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Check Out Our Website!

<http://www.childhoodbraintumor.org>

THE EPIDEMIOLOGY OF BRAIN TUMORS IN CHILDREN PART 1: Descriptive Epidemiology

Melissa Singer, M.D. &
Julianne Byrne, Ph.D.

Among the childhood malignancies, central nervous system tumors are the most common solid tumor and the second most common malignancy, after leukemia, and represent 20% of all childhood cancers (Figure 1). Central nervous system, or CNS, tumors refer to neoplasms that originate in the brain and spinal cord, with over 90% located in the brain. Approximately one in every 30,000 to 40,000 U.S. children will get a brain tumor. Current treatments include surgery, radiation and chemotherapy. Improving survival in pediatric brain tumors continues to be a challenge. Between 1985-1994, 67% of children with malignant brain tumors survived five years or more from diagnosis (Gurney, 2001). This compares favorably to 59% five-year survival between 1975-1984, and not so favorably to 75% five-year survival between 1983-1990 for children with acute lymphoblastic leukemia (National Cancer Institute, 1996).

CNS tumors are heterogeneous in regards to histology and clinical course and are therefore difficult to classify. Malignancies are grouped according to the International Classification of Childhood Cancer (ICCC) system in broad histological categories. From 1975-1995 astrocytomas accounted for 52% of CNS malignancies, PNET (primitive neuroectodermal tumor

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Ten Years Later: "Wheel of Fortune"

Hello,

For all of you who do not know me, my name is Michael Schoenfeld and I am twenty-one-years old and an eleven-year cancer survivor. I was diagnosed in 1990 with a medulloblastoma in the cerebellum of my brain. I received radiation and chemotherapy and finished my last chemotherapy in 1993. I have been cancer-free for 11 years (knock on wood) and am currently attending the University of Maryland, College Park where I am studying Government and Politics.

My father, Stephen Schoenfeld, one of the directors of the CBTF, asked me to write an article to reflect on what my life has been like ten years after cancer. At first, I did not want to write an article about myself, I felt like it would be conceited, but then I thought quite the contrary. That is, it would benefit everyone (parents, patients, families and friends) to hear what life can be like ten years down the road.

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Michael at age 11.

Epidemiology (continued from page 1)

including medulloblastomas) 21%, gliomas 15%, ependymomas 9% and other CNS tumors 3% (Figure 2). In this article, we are considering primary (originating in the CNS) and malignant brain tumors only.

Unfortunately, the incidence of malignant pediatric brain tumors is on the rise with a 25% increase in brain cancer incidence from 1973-1991 among children aged 0-15 (National Cancer Institute, 1996). However, during the same time interval mortality declined by 8%. Various factors have been investigated to account for this increase in incidence. Among them have been: 1) improvements in diagnostic techniques, and 2) environmental exposures, such as food preservatives and electromagnetic fields. These topics are the subjects of much research and investigation, but firm results have been inconclusive.

Changes in Incidence

Every year, about 2,200 US children aged less than 20 years are diagnosed with a malignant brain tumor (Gurney, 2001). The overall annual incidence in the United States of pediatric malignant CNS tumors is about 28 per million children younger than 14 years of age (Bunin, 2000).

a. Differences by age: The overall incidence of CNS tumors is highest in children younger than 8 years of age. This difference is largely attributable to cerebellar PNETs (medulloblastomas), brain stem gliomas and ependymomas that occur almost exclusively in children less than 10-years-old. According to SEER data, the average annual incidence of CNS cancer between 1986 to 1994 varied only slightly by age of diagnosis from infancy through age 7 years (36 per million). For all CNS tumors from age 7 to 10 years, a 40% drop in the incidence rate was observed, with a slight increase from ages 10 to 12, and a second decline from age 12 to 20 (Figure 3). For all ages, the incidence of astrocytomas was highest, peaking at age 5 and 13 years (20 per million). For ages 0-3 years, PNET and ependymoma rates were highest (11 and 7 per million respectively) and then steadily declined. Gliomas had the lowest incidence during infancy with peaks at ages 8 and 17 (9 and 7 per million). Overall ependymoma was the rarest type of brain tumor in children ages 3 to 20 years (Gurney, 2001).

