

20 Years of Caring

The Wert twins, Nicholas James and Patrick Stanley, were born at 26 weeks gestation in the high risk birth unit at the Ottawa General Hospital. They each weighed less than a pound and a half.

“**T**he last thing I can remember about my time in the delivery room was seeing my husband’s back as he was asked to leave the room. I felt so scared and all alone, not knowing where or how our babies were doing.

In fact, only minutes after they entered the world the twins had been whisked over to the Neonatal Intensive Care Unit at CHEO. While I had no knowledge of the complex equipment being used to monitor my babies, the nurses explained everything to me and encouraged me to touch the babies through the holes in the isolettes. The nurses and doctors warned us there would be a lot of ups and downs, as is the case with all premature babies. But no amount of instruction could possibly have prepared us for the emotional roller-coaster on which we had embarked.

The next weeks were a blur of tests, infections, feeds, x-rays, oxygen rates, setbacks and endless trips to the hospital. We monitored their progress very carefully and if they were having a good day - so were we. The support provided by staff at CHEO was above and beyond the call of duty. At times, the only way we could get a decent night’s rest was knowing that they were at CHEO.

By six weeks of age they weighed only 2 pounds each. We had not been able to feed them yet and the simple pleasures, such as holding them in our arms, were all too infrequent.



Patrick seemed to have started each week of his life with some sort of complication. Week 1 his lungs were in bad shape - the alveoli were bursting; week 2 Necrotizing Enterocolitis (NEC), an intestinal disorder, resulted after just a few hours on milk; week 3 lung problems again, this time retained fluid in his body was causing him difficulty in breathing; week 4 an infection from his eyes had settled in his ET tube requiring antibiotics to clear it; and during week 5, old blood was being excreted from his stomach as the result of a stress ulcer.

I would call in several times a day to get progress reports on the boys. Just when I thought we had climbed another mountain, we would be faced with even tougher decisions.

Initially Nicholas seemed to have been spared the complications that Patrick faced, however as the weeks went by this would change.

The first hint that all was not well came when he was 11 weeks. What doctors had originally thought was a swollen windpipe had turned out to be more serious and ultimately led to a tracheotomy. Several weeks later a disease affecting the retina was also discovered. The final blow came at 15 weeks: there had been some deterioration of the right side of the brain and the outlook was not positive.

We were told that we might be faced with anything from mild to severe seizures potentially uncontrollable with medication, limited use of his left side, impaired vision, moderate retardation, and other complications which would likely require institutionalized care. He may not even know us as Mom and Dad.

To look at Nicholas then you would never have known - he seemed so peaceful - yet inside his little head he suffered damage that would never allow him to see, touch, hear, feel and experience all the wonderful things we tend to take for

granted. This was the most difficult time we had faced. We were afraid to call the hospital for fear of further bad news; our hopes and dreams for our little family had been shattered.

The next weeks and months brought times of joy and progress for Patrick and on October 25th, at 22 weeks and 7lbs 3oz, he was discharged. At the same time our visits to the hospital to see Nicholas



continued. He had been moved to 5N, the TLC unit, where the emphasis was placed on his growth and development.

The twins first Christmas was fast approaching and while we were busy with the usual holiday preparations, we couldn't help the disappointment we felt that only one of our boys would be home for the holidays. Nicholas' CHEO family made a special effort to ease our pain with gifts, holiday treats, and a visit from Santa Claus to our little one.

The new year brought wonderful news for Nicholas. The doctors noticed that he seemed to be developing. He had started speech

therapy, was tolerating more foods, and was getting stronger each day. There was hope that with time and growth Nicholas' trach could be removed, and there was even talk of him coming home! A team of nurses, doctors, technologists, social workers, and many others worked to educate and prepare us for the 24 hour care that would be required for Nicholas in the home.

On May 19th we said good-bye to some very good friends on 5N and closed a chapter in our lives. We had spent close to a year at CHEO, and it was difficult to leave behind the staff and other parents that we had come to know so well. Every one of them has their own story, their pain and their joy...ours was Nicholas, and he was finally coming home.

It is now spring of '94, and other than minor developmental delays in motor skills and their slightly smaller size, the boys are doing just fine. In fact, in their recent Neonatal follow up tests their performance was well within the acceptable ranges for children their age - a far cry from the little beings that came into the world 14 weeks early. The future looks very bright for the Wert twins thanks to the love of the many people that cared for them, and the dedication and hard work of the miracle workers at CHEO. Without them, we know Nicholas and Patrick would not be here today. ”

Nancy Wert
Cornwall, Ontario

