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PEDIATRICS

Parents Are an Inspiration to Us All - Turning Grief into Action

BY MARY CAMPBELL

What could be worse than suffering the loss of a child? I find myself contemplating that unthinkable scenario all too often. As executive director for the Brain Tumor Foundation for Children (BTFC) for six years, I have known far too many parents who have suffered such a loss. But I still cannot imagine how extremely difficult it must be. As the mother of four healthy children, it is incomprehensible to me and too painful to even imagine.

I am, therefore, continually inspired by parents who turn their grief into action to help others.

My most recent inspiration comes in the form of Treza and Eddie Johnson of Alpharetta, Georgia. In July of 2003 their beautiful 3-year-old son Kendall was stricken with a diffuse intrinsic pontine glioma. Tragically, there is little hope for children with this tumor that invades the brain stem, or lowermost portion of the brain. Kendall succumbed to the disease just nine months following his diagnosis, during which time he endured



The Johnson family

chemotherapy treatments to extend his life and allow his parents precious time with their son.

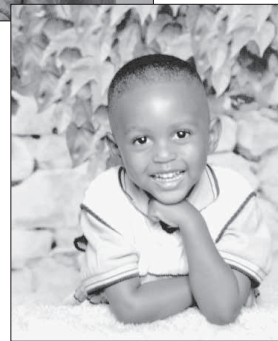
I first met Treza and Eddie at Children's Healthcare of Atlanta on a "brain tumor clinic" day soon after Kendall's diagnosis. Visiting with families on clinic days is one of the services provided by BTFC. I was immediately impressed with their strong faith and prayed that it would help them through the difficult road ahead, which it did. Following Kendall's death, Treza contacted me and said she and Eddie wanted to get involved to help other families who were traveling this difficult journey.

I asked Kay Weaver, a board member who had also recently lost her son - Gregory at age 17 - to join Treza and me for lunch. Certainly only a parent who had lost a child could understand. Treza, who was expecting a child in just a few months, was eager to get started doing something to make a difference. I wondered how this young woman, with a brand new baby on the way and a full-

time job, was going to find the time. The two moms hit it off and Treza helped with an event to benefit our Butterfly Fund, which provides emergency financial assistance for families struggling to make ends meet while caring for their child. The Johnsons and the Weavers had a special place in their hearts for the families who must deal with overwhelming financial burdens when their children were sick.

In September, 2004, Kennedy Johnson was born, providing her parents with a new source of joy. The Johnsons continued to help at the

Foundation whenever possible and a year later, Treza called to tell me she was expecting, this time with twin boys! She excitedly related to me the story of how shortly before Kendall's death, when she was pregnant with Kennedy, Kendall told his mom and dad he wanted her to have two babies - two boy babies, before finally saying he wanted a girl baby. Imagine the feelings of Treza



Kendall Johnson

and Eddie to know that Kendall's wish was coming true! Cameron and Christian were born in January, 2006 to the delight of their parents and big sister Kennedy.

Now there surely will be no time for this busy couple to be involved, I thought. But Eddie enthusiastically joined our Board of Directors in 2006, jumping right in to help with an upcoming fundraiser.

With three small children and still employed full-time, Treza was not satisfied to have Eddie doing all the work. So on May 19th, she pulled off the inaugural "A Taste of Hope" fundraiser for BTFC in the couple's neighborhood. This event, which included samplings of cuisine donated by more than 15 local restaurants, was a celebration of Kendall's life and a way for neighbors and friends to help.

I would like to salute Treza and Eddie and the many other parents I know who, despite the pain of an unfathomable loss, and despite a hectic schedule, do what is necessary to make things better for another child and another family. You are to be commended.

Mary Campbell is Executive Director of The Brain Tumor Foundation for Children, Inc.

The Brain Tumor Foundation for Children has provided information, social and emotional support, financial assistance, and much more for children with brain and spinal cord tumors and their families since 1983. To learn more call (404) 252-4107 or visit www.braintumorkids.org.



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