b. Differences by sex: The overall incidence of invasive CNS tumors between 1990-95 for children ages 0-20 was 24% higher in males than females, with rates of 30 and 24 per million respectively. PNETs showed the largest difference between males and females, followed by ependymomas. There were more males than females with CNS tumors for both white and black children, with a greater difference between boys and girls seen among white children (Gurney, 2001).

c. Differences by race: CNS tumors are more common in white children compared to black children, with an 18% higher rate between 1900-95. The greatest difference was seen in white males at a 26% higher rate, compared to an 8% higher rate for white females (Gurney, 2001).

Changes over time

Pediatric CNS cancer incidence is increasing at an estimated rate of 1.5 % a year. There is a considerable debate as

to possible etiologies. Improvements in diagnostic technology may be responsible. The question arises: Is increasing incidence a true rise in new cases or is it an artifact of improved detection by computed tomography (CT) and magnetic resonance imaging (MRI)? In addition, changes in neurosurgical practices, such as stereotactic biopsies, might have contributed to better identification and reporting of pediatric brain tumors as well.

Between 1984 and 1985, the incidence of CNS malignancies jumped from 24 to 30 per million and then remained steady (Gurney, 2001). The timing of this increase coincides with the introduction of MRI in the United States in 1986. This jump could therefore be due to improved imaging modalities that became widely available in the mid-1980s. This observed jump has been seen only for CNS tumors compared to other malignancies during this time, and occurred over a short period. If environmental causes were responsible, a linear increase in incidence would be expected. Although the increase in incidence may be due to improvements in technology and detection, environmental exposures are still a major concern including N-nitroso compounds, food preservatives, and electromagnetic radiation. Future studies will be done to evaluate possible role of different exposures in the etiology of pediatric brain tumors.

Survival after CNS tumors

Although children with malignant CNS tumors do not have as favorable a prognosis as do children with other cancers, five-year relative survival rates increased from 59% between 1975-84 to 67% between 1985-94. During these time periods, the greatest increase in survival by age was seen in ages 15-19 by 15% (from 62-77%) with only a 2% increase in ages 0-5 (from 54-56%). Males had a greater increase in survival of 9% compared to 2% for females. White and black children had similar increase in survival of 6% and 5% respectively. These increases were seen in all tumor types with the greatest improvement in ependymomas (39% to 56%) followed by gliomas (46% to 57%) (Gurney, 2001).

Survivors of pediatric brain tumors may have significant long-term morbidity from their disease and treatment. Fortunately, survival rates for childhood CNS tumors continue to be on the rise as improvements in therapy are being pursued to improve patient survival.

Risk Factors

Like most pediatric cancers, no specific risk factor explains more than a small proportion of childhood brain tumors. The known risk factors for childhood brain tumors include ionizing radiation and certain genetic conditions. Therapeutic doses of ionizing radiation to the head increase the risk of brain tumors in children (Bunin, 2000). Some hereditary conditions clearly predispose to CNS cancer in children. These include neurofibromatosis type 1, nevoid basal cell carcinoma syndrome, tuberous sclerosis, Turcot syndrome and Li-Fraumeni syndrome (Bunin, 2000). These diseases are rare and not all children with these conditions will

(continued on page 4)

Ten Years Later (continued from page 1)

I have to say that my tenth anniversary did not start off with a BANG, but a BLOW to me and all of those around me. Although the worst part of surviving cancer is over, there are still things that must be done in order to ensure a healthy lifestyle down the road. For me, one of these things is a yearly MRI. I must tell you that I still have a scan done as well as yearly visits to the neuro-oncology clinic at Children's Hospital. Yes, I am probably one of their oldest patients and chuckle when I am asked if I have ever been stuck with a needle or had an MRI. But I feel very comfortable. The quality of care is second to none and no other doctors will ever be able to understand my condition better than they do.

