



Tess Clark



The Children's Hospital

Tess Clark made her first appearance at The Children's Hospital's Neonatal Intensive Care Unit at just five days old. Born with a genetic disorder so rare and complex it was coined the "Tess Clark Syndrome." She would spend the first four years of her life in and out of the hospital.

At birth, Tess presented craniofacial abnormalities that caused dangerous pressure to build around her brain. The seams between her skull bones were improperly fused together not allowing for the rapid brain growth experienced during infancy.

Filled with trepidation and armed only with the reassurance of their doctor, her parents set out to save their little girl's life.

Within ten weeks Tess began a series of complicated surgeries. Doctors worked carefully to rebuild her skull, freeing up space for her brain to grow, and placed a permanent shunt in her brain to drain the spinal fluid that had pooled there.

An astonishing 37 surgeries followed. Through each challenging procedure, Tess's little body endured and her strength and spirit shined through.

Perhaps the most remarkable procedure was a new technique that literally moved Tess's facial bones forward a whole inch. A titanium frame was attached to her face with pins inserted in the bones near her eyes and nose. Her parents had to turn the screws each day to slowly move her face forward. The innovative procedure changed Tess's appearance dramatically. It also enabled her to eat by mouth eliminating the feeding tube she had depended on since birth and allowed her to breath without the aid of a tracheotomy (an apparatus surgically inserted in the neck to open a direct airway through an incision in the windpipe).

A breathing apparatus for sleep, hearing aids and glasses are just a handful of interventions that have allowed this amazing little girl to grow, develop and, eventually, thrive.

The discouraging clouds of doom that overshadowed Tess's early years have long since parted.

Her tracheotomy scar is beginning to fade and the other reminders of surgeries past are hidden under a gorgeous mane of golden locks. Her parents are finally able to step back as Tess leaps forward, excelling in school and challenging herself in skiing, music and softball, where her team nicknamed her "Muscles."

The future is bright for little Tess Clark.



Helping Children in Your Neighborhood