

## **“Sometimes the smallest things take up the most room in your heart.” - Winnie the Pooh**

November marks Prematurity Awareness Month. This month, I am honoring my three children who were all born prematurely. I'm so proud of how far they have come in such a short time. I'm sharing my story in hopes to connect with other preemie parents out there who have had similar journeys as myself, and to raise awareness about life as a preemie parent because the journey can be very different from that of full term babies.

According to the March of Dimes, 1 in 10 babies are born prematurely. These babies are born prior to 37 weeks gestation. My three-year-old twins were born at 34 weeks and my six-month-old daughter was born at 35 weeks. Being a preemie parent can be a challenging journey, but this experience has taught me so much and has ultimately led me to becoming part of the Collaborative Community Mission.

When my twins were born during the summer of 2016, they spent time in the NICU (neonatal intensive care unit). My daughter was able to come home after two weeks, but my son was there six weeks due to medical complications. The NICU can be an overwhelming place. Lights are low, monitors and alarms sound frequently, and teams of nurses and doctors are all over. Everyone speaks in a quiet voice, not to disturb the babies. The sights, sounds, and smells will be forever etched into my memory.

I had to wait over a week to hold my son for the first time because he was hooked up to so many monitors and tubes. The first days were spent watching this tiny baby in an isolette. I learned a plethora of medical terminology and about a variety of medical procedures. It was a rollercoaster of ups and downs in those six weeks. We celebrated tiny milestones along the way: moving out of the isolette, each time a tube or monitor was removed, feedings when he ate a few more milliliters, the day when he was breathing room air on his own. There were so many unknowns through all this: When would my son be able to come home? Would there be any long-term effects of him having a medically complicated, premature birth? My twins were barely half the weight as a typical full-term baby when they were born. Despite their tiny size, these babies overcame so much. They fought, and they overcame odds.

Eventually the twins were reunited when my son was able to come home. The journey, however, wasn't over just because my babies were home. Like many preemie parents, I was given a list of required medications to be administered at home and there were follow up appointments with various specialists in the months that follow.

My son showed signs of developmental delays early on and began physical therapy and occupational therapy services through Early Intervention, and eventually speech therapy. The therapists came to our home to work with my son and in between sessions, my husband and I worked with him. I learned things about early childhood development that I probably otherwise wouldn't have known. My

son was slowly making progress, thanks to his amazing team of therapists and doctors. By his first birthday, he was weaned off the medications and he no longer needed to see most of the specialists. Life was feeling more normal.

Fast forward to May 2019. The twins were still doing great. My son just had his IEP meeting and we were preparing to transition from Early Intervention to preschool services. I was also 35 weeks pregnant with a healthy baby girl. I went in for a routine appointment when something unexpectedly came up and my daughter needed to be delivered right away. Memories of the NICU flooded back, and I panicked because I was afraid of the complications we ran into after the twins were born. Thankfully, my daughter was doing well overall and was in the NICU for relatively minor issues that required just a few days to resolve.

Today everyone is doing amazing. My 3-year-old daughter has been meeting all her milestones at the appropriate times. My son continues therapy twice a week with a local preschool therapy group and my husband and I continue to work with him at home. While he may be behind in some areas, he has overcome so much, and I know he will catch up in time. He has mild sensory issues, but we are learning how to help him manage. My youngest daughter caught up quickly, despite her tiny size at birth. Having had two premies already, I feel like I know what to watch for and know what to do should any concerns arise. She isn't receiving any services, but my experience through my son's therapy has given me a repertoire of exercises and activities that I can do with her to help keep her on track.

One of my biggest takeaways through all of this is that things happen for a reason, and I try to find an opportunity to learn something from every challenging situation. In my case, my kids have taught me how resilient our tiniest babies can be and how much they overcome. Looking at them today, you would never know they were premies or had any type of health issues when they were born. I'm thankful for how far they have come and for the amazing doctors, nurses, and therapists that have helped my family over the last three and a half years. This journey hasn't been easy but has taught me so much. I researched everything I could to help me better understand my children's care and to be their best advocate. With every specialist we saw, I retold their story over and over. It's so important to provide as much information and ask as many questions as possible. Notes in their medical charts may not always tell everything and as parents we need to complete the puzzle. We know our children best and we need to advocate for them.

My experience as a preemie parent also brought me to the CCM. When Jessica invited me to join the team, I immediately said yes. I saw it as an opportunity to help others in my community, as well as a chance to connect with other families. I feel fortunate that Early Intervention was an option for my son when he needed therapy services as a young baby. Not all families have that option available to them. There are many great resources available online and locally for families who have children with special needs. One goal I have as part of the CCM team is to find those resources and share those with our community through social media and through the events we are planning to hold in the next year. Education and advocacy is so important in helping our children. In addition, for us parents who have premies or special needs children, we need support too! It's not an easy journey and as a collaborative

community, we can help each other through the process. Together we can create a supportive network to help each other learn and grow, and so that opportunities are available to everyone.

We'd love to hear from you! Whether you are a preemie parent, a parent to a child with special needs, or a parent who needs extra support, we'd love your input-on areas of need. Email us at [collabcomm.mission@gmail.com](mailto:collabcomm.mission@gmail.com) or DM us on Facebook or Instagram @collcomm.mission.