During my yearly MRI in July of 2000, the scan revealed a small, non-malignant tumor at the frontal lobe of my brain. According to the doctors, the tumor was a side effect from the radiation treatment I received. It was a small meningioma, which can "pop up" after radiation treatment. Luckily, only one appeared at the surface of the brain. So a week later, I found myself in the same hospital, having surgery where I was ten years before. I was able to appreciate the advancements in research and technology, for I had my surgery on a Friday, and the next day was sent home with only adhesive tape and stitches in my head (also I had trouble wrinkling my forehead for a couple of days). After a weeks rest, I returned to the normalcy of life, went back to my summer job and eventually started school in the fall. (Honestly, I liked being pampered at home!)

The "college life" is great except for all the work you have to do. Well, the next big event in the tenth year of survivorship came in October when, after two auditions, I was selected to be one of the representatives of the *Wheel of Fortune's* "College Week" in Washington, DC. I was very fortunate (pun intended) to have such an experience and I did not take a minute of it for granted. Not only did I get to meet Pat Sajak and Vanna White, I was the Grand-Prize winner for the show. I won \$7,500 and a Toyota MR2 Spyder. Although I could personally pick out the color of the car, I left



Michael with his beautiful new red Toyota Spyder; winnings from being a contestant on the Wheel of Fortune.

that duty to my father because I was spending the Spring Semester in Spain where I lived "La Vida Loca" and had one of the most enriching experiences of my life. If you ever get to travel our of the country, go to Spain, it is full of so much history, culture, wonderful architecture and food (I can say that I ate my way through Spain.) Now I am paying the consequences and go to the gym almost every day.

Coming back from Spain and ending my somewhat roller coaster ten year anniversary, I still have much to look forward to. In August, I was the Co-Best Man at my brother's wedding. Then in October, I will share in the festivities at my cousin's wedding.

I am not here to write about myself for the sake of boasting or egotism. I am writing this article to inform you, the reader, of what life can hold in the future after treatment.

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United Through Support

All of us in the brain tumor community reach out in sympathy to the victims of the tragic events in New York City , Pennsylvania, and Washington, DC on September 11.

As anyone affected by a brain tumor knows, individual persistence, determination, and faith provide a firm base when a crisis strikes but it's the support and love of family and friends that helps us get through the day-to-day process of recuperating from tragedy.

We wish the best to all of those affected by these events as they move from the darkness of September 11 into the light of the future.

BIG DOG COMMEMORATIVE TEE SHIRT TO AID IN THE RELIEF EFFORT

In united support Big Dogs has designed a commemorative tee shirt to benefit the relief efforts including the American Red Cross, NY Firefighter's Fund and many others. Big Dog will donate \$5 from each tee shirt sale to the charities directly involved with the relief effort including the American Red Cross and the NY Firefighters Fund, among others. Go to the CBTF website: <http://www.childhoodbrain.tumor.org> for the Big Dog link to order or go directly to their website: <http://www.bigdogs.com>.

Epidemiology (continued from pg. 2)

get brain tumors.

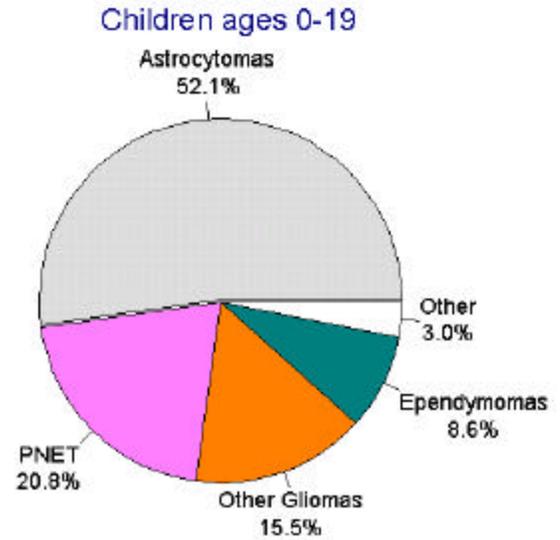
A number of other potential risk factors are linked to CNS tumors from which the evidence is less conclusive. These include family history, N-nitroso compounds, consumption of cured meat, nutritional habits during pregnancy, pesticides, and of more current interest, electromagnetic fields. These will be discussed further in the second part of this two-part series, which will deal with the risk factors for childhood brains tumors.

