

TJ's Story: Why We Ride

Dear Friends,

Our family's story begins in October of 2003 with a routine CT scan for our 1 ½ 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.

Wake us up from the nightmare

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 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 no guarantees on what tomorrow will bring.

Fighting for TJ's life

TJ's surgery was considered "relatively" successful in that 80% of his Juvenile Pilocytic Astrocytoma ("JPA") tumor was removed. But the remaining portion is intertwined with his brain stem and is inoperable. TJ's overall prognosis is uncertain and outcomes vary dramatically.

Even the more fortunate children face tremendous challenges. Brain tumors by definition are difficult to treat, and the most effective treatments often have punishing and permanent adverse side effects. Before starting chemotherapy, parents must sign a release form describing the risks involved in the use of chemotherapy with children.

Our release was 17 pages long.

We had to laugh (and cry) when we were comparing the two treatment options: Should we go with Treatment One, which had a high probability of kidney damage, severe hearing loss, and numerous other irreversible side effects, or Treatment Two, which has been known to cause severe liver damage and secondary leukemias? Neither was even guaranteed to help TJ.

Unfortunately, our decision soon became moot. TJ's tumor began growing again after his first year long treatment ended in February 2005. TJ started the second treatment option in June of 2005 and finished in May of 2006. He endured 110 weeks of toxic chemotherapy treatment. Yes, over two years.

Living Day to Day

Our families experience since TJ's 2006 treatment ended has been a roller-coaster ride to say the least. TJ has now "used up" the two standard chemo treatments and his bone marrow has still not recovered from the toxic chemotherapy which is concerning and not fully explainable by national experts. In addition, TJ's tumor had shown "activity" on recent MRIs and we have been told by senior doctors at two leading national centers that they would recommend either immediate radiation or starting another regimen of more experimental chemotherapy. For now, we are proceeding with the advice of our wonderful primary care Dana-Farber oncologist with a "watchful waiting" strategy. We have very frequent scans praying that the time we are buying now equates to less damaging long-term side effects for TJ, if and when he needs to be treated again.

Our experience drives home the harsh reality that all parents of children with brain tumor patients face – that even when "off treatment" the clock never stops. One parent accurately likened it to "trying to live a normal life while a time bomb continues to tick in your child's head." Reading the parent bulletin boards is a necessary part of our life since we learn much from other parents, but we also are reminded daily of the heartache of children in intensive care, shunts malfunctioning, more repeat brain surgeries than you can imagine, and the pleas for help from parents trying to control the countless side effects that these toxic "treatments" cause while trying to stop these hideous tumors.

Most incredible through this whole ordeal has been TJ's indomitable spirit. He has been blessed with an enthusiasm for life and a courage that is hard for us to fathom or fully articulate. We like to think God has blessed TJ with a fortitude that he knew TJ would need for his difficult journey. Remarkably, he has rarely complained despite years of innumerable clinic visits, MRIs, middle-of-the-night hospital trips, and a steady stream, until recently, of incredibly nasty medicines. Even when we had to tell him recently that we thought he was going to have to start more chemotherapy he answered in his typical easy going way that it was ok, he didn't mind going back to the clinic. He is now in First Grade and doing very well and spends his waking hours smiling, laughing, running around the house at full speed, and playing ball with his brothers, 10-year-old Michael and 11-year-old Jack. He loves basketball, soccer, reading and has even started piano lessons. The boys love for each other and the older boys' kindness has been, by far, the most effective therapy for TJ.

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 throughout this challenging period. The outpouring of support from family and friends has been overwhelming, and to this day we continue to receive the generosity and prayers of many wonderful people. It has made all the difference in this ongoing marathon and we believe your ongoing prayers have helped protect TJ from further harm.

Throughout our ordeal, 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 in their last bike ride. 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, one with a brain tumor, we were just doing our best to keep our head above water. We actually were comforted thinking the medical cavalry was on its way that would save TJ's life.

Reality sets in

Then we learned the brutal truth from doctors and researchers: **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 disturbing 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 that TJ has been given 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 no money to fund it.**

Hope for progress

Our disbelief turned first to shock and then to a burning conviction that if something was going to happen then it needed to start with us. We don't have a choice because TJ doesn't have a choice. And we couldn't live with ourselves if we didn't do everything we could to help TJ now and reach out to others to join the fight.

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 \$1,000,000 in last year's 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](http://www.fightplga.org)).
- Conducting our second nationwide competitive research grant process for PLGAs in partnership with the Brain Tumor Society with grants funded in 2008
- A full list of our projects is available at www.fightplga.org/research

We need your help – Team TJ rides again!

We hope this progress demonstrates our commitment to apply our business skills and passion to this life and death 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 cold, hard facts that we need much more funding to make a major difference for TJ and kids like him. On Sunday, May 31st, 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" 2009 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 for TJ's specific disease.**

Many of you have asked over the many months how you can help our family. We've always been uncomfortable imposing on friends and family since everyone is faced with their own challenges. But we've resolved that we owe

it to TJ to put our apprehension aside because he is in a race against time. **We believe that these dedicated fundraising dollars will result in research that could literally save TJ's life.** We hope you'll consider making a donation in honor of TJ. Please see the [donation page](#).

Our personal goal this year is for Team TJ to raise \$200,000 from the bike ride. With other families, we hope to raise targeted JPA research funds from the ride of over \$1,000,000. 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".

We are also hoping with your help to multiply the number of people we can touch with TJ's story. Please consider forwarding this message along to your friends and family – we think that this could be incredibly powerful in helping our son and raising awareness of this neglected children's disease.

The Possible Dream

Being in this surreal position makes you yearn for the truly important things for your children. In our past letters we talked about a simple dream for our son. In it, we envisioned TJ thirty or so years from now with his wife and his own three boys at the beach playing baseball with a huge smile on his face. The only lasting remnants of the fight of his life: his faded scar. It is a prayer that continues to this day so that he can be a fully functioning adult with sound mind and body.

Your support this past year and our initial progress makes us believe even more strongly that miracles can happen and this dream can be a reality. While we have just started on this journey and need significant financial resources to make meaningful progress, we believe that we can achieve great things together.

From the bottom of our heart, we thank you for considering helping TJ, our family and the thousands of other children fighting the good fight and racing the clock for a cure.

Love,

Liz and John

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