body's filter to control electrolytes, fluid balance, pH and blood pressure.

- The ureters move urine from the kidneys to the bladder. The ureters and the bladder are joined with a flap valve. The **flap valve** keeps urine flowing one-way (down the ureter and into the bladder).
- The bladder is a balloon-like organ. It stores urine until it's emptied during urination. Urine is prevented from flowing back up into the ureters by the flap valves.
- The urethra is a tube at the bottom of the bladder. During urination, urine exits the body through the urethra.

### What is Vesicoureteral Reflux?

When the ureter flap valve doesn't close in the bladder, urine can flow back up to the kidneys. This is a condition called **vesicoureteral reflux (VUR)**. This type of reflux may happen in one or both ureters. It happens when a birth defect or damage from an infection, causes a flap valve to stay open. Bacteria from the bladder can then enter the kidneys. This is why VUR can become a serious problem. It could lead to kidney infections that can lead to **kidney damage**.

If the urine flows backward all the time it can cause the ureters and kidneys to become bigger, causing problems. As reflux becomes worse, the risk of kidney damage is higher. Luckily, the kidneys are strong organs, and in most cases, a small amount of damage won't cause many problems. But major damage could require long-term treatment, like **dialysis**.

If your child has repeat **urinary tract infections (UTIs)**, evaluation for VUR is necessary. He or she may need treatment.

### What Causes VUR?

VUR is most often caused from a congenital birth defect in the bladder valve. There could be a shorter-than-normal attachment between the ureter and bladder. There could be a valve that doesn't work. In other cases, reflux can occur when a child doesn't urinate as much as they should. Or, it could be from repeat infections with scar tissue.

VUR can develop in two forms, primary and secondary:

- **Primary VUR:** Occurs from a birth defect in the flap valve between the bladder and a ureter. As a child grows, the ureters grow too. Age and growth may improve the way the valve works, so the reflux may stop. This type of VUR is considered genetic since several family members may have it.
- **Secondary VUR:** Occurs from a block or malfunction in the urinary system. The block can be from repeat urinary tract infections (UTIs) or swelling.

## VUR and Infections

A urinary tract infection (UTI) is a bacterial infection of the urinary tract. It may involve the kidney, the bladder or both. About 1 out of every 3 children with a UTI is found to have VUR.

Infections in the urinary tract, kidney and bladder could mean your child has VUR. It's important to know the signs.

The signs of UTIs in babies may not be as clear, but may involve:

- Fever
- Fussiness
- Vomiting
- Diarrhea
- Poor weight gain
- Foul smelling urine

Older children can also have UTIs without any clear signs.

Some signs of a **kidney infection** are:

- Fever
- Pain in the belly or lower back
- Feeling ill in general
- Feeling sick to the stomach
- Vomiting

Signs of a **bladder infection** are:

- Painful and frequent voiding (urinating)
- An urgent need to go
- Wetting (a lack of urinary control)
- Cloudy or foul smelling urine

The bacteria that cause UTIs are often from the child's feces. Even with clean habits, bacteria can gather in the groin, and enter the urethra and bladder. If your child has VUR, the bacteria may travel to the kidney(s) and cause an infection.

Though VUR is most often found after a UTI, these two problems are not always related.

Many children suffer no pain or kidney damage from VUR. But for those who develop repeated UTIs and kidney scarring, the damage can be serious. Many children with VUR do not urinate often or empty their bladders completely. These toilet habits leave children at a higher risk for getting a kidney infection.

## GET DIAGNOSED

Reflux is found with a test called a Voiding Cystourethrogram (VCUG). This is a type of x-ray of the bladder. It takes about 15 to 20 minutes, and involves:

- Placing a catheter (a thin plastic tube) in the urethra
- Injecting fluid with a contrast x-ray dye through the tube to fill the bladder
- Asking the child to pass urine
- Having the child lie down on an x-ray bed to take pictures of his/her bladder. The pictures show if the dye flows backward to one or both kidneys

To get clear images with a special camera, a small amount of radioactive tracer is used in the dye. This type of test is called a Radionuclide Cystography or a bladder scan.

Inserting a catheter into private parts is not a comfortable process for anyone. Many children become upset. It helps to talk with your urologist before the test. In some medical centers, the study can be done with light **sedation**. General anesthesia is not used because it puts the child to sleep. This

test works best when the child is awake and urinating so the doctor can see whether or not there is reflux.

