

# Rural parents' experience in receiving care for their newborn with Lyme disease

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**LJ:** I was bathing our newborn daughter, Violet, and saw a tick on her left arm. Three days later, she was very sleepy and hard to rouse. I noticed a rash — it wasn't a bullseye, but it was definitely red. We live in a rural area and I made the decision to drive the 1.5 hours to SickKids, with her being only 4 pounds. I figured we would likely be shipped there anyways.

pass because only one of us was supposed to be there. It was really emotional for me.

**LJ:** After a few days in hospital, Violet was really only there for her daily [antibiotic] infusions through a PICC [peripherally inserted central catheter] line. They were trying to transfer us to a closer hospital, but one local hospital wouldn't take her

every day at work, but its different when it comes to your own child. And I don't typically work with babies. I knew it was being done correctly and that was reassuring, but I did have anxiety around it.

I now have tick PTSD [posttraumatic stress disorder]. We have 55 acres of hay field surrounding us and it has definitely changed the way we play outside. — Leah Jobb and Garrett Dekeyser

## I found it strange that a hospital wouldn't take her because of the PICC line, yet it was okay for me to give her infusions at home.

She was in hospital for 10 days. It was stressful. Her twin was still in a hospital closer to home. Because of COVID-19 restrictions, Garrett was only allowed to visit for 4 hours a day. I felt very isolated. I was staying at SickKids with Violet on a little bed and was experiencing some depression and anxiety. We also had a 3-year-old at home, so that was difficult.

**GD:** It's a 3-hour drive there and back. I was leaving one kid at home to see another. I made everything hard and all the COVID-19 protocols were a pain in the butt. There was some difficulty with me getting a visitor's

because of the PICC line and the other didn't have beds. And there was a real shortage of home care nurses. Luckily, I am a specialized infusion and injection nurse. They showed me how to set up the pump and do PICC care, so we went home and I did her infusions.

I found it strange that a hospital wouldn't take her because of the PICC line, yet it was okay for me to give her infusions at home. I was nervous Violet would pull the PICC out and I would have to do emergency care. I felt extra cautious about cleaning and making sure I was flushing and locking it properly. I do it

### As told to Victoria Saigle MSc

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This article has not been peer reviewed.

Consent has been given for this perspective to be shared.

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