



A CLOSER LOOK AT MENSTRUATION

Patty recalls her daughter Jessica's first period at age 14, but Jessica did not have a regular cycle until 16. Jessica experienced pain and discomfort and her flow was heavy. She requested frequent warm baths to alleviate the pain and refused to wear sanitary pads, which led to her wearing pull-ups during the week of her period.

As Jessica's flow became heavier each month, Patty consulted the gynecologist. The first option was for Jessica to receive a shot every three months that would release progestin, a hormone that prevents pregnancy. In most women, this shot also causes fewer and lighter periods. Patty spoke with several other women who had personally used the shots and many reported uncomfortable side effects.

"I knew that if Jessica had any changes in the way she felt, we would see this in her behavior, which was already a problem," Patty says.

Jessica's gynecologist then recommended a hysterectomy. Patty's first step was to speak with another family whose daughter with CdLS had already been through the procedure.

"It was a hard decision to make because I am a nurse and know what complications can happen with surgery and anesthesia," says Patty. "We worried about Jessica being so small and having her uterus removed without any trauma to other organs. It was very scary."

The fact that Jessica's parents had a long-standing relationship with, and trusted, her doctor helped them to move forward with the procedure. Jessica, then 17, did very well during the surgery and with her recovery.*

"She had a tube in her bladder that I was very concerned that she would try to pull out, but she did not. She took two Tylenol the first day for pain and was up walking the halls," says Patty. "We were also afraid she would not let the incision heal because she picks a lot. But after I told her that it was her doctor's "boo boo," she left it alone."

Since the surgery, Jessica no longer has her period. Her ovaries were not removed so no hormone therapy was needed. She has them checked by ultrasound every two years. Patty shares that "Jessica's experience could not have been any easier."

Patty's advice to other parents who have to make a similar decision is to be selective with whom they speak with to minimize potential negative feedback from differing opinions of friends and family. "We knew what was best for Jessica and I am glad we did it."

*Please note, laws differ in each state. The state you live in may require you to obtain a court order for a hysterectomy if your daughter is over the age of 18. Consult with your child's physician.