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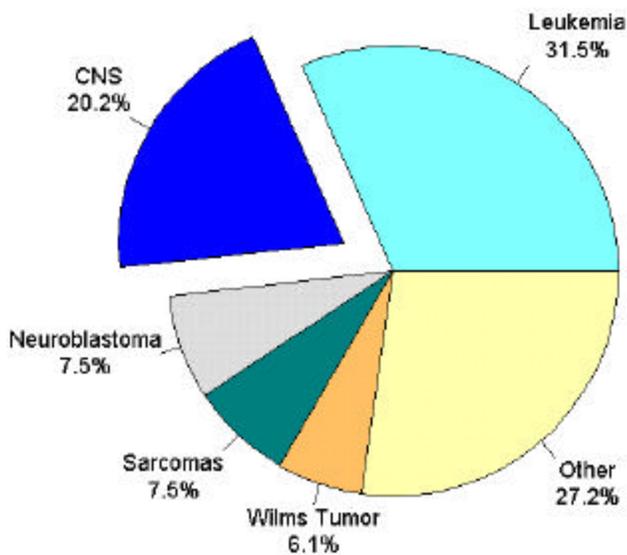
Dr. Melissa Singer is a Fellow in the Department of Pediatric Hematology/Oncology at the Children's National Medical Center, Washington, DC. Dr. Julianne Byrne is a Research Professor in Pediatrics at the Children's National Medical Center, Washington, DC.

Figure 2. Malignant CNS Tumors of Childhood



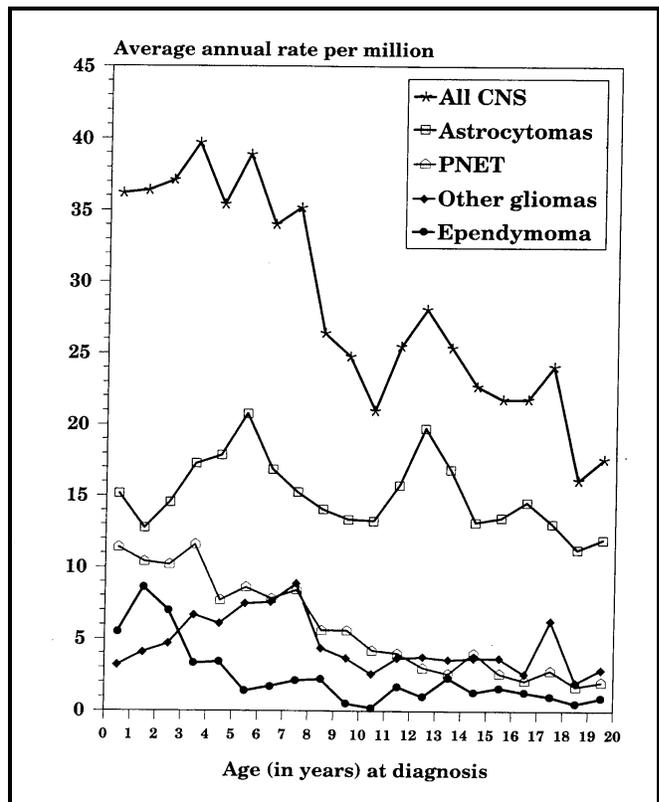
from SEER Pediatric Monograph, 1975-1995, Bethesda, 1998

Figure 1. Childhood cancer by type
Children ages 0-14



from American Cancer Society "Facts and Figures, 2001"

Figure 3. (below).
Malignant CNS Tumor Age-specific Incidence Rates Children ages 0-19



CBTF's Family Retreat Day Fall 2001

The Childhood Brain Tumor Foundation held Family Retreat Day in Laytonsville, MD on October 7, 2001. A total of 72 people attended including the volunteers. It was a beautiful day and the CBTF would like to thank Bev Gough for providing the food and show. Thank you to our marvelous speakers. The families were truly appreciative and learned a great deal. We would like to thank all volunteers for helping throughout the day.

We started the program with a great lunch and chatting together and getting to know each other. The children went off to their special program with entertainer, Jim Hossick and the parents went to Session 1.

