
Welcome to TeamJake ~ Proud sponsor of the PLGA Foundation

Welcome

Welcome to Team Jake. We have set up this site to increase pediatric brain tumor awareness in order to help Jake and the thousands of other children living with a brain tumor.

Please join Team Jake on May 23rd, 2010 for the PLGA Foundation's "Geared Up For Kids" Ride 2010.

Date: May 23, 2010

Title: "Geared Up For Kids" Ride 2010 Date: Sunday, May 23, 2010

Time: 8:00 am - 2:00 pm

Place: Wompatuck State Park, Hingham, MA

Description: Join us for the 2nd annual PLGA Foundation Bike Ride and Family Fun Festival. Ride one of three routes, the 10 mile "family friendly" route, the 25 "more challenging" route or the 50 mile 'whopper' route. Families, friends, colleagues invited.

Our Fight

On June 7, 2005, our son Jacob Ryan Gainey (then age 7) was diagnosed with a type of brain tumor called a fibrillary astrocytoma. Fibrillary astrocytomas fall under the broader category of Pediatric Low Grade Astrocytoma, and we will use "PLGA" throughout this website. PLGAs are the most common form of pediatric brain tumor representing about 30% of all children's brain tumors.

We went from looking forward to a summer full of carefree family fun to one full of angst and anxiety. See Jake's Story for more on his journey. As difficult as the initial diagnosis and all the medical treatments has been coping with the realization that there has been little research conducted in Jake's type of tumor. We were frustrated as we asked doctors who were the thought leaders in PLGA and were met by blank stares. The treatments options available today are outdated and highly toxic often resulting in permanent neurological deficits and impairments. We thought there was a medical cavalry rushing in to help us and our son. We were wrong.

Brain tumors are the number one cause of cancer death in children and the number two overall cause of childhood death after accidents. While significant strides have been made in many forms of childhood cancer, pediatric brain tumors have all been left behind. Treatment options for PLGAs are typically a combination of surgery, chemotherapy and radiation. Whether standalone or in combination, all of these options would have significant impact on anyone let alone a child with a developing brain.

We have seen the harmful impact that two extensive neurosurgeries has had on Jake and have watched him struggle to recapture the life he knew before he was diagnosed. We have witnessed the 15 month poisoning of our son with highly toxic chemicals which indiscriminately attacked his body and mind as much as his tumor. Sadly, the standard of chemotherapy for PLGAs which consists of a regimen of Carboplatin and Vincristine hasn't changed for 25 years. Just as importantly, 70% of children who undergo this toxic regimen are likely to need further chemotherapy and/or radiation in an attempt to halt future tumor growth. As parents we find this unacceptable and hope you do as well.

How You Can Help

We have become part of a parent led, grass roots effort to fight for research for PLGAs including forming the Pediatric Low Grade Astrocytoma Foundation, a non-profit 501c3 charity. Ken serves on the Board of Directors for this organization which is dedicated to PLGA research with a goal of developing kinder, more effective treatments. In the last two years, families associated with the PLGA foundation have raised over \$5.5mm and funded some major initiatives including the first and only Pediatric Low Grade Astrocytoma Program at the Dana-Farber Cancer Institute with a \$2mm grant. See Funded Research for more information. We need to do more but we can't do it without your help. We are in a race against time and the clock is ticking.

Please help Jake and thousands of other children by making a donation to the PLGA foundation. Lastly, please share Jake's story with your family and friends.

From our family to yours,

Ken, Charise, Jake, Sammy, Luke, Bella and Charlie Gainey