

THE PEE WEE POST

THE CHKD NICU FAMILY NEWSLETTER

Edited by Marnie Dyer, NICU Family Support Coordinator (668-8016) and Erin Slagle from the NICU Family Advisory Council

In this issue of the PWP, we would like to introduce the current members of the NICU Family Advisory Council (FAC). We are a group of parents of NICU graduates, bedside nurses, doctors and support staff members who work together on projects that will improve the NICU experience for current and future NICU families. Our goal is to ensure that our patients receive compassionate and family-inclusive care, and to empower families to be strong advocates in their child's care. The parent members of the Council are advisors to NICU leadership on the role and experience of the NICU family. The nursing members are strong advocates for the family's role in their baby's care, while upholding the safety guidelines of an Intensive Care Unit, and they carry the message of the FAC back to their co-workers at the bedside.



Salima Ramos is the mom of Aubrey. Aubrey was born with an omphalocele and a cardiac defect that required open heart surgery. Aubrey also eventually needed a trach after being unable to come off the ventilator. Aubrey spent 14 months in the NICU! She is now 4 years old and a joy to all. This is Salima's 2nd year on the FAC.



Amy Harris is the mom of Wilder, who was born at 36 weeks. He quickly showed signs of significant respiratory distress and then PPHN, and was transferred to CHKD in critical condition. After recovering from the PPHN, Wilder improved quickly and was discharged in just under 1 month. He is now almost 3 and goes nonstop. This is Amy's 2nd year on the FAC. Amy is a great resource if your baby has been diagnosed with PPHN.



Tracey Miles is mom of Ifedayo, also affectionately known as AY. AY was born at 25 weeks gestation and spent 8 1/2 months in the NICU. AY experienced many ups and downs during his stay, and eventually went home with a VP shunt, a gtube and oxygen. At 2 1/2, AY is now off oxygen and the gtube, and is doing great! This is Tracey's first year on the FAC.

This is the 9th year of our NICU FAC, and we are very proud of our accomplishments! Some of our projects include the NICU Journey Bead Program, the NICU 101 Parent Book, the NICU section of the CHKD website (including the blogs), the planning of the annual NICU Reunion, and the NICU Store. Some things are more behind the scenes, including a video of parent stories used for new nurse education, input on the NICU Renovation, and input on NICU policies and procedures. FAC volunteers also come in monthly to help with our footprint crafts, speak at Dine & Discover, and work on various committees. Ask your Social Worker or one of the NICU Support Coordinators if you'd like more information on how you might join the FAC after discharge. We can also connect you with one of our FAC members for support during your NICU journey.



Dave Harris is the dad of twins DJ and Dawson, who were born at 29 weeks gestation. Dawson spent 2 months in the NICU, and DJ spent 3 months. They are now 3 years old and are just adorable! This is Dave's 3rd year on the FAC and is a great resource for NICU dads and parents of twins.



Danielle and Sheldon Bryant are the parents of Logan, who was born at 26 weeks gestation. He suffered at Grade 4 IVH and received a reservoir to control his hydrocephalus. He eventually received a VP shunt and went home after 3 months in the NICU. He is now a feisty almost 2 year old. This is Danielle and Sheldon's first year on the FAC.



Erin Slagle is the mom of twins Hayden and Scarlett, who were born at 27 weeks. Hayden spent 3 months in the NICU, and Scarlett went home at just under 4 months. They will be 4 years old in July and are doing great! This is Erin's 3rd year on the FAC and is a great resource for parents of twins.



Sarah and Scott Furlough are the parents of Cooper and his twin brother, Logan. Logan was born at 25 weeks and after 5 months, he passed away in the NICU. Cooper was born 6 days after his twin brother and went home after 2 1/2 months. He is now 14 years old, is smart and kind, and swims competitively year round. Sarah and Scott are resources for families who have suffered loss of a NICU baby or a twin. This is their 2nd year on the FAC.



Melinda Ollenberger is the mother of Elise, who was born at 28 weeks and spent almost 3 months in the NICU. Elise's NICU journey included NEC and surgery for a bowel obstruction. She is now almost 2 and brings such joy to her family. Melinda is also the mom of Amelia, a daughter who had complications after her full term birth and passed away 4 days after her birth. This is Melinda's first year on the FAC.



Sarah Pope is the mom of Bennett and this is her 3rd year on FAC. Bennett was born full term with a rare genetic condition that ultimately required him to be trached and Gtube dependent. He spent 4 months in the NICU and 2 months in the TCU. He is 4 ½ years old now and talks non-stop. Sarah is very involved as a resource to families whose babies will go home with medical equipment.

Allison Planchak is the mom of Will, who was born at 24 weeks gestation and spent 4 1/2 months in the NICU. During his stay, Will experienced IVH and NEC, including a bowel perforation and ostomy. Will is now almost 4 years old and is thriving after a very rocky start. This is Allison's 3rd year on the FAC. She is a great resource for many of the obstacles suffered by very premature babies and also on having a full term baby after a 24 weeker.



Monica Holland is the mom of Hudson, who was born at 28 weeks and spent 3 months in the NICU. Monica has experience transferring from another hospital to CHKD. She is also expecting her second baby and is hoping for a full term birth this time around. This is Monica's 2nd year on the FAC.

Joe and Courtney Greco are parents of twins Brooklyn and Roman. The twins were born at 26 weeks gestation. Roman spent 4 months in the NICU, and Brooklyn went home with a Gtube after 6 months. They are precious almost 2 year olds who are into everything. This is Joe and Courtney's first year on the FAC.

Emily Munoz is the mom of Damien. Damien was born with Cornelia de Lange Syndrome, a genetic condition with growth and motor deficiencies and physical anomalies. Emily is an amazing advocate for Damien, who spent 7 1/2 months in the NICU and is now 4 years old. She is a great resource for families with a baby who has a genetic diagnosis or is going home with a Gtube. This is Emily's 3rd year on the FAC.



Shannon Jones, RN. 5th year on FAC



Rachel Snyder, RN.
1st year on FAC



Melissa McCann, RN, IBCLC.
1st year on FAC



Taylor Hannah, RN. 3rd year on FAC

THE AMAZING NURSES OF THE FAC!



Alexis Davis, RN. 1st year on FAC



Yvonne Swisher, RN, and NICU Clinical
Care Leader. 2nd year on FAC.



Jessi Black, RN, IBCLC.
2nd year on FAC



Lauren Wood, RN. 2nd year on FAC.



Diane Brown, RN. 9th year on FAC



Stephanie Leverett, RN. 1st year on FAC