Session 1 was lead by Dr. Constantine Stratakis, Head of Unit of Genetics and Endocrinology, Developmental Endocrinology Branch, National Institutes of Health. The session was entitled "Endocrine Issues for Pediatric Brain Tumor Patients". The topics addressed were growth of a child with a brain tumor after treatment, growth hormone and tumor development, puberty of a child with a brain tumor after treatment, and other endocrine dysfunctions: adrenal and thyroid insufficiencies. Concurrently, Stacey Springer, LCSW-Clinical, Johns Hopkins Medical Center, facilitated a session entitled "Time to Heal" for bereaved families.

Session 2, facilitated by Yvonne Bush, LCSW-Clinical, Georgetown University Medical Center. The session was entitled "The Stress Test" and dealt with understanding stress and what to do about it. Everyone placed themselves on the road map of stress that Yvonne had created. Then Yvonne moderated a discussion about the various stressful issues.

In Session 3 Judy Greenberg, M.S., OTR, Ivymount School, Coordinator for the Center for Outreach in Education and her speaking partner Amy Freedman, language pathologist, were in charge of the session, which was called "Dealing with Treatment Side Effects for Patients". These strategies are helpful for individuals experiencing trouble following directions, distraction, memory, sequencing, visual issues, speech and language issues, and sensory and motor issues. A question-and-answer period was included and everyone learned some helpful tips.

The children and volunteers were busy all afternoon with activities including musical entertainment, putt-putt golf, arts and crafts, and playground. The day closed with children choosing a special gift to take home.

§



Dr. Stratakis during the question and answer session.



Judi Greenberg and Amy Freedman



Jim Hossick entertaining the volunteers and children.

Celebrating 50 Years of Brain Research New Discoveries, New Hope

The National Institute's of Health, The National Institute of Mental Health and The National Institute of Neurological Disorders and Stroke held an excellent symposium for their 50th anniversary of brain research on October 9-10, 2001. Session 1 on October 9 was titled, The Communicating Brain and some individual topics were: Ion Channels Make Electrical Signals in the Brain; Neural Messengers; Mood Disorders; and New Drug Development. Session 2 was the Changing Brain and some topics were: Genes and the Brain; Neurogenesis; Form from Function in Brain Wiring in Development; Brain Plasticity Contributing to Variations in Human Performance Ability; and My View with guest speaker Christopher Reeve. Mr. Reeve's powerful speech stressed the great need for more research. The physicians provided detailed information on their subjects and discussed opportunities in research for the future for a variety of brain disorders. During the session on Brain Plasticity Dr. Michael Merzenich from the University of California clearly explained that the brain is built for change and that it processing and performance are continuous throughout our life spans.

On October 10 Session 3 was titled The Vulnerable Brain. Some sessions were: Treating CNS Injury; Panel of Nobel Laureates – Paul Greengard, Ph..D; Eric Kandel, M.D., Stanley B. Prusiner, M.D., and Torsten Wiesel, M. D. Session 5, the final session included a great deal about mental health, such as, Memory; Emotion, Developing Minds/Developing Brains; How the Brain pays Attention; and Cognition and Emotion—The Frontier of Health.

The comprehensive symposium assured all attendees that research continues to move forward with great strides with the genome project offering a standout example of how much hope the future holds.

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Run With the Saints In Memory of Lauren Lockard

On Saturday, November 3, 2001 John Paul II Catholic School in Houston, Texas will hold their annual "Run With the Saints Fun Run" an event in memory of Lauren. Lauren lost her battle to brain cancer in 1999. Please check our website for more details. We will be sure to report on this fun-filled event in a future newsletter.

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A large crowd at the start of the November 2000 race for Run With the Saints. Participants look forward to the 2001 event.



Medulloblastoma & PNET E-mail Discussion Support Group

The medulloblastoma and PNET E-mail Group is an e-mail based support group for those dealing with medulloblastoma/PNET tumors—parents, other family members, friends, and patients themselves. The group consists of approximately 300 members.

