



**TREES FOR LIFE™**

*Cultivating The Cure • Texas Children's Cancer Center*

## Patrick DeClaire – A Family's Journey with Cancer

Your child has cancer. What would it feel like to hear those words? It's a diagnosis that changes your life. It changes your child's life. It changes the lives of your family and everyone you know.

Patrick was nine when he was diagnosed with Stage 4 Neuroblastoma, a cancer of the nervous system. Patrick's mother, Laurie DeClaire, describes her reaction as complete shock. She often explains that absolutely nothing can prepare you for the moment you're told that your child has cancer. Then comes the longing – an intense longing for survival, an ache that consumes you and injects into your spirit an unspeakable fear. Fear for your child's future. Fear for the pain and suffering your child will endure. And, fear for your potential future without your child.

Laurie also describes the anguish she felt when her husband Chris told Patrick the news. Patrick looked at his dad and said, 'Daddy, you can die from cancer.' The raw and painful answer was, "Patrick, darling, some children do die, but we are going to do everything we can to make sure that doesn't happen." It was a humbling hope that just maybe Patrick could survive.

Patrick's symptoms were an occasional backache and fever. However, his cancer was severe. He had tumors along his spine, and one on the spinal column that threatened complete paralysis. His bone marrow was 100% cancer cells, and his bones from the top of his skull to his legs were compromised.

Facing the devastation of this complete and complex diagnosis, the DeClaire family turned to the Texas Children's Cancer Center (TCCC). Dr. Wendy Allen-Rhoades explained Patrick's situation as a difficult disease to treat. Stage 4 Neuroblastoma is rare and needs every modality of therapy we offer. One physician can't do it. Patrick would need a team of doctors, nurses, child life specialists, surgeons, and everybody working together to help him. Together, TCCC and the DeClaire family faced down Stage 4 Neuroblastoma, a journey of pain, suffering, help, hope and healing – always seeking courage from Patrick's indelible smile.

The start of Patrick's treatment began when the team of TCCC physicians customized a treatment plan to aggressively attack the cancer on several fronts. Patrick received chemotherapy and scans were in scheduled three-month intervals. Patrick remembers that the treatments were difficult for him, creating nausea and debilitating weakness. Patrick describes this as the most difficult part – just feeling badly all the time for months

on end. Numerous rounds isolated him from his friends, classmates and completely separating him from the life he knew.

While the medicine almost killed him in an effort to keep him alive, the family waited for the days Patrick would have his scans. Each scan would answer the burning question: Is the cancer reducing? Laurie felt feeble as severe emotional pain gripped her. She was so scared. She remembers crying out to God for the hope she craved, "Please God, please let my child live!"

The first miracle along the journey with cancer came during those initial rounds of chemotherapy when the dangerous spinal tumor went away. Patrick, with his little bald head, had a smile that sparkled with hope. That hope was a start, but vast amounts of cancer remained in his body.

Imagine approving a therapy where doctors administered so much radiation that your child must be placed in a lead-lined room for three days completely alone. A radiation so strong that it seeped out of his small and fragile body making him, literally, radioactive and a danger to others. Laurie and Chris managed Patrick's care during those days, as caregivers were not allowed in the room with him. This drug study therapy called MIBG radiation targets the tumors and delivers radiation to specific areas. While it sounds barbaric, this therapy was promising and necessary because of the vast amounts of cancer remaining in Patrick's body. MIBG radiation was successful in reducing the cancer, but still a significant amount of cancer remained.

The next recommended step was surgery and targeted radiation. A highly skilled neurosurgeon at TCCC removed the remaining tumors on Patrick's spine. While recovering from this surgery, Patrick went back to the operating room for an emergency surgery to repair a collapsed lung. The recovery was long and arduous, but he endured. Following these successful surgeries, Patrick started radiation again.

This radiation was not for the faint of heart. Precise and targeted radiation was required. Molds were made of Patrick's body, and a mesh-type mask was formed to the shape of his face and head. The mask was bolted to the table and his body fit securely into the molds. This kept Patrick completely immobilized while the radiation was delivered to the spine and skull.

During this procedure, Laurie's heart broke and she openly wept as she sat outside in the waiting area imagining her son bolted to a table and pelted with life-saving lasers. One doctor recalled a time Patrick was in a lot of pain. She told Patrick she was so sorry he was going through this – his reply, "it's no big thing, I got this." Patrick's positive attitude, along with a strong support system, helped him in his fight against cancer. But, the battle was far from over.

Scans revealed more cancer. The next-to-the-last hope was a stem cell transplant. But, Patrick's current cancer levels were considered not within the range for the transplant – the cancer levels were just too high. Left with no other good options, the decision was made to try the stem cell transplant anyway. But, first, Patrick would undergo a high-dose of chemotherapy administered prior to the transplant. This drug racked his body with pain

and completely debilitated him. He slowly recovered again.

Patrick fought to become strong enough to qualify for the transplant. Patrick had the stem cell transplant, and then another recovery began again. Slowly and arduously Patrick fought against the debilitation of his body as he recovered from the stem cell transplant. After all he had endured, this got worse. He endured many weeks of isolation required to avoid an infection. The soft tissues in his body became inflamed and infected. The sores in his mouth were black and burned with pain. Day after day Laurie and Chris watched Patrick survive more pain and suffering in his lifetime than many adults experience in theirs. But, alas, the cancer remained. All readily available remedies were exhausted.

Patrick's oncologist then made a Plea of Compassionate Use to the Food and Drug Administration (FDA) for a study drug called CH14.18. This experimental drug is a type of antibody therapy that targets cancer cells and destroys them. The therapy was painful and complicated, but in the end – Patrick's cancer relented! Laurie knows in her heart that this cutting edge research saved their son! Medically speaking he's in remission. She believes that he is healed.

Patrick is currently enrolled in a study and is taking DFMO, a drug that keeps cancer in remission. Patrick's future is not guaranteed, but he is making plans. He wants to go to college and become a child life specialist at Texas Children's Cancer Center. He currently serves as a TCCC Ambassador. His life's goal is to make children happy and give them hope that they can get through cancer.

Laurie and Chris are eternally grateful to TCCC and TCH – the oncologists, the research doctors and the donors who made the discovery of new therapies possible. They pray cancer will be eradicated in our lifetimes. Specifically, they long for the day that no parent hears the words your child has cancer, and the children of tomorrow won't wonder if they will die at 10 years old.

Trees for Life supports research for life saving therapies and research conducted at TCCC. TCCC is conducting the types of therapy that saved Patrick, and the many therapies others need to survive. Trees for Life is guided by the belief that every child is precious and worthy. And, founded on the principle that children with cancer have hope and blessings in their lives. These blessings include the countless people who support cancer research and fight for a cancer cure!!

