

The Hummingbird Program

Meet Malaya

Amanda and Bryn couldn't wait for the birth of their second child, a girl, to complete their family and give their son, Kai, a sibling. Amanda gave birth at home as planned, but her midwives quickly realized something was terribly wrong. After a traumatic delivery, Malaya was born and the midwives immediately noticed her abdomen was incredibly enlarged. She was also in cardiac arrest. Malaya was rushed to York Hospital where she stayed in the Neonatal Intensive Care Unit for five days until she was stable enough to be flown by Life Lion to Penn State Children's Hospital. She spent three weeks in the NICU followed by three weeks in the Pediatric Intermediate Care Unit.



During this time, Malaya was diagnosed with a rare genetic condition called Microcolon Megacystis Intestinal Hypoperistalsis Syndrome (MMIHS). This means she has an enlarged, floppy bladder and can't urinate on her own. She also has an extremely small colon and no motility in her intestines. She is TPN and lipid dependent for 20 hours a day, has a G-tube to receive nutrition and needs to be catheterized every four hours.

While there were many uncertainties during Malaya's hospitalizations, one thing was constant during her time at Penn State Children's Hospital— the support of the Hummingbird Team. During the family's darkest moments of confusion, frustration and stress, Amanda says the Hummingbird Team, especially Nicole Hahnlen RN, CHPPN, embraced Malaya and served as an extended family. "Nicole was always an advocate for us. She helped us understand all of the medical jargon, coordinate care with other hospitals and pushed our nursing agency to provide additional staffing," says Amanda.



Malaya will continue to receive support from the Hummingbird Team as she grows. She may even be a candidate for a small bowel transplant in the future. But for now, Malaya is a very happy 8-month-old whose adorable smile brings joy to everyone she meets.

Thank you for supporting the Hummingbird Program, which provides ongoing clinical, psychological, social and emotional support for patients with complex medical conditions.

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