



The Childhood Brain Tumor Foundation

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Neurotransmitter

Communicating our message.
Spring 2006

[Http://www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

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Survivors of Childhood Brain Tumors: the Potential for Late Effects

Sara Bottonley, RN, MSN, CPNP

The survival rate of patients with childhood brain tumors continues to improve. However, survivors are at risk for a variety of physical, medical, cognitive, and/or psychosocial late effects. These late effects may be directly related to the type, location and extent of the brain tumor itself or a result of treatment, which may include surgery, chemotherapy and/or radiation therapy. Age at diagnosis may also play an important role in a child's overall outcome, with infants and young children having a higher risk of long term treatment-related side effects. Finally, a very small number of children are at a higher risk of treatment related late effects because of rare inherited conditions that predispose normal tissues to severe side effects, particularly after radiation therapy.

To assess your risk for late effects it is important that you know what therapy you received. If you are followed in a survivor program through the cancer center where you were treated for your brain tumor, you may have already received this information. However, if you don't have this information you may request it. If you are not followed regularly, you may contact the cancer center where you were treated and request a treatment summary or a release of information form to obtain the medical records about your treatment.

Some of the more common late effects that may occur following treatment for a brain tumor are summarized below. It is very important to keep in mind that you may experience none, one, or several of these problems in the months or years after your treatment ends.

Educational: Learning disabilities, which may be range from subtle to profound, may occur after treatment with radiation to the brain or whole body. Surgery, especially for tumors located in the part of the brain known as the cerebral hemisphere, may also be associated with learning disabilities.

Additional risk factors: Younger age at the time of treatment or female gender.

Recommended evaluation: Neurocognitive testing (testing to evaluate intellectual ability, visual-

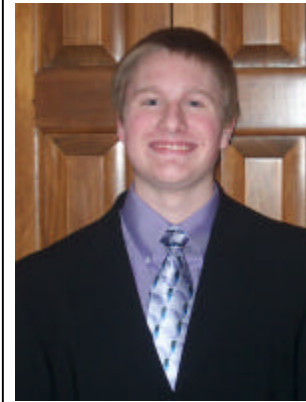
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motor and motor skills, language, memory and learning, academic achievement, behavior and social functioning) by a pediatric neuro-psychologist familiar with the late effects of childhood cancer therapy.

Intervention: If weaknesses or deficits are detected, then school programs may need to be developed or modified in order maximize the student's learning potential.

Ryan's Story



It was September 2003, our son Ryan, 13, was playing catch in the backyard with his Dad; Ryan loved to play baseball and had just completed playing with a travel team that summer. Ryan complained of some light double vision which

seemed to come and go, so we made an appointment with the optometrist. The following day the optometrist examined Ryan and asked several questions. The optometrist felt the vision problem was due to a virus as Ryan had been sick the week before and felt he would improve after a week or so, but he suggested a MRI purely as a precaution. He stated that in all his years of practice he had never seen any issues, but wanted to be safe.

(continued on page 3)

(continued on page 2)

Late Effects (*continued from page 1*)

Neuroendocrine (Hormones): Changes in thyroid hormone, growth hormone, reproductive hormones and other hormones, may occur after treatment with radiation to the brain or whole body. These hormonal imbalances or deficiencies may lead to hypothyroidism (low thyroid), hyperthyroidism (high thyroid), growth delay or short stature, delayed or early puberty, osteoporosis (weak bones) or obesity.

Additional risk factors: Higher dose of radiation, younger age at time of treatment, and surgery to the brain, especially near the pituitary gland may increase the risk of development hormonal problems.

Recommended evaluation: Yearly physical exam with measurement of height, weight, assessment of pubertal status, and appropriate blood work for specific concerns.

Intervention: Specific to the problem, may include hormone replacement such as treatment with growth hormone for growth hormone deficiency or thyroid hormone for hypothyroidism.

Reproductive (Fertility): Both male and female fertility may be affected after treatment with radiation to the brain (especially higher doses to the areas of the brain such as the hypothalamus well being. or pituitary gland) and after treatment with some chemotherapy agents such as cyclophosphamide (Cytosan), melphalan (Alkeran), lomustine (CCNU), and cisplatin (Platinol).

Additional risk factors: Children who are undergoing puberty during treatment may be at a higher risk of infertility.

Recommended evaluation: Yearly evaluation with appropriate hormone testing and monitoring of pubertal status. Semen analysis may be recommended in males.

Intervention: Evaluation and treatment by endocrinologist (hormone specialist) as needed.

