

## Layne's Journey

*A NICU alumni story*

**I WAS IN A VERY SERIOUS** condition by the time I reached UWMC. I had severe preeclampsia, severe HELLP syndrome that was making my organs begin to shut down, and I had had a stroke.

My son had it even worse. The doctors figured he had stopped growing around 20 weeks, parts of him had atrophied, and some of his organs were not working well. At 28 weeks, they said neither of us had good odds.



*Layne in the NICU*

When I had placental abruption, Layne was born via emergency Cesarean section. It was not what I had expected my childbirth experience to be, but he was absolutely beautiful, all 1 pound 7 ounces of him.

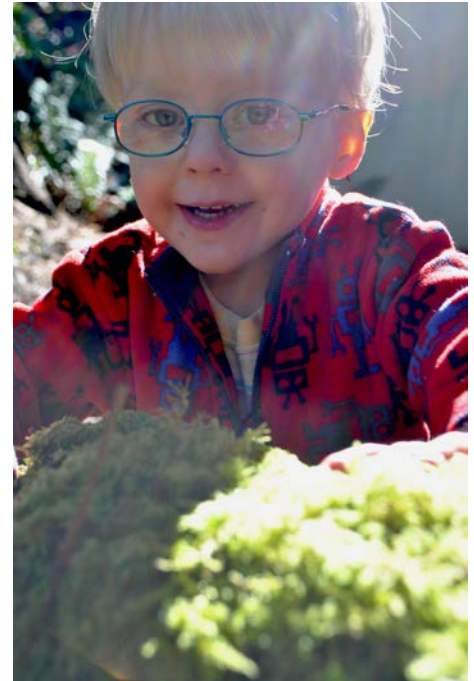
I couldn't hold him for nearly a month due to the ventilator. During that month, he had been through so much – central lines, needing the ventilator, belly infections, heart surgery, blood transfusions. There were days when he would do well and days when we thought we would lose him.

The very first day of his life, we began a ritual that we have continued his entire life – we read him books every day. It gave me something to do to feel a connection with him and to feel like I was doing *something*.

Layne continued to have problems breathing and eating throughout his stay in the NICU. After 2½ months, we left the NICU.

An anxiety developed within me after he came home – a hyper-vigilance and an over-protection. Layne has had many struggles outside the NICU as he has grown. He has had emergencies where he severely struggled with breathing, and he stops breathing in his sleep every day. He still aspirates and has had a hard time learning to drink.

He has had a terrible time with his immune system, fevers, and infections. He has had neurological problems and surgeries. He has developmental delays, but has worked so incredibly hard and has done amazing things we never thought he would do.



*Layne at 3 years*

Once we left the NICU, it was not over. There were still trials, and our time in the hospital would not be over. I also have been seriously ill since my pregnancy, and have discovered that I have 5 autoimmune diseases.

Layne and I have not fully recovered from our experience, and we are both left disabled. BUT we both *lived*, which was not expected, and we are both happy just to have the chance to be here with each other.

My husband and I have a beautiful son, and our family, although full of adversity, is also very full of love.

### **What is one thing you wish someone had told you about the NICU?**

You can develop post traumatic stress disorder.

### **What is one survival tip you would like to pass on to a new NICU parent?**

Find a ritual that makes you feel connected with your baby every day. We read Layne 1 or more books every day. So even when we couldn't hold him, or even when we couldn't touch him, we could still feel like there was a moment we could share together. It helped us feel like there was something we could do for our baby during a time when we felt useless.