“Strap yourselves in tight, hold on and brace yourselves, this is going to be a long and scary ride, but I promise, you won’t want to ride again when it is over.”- A veteran NICU mom

The NICU journey is almost universally called “a roller coaster ride”- it is full of unexpected ups, downs, twists and turns and most importantly, you as the parent have no control. You have to put full trust in your faith, your family, the multitude of doctors, nurses, respiratory therapists and residents taking care of your child. You don’t know what is coming next. You ask yourself daily, will this be a good day or a bad day? Today, my child will make progress and triumph- I will feel victorious. Tomorrow my child will regress and catastrophe will strike- I will feel defeat.

Tara Lorson understands the “roller coaster ride” as well as any veteran NICU mom. Her daughter, Harper Adrianna, spent 265 days in the NICU/PICU at Janet Weis Children’s Hospital at Geisinger Medical Center in Danville, Pennsylvania. Harper was born at 31 weeks gestation and as Harper’s time in the NICU raced along, it was discovered she also had a diagnosis of Beckwith-Wiedeman Syndrome, Dandy Walker Syndrome, various cardiac conditions, Agenesis of the corpus callosum, tracheomalacia (floppy trachea) and eventually, hydrocephalus. Perhaps the biggest twist for the Lorson family was when they found out that Harper would require a tracheostomy and would most likely need to go home on a ventilator.

“We just didn’t know what to do,” said Tara, “the prospect of Harper coming home on a ventilator was so overwhelming. It seemed like there was so much to research and prepare. We didn’t know where to start. It was all so scary.”

Phoebe Beckley, the March of Dimes Family support specialist knew what to do when she found Tara Lorson looking for support. She had recently begun working on a specialized NICU family support program through Parent to Parent of Pennsylvania, the largest Peer mentoring network in the state for families who have a child with a disability or special needs. The program is designed to provide support for families whose children are patients in the Geisinger Medical Center NICU. The program seeks to match veteran NICU families to other families currently in the middle of their NICU “rides.” The program provides hope and support to families in a way that no one else can; given by other families who have lived the NICU experience. She called the local Regional Coordinator, Nicole Golden, a veteran NICU mom herself and made the referral.

“I’ll never forget my first call with Tara. Harper had just undergone a bowel resection that day and Tara was just a nervous wreck. I reassured her that my son had undergone the same surgery and was now a thriving 5 year old boy” says Nicole Golden, former North Central Regional Coordinator for the Parent to Parent of PA program. “When Tara then explained that Harper would be receiving a tracheostomy soon and would most likely be going home on a vent, I knew right away who the perfect match would be.”
Golden then called up Peer Supporter, Laura Elliot, a “specialist” in children who go home on ventilators as she had lived it with her son, Joshua. Elliot is a very dedicated parent and supporter for families who are taking their children home through home-vent programs. In fact, she herself researched, wrote and published a 64 page guide for families on how to prepare and care for their child at home on a ventilator. Laura was more than happy to support Tara Lorson, and the match was made.

As Harper’s story continued, Laura was there for every unexpected twist and turn. “She was an absolute God send” says Lorson. Laura and Tara talked or communicated via email or Facebook every few days throughout Harper’s NICU/PICU stay. Suddenly, Harper’s journey reached a terrifying pinnacle. It seemed that Harper needed a procedure that was going to require her transfer to Children’s Hospital of Philadelphia (CHOP) far away from the family’s home. Laura Elliot went to work immediately gathering families in the area to be prepared to support the Lorsons as soon as they arrived. Luckily, Harper did not have to be transferred, but the family knew that there was amazing support waiting for them if they needed it.

When the Lorsons were climbing their final hurdle and Harper’s discharge drew close, Laura went to work, sharing vital information on preparing for Harper’s release. “Is life with a trach-vent child at home still chaotic and busy? Of course! But, the focus is on Harper, rather than wondering where all the supplies are, anxiety about power outages, etc. I like to think that some of what I learned ‘the hard way’ will not be learned that way by another family.” Even more significantly, because Laura had so much experience in taking care of a child with a trach/vent, the Lorsons were able to accelerate their preparations for Harper’s discharge- cutting her NICU/PICU journey short by nearly a full month!

Harper’s story shows the true power of Peer Support- not only the hope and emotional support the family receives, but the power of information. It also demonstrates the importance of collaboration; the partnership between Geisinger Medical Center and Parent to Parent of PA gave Harper Lorson more than just medical care. This incredible story illustrates that a Peer Supporter is more than just a shoulder to cry on, but a co-passenger in a family’s journey, providing a steadying hand when their cart is about to become de-railed and thrown off-track.