

Why We Ride [view pdf version](#)

Dear Friends,

Our family's story begins in October of 2003 with a routine CT scan for our 1½ year old son, Timothy ("TJ"), to "just rule out some things." TJ had not been gaining weight through the summer and while specialists were convinced it was a digestive issue, they could never get to a definitive diagnosis.

We sat in a neurosurgeon's office at Children's Hospital just hours after his scan knowing something wasn't right. Then the doctor spoke in what felt like slow motion. "Mr. and Mrs. Ragnoni, your son has a very large brain tumor. It is in a very delicate area at the base of his brain stem. We have to operate immediately and won't know much more until then." The rest was a blur. Five hours earlier our most important family issue was choosing Halloween costumes for the three boys. Thus began our new journey through an 8-hour brain surgery, two year-long chemotherapy treatments and an ongoing journey.

TJ's surgery was successful in that 80% of his Juvenile Pilocytic Astrocytoma ("JPA") tumor was removed. His overall prognosis is very good, but other children with this disease are much less fortunate and outcomes vary dramatically with this disease.

We are grateful to report that TJ is now 9 years old and doing extremely well. We also think he was aided greatly by a healing trip to Our Lady of Lourdes Basilica in France in 2009 and is truly god's miracle. We continue to regularly monitor his situation.

Help is on the way—or is it

We have been truly blessed with incredible doctors, nurses and clinicians at the Dana-Farber Cancer Institute and Children's Hospital in Boston over the years. The support from family and friends has been overwhelming, and to this day we continue to receive the generosity and prayers of many wonderful people.

Throughout the early years, we were certain that major advances were being made against TJ's disease. How could there not be? We'd all heard of the Genome project and cancer breakthroughs. We saw the Pan Mass Challenge raise millions of dollars for Dana-Farber each year. We idyllically had this vision of researchers in labs across the country cracking the code on more effective chemotherapies and cures for children's brain tumors, Low Grade Astrocytomas, and, specifically, Juvenile Pilocytic Astrocytomas. And having three boys under the age of 6 at the time, we were just doing our best to keep our head above water. We actually thought the medical cavalry was on its way to save the day.

Then we learned the facts from doctors and researchers: At the time, nothing was being done to cure—or even significantly improve treatment of—JPA brain tumors and other related Pediatric Low Grade Astrocytoma ("PLGA") brain tumors.

The facts

- Brain tumors are the leading cause of cancer deaths in children
- Despite affecting thousands of children and being the most common type of pediatric brain tumor, Juvenile Pilocytic Astrocytomas and all Pediatric Low Grade Astrocytoma tumors, are an "orphan disease." That means there is no major foundation, celebrity, or deep-pocketed organization that has taken up the cause
- The chemotherapy drugs given as the standard treatment were developed 25+ years ago and there has been minimal advancement for the treatment of PLGAs since then. This, despite researchers' acknowledgement that newer drugs developed for other tumors and cancers could be more successful and pose much less risk to the children on these treatments
- The funding directed at adult brain tumors, albeit limited, does not help children with PLGAs since the tumors act very differently
- **There are scientists interested in studying PLGAs and proven research steps that could be taken to unlock a cure for PLGA tumors BUT there has been little money to fund it**

Hope for progress

The lack of progress led us to work with other parents to get involved. Until Team TJ, and other parent families began this fight, there was NO meaningful research occurring in PLGA tumors. A lonely orphan disease with little hope of breaking the cycle of "no funding leading to no researchers being interested in the field."

We are excited to report that we've made important strides in getting the cancer research community to take notice and get involved—and it is directly because of your kindness and financial support. Combined with several other families, we raised over \$600,000 in last year's Geared Up For Kids bike ride that we've used to target research to directly help TJ and children like him. Our progress includes:

- Establishing a multi-year, \$2+ million pediatric brain tumor program focused on Low Grade Astrocytomas at Dana-Farber Cancer Institute with the major support of several other families in March, 2007
- Founding the Pediatric Low Grade Astrocytoma Foundation, a 501(c)(3) charitable organization, with several other families. The first foundation in the country that funds research specifically for low grade children's brain tumors (more information available at www.fightplga.org)
- Over the past three years, funded 5 international researcher/clinician conferences and over a dozen PLGA targeted research projects.
- A full list of our projects and progress is available at www.fightplga.org/research

We need your help—Team TJ rides again!

We hope this progress demonstrates to you our commitment to apply our business skills and passion to this problem. We are focused on making each dollar donated by you work incredibly hard to make progress for our children as rapidly as possible. Along with this progress we've unfortunately learned the facts that we need much more funding to make a major difference against this disease.

On Sunday, May 22nd, we take another step on our road to a cure. Our whole family will be riding, along with other members of Team TJ, in the "Geared Up For Kids" 2011 Ride sponsored by the Pediatric Low Grade Astrocytoma Foundation ("PLGA Foundation"). We started the PLGA Foundation to focus research specifically on pediatric brain tumors. We are fortunate that all money raised by Team TJ will go directly to finding better treatments and a cure specifically for children's brain tumors.

Our personal goal this year is for Team TJ to raise \$100,000 from the bike ride and have over 100 Team TJ riders. With other families, we hope to raise targeted JPA research funds from the ride of over \$850,000. We also hope that, if possible, you will consider joining TJ's team as a rider and fundraiser. The ride is a wonderful way to spend a Sunday morning and has rides distances of 10, 25 or 50 miles which allow for people of all ages to ride in the event. We can also guarantee some fun considering the wonderful people already committed to riding. If you can't ride you can participate in raising funds as a "virtual rider."

Your support this past year and our ongoing research progress makes us believe even more strongly that we can make a real difference for these children and families. From the bottom of our heart, we thank you for considering helping support this important cause.

Love,

Liz and John

Ride website: www.teamtj.gearedupforkids.org

Liz and John Ragnoni (email ljmr@comcast.net)

Foundation website: www.fightPLGA.org