The group is primarily for support but offers the following opportunities:

1. Exchange of information and experiences.
2. Get answers to questions from the professionals on the list.
3. Double-check what our doctors are saying and prescribing.
4. Discuss treatments, new and old.

This group is an invaluable resource for those who are dealing with medulloblastoma/PNET. At times patients and family members often feel isolated, as if they are dealing with this alone, unable to find others in the same situation.

There are two ways to join:

- Send a blank e-mail: medulloblastoma-subscribe@groups.com
- Alternatively, visit the subscription URL at : <http://www.egroups.com/subscribe/medulloblastoma>

Other Online Support

Cerebellar Mutism:

<http://www.egroups.com/group/cerebellarmutism>

EpendyParents

ependyparents@braintrust.org

Medulloblastoma tumor list

Medulloblastoma-subscribe@onelist.com

Send an e-mail with no message in the subject or body..

§

Gene Expression Analysis of Medulloblastoma

The Childhood Brain Tumor Foundation is proud to announce year 2001 funding of a promising research study entitled, “*Gene Expression Analysis of Medulloblastoma*” submitted by Dr. Tobey J. MacDonald of Children’s National Medical Center. The initial results of this study have been published in the October issue of one of the leading scientific journals, *Nature Genetics*. In addition, this promising new research has recently received some media attention from local as well as national television news stations.

Dr. MacDonald hypothesized that since the histologic features (microscopic appearance) of medulloblastoma have thus far failed to provide an accurate predication of the clinical biological behavior of medulloblastoma in children, examining the specific genetic events that have a role in the biological behavior of medulloblastoma may provide a clearer understanding of this tumor. Using a new genetic screening approach, Dr. MacDonald was able to identify a set of genes that appear to control the spread of medulloblastoma that may also serve as new therapeutic targets in this disease. The purpose of his future project is to expand the gene expression analysis in medulloblastoma in order to further characterize and identify additional novel therapeutic targets. This will be achieved by molecular analysis utilizing expanded oligonucleotide arrays (Affymetrix “gene chips”) that can screen approximately 10,000 human genes simultaneously. He also plans to obtain preliminary data regarding the outcome of molecular subtypes of medulloblastoma by using the time to disease progression and overall event-free survival as endpoint measurements in cohorts of identically treated patients..

We thank all of our supporters who have helped make it possible for us to fund this study, previous studies, and other projects that are of great importance to the pediatric brain tumor community.



Recently, The Childhood Brain Tumor Foundation funded a special educational project entitled, “Proposal to benefit the pediatric brain tumor patients/families of Inova Fairfax” by James T. Cooney, Educational Services Coordinator. In a later issue we will include a story about the benefits the patients have received from this project.

We are also excited to announce our continuing support for the Childhood Ombudsman Program that offers services to families on a national level. If you are dealing with educational, insurance or employment issues, please contact CBTF for contact information and we will put you in touch with one of the Ombudsmen.



In Memory of
Ian Lennon Hahn

January 5, 1987 - August 3, 2001

With Love from
His Family

I give you this one thought to keep,
I am with you still - I do not sleep.
I am a thousand winds that blow,
I am the diamond glints on snow,
I am the sunlight on ripened grain,
I am the gentle autumn rain.

When you awaken in the morning's blush,

I am swift, uplifting rush,
Of quiet birds in circled flight.
I am soft stars that shine at night.
Do not think of me as gone -
I am with you still- in each new dawn.

Anonymous

CBTF extends its sincerest sympathy to the Hahn family. We will miss Ian, he was a remarkable young man. Thank you to the Hahn family for always being so supportive of CBTF and what we strive to achieve.

