In February, 2012, Nicole Golden, North Central Regional Coordinator for Parent to Parent of Pennsylvania, received a referral from Early Intervention for a family who had a six-week old little boy. Nicole shares their story of how a parent match helped to fill a much needed void.

I had no idea what the child’s diagnosis or special need(s) was/were and I called the family to enroll them in our program. A distraught mother answered the phone. She told me that she, her boyfriend, and her three-year-old son had been anxiously awaiting the arrival of a new baby boy, due on Christmas day. The mother, Dawn, told me she had gone into labor a few days early and was excited at the prospect of bringing home their new edition by Christmas time. Things did not go as planned.

Initially, at delivery, doctors knew there was something unusual about her son, Dakota, and whisked him off to the Neonatal Intensive Care Unit (NICU), to try to come up with a diagnosis. After three weeks in the NICU, Dakota was sent home with a tentative diagnosis of Lissencephaly, which literally means “smooth brain,” and is a rare brain formation disorder. They were given a computer printout, giving them some information about the condition, but left the hospital more confused.

Dawn turned to the internet for information, but it only made her more confused and worried. Her Early Intervention team referred the family to Parent to Parent of Pennsylvania so we might find her a Peer Supporter whose child had been diagnosed with the same condition.

I searched our database of over 1,350 Peer Supporters, after our initial phone call to see if I could find the family a good match. I felt that this family really needed a positive and informative Peer Supporter who could provide emotional support and guide them through this early time in their son’s life. Luckily, we were able to find a previous Pennsylvania Peer Supporter who had moved to Georgia. Her six-year-old daughter also had a diagnosis of Lissencephaly. I knew immediately after speaking with this Peer Supporter that she was a good choice for this new family. Our long time Peer Supporter was patient, empathetic, and informative. She had a good sense of how much information and support the family could handle at any given time.

When I followed up with the family a few weeks later, the baby’s grandmother, Janet, answered the phone. She told me that Dawn spent over an hour on the phone with her peer supporter. She said the peer supporter was like “a textbook” on her grandson’s condition. In fact, Janet reported that the family received more information from their Peer Supporter than they had from any other source! She said her son, David, and Dawn kept their Peer Supporter’s phone number in their wallets. She said their Peer Supporter also had her husband speak to David, the baby’s father, to provide support from a “dad’s perspective.