

# Part I

Sara and Matt had a loving relationship and successful careers. With the birth of their daughter Kayle they felt their lives were complete. Kayle was a thriving, beautiful, fair skinned baby with sparkling blue eyes. Within the first few weeks of life she grew at an astonishing rate, developing the gentle, soft curves that make babies so lovable. Then suddenly the fairytale existence of the new family was abruptly ended.

By the time Kayle was six weeks old her eyes were continually filled with tears. She cried throughout the day and most of the night. Kayle began to run intermittent fevers and Sara noticed that she had a lump that would periodically bulge from her groin. Motrin and Tylenol seemed to take care of the problem. Despite the use of cloth diapers and meticulous cleaning, Kayle also developed a raw redness and peculiar rash. Sara repeatedly called the pediatric nurse but she seemed to act as if Sara was just being an overly anxious new mother.

The physician, Dr. James, was not much more concerned. "I think it's important for you to get back to work, so you have more diversity in your life. Kayle's crying is most likely the result of colic causing her to experience indigestion. The rash is probably simply from not changing Kayle's diapers enough. You may want to try some A&D ointment."

Sara felt totally inadequate as a mother and vowed to do all she could to meet the needs of her daughter. Sara began a bland, but balanced diet and routinely changed Kayle's diaper every 30 to 60 minutes throughout the day. Sara noticed that her daughter's diapers were never soaked and often were coated with a thick yellowish discharge. This too was brushed off by one of the group pediatricians as probably due to a normal vaginal discharge caused by the withdrawal of maternal estrogen stimulation. When Kayle continued to cry and the rash worsened, Sara again called the doctor's office.

"Continue to use the A&D and leave Kayle diaper-less for several hours a day," the nurse advised.

Again Sara obliged. Kayle's crying worsened and even her seasoned grandmothers were reluctant to hold or watch her. Sara decided to postpone returning to work for a year so that she could take care of Kayle.

By the time Kayle was three months old both she and Sara looked haggard. The constant crying and sleepless nights had taken a toll on them. Matt insisted that they go into see the doctor. Kayle was no longer gaining weight or growing, and the groin bulge was now prominent enough for the doctor to acknowledge an inguinal hernia. Sara and Matt felt relieved, believing that this was the source of their daughter's problems and the end to a nightmare existence.

"This type of surgery is routine," Dr. Broward, the surgeon, said reassuringly. "It's a simple, uncomplicated repair. When Kayle recovers she will feel much more comfortable."

The surgery went well and Kayle came home the next day, but the crying continued. In fact, if anything, she seemed worse than before the surgery and now she was hardly taking in any nourishment. Sara found that again Kayle was running a fever. She called the pediatrician, who advised her to call the surgeon. The surgeon felt that Kayle was probably holding her too much and that the fever was unrelated to the surgery. Sara called the pediatrician back, who agreed to see Kayle.

By this time Kayle's fever was climbing and her once pale skin was now a bright red. In the waiting room, a nurse approached Sara and Kayle, "You must keep your baby protected from the sun." Sara again felt victimized and began to wonder if she would ever find anyone able to determine the cause of Kayle's problems.

#### Questions

1. What symptoms has Kayle exhibited over the first months of her life?

2. What bodily system might a doctor want to focus on in light of these symptoms? Why?

#### Surgical vs. Medical Management

by Kari Mergenhagen, University at Buffalo, State University of New York

## Part II

The nurse weighed and measured Kayle, then promptly took her temperature and reviewed her symptoms with Sara. Doctor Hubble was assigned to check Kayle. He had completed an internship and some research in pediatric urology and immediately recognized the symptoms. Kayle's recent hernia operation combined with her current problems was a red flag for potential urology related troubles. He requested a urine sample, which was successfully accomplished with a catheter, a procedure that was decidedly uncomfortable for both Kayle and Sara. The specimen was loaded with pus and blood cells.

"I think that in light of the urinary tract infection, Kayle should immediately begin an antibiotic," said Dr. Hubble. "She also needs a VCUG. This is a voiding cystourethrogram used to determine if the flow of urine is abnormal. I also want Kayle to have an IVP, an intravenous pyelogram, used to detect anatomic abnormalities."

By the end of the week both tests had been completed and Sara, Matt, and Kayle were back at the pediatrician's office for a consultation.

The tests had revealed a diagnosis of bilateral duplicate collection systems (four ureters instead of the usual two), hydronephrosis (urine collecting in the kidney pelvis), and grades four and five reflux (urine doesn't empty normally and backs up into the kidneys). Kayle's kidney function was markedly decreased on the right and partially limited on the left.