Remembrances

- | | |
|-------------------------|---------------------|
| Stephen Boyce | Rebecca Lilly |
| Charles Bradfield | Lauren Lockard |
| Jeff Brown | Margie Kane |
| Kelley Bula | Emily Mau |
| Charles Byrum | Charita Miles |
| Catherine Cason | Hannah Miller |
| Ryan Caspar | Thomas Murray |
| Laira Caverly | Herschel Parham |
| Edward Chimilewski | Grace Powers |
| Ryan Crozier | Nicole Ringes |
| Shawn Edwards | Daniel Roever |
| Michael Weidong Fan | Andrew Rypien |
| Barbara Waxman-Fiduccia | Lynda Santelli |
| Daniel Fiduccia | Amy Schiller |
| Ian Lennon Hahn | Luke Shahateet |
| Katie Harris | Courtney Shelby |
| Erica Holm | Phil Shepsle |
| Ryder Howie | Lisa Soghomonian |
| Talbert Hughes | Teresa Stargel |
| Ben Jacobson | Symphony Ann Taylor |
| Kristi Johnson | Jaime Vanderheyden |
| Frances Lewis | Josie Wynn |
| Wesley Lewis, II | |
| Wesley Lewis, Jr. | |

Baby Jay's Journey

August 20, 1999 – April 7, 2000
As witnessed by his Nana

Here I sit just daydreaming
Of your sweet little face
When Mommy and Daddy peeked
Into your little space.

This precious child touched our lives
As gently as a summer breeze
He didn't ask for anything
Just a chance to love and please.

A brave little soldier
Gentleness beyond his years
So many smiles and coos
So very few tears

Each day he brought sunshine
To every life he touched
He captured all our hearts
Oh we loved him, so very much.

Such love I've never witnessed
Such compassion forever shown
The bonding of a family
Trying to bring their baby home.

Most days he was so happy
Full of sparkle and fun
But his days were to be shortened
When all was said and done.

He slipped into Heaven
A band of Angels by his side
In the warmth of his parents arms
The light of Heaven as his guide.

And so with trust and broken hearts
Placed him in our heavenly Father's arms above
Impatiently waiting to hold him again

Sending each day, our eternal love.
Until then sweet boy, precious son,
little prince...until then
You are dearly missed.

In the near future we will include the full length version of this poem on our website.



In Memory of
Michael Weidong Fan
With Love
from
His Parents

Baby Jay
with sister
Emma.



Our mission is to support and fund basic science and clinical research for childhood brain tumors. We are dedicated to heightening public awareness of this devastating disease and improving the quality of life for those that it affects.



UPCOMING EVENTS

SAVE THE DATE: Saturday, April 20, 2002, Casino Party Benefit to be held at the Barns at Wolftrap. Detailed flyers about this action-packed, exciting event will be available shortly. If you know someone who would like to be a corporate sponsor for this event or are interested in more information, please call CBTF: 301-515-2900

Sunday, April 28, 2002, The Dan Fiduccia Spring Biathlon to be held at Maderia School, McLean, VA. We welcome corporate challenges for the event. For information about this event call Gib Smith 703 - 849-1980

WORKPLACE GIVING

Thank you to those who choose us as their charity!

CBTF is in the

- *Combined Federal Campaign,
- *Children's Charities of America (National),
- *United Way

Most Campaign Donations can be made for the United Way through the "donor option" or "donor choice." Please check with your employer in reference to United Way campaigns.

Please put CBTF's designated number **2742** on your pledge card.



Gift Matching Opportunities

Many companies offer a matching gifts program to support charitable organizations. Your human resources department can tell you if such a program exists in your organization. Generally, they have a form that would be sent regarding a contribution that has been made stating they will match the contribution. We would return the form to the employer with the proper acknowledgement and information required.

**Thank you to our webmaster
Tim Ratliff for maintaining our website.**

<http://www.childhoodbraintumor.org>
E-mail:
cbtf@childhoodbraintumor.org

Life isn't a matter of milestones,
but of moments.
Rose Kennedy

Editor: Jeanne Young
Contributing Editors: Colleen Snyder, Elizabeth Irvin
Contributing Writers: Julianne Byrne, Ph.D., Michael Schoenfeld, Melissa Singer, M.D., Keith Irvin, Gib Smith
Graphic Design and Production: Samar Caverly, Elizabeth Schroth, Jeanne Young

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In Honor of: _____

On the occasion of: _____

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Optional Phone: _____

Please make checks payable to:

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Card# _____ exp. ____/____

Note: Minimum charge donation is \$20

Name: _____

Address: _____

City/State/Zip: _____

Optional Phone: _____