

## Chloe Grace's Story



Chloe Grace was born in April 2010 with Spina Bifida (L1), Myelomeningocele, Arnold Chiari Malformation Type II, Hydrocephalus, and Bi-Lateral Clubbed feet.

Born via C-section, at 38 weeks gestation, she was less than 24 hours old when she underwent 5 hours of major neurosurgery to close her back, repair the myelomeningocele, and shunt the hydrocephalus.

After her surgery, Chloe Grace's neurosurgeon advised us that her condition was worse than expected and that she would be 100% wheelchair bound. We remained positive and did not accept the diagnosis as final, believing that Chloe Grace would decide her future. We knew from the start that she was a special gift to us, and we never considered "returning" the gift because she would be different than most. As a result of our faith and trust, God has been by our side every "STEP" of the way.

After spending 10 days in the NICU, we finally brought our baby home --only to face several other surgeries in the very intense first 18 months of her life.

In June of 2010 she underwent her second surgery, an Achilles Lengthening for her left foot, which was severely clubbed at birth. In August 2010 a third and unexpected surgery was performed, an emergency shunt revision due to a shunt malfunction. In September of 2011, she underwent a fourth surgery, another Achilles Lengthening on her left foot.

She also experienced a slight case of Torticollis in her first year, which self-corrected as she got stronger. We see an Ophthalmologist for a wandering right eye and stigmatism which may require corrective surgery in the future.

As far as bowel and bladder function, all seems to be functioning perfectly. Chloe Grace's ultrasounds and tests are perfect (doctor's words) which is nothing short of a miracle, given the original prognosis. To date, she has not had any bladder/urinary tract infections; another great sign that all is going well with her urologic functions. We have even started to potty train!

Through the Early Intervention Program sponsored by the ARC of Somerset County, Chloe receives three kinds of therapy per week: physical, occupational, and speech. She is very motivated and smart, and all her therapists and doctors agree that she is responding well and making great progress. Her determination helps her to achieve the goals set by her medical team, and she continues to grow stronger and participate in routine daily activities. Her orthopedic doctor believes very strongly that she will walk and should not need a wheelchair. With the aid of braces and crutches, she is expected to ambulate independently. Currently, Chloe Grace is walking with the aid of her braces and a pediatric walker, and this offers her some independence as well as the opportunity to feel physically equal to other children her age. Her greatest challenges at this time, and looking ahead, are her gross motor skills (she is functioning at an 11 month old level) and trying to build her stamina to ambulate independently in both small and larger social environments. Chloe Grace also faces challenges on a daily basis performing routine activities like getting dressed, putting on her braces, and bathing. We continue to work on building the skills necessary to help her become as independent as possible. Chloe Grace will start Pre-School Disabled in Bridgewater this April when she turns 3, and she is really excited about going on the bus and starting school.

Chloe Grace has taught us so much about life and appreciating the gift of life, even amidst the challenges and unknowns. She loves to dance and play musical instruments; she loves swimming, singing, coloring and cooking with Mommy. She brings tremendous joy to our family, and all who meet Chloe Grace can't help but fall in love with her personality. She is our inspiration, our greatest teacher, and she gives our lives a beautiful, privileged purpose.