Hearing: Hearing loss, speech delays and tinnitus (ringing in the ears) most commonly occur after treatment with the chemotherapy agent cisplatin (Platinol). Hearing loss may also occur after radiation to the brain (especially if the beam is directed toward the brainstem or the ear) or after neurosurgery. Hearing loss rarely occurs after treatment with the chemotherapy agent carboplatin (Paraplatin)

Additional risk factors: Age less than 4 years at time of treatment, cisplatin total dose of 360 mg/m² or higher, radiation doses greater than 30 Gy, exposure to antibiotics such as gentamicin or tobramycin.

Recommended evaluation: Audiogram (hearing test) at baseline and periodically throughout treatment for children who will receive chemotherapy with cisplatin or carboplatin. Additional follow-up based on audiology results.

Intervention: Amplification systems (hearing aids).

Emotional & Behavioral: The brain is the control center of emotions and responses. Treatment with radiation to the head and surgery to the brain thus may alter emotional responses.

Additional risk: Location of the tumor, higher doses of radiation, and extent of surgical involvement.

Recommended Evaluation: Evaluation by a mental health professional, social worker, psychologist, psychiatrist or counselor as clinically indicated.

Vision: Visual loss can result from tumors that affect the optic nerves (nerves to the eyes) or after radiation in the area of the optic nerve. Cataracts may occur after treatment with radiation to the brain, spine, and total body.

Additional risk factors: Long term use of dexamethasone or other steroids such as prednisone.

Recommended evaluation: Ophthalmologic (eye) evaluation.

Intervention: Ongoing ophthalmologic follow-up once visual loss or a cataract has been identified. Cataracts may eventually require surgical removal.

Vascular (Blood Vessel): Radiation to the brain can damage blood vessels and decreased blood flow or hemorrhage (bleeding). Stroke is a possible consequence of decrease blood flow to the brain.

Additional risk factors: Radiation to an area of the brain known as the diencephalons. Patients with hereditary conditions such as neurofibromatosis type 1 (NF-1) may be at increased risk of vascular problems following radiation.

Intervention: In some cases a special surgical procedure may be recommended to decrease the risk of a stroke.

Dental: Increased risk of cavities, shortened or thinning roots, missing or small teeth, problems with enamel, and abnormal growth of jaw may occur after treatment with radiation to the brain, head, and total body or after chemotherapy.

Additional risk factors: Younger age at time of treatment, particularly if younger than 5, and higher doses of radiation.

Recommended evaluation: Dental cleaning and evaluation every 6 months.

Intervention: Good oral care and as recommended by a dentist.

For additional information on survivorship issues and guidelines for the screening tests recommended after treatment with specific chemotherapy, radiation therapy and surgery please see the Children's Oncology Group (COG) public website. This web site can be a great guide for both you the survivor and also for your primary health care provider. The web address is: www.survivorshipguidelines.org

There is no upper age limit at which time your physician can say that late effects will no longer occur. It is important to remember that you may experience none, one or several of these problems in the months or years after your treatment ends. Therefore, lifetime follow-up (medical surveillance) with a medical care provider who is familiar with the potential toxicities is highly recommended for your continued health and well being.

Written by Sara Bottonley, RN, MSN, CPNP

Clinical Director of the Long Term Survivor Team at Texas Children's Cancer Center.

Ryan's Story (continued from page 1)

We scheduled an appointment for Ryan's MRI, but we had to change it because Ryan's grandmother passed away that week. Ryan was very close to her. The appointment was rescheduled for a couple of days following the funeral. From there, all of our lives changed dramatically.

We took his films from the local hospital to a neurologist in Fort. Wayne, Indiana. She immediately showed us the film and stated the images were "abnormal". Having never seen a brain scan before, it was obvious even to us that there was a problem as there was a massive "white area" on the scan. She sent us immediately to the emergency room in Fort-Wayne. The doctor conducted several physical tests; he was surprised Ryan had no symptoms. He recommended we head to Indianapolis immediately to Riley's Children's Hospital because they had more equipment and pediatric brain tumor specialists that may have more treatment options to offer. We made the very quiet three hour drive, arriving very late that evening. Ryan was examined again in Riley's Children's emergency room, the doctor was also surprised he showed no symptoms and then ordered a more sophisticated MRI.