"I feel that you need to take Kayle to a specialist," Doctor Hubble advised. "I recommend Dr. Leftt, a surgeon who is an expert in pediatric urology. I also want you to be aware that within the pediatric urology community there is some disagreement on the course of treatment—medical versus surgical management. You may also want to consult with Dr. Wright. He's equally as competent, but will most likely take a medical view of how Kayle should be managed. Perhaps you should meet with both doctors before making a decision. Right now I think Kayle should have a daily antibiotic to prevent further infections and damage to her kidneys."

## Questions

- 3. Do urology reflux problems have a genetic component?
- 4. Why did Dr. Hubble correlate the hernia surgery with an inherited kidney disorder?

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### Part III

Dr. Leftt asked Sara and Matt to sit down as he pulled out Kayle's x-rays and explained that the four tortuous-looking, bulging tubes attached to odd-shaped, lumpy masses were Kayle's ureters and kidneys. The abnormal number of ureters and unusual shape of the kidneys pointed toward a hereditary component, and Dr. Lett felt certain that this trait had been handed down by a near relative. He advised that the only course of treatment was surgery to taper and reimplant all four ureters higher into the bladder and the creation of a flap valve apparatus to prevent urine from reversing into the kidneys.

"The surgery, of course, is not risk free," Dr. Leftt emphasized, "but without it Kayle's kidneys may suffer irreversible damage. The severity of the reflux will be reduced, but not eliminated. This allows for growth, but leaves a continued risk of infection. For this reason Kayle will need to continue antibiotics, initially be monitored weekly and have periodic tests for several years until her urinary system functions normally. The surgery will prevent scarring and further loss of kidney function."

Dr. Leftt had a kind but firm approach. He reviewed the number of surgeries he had done, the type of research he was involved in, and the devices he had invented to bring about higher surgical success rates. In addition to the usual complications of surgery including ineffectiveness and death, he told Sara and Matt that Kayle's right kidney could remain stunted and minimally functional. The surgery would take four to six hours, and Kayle would be in intensive care for two days followed by up to a week of hospitalization. If Sara and Matt opted out of surgery, Dr. Leftt felt that there was a good chance that Kayle's kidneys would fail within a year or two, necessitating the need for dialysis or a kidney transplant.

Despite having a growing number of patients in the waiting room, Dr. Leftt spent an hour with Matt and Sara. He concluded by saying, "If Kayle were my child, I would seek another opinion. She has a very serious problem that needs careful consideration and needs to be addressed soon."

## Questions

5. What is the hereditary risk for a sibling or a future child of Kayle's in developing urological problems?

6. What is the success rate and what are the potential complications with ureteral reimplantation surgery?

7. Could Kayle survive if her right kidney was barely functioning?

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## Part IV

A few days later Sara and Matt met with Dr. Wright. Again the findings and x-rays were reviewed. Dr. Wright felt that there was no urgency to treat Kayle surgically. He explained that Jeanne Smellie, a pediatrician in the United Kingdom, had successfully treated many children with long-term prophylactic use of antibiotics.

"Some children like Kayle," Dr. Wright gently explained, "will outgrow the reflux as their bladder base grows and the ureterovesical tunnel elongates. It's foolish to rush into a surgical procedure with all the inherent complications if the infections can be managed medically."

He reassured Sara and Matt that weekly urinalysis and periodic VCUGs would allow them to closely monitor the functioning of the kidneys. "Many times when an initial VCUG is taken the child may have been ill and dehydrated. This will inevitably show up as a greater reflux than the child actually has."

Dr. Wright ended by saying that if the reflux persisted beyond the age of eight, Kayle would then require surgery.

Sara and Matt felt confused and asked Dr. Wright these additional questions...

### Questions

8. Will an antibiotic prophylaxis approach prevent Kayle from getting urinary tract infections?

9. Do we need to worry about the emergence of antibiotic resistant organisms or an overgrowth of other potential pathogens?

10. What is the success rate for managing Kayle using a medical, prophylactic antibiotic approach?

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### Part V

Matt and Sara had several months in which to make their decision on how to best treat their daughter Kayle. Dr. Wright felt that Kayle's infection was under control with the use of antibiotics and advised them to continue this course. Dr. Left felt it was best to wait until Kayle was about six months old and infection free before undergoing an operation. This allowed Matt and Sara plenty of time to review their options and make a sound decision.

Over the next few months Kayle developed allergic reactions to Sepra, Cefzil, and Cipro. She also had breakthrough infections while on antibiotics and a significant thrush developed, which is a yeast infection in her mouth.

During this time Matt and Sara researched their own family medical history. Sara found out that a nephew had horseshoe shaped kidneys, which were discovered after a football injury, and that her grandfather, whom she never knew, died at a young age from kidney failure.

### Question

11. If you were Matt and Sara would you chose medical or surgical management for treating Kayle? Why?

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