

March 5, 2007

Dear Friends and Family:

As many of you know, in June 2005, our world was turned upside down when our son, Jake, now age eight, was diagnosed with a brain tumor.

By far, the last two years have been the most challenging that we've ever experienced. Despite that, we have been overwhelmed by how fortunate we are in many ways. Most notable are the compassion and extraordinary support of our families, friends and community. Knowing you are in our corner makes it possible to face every day.

After two neurosurgeries and 15 months of chemotherapy, we are at the place oncologists refer to as "*watchful waiting*." Jake's tumor is stable for now, but we have no way of knowing how long this will last. He is being closely monitored through MRIs every twelve weeks. Jake has already used one of the only two partially effective treatments, and the potential side effects of the next one are horrible, including sterility, slower cognitive functioning and liver damage.

In the meantime, we are learning a great deal about Jake's tumor type and his long-term prognosis. What we have learned thus far is nothing short of shocking and alarming. While low grade astrocytomas are the most commonly diagnosed type of pediatric brain tumors and represents the largest cause of pediatric cancer death in children, regrettably, it remains an "*orphan disease*" i.e. no advocacy organization; no change in survival rates; no steady stream of funding for research; and no meaningful change to the state of understanding of this disease. Consequently, the two treatment options that exist are only partially effective (70%) and frequently come with devastating side effects. That these two chemotherapy regimens were developed 25 years ago, and little has been done to advance knowledge and treatment of this dreadful disease since then, is unacceptable to us.

So here's what we're doing about it.

On Sunday, May 20th, we will join in the Brain Tumor Society's "Ride for Research" under the **TEAM JAKE** banner. Every dollar raised by **TEAM JAKEe** in this bike race will go towards supporting pediatric brain tumor research which we hope will help Jake and the thousands of other kids who, like him, are afflicted with this potentially deadly disease.

Please consider participating:

- 1 **Join the ride.** There will be 10, 25 and 50-mile routes through historic and scenic Concord and Lexington that are perfect for road warriors and families alike. Those who ride with us must commit to raising \$300 dollars – of course we're thrilled if you can raise even more! To register go to www.braintumorsociety.org and click on the Ride for Research icon. Make sure you register to ride for **TEAM JAKE**.
- 2 **Sign up to virtual ride.** If you want to help spread the word, but won't be able to physically ride on May 20th, you can sign up as a virtual rider. Jake gets a thrill every day when he checks the website to see if there are any new riders joining his team. There is no minimum fundraising commitment. Last year, virtual riders raised more than \$100,000!
- 3 **Donate outright.** If riding is not your thing, we hope you would consider making a donation to Jake or one of the other riders on **TEAM JAKE**. To donate online, go to www.braintumorsociety.org and click on the Ride for Research icon. Click on "donate" and then "Find a participant to sponsor." Please enter Jake Gainey or any **TEAM JAKE** rider. There is also a direct link on www.teamjake.org. If you prefer to write a check, please make it payable to The Brain Tumor Society/Team Jake and mail it to the address on the front of this letter.
- 4 **Ask your employer about matching gifts.** Many employers will match employee donations to a nonprofit. This doubles the impact you can have.
- 5 **Spread the word.** If you know other people that would like to be on **TEAM JAKE** as a rider or virtual rider, please share this information with them and ask them to ride for **TEAM JAKE**. Or please just help spread the word. Our website has a letter you can use to tell other people you support **TEAM JAKE**.

Please also visit our website www.teamjake.org where you will find a form letter for your fundraising effort if you are riding or virtual riding and another if you aren't riding but want to let others know you're committed to helping us. If you have any questions, please email us at c.gainey@cox.net or call 860-659-4424.

How donations will be used:

We have joined with three other families, whose kids are fighting to survive this diagnosis. **TEAM JAKE** is riding alongside Team TJ, Team Samantha and Team Lucy to raise dedicated funds for pediatric brain tumor research. Over the past two years, our families have championed our kids and led the push for more pediatric brain tumor research. Our coalition of families has raised money to fund the following:

- 5 Pledged \$2 million dollars to create the **first and only** Pediatric Low Grade Astrocytoma Program at the Dana Farber Cancer Institute.
- 6 Funded a joint genomics/proteomics project of low grade astrocytomas at Washington University and Children's National Medical center in Washington D.C.
- 7 Funded a \$100,000 grant to conduct a immunohistochemical analysis of low-grade astrocytomas which has helped validate three drugable protein targets.
- 8 Initiated, with the Brain Tumor Society, a national "request for proposals" process, the result of which will allow funding of outstanding peer-reviewed pediatric low grade astrocytoma research projects.

This research and advocacy is a start and much more needs to be done if we are to have any impact that will help Jake and kids like him in their lifetimes. It will also prove instructive in understanding adult brain tumors as well. That's why we're riding. It's simple. If we can direct dollars for research, we'll get new, better, kinder treatments for Jake and other kids.

We know there are many worthy causes seeking your attention and support. Needless to say, this has become very important to us and we are driven by a vision of a grown-up, healthy Jake doing his own part to change the world for the better. Please join us. We appreciate whatever you can do.

With our warmest regards and gratitude,

Charise and Ken Gainey