Cole Petrie FAQ Sheet

This FAQ sheet was designed to hopefully answer any questions that you may have regarding our journey through the world of childhood cancer with our son, Cole. This is in anticipation of media questions that may be asked in conjunction with the "Mountain of Hope" Campaign by the Childhood Cancer Foundation. For current information regarding Cole's struggle with neuroblastoma, please refer to his Caringbridge website that is updated frequently – www.caringbridge.org/visit/colepetrie .

Child: Cole Leonard Petrie
Age: 4 years old
Parents: Brian and Jennifer Petrie
Siblings: None
Reside: London, Ontario
Cancer: Neuroblastoma

Can you tell us a bit about Cole?

Our only child, Cole, is the light of our lives and has been since the day he was born 4 years ago on July 5, 2001. We waited a long time and endured a lot to be able to conceive him, which makes him all the more precious to us. He is a sweet, intelligent, intuitive, and sensitive child with a lot of determination and spunk. He has a wonderful imagination and can't decide what he likes to pretend more – that he's a pirate or a knight! He tends to be a bit cautious when meeting people for the first time, but once he's comfortable he loves to have fun and has a great sense of humour. He has the most beautiful and big smile that can warm any heart. He has big brown eyes with very long eyelashes and blond hair. Currently, due to treatment he has no eyelashes or eyebrows and just the odd hair on his head.

When did you first notice something was wrong? What were his symptoms? How and when was he diagnosed? What is his diagnosis? What is his prognosis?

For the most part, he was a healthy child with only a couple less significant issues until the summer of 2005. Cole just hadn’t been himself over the summer with vague complaints of being tired, abdominal and hip pain as well as lack of stamina and interest in his normal activities. Looking back we now realize he had other telltale symptoms of night sweats, temperature irregularities, and rapid heart rate which we attributed to a very hot summer. We took him to our Dr. and she sent him for a leg length X-ray since he had been complaining of hip pain as well. Everything seemed normal. He had been born with hip dysplasia so we naturally thought it might be related to that. We made an appointment with our orthopedic specialist but couldn't get in for several months. By September, we were noticing his stomach was distended and his symptoms were worsening. His daycare thought something was wrong as well. He seemed to be eating less and losing weight. Again back to the Dr.'s who then thought perhaps he might be constipated and sent us for another x-ray, which again showed nothing.

Cole's grandmother had passed away in August and he was beginning JK in a couple weeks, so we were starting to think that it was some type of emotional upset that was affecting him. We took him back in again to request some blood work hoping to get to the bottom of this and determine whether it was a physical or emotional problem. When the blood work came back indicating low hemoglobin and elevated liver enzymes, our Dr. scheduled him for an ultrasound. On ultrasound, it was thought to be two tumours and we were sent immediately to emergency for a CAT Scan. The scan actually discovered one tumour the size of a football filling his abdominal cavity originating from his right adrenal gland. On that day, Sept. 16, the day that changed our lives forever, we were told that it was probably a type of childhood cancer called neuroblastoma. Later, tests revealed that the cancer had spread into his bone marrow as well. After all tests were completed, we were told that Cole did have Stage IV Neuroblastoma, an aggressive cancer that requires equally aggressive treatment. We initially spent 4 days in the ICU and then up to the 7th floor oncology ward for 39 days before Cole was stabilized and able to go home. We were given a prognosis of a 35% chance of surviving 3 years.

Where is he in his treatment plan? What is the protocol of treatment for this cancer?

The protocol of treatment includes 2 rounds of chemotherapy, then a stem cell harvest in Toronto at Sick Kids Hospital, then back to London for 3 more rounds of chemo. This was followed by surgery to remove the tumour. Although the chemo had reduced the size of the tumour substantially, the surgeon was only able to remove about half of it because it had wrapped around and attached itself to the aorta and venacava arteries. This was followed by another round of chemo and after numerous tests and scans, we were sent to Sick Kids to begin his stem cell transplant. Unfortunately, after being admitted for just 1 hour, we were told that one of Cole’s tests done in London had shown neuroblastoma cells in the bone marrow fluid. Because of this, the transplant could not proceed and we were sent back to London where it was decided that Cole needed to have 2 more rounds of chemo to hopefully bring about a better response in his marrow. Our goal is to be able to proceed back to transplant as this provides the best-known approach to saving his life. The protocol dictates that radiation and 6 months of retinoic acid (a form of Vitamin A) be given after transplant.

How has this affected our lives?

Our journey in the world of childhood cancer has turned our lives upside down. Neither Brian nor I are working at the moment due to emotional stress and because 90% of our time is spent either admitted in hospital or in clinic due to the aggressive treatment and amount of care that Cole has required. Although our world came crashing down, we have been lifted up by all the amazing support that we have received from our wonderful family, friends, neighbours and the London community. Our eyes have been opened to the realization that there are far too many innocent children suffering with cancer and we have met the most remarkable and courageous children and parents during our journey. We continue to hope and pray that we will be given the opportunity to watch Cole grow into a young man.

How has Brandon helped?

When Cole was newly diagnosed, Brandon Schupp, the son of Cole's caregiver for a number of months felt that he wanted to be able to help him, so after contacting a mentor of his that gave him some ideas on how to fundraise, he and his mother, Ann, initiated a garage/bake sale which was a phenomenal success. Brandon had taken Cole under his wing during the time that he spent in their home. He switched his focus from his own mountain climbing hobby goals to concentrating on earning money by doing odd jobs to be able to donate to Cole. Many others became involved including family and friends as well as the community at large and a successful silent auction was held late in November of 2005. We were overwhelmed with the generosity and big hearts of everyone who became involved with these fundraisers and Brandon was the catalyst for this.

How do we feel about the "Mountain of Hope" campaign by the Childhood Cancer Foundation?

Brian and I are so blessed and touched to see all the good that has grown from Cole's struggle with neuroblastoma. It brings hope to our lives and we feel that there is a higher purpose to his illness and that is the opportunity to bring people across this land together for such a worthy cause. We want to lend our hand whenever possible and we have given our permission to have Cole's caringbridge website address published so that people will be able to follow our personal journey. We look forward to being able to inform the public and bring about a better understanding of the struggles that parents and their children with cancer face everyday as well as the need for research dollars to one day hopefully eradicate childhood cancer deaths. Our wish is to bring a human face to this vital, nation-wide campaign through the sharing of our innermost hopes and fears. We are also so proud of Brandon and the many other wonderful people that are working very hard to make this campaign a success to benefit the 10,000 children in Canada that fight so courageously to survive.