

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

Ryan's Story

by Pat Schlosser

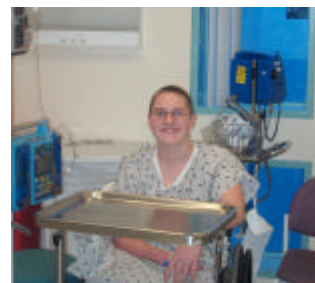


It was September 2003, our son Ryan, 13, was playing catch in the backyard with his Dad; he loved to play baseball and had just completed playing with a travel team that summer. Ryan complained of some light double vision which seemed to come and go, so we made an appointment with the optometrist. The following day the optometrist examined Ryan's eyes and asked several questions. The optometrist felt the vision problem was due to a virus as Ryan had been sick the week before, and felt Ryan would improve after a week or so, but he suggested a MRI purely as a precaution. He stated in all his years of practice he had never seen any issues, but wanted to be safe.

We scheduled an appointment for Ryan's MRI, but we had to change it because Ryan's grandmother passed away that week. The appointment was rescheduled for a couple of days following the funeral. From there, all of our lives changed dramatically.

We took Ryan's films from the local hospital to a neurologist in Fort Wayne, Indiana. She immediately showed us the film and stated the images were "abnormal". Having never seen a brain scan before, it was obvious even to us that there was a problem as there was a massive "white area" on the scan. She sent us immediately to the emergency room in Fort Wayne. The doctor conducted several physical tests; he was surprised Ryan had no symptoms. He recommended we head to Indianapolis immediately to Riley's Children's Hospital, because they had more equipment, pediatric brain tumor specialists that may have more treatment options.. We made a very quiet three hour drive, arriving very late that evening. Ryan was examined again in the Riley's Children's Hospital emergency room and their doctor was also surprised he showed no symptoms and then ordered a more sophisticated MRI.

After several additional tests, they developed a plan and scheduled Ryan for surgery two days later. We were all extremely nervous and shaken. Ryan went to surgery at 8:30 a.m., September 15 and 14 hours later, we got to see Ryan in the recovery room. They had removed the very large tumor and the surgery went as well as expected. Ryan did fine in surgery, however he had significant trauma. Ryan's entire right side was entirely immobile, his face and shoulder, were all drooping, he could not move his right arm or leg. The next few days were very difficult as his memory was also greatly impacted, he could not even remember our names, nor identify basic objects. All we could do was simply watch and wait. The pathology came back after a week and showed that Ryan had JPA, juvenile pilocytic astrocytoma.



The following weeks Ryan continued to gradually improve as we were sent to intensive rehabilitation. He had to learn to read, walk, eat and talk all over again, it was a long process. He progressed gradually from his wheel chair to a walker and eventually with the help of a brace was able to walk again (a thrilling day!). He also regained much of his mental function, but his memory was still impaired. He had no function of his right arm at all for several months. Through extensive therapy he continued to improve and even gained some movement back in his right arm.

We continued with follow-up visits every three months. Almost a year exactly from the first surgery, more devastating news, Ryan had four new tumors reappear in the area of the original tumor. Our neurosurgeon was very thorough and acquired several outside opinions. Ryan went through surgery again in

Indianapolis, this time he was in surgery for 8 hrs, everything went as planned. He had only minor setbacks this time and following a rough couple of days then recovered quickly. The day before they planned to discharge Ryan, he had another MRI; they found another tumor in the third ventricle and near the vital center of the brain, the hypothalamus. It is inoperable. The surgeon stated we had plenty of time to acquire opinions on what to do next and we should let Ryan recover.

The following weeks we had many road trips to visit five leading institutions in the U.S. The opinions were very diverse on what to do next, ranging from attempting surgery to remove the portion they could reach, extensive chemotherapy, and differing levels of radiation. The final visit was with Dr. Packer in Washington D.C., a friend of our Indianapolis neurosurgeon. He proposed a new chemotherapy regimen to monitor Ryan over a longer period of time and avoid some negative consequences of the other treatment options until Ryan is older (cognitive loss and hormone deficiencies). Ryan has now been in chemotherapy for almost one year under the watch of Dr. Packer. His tumor has remained "stable" and although Ryan is disappointed it is not shrinking, at least it has not progressed.

Ryan is now 15 and has continued to improve physically (some movement in his right arm and hand) and also made dramatic cognitive improvements since his first surgery. He is able to walk well with only an AFO (ankle-foot orthotic) brace, he is doing well in school and enjoys being with his friends.

Ryan will complete his chemotherapy sequence in the spring of this year. We do not know what the future holds, but hope and pray for his recovery and advancements in the medical world so he may be cured.

*Written by Pat Schlosser, Ryan's mom.
2006*