



Insight



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Children With Brain Tumors Don't March

By Drs. Michael A. Glueck & Robert J. Cihak

<http://www.JewishWorldReview.com> | I am a diagnostic radiologist. I am a physician whose role as a specialist is that of the doctor's doctor. And contrary to what some may think of doctors, I am a living, breathing, cardiac-beating and crimson-bleeding human being.



In the past two weeks I have learned of serious illness involving the child and grandchild of two of my closest friends, unnervingly both diagnostic radiologists. One is a writer. The other a distinguished professor who played a significant part in the training of both my writer friend and myself.

Both of these children have benign brain tumors diagnosed in radiology.

My radiological peers, with the assistance of science, technology, X-rays, electrons, protons, gamma rays, magnetism, supercomputers and a myriad of scanners, can look virtually anywhere. Are these experts who in addition often super-specialize in one of a couple dozen subspecialties of radiology really all-knowing? Does their knowledge make them immune, impervious and impenetrable to disease? Are they better able to deal with the treachery, tricks and turmoil of Mother Nature? Are they and their children exempt from the despair of disease?

A few say yes because their familiarity with the inner workings of the complex system makes it easier to cope. They know who to call and what to expect.

But most say no, as their knowledge only makes them aware of what comes next and the many things that can go wrong. Comments one physician, "No matter how much you know, the heaviness in the heart and chest remains."

Notes the Brain Surgery Information Center's Web site: "The world of childhood brain tumors has no welcome sign leading into it. No matter what anyone says to minimize the situation, this statement is one of the most painful sentences a human can hear. The combination of fear, shock, and pain is much to bear."

Each year over 185,000 people in the United States will be diagnosed with a primary or metastatic brain tumor. Brain tumors are the leading cause of cancer death in children under age 20, now surpassing acute lymphoblastic leukemia. In the United States the overall incidence of primary brain tumors is more than 11 per 100,000 people. Children have roughly half of these tumors. It is also shocking to learn that approximately 21 percent of children's brain tumors are considered "benign."

Brain tumors in children are different from those in adults and are often treated differently. In addition, due to either the effects of the tumor or the treatment required to control it, survivors of childhood brain tumors often have severe neurologic, neurocognitive and psychosocial conditions.

Benign brain tumors, those that don't metastasize, harm by mass affect (pressure within a rigid bony skull), interference with normal function, and partial obstruction or complete blockage of cerebrospinal fluid flow.

Pediatric brain tumors most frequently come from "young" cells. These are cells that are still developing ("immature" or "primitive" cells) and have not reached full maturity. For every normal brain cell type, there is a corresponding tumor that can arise from it.

There are other tumors that come from non-brain origins, such as teratomas, meningiomas, skull bone tumors, and blood vessel tumors.

Children also have unusual tumors of the developing brainstem, hypothalamus and optic nerves (juvenile pilocytic astrocytomas and teratomas).

One of the children mentioned above has a meningioma. The other has a juvenile pilocytic astrocytoma.

Samantha, age 4 (3 at diagnosis), with reddish-brown hair and dark brown eyes, now weighs 32 pounds. She is the grandchild with the juvenile pilocytic astrocytoma. Samantha's bottom line is that an estimated 70 percent of patients with this diagnosis will survive 10 years, with many potential quality-of-life issues among those survivors.

There are now an estimated 267,000 people with "benign" brain tumors, which translates to 267,000 heartbroken families. So why is there so little research support and media coverage for these tumors? For economic and other reasons these are not today's politically correct diseases.

Unlike patients with breast, ovarian and prostate cancer or AIDS, little children with benign brain tumors are unable to rally, march, demonstrate, swing large posters or lobby Congress. There are no 3-year-old high-profile celebrities with the disease. For reasons of politics and sex, little kids get the short end of the stick.

People need to understand why research for children's benign brain tumors is so under-funded and how the suffering and effects of treatment for a benign tumor may be just as great for the child and the family as for a malignant tumor.

And perhaps we should coin a new term, "orphan diagnosis," for an illness or disease that is not currently in vogue

and therefore does not get the research funding or respect it deserves.

Samantha's grandmother notes, "We are riding 15 of the 25 miles and then volunteering in the Brain Tumor Society's 'National Ride for Research' Bike Ride on May 15." They hope that you can join them personally or spiritually in this journey for their children and yours.

The Brain Tumor Society is a national advocacy organization for brain tumors. Its Web site is www.tbts.org and its phone number is 800-770-8287.

So in sum, does being a physician make it easier to deal with a bad diagnosis in our own families or those of friends? Probably not but it should help us empathize and sympathize with patients and families and thus make us better doctors.

Editor's Note: This week's commentary is written by Michael Arnold Glueck, M.D.