Your doctor may recommend your child take an antibiotic before or after the test. This is done to prevent infections from the catheter.

As part of the evaluation, a child with a UTI should get an **ultrasound** of the kidneys. This tests looks to see if there are any abnormalities of size, appearance or swelling of the kidneys. If reflux is found, more tests are done to see how well the kidneys work and look for any possible kidney damage. In some cases, a nuclear kidney scan can be done to check how well the kidneys work and look for kidney damage.

## How is VUR Measured?

Reflux is diagnosed with a “grading” system. The lowest grade diagnosed (Grade I) means that the problem is fairly minor. The highest grade (Grade V) is more serious. The x-ray shows how much urine is flowing back into the ureters and kidneys. Knowing this helps the doctor measure the grade of VUR and decide what type of treatment is best.

In children with reflux and UTI, kidney damage can occur. Higher grades of reflux are linked to a greater risk of kidney damage.

The most common system to **grade reflux (the International Study Classification)** includes five grades:

- Grade I: urine going into the ureter only
- Grade II: urine reflux into the ureter and the renal pelvis (where the ureter meets the kidney), without swelling (**hydronephrosis**)
- Grade III: reflux into the ureter and the renal pelvis, causing mild swelling
- Grade IV: reflux into the ureter and the renal pelvis, resulting in moderate swelling
- Grade V: reflux into the ureter and the renal pelvis, resulting in severe swelling and twisting of the ureter

## What is the Risk for Kidney Damage?

During your visit your doctor will ask a lot of questions and give your child a physical exam. The goal is to learn the level of risk for kidney damage. This will direct the type of treatment needed.

The doctor will ask:

- Does the child pass urine regularly?
- Does the child have normal bladder control during the day?
- Can the child empty his or her bladder fully?
- Does the child have **constipation**?

Many children with reflux also have **dysfunctional elimination syndrome** or **bowel-bladder dysfunction**.

This is when the child doesn’t urinate or eliminate feces often or fully. These children have a higher risk of kidney infection and damage. On the other hand, children who have normal bladder control and lower grades of reflux are at lower risk. Bladder and bowel elimination problems must be treated and managed first.

If the kidneys become damaged, fail and no longer work, harmful wastes build up in the body. This leads to high blood pressure, fluid buildup (edema), salts and acids in the blood getting out of balance, decreased red blood cells and weak bones. It can be dangerous, even deadly. Thus, protecting the kidneys from damage is a high priority for treatment.

## GET TREATED

### Non-Surgical Treatment

The goal of medical (non-surgical) treatment is to prevent UTIs and kidney damage. As your child gets older lower grade reflux often goes away. This is because the junction between the ureter and bladder grows longer as the child grows. The average age for this to happen is 5 to 6 years old. Another option for some children is **Watch and Wait**. This is when your child is monitored closely for any changes in health, hoping to see if he/she will outgrow VUR.

Other medical treatments may involve:

- Encouraging your child to use the bathroom regularly
- Making sure your child has regular stools and bowel training

- Taking a daily low-dose antibiotic to prevent UTIs
- Using other medicines to correct constipation and abnormal urination if your child has “bowel-bladder dysfunction”

*“Some parents don’t want their children to take antibiotics for long periods because they are worried about antibiotic resistance. However, if parents understand the risk of not taking drugs and promise to monitor the child closely, this can be an acceptable alternative to long-term medication.” –Addison’s pediatric urologist*

## Surgical Treatment

The goal of surgery is to cure reflux and avoid kidney damage. There are various surgical options to correct reflux. These include an “open” operation, endoscopic injection therapy and robotic-assisted **laparoscopic surgery**. Your urologist will help you choose the best option for your child.

### “OPEN” URETERAL REIMPLANTATION (URETERONEOCYSTOSTOMY)

- The surgeon will make a cut in the lower belly. He or she will fix the flap-valve attachment of the ureter to the bladder. If needed, a blockage will be removed. This is often done in the hospital and involves staying 1 to 3 days in the hospital.
- In some cases, the operation can be done using a robot to assist the doctor to make smaller incisions (cuts), avoiding the sensitive belly area.

