



# Children's Brain Tumor Foundation

Embracing the challenge today gives hope for

## A Father's Promise By Nick Schiaffo

On April 8, 1998, the lives of our family changed forever. It was on that day that our only child, Daniel, was diagnosed with medulloblastoma, the most common form of childhood brain tumor.

Three days later, our son underwent craniotomy to remove the tumor, followed by 31 radiation treatments and 9 months of chemotherapy. It was determined in April of 1999 that Daniel was in remission. But later that same year, on December 9, we received the devastating news that the brain tumor had returned, and on Christmas Eve, he once again began his long journey into wellness. It was this second time around that we witnessed grace, dignity, and courage from our son the likes of which we had never experienced before. Daniel never complained about his illness or the complications of it. In fact, he was only apologetic about it. One can imagine a parent's heartbreak upon hearing a child say he is sorry for being sick.

A week prior to the stem cell transplant that we hoped would save his life, I asked Daniel if he was scared. His reply was a simple "No." I was never so proud of anyone as I was of him at that moment. He was truly my hero. On May 29, 2000, just 4 days into the transplant, Daniel passed away in his mother's arms. Moments before he drew his last breath I promised him that I would do whatever possible to eradicate this disease.

A few weeks prior to Daniel's passing I was asked to supply a picture and a story of Daniel to be displayed in Washington, DC, during Brain Tumor Action Week. I did so with the hope that seeing this wonderful child with the beautiful smile might bring awareness and understanding about the plight of brain tumor patients. The following year I became active with the North American Brain Tumor Coalition. Traveling to Washington and meeting others who had lost ones or

were themselves afflicted with this horrible disease brought me perspective as well as inner peace and healing.

Although my wife and I thought that we were all alone in this fight, we learned that we were just one family of many. Talking openly with others brought new realizations of the work that I could do—not only to support others but to help fight this disease.

I also became active in the Virginia Transplant Council and Old Dominion Eye Foundation, serving on their boards, working to bring awareness of the importance of organ donation. We ourselves had given the only gift we had, the gift of our son's corneas. Daniel now lives on in others.

After many months of lobbying, on June 19, I was on hand when the Senate Health, Education, Labor & Pensions subcommittee passed the Benign Brain Tumor Cancer Registries Amendment Act (S. 2558), which was given full approval by the Senate a couple of weeks later. The Act is aimed at improving data collection to understand the burden of both benign and malignant brain tumors,

enhancing the brain tumor research effort, and advancing care for brain tumor patients. S.2558 will have a positive impact on brain tumor research and treatment, and hopefully, one day, lead to a cure.

On that morning in Washington I felt a true sense of pride and accomplishment as a parent. Even though there are many battles yet to be won, I hope to see a cure for brain tumors and all cancers in my lifetime. Every night when I leave work I look up to one particular star and say "Goodnight Daniel." This star always appears to be looking at me, offering inspiration and hope. When a cure comes and I see that bright star winking at me in the night sky, I will have fulfilled my promise to my son.

