

For Patrick

By Erin Chance, Patrick's mother and cancer research advocate

It's hard to describe how you feel when your child is diagnosed with cancer. It's the worst possible news for a parent. Doctors diagnosed our son Patrick, at the age of 3, with neuroblastoma. He had a tumor of the sympathetic nervous system, and it changed the way my husband, Stephen, and I saw the world. We knew that we would do everything we could to help Patrick beat this disease. And we never gave up hope that Patrick could be the one to beat stage IV neuroblastoma.

Patrick was such a strong patient, taking harsh treatments with a smile and a positive attitude. He would much rather have been fishing or bird watching, and we tried to keep his life as normal as possible despite his battle with cancer. While he was fighting, we vowed as a family to raise money to fund new treatments for neuroblastoma and formed Press On to CURE Childhood Cancer, a named fund of CURE Childhood Cancer, Inc., to fund less toxic, more effective cancer therapies.

On what would have been his 9th birthday, Patrick passed away on Jan. 9, 2012, but we knew that wasn't the end of his story. When we learned that Children's had decided to start a specialized radiation therapy program, it was the perfect opportunity to honor Patrick's legacy in a special way. On January 9, 2013, we helped dedicate Children's new MIBG (metaiodobenzylguanidine) therapy room in Patrick's name. What's special about MIBG treatment is that it allows the patient to be injected with a radioactive drug that targets the cancer cells directly, causing less damage to other parts of the body.

Because of our personal experience during Patrick's four MIBG treatments, my husband and I wanted to help design the space. We envisioned two rooms: one for the patient and one for the family. When Patrick received MIBG treatment, he was radioactive for several days, and we had to limit our interaction with him to protect our own bodies from radiation exposure. It was extremely tough not to be able to hold or touch your child and to be separated visually from him by solid lead



 Patrick Chance was diagnosed with nueroblastoma at the age of 3, but that didn't stop him from being full of life.

shields. We recommended installing televisions in each room along with three-way video and microphones, so that patients and parents could see and talk with each other on the monitors and even play video games together. The nurses can also use the monitors to watch over the child. It was important to us to provide better nursing care for the patient while protecting the nurses from continuous radiation exposure.

Although it was emotionally difficult to go back to Children's for the grand opening on the anniversary of his death, it was the perfect way to celebrate his memory. In many cultures, if you die on your birthday, it's a sign you perfectly completed your mission on earth. For me, dedicating this room a year after Patrick died was another completion of that circle. It was part of fulfilling what I believe was his mission on earth: touching people's lives and changing the course of childhood cancer treatment.

Until childhood cancer is cured, we plan to continue our mission and fundraise on behalf of cancer research and treatment. We know that Patrick is still fighting beside us, continuing his own desire to heal people. I can't think of a better way to honor his life. ☚