### ENDOSCOPIC INJECTION SURGERY (LESS INVASIVE) INVOLVES:

- The use of a **cystoscope**. This is a long, thin lighted tube with a lens, inserted into the urethra used to see into the bladder.
- A special gel is injected through the cystoscope into the area where the ureter enters the bladder. The gel can help the flap valve to close.
- In most cases, this type of surgery can be done on an outpatient basis, allowing the child to go home the same day.

## AFTER TREATMENT

Once VUR is corrected, it is not likely to come back. The problem is often cured.

If surgery was necessary, a hospital stay is required for a few days. A catheter is often used at first to drain the bladder while it heals. This may take 1 to 3 days. Follow up with the urologist after surgery is important. Ultrasound tests will be done to make sure the kidneys and bladder are healing well. Several months after the operation, an x-ray will usually be done to see if the operation was successful.

As standard follow-up, the doctor will want to regularly monitor the blood pressure, height and weight of your child. Urine tests may also be done to look for signs of a future infection. In some cases, ultrasound or cystography may be recommended annually to observe kidney growth.

## PREVENTION

After VUR treatment, your child should feel much better. You may be asked to see your urologist for follow-up exams to make sure all's well.

To keep healthy, it will be valuable to prevent or quickly treat future UTIs. Treating infections quickly will lower the risk of kidney scarring. Some urologists may recommend that infant boys become circumcised to prevent infections.

During the “Watch and Wait” period, some providers suggest a long-term, low-dose antibiotic to prevent UTIs.

This recommendation is often based on the child's history of infections and bladder health. The other choice is to take a high-dose antibiotic when an infection is found. Some studies say that antibiotics lead to higher risks of health problems in adulthood. It could also lead to problems with a loss of good-bacteria needed for a healthy body. Parents need to talk with their children's doctor to choose the best preventative option for their child.



## Appendix A: Important Questions

### FREQUENTLY ASKED QUESTIONS

#### *How much water or other fluids should my child usually drink?*

Most children drink when they are thirsty. But if your child often gets UTIs, then he/she should drink more water. It is important that children keep their urine diluted and to regularly empty their bladder. A good strategy is to have your child drink one or one-and-a-half cups of water at each meal. Children should also drink between meals.

#### *Do bubble baths cause UTIs?*

No, bubble baths do not cause UTIs. Bubble baths can cause skin issues in the female vaginal area. These skin issues can affect urination and increase the risk for a UTI.

If your child likes bubble baths, then just make sure all of the soap is washed off at the end of the bath.

#### *Is there anything specific I can do to prevent my child from getting a UTI?*

Yes, you can ensure your child:

- Drinks a lot of water
- Goes to the bathroom often
- Maintains a good diet. He/she should eat a lot of vegetables and food with fiber to lower the risk of constipation (not being able to have a bowel movement)
- Limit the amount of processed sugars he/she eats

#### *Should my child take antibiotics to prevent future UTIs?*

This is a question you will need to ask your child's urologist. Some children do very well when they take a small dose of antibiotics every day to prevent infections. This is known as Continuous Antibiotic Prophylaxis or (CAP).

#### *What are my child's risks vs. benefits of long-term antibiotic use?*

The benefits of long-term antibiotic use are:

- Preventing infections
- Avoiding possible kidney damage

The risks of long-term antibiotic use are:

- Allergic reactions to antibiotics
- The bacteria causing the infections may resist antibiotic treatment. This means the drugs will no longer get rid of the infection or have an effect. Your child will not

become **immune** to antibiotics. But bacteria can change and become resistant to antibiotics over time.

### QUESTIONS TO ASK YOUR DOCTOR

- ☐ How did my child develop VUR?
- ☐ What treatment do you suggest?
- ☐ Is there anything I can do to help my child feel better?
- ☐ If we "watch and wait": How will I know if my child is getting better or worse?
- ☐ How soon should my child feel better? Should I call you if my child doesn't feel better by then?
- ☐ If surgery is best: why and what type?
- ☐ What will recovery from surgery be like?
- ☐ How long do you recommend annual visits?

## Appendix B: Glossary

### BLADDER

The hollow balloon-shaped organ in which urine is stored before it moves through the urethra. Urine is prevented from flowing back up into the ureters by the flap valves.

