

This story was written for the Childhood Brain Tumor Foundation, Germantown, MD.

## A Message from Kyle



By the time you read this I will have just turned nineteen, completed my first exams, and most importantly finished my third year tumor free.

Life is pretty good right now. I am a third of the way toward receiving my BS degree in Industrial Design from the Art Institute of Philadelphia. I enjoy my classes and hope to make the Dean's List again this quarter. I am living in downtown Central Philadelphia one block from my school. My roommates are great, pretty much everybody gets along and we are always out doing something in the city. I'm working at McFadden's Bar & Grill on Third Street. (I'm the guy carrying around cases of beer, taking out the garbage, cleaning the dirty glasses and pretty much whatever else rolls down my way.) Actually, the job is great and the money comes in real handy when I am hungry. My parents have helped me a lot with school expenses, but I am pretty proud of the fact

that since I started working there last January I have covered all of my daily living expenses.

I get homesick sometimes and try to get home every two or three weeks. I either take the train or bribe my Mom to come and pick me up. I really enjoy seeing my family, my cousins, and sleeping in my own bed. I hang out with some of my friends from high school when they are home from school.

I still see my surgeon, Dr. Feldstein, once a year after my annual MRI to check for any unusual cell growth in the area where my tumor was removed. This is always the worst time of the year, not seeing Dr. Feldstein; he is terrific, just the stress of worrying if the tumor is back. Craniopharyngiomas are a recurring type of brain tumor, even on my best days there are moments when I think, is it back? Dr. Softness, my endocrinologist and I see each other four times a year for adjustments to my hormone replacement regimen. Currently, I take five different replacement medications to supplement pretty much anything my pituitary gland would have taken care of under normal conditions. I am 5 foot 9 inches now, weigh 135 pounds and am still growing. My hormone levels have to match my weight and support my body as it continues to grow so adjustments are always needed. I'm lucky to have Dr. Softness, without a lot of medical history for physicians to draw from, his experience is pretty much what we rely on to keep me healthy. So far so

good.

My life looks pretty normal to my friends at school and work. I work hard at keeping it that way. But the truth is the daily medical replacement therapy is still like a job or a class I don't enjoy, but have to do. Sometimes I just don't want to deal with it, but that is not an option. Without my medicine I just crash. Remembering to replace my prescriptions in time to avoid running out of the medicine is difficult too because I'm pretty booked and sometimes I wait up to the last minute. Thanks to George at my pharmacy who looks out for me, I have never been in too much distress.

Listen, I'm not complaining. I like my lifestyle, and the meds are a small part of it considering everything else in my life. From March 19, 1999, the day they removed my tumor forward; I can finally say I feel good when I wake up in the morning, or, sometimes in the afternoon.

Before my diagnosis and operation to remove the Craniopharyngioma, I lived with the daily pain and other symptoms of the unknown cause of my illness. I never gave up the hope of finding the cause and the cure. My doctors provided me that cure. My family and friends supported me during my recovery from the surgery.

Today there are still many questions that my doctor cannot answer about my condition, pan-hypopituitarism. All of my pituitary gland functions are supported wholly by medicines self-administered daily. The long-term effects of this replacement therapy are vague. But I have the same hope and persistence I've always had that the future will bring some answers. Those answers lie in research. Your support of the Childhood Brain Tumor Foundation (CBTF) helps bring those answers closer. Over the past three



years the improvements in my medications and how they are administered have been significant. I am grateful to everyone, to all the supporters of Kyle's Heroes for the tremendous results of your efforts and the contributions to groups like CBTF.

I speak for myself and others like me, especially the kids, who seem to have a normal life but inside feel different, your sacrifice and gifts are greatly appreciated by all of us.

*by Kyle Killeen, Survivor*

With the success of each year come the challenges of a new one. Despite all the tragedies and hardships and a struggling economy the Kyle's Heroes family continues to grow. With the inspiration of Kyle and the generosity, support and hard work of everyone involved, we will continue efforts to make a difference.

*by Jim Killeen*