After several additional tests, they developed a plan and scheduled Ryan for surgery two days later. We were all extremely nervous and shaken. Ryan went to surgery at 8:30 a.m., September 15 and 14 hours later, we saw Ryan in the recovery room. They had removed the



very large tumor and the surgery went as well as expected. Ryan did fine in surgery, however he had significant trauma. Ryan's entire right side was entirely immobile, his face and shoulder, were all drooping, he could not move his right arm or leg. The next few days were very difficult as his memory was also greatly impacted, he could not even remember our names, nor identify basic objects. All we could do was simply watch and wait. The pathology came back after a week and showed that Ryan had JPA, juvenile pilocytic astrocytoma.

The following weeks Ryan continued to gradually improve as we were sent to intensive rehabilitation. He had to learn to read, walk, eat and talk all over again, it was a long process. He progressed gradually from his wheel chair to a walker and eventually with the help of a brace was able to walk again (a thrilling day!). He also regained much of his mental function, but his memory was still impaired. He had no function of his right arm at all for several months. Through extensive therapy he continued to improve and even gained some movement back in his right arm.

We continued with follow-up visits every three months. Almost a year exactly from the first surgery, more devastat-

ing news, Ryan had four new tumors reappear in the area of the original tumor. Our neurosurgeon was very thorough and acquired several outside opinions. Ryan went through surgery again in Indianapolis, this time he was in surgery for 8 hrs, everything went as planned. He had only minor setbacks this time and following a rough couple of days then recovered quickly. The day before they planned to discharge Ryan, he had another MRI; they found another tumor in the third ventricle and near the vital center of the brain, the hypothalamus. It is inoperable. The surgeon stated we had plenty of time to acquire opinions on what to do next and we should let Ryan recover.

The following weeks we had many road trips to visit five leading institutions in the U.S. The opinions were very diverse on what to do next, ranging from attempting surgery to remove the portion they could reach, extensive chemotherapy, and differing levels of radiation. The final visit was with Dr. Packer in Washington D.C., a friend of our Indianapolis neurosurgeon. He proposed a new chemotherapy regimen to monitor Ryan over a longer period of time and avoid some negative consequences of the other treatment options until Ryan is older (cognitive loss and hormone deficiencies). Ryan has now been in chemotherapy for almost one year under the watch of Dr. Packer. His tumor has remained "stable" and although Ryan is disappointed it is not shrinking, at least it has not progressed.

Ryan is now 15 and has continued to improve physically (some movement in his right arm and hand) and also made dramatic cognitive improvements since his first surgery. He is able to walk well with only an AFO (ankle-foot orthotic) brace, he is doing well in school and enjoys being with his friends.

Ryan will complete his chemotherapy sequence in the spring of this year. We do not know what the future holds, but hope and pray for his recovery and advancements in the medical world so he may be cured.

Written by Kevin Schlosser, Ryan's dad.

Couples' Communication: Connecting with your Partner

On Wednesday, December 7, 2005, the Brain Tumor Foundation for Children; Children's Brain Tumor Foundation; and The Childhood Brain Tumor Foundation jointly sponsored a free teleconference for parents of children with brain tumors. Four couples generously shared their communication experiences, moderated by Nancy Cincotta, LCSW, Director of Psychosocial Services, Camp Sunshine, Point Sebago, Maine. The parent shared their personal styles of communication.

The couples candidly discussed their reaction to diagnosis; their individual coping styles; how each partner may have its own communication style; importance of intimacy; journaling as a method for communication.

We are appreciative of the participants for their openness in sharing their personal communication tips and experiences. Nancy Cincotta was a terrific moderator and provided excellent pre-conference informational materials.

Reprint correction (2005 Grant Funding)

"Determination of TP73 Expression and Function in Medulloblastoma"

Dr. John Kim, Baylor College of Medicine, Texas Children's Cancer Center

Medulloblastoma (MB) is the most common malignant brain tumor of childhood. Unfortunately, combined therapy with surgery, radiation and chemotherapy fails to cure many children. Survivors are often left with significant long-term complications of their treatments. Developing more effective and less toxic treatment requires a better understanding of MB growth. MB appears to arise in developing brain cells. The TP73 (p73) gene regulates normal brain development. TP73 can be found in two opposing forms: in the brain and in MB: TAp73, which limits cell growth, and Np73, which promotes growth. The overall effect of TP73 reflects the balance of its mutually opposing forms. We propose that Np73 promotes MB growth by antagonizing TAp73. The overall goal is to determine the activity of TAp73 and Np73 in human MB cells and in mouse MB. Our proposed studies will determine how TP73 forms modulate growth of MB and its response to radiation and chemotherapy; ultimately paving the way for clinical studies of TP73 as a therapeutic target.