### BLADDER INFECTION

Most bladder infections are caused by strains of E. coli, bacteria that live in the gut. When the bladder becomes infected, it can be painful to urinate (along with other symptoms) and treatment is often required.

### BOWEL-BLADDER DYSFUNCTION

A condition involving problems with urinating and passing stool. This includes a loss of control with urine or bowel movements.

### CONSTIPATION

A problem with emptying the bowels of waste.

### CYSTOSCOPE

A long, thin lighted tube with a lens that is placed through the urethra to see into the bladder for diagnosis and treatment.

### DIALYSIS

A treatment that removes waste, salt and extra water from the body, keeping a safe level of certain chemicals in the blood and helping to control blood pressure. When kidneys fail, dialysis keeps the body in balance. It is done in a hospital, clinic or with a machine at home.

## **DYSFUNCTIONAL ELIMINATION SYNDROME**

A condition occurring when children wet themselves often because of an odd pattern of urination, or when parts of the urinary tract don't work together.

## **ENDOSCOPIC INJECTION SURGERY**

A surgical option for VUR involving a special gel to be pushed through the bladder with the use of a catheter. The gel, placed near the valve at the opening of the ureter, prevents urine from going back into the ureter and helps the valve close.

## **FLAP VALVE**

The valve that joins the ureters and the bladder which serves to keep urine flowing one way (down the ureter and into the bladder).

## **GRADING REFLUX WITH THE INTERNATIONAL STUDY CLASSIFICATION SYSTEM**

A system that measures the severity of VUR, used for diagnosis and treatment. It includes five grades, ranging from Grade I (lowest risk for kidney damage) to Grade V (highest risk for kidney damage).

## **HYDROENPHROSIS**

Swelling with fluid.

## **IMMUNE**

To be resistant to something — when your body is not affected by a drug and/or an infection.

## **KIDNEYS**

Two large, bean-shaped structures that remove waste from the blood. The kidneys also control electrolytes, fluid balance, pH levels and blood pressure.

## **KIDNEY DAMAGE**

Harmful waste builds up in the body and cause the kidneys to no longer work. This can lead to high blood pressure, fluid buildup (edema), off balance salts and acids in the blood, fewer red blood cells and weak bones. Kidney damage can be very harmful, even deadly.

## **KIDNEY INFECTION**

An infection in the kidneys caused by bacteria or a virus. It can cause people to feel very sick, and it requires treatment.

## **LAPAROSCOPIC SURGERY**

Surgery done with thin, tube-like instruments that allow several small cuts to be made, rather than one large cut.

## **SEDATION**

When medicine is used to relax you.

## **ULTRASOUND**

A procedure that uses frequency waves to diagnose problems. It can also be used for therapeutic purposes.

## **URETERS**

Two thin tubes that carry urine downward from the kidneys to the bladder.

## **URETHRA**

A thin tube that carries urine from the bladder out of the body. In men, it also carries semen.

## **URINARY TRACT**

The organs that take waste from the blood and carry it out of the body in the urinary tract.

## **URINARY TRACT INFECTION (UTI)**

An illness caused by harmful bacteria, viruses or yeast growing in the urinary tract.

## **UROLOGIST**

A doctor who specializes in the study, diagnosis and treatment of urinary tract problems.

## **VESICoureTERAL REFLUX (VUR)**

A condition where the ureter flap valve doesn't close properly in the bladder. This causes urine to flow back up to the kidneys. It can cause kidney damage if left untreated.

## **WATCHING AND WAITING**

A form of medical treatment where children regularly visit their doctors and are monitored for changes in health. This method is often used to see if the child will grow out of VUR.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

## ABOUT THE UROLOGY CARE FOUNDATION

The Urology Care Foundation is the official foundation of the American Urological Association. We provide up-to-date information about urologic health issues. Our materials are based on the American Urological Association guidelines and recommendations. We offer a wide range of educational materials to help patients make good choices about their care. We want to help patients take an active role in their health – whether they have just been diagnosed or have been dealing with the problem for a long time.

To learn more about different urologic issues, visit **[UrologyHealth.org/UrologicConditions](http://UrologyHealth.org/UrologicConditions)**. Go to **[UrologyHealth.org/FindAUrologist](http://UrologyHealth.org/FindAUrologist)** to find a doctor near you.

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