Personal Excerpt by Dr. Kim

Pediatrics became the focus of my clinical interests because of its intrinsic orientation toward developmental issues. I have since had the great fortune of serving children and their families who have charged me with my life's work. No group of patients and families appeared to need productive translational research more desperately than those suffering from brain tumors. Therefore, during my post-doctoral research, I sought to apply emerging concepts and advances in genomics and developmental neurobiology to address problems in pediatric neuro-oncology.

The Dan Fiduccia Annual Spring Biathlon

Sunday, May 7, 2006

8:00 a.m.

Maderia School, McLean, VA

Food and fun for everyone!

The registration form is posted on our website: <http://www.childhoodbraintumor.org>

For more information please call
Gib Smith, Race Director, 540-822-4355

If you are unable to join us and would like to support this event, send your tax deductible contribution to the Foundation by using our donation form on page 8 or our online Give Button. Tax receipts will be sent to sponsors.

Gala Party and Casino Night

A fund-raiser to benefit the
Childhood Brain Tumor Foundation

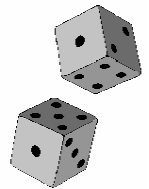
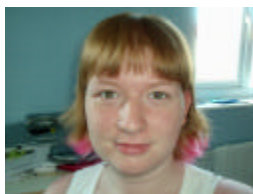
Saturday, November 11, 2006

7:00 to 11:00

Glenview Mansion at the
Rockville Civic Center

Join us for buffet dinner, open-bar, silent auction, live entertainment, and casino fun.

Raising funds while having fun. Proceeds from our Biathlon, Casino Party and other fund-raising events will help CBTF fund vital research, giving hope to children and their families. All donations are tax-deductible and will be acknowledged.

**March 2006, Mel's Message of Hope, An Update:**

I thought I would give you a little up-to-date message; well, I am still at college and have managed to make it through almost a whole year now in the fine arts curriculum. It is great, I am loving it. I am taking extra support

classes for math, handwriting, spelling and all of the basics that I basically forgot how to do. It is going well, as I am being entered for my level exam next week for numeracy, so all is well on that front!

Mel is 16-years-old and lives in Billingham, England. She is a survivor of optic nerve glioma.

H appy B irthday

Heather Merrbach
Garrett Parham
Catherin Preece
Julian Tash
Ashley Young
Susan Young



I n H onor of
Michael Glasener
Maria Leuzinger
Shelley Locke
Samantha Janower
T. J. Ragnoni
Lorraine Schoenfeld
Stephen Schoenfeld
Kate Shipman
Elizabeth Valentine

Sean's Story



Sean and Sophie

On September 14, 1999, when my four-year-old son Sean and I walked hand in hand through the doors of the Coffs Harbour Hospital, I had no inkling of what was about to happen. I suppose I should have known something was seriously wrong with Sean, given that I was a registered nurse and that he had been experiencing neurological symptoms for several weeks. Because he had been such a healthy

and happy little boy until recent times, a brain tumor was the last thing I, or anyone else, including his local doctor expected. Expected or not, the following words uttered by an intern after an emergency CT scan had been attended changed my life "Sean has a lesion in his brain," the young doctor tearfully said. "It is probably a tumor." And it was--a great big golf ball of a thing that was never definitively diagnosed.

Sean's pontine glioma was an aggressive cancer that it took him from us within four months. Sean's lesion didn't stop growing just because he was anesthetized that sunny spring day for a four hundred mile air ambulance flight southwards from our beachside home to Sydney. The intravenous and then naso-gastric tube dexamethasone slowed things down. It would be weeks before Sean volunteered to hold my hand and weeks before he rediscovered his smile.



After several days of non-invasive tests, a brain biopsy, and lots of frustrating waiting around in the Children's Hospital at Westmead, Sydney, radiotherapy was commenced. Radiation did reverse a great many of Sean's symptoms but ever so slowly and not until he suffered a stroke. It was this stroke that caused Sean's left-sided paralysis, which affected his rehabilitation.

Being the recipient of terrible information is like being pummeled to within an inch of your physical and emotional life. The parents of brain tumor children receive such information on a daily basis, sometimes several times a day. My wife Jane and I learned to take on board such news with equanimity. What right had we to express pain and sadness publicly, especially in front of Sean, we asked ourselves, when our son was fighting his battle on a daily basis without understanding why. "The doctors caused the lump in my head," he finally told me.

Because of his age Sean had all thirty radiotherapy treatments under a general anesthetic. Because of the affect the tumor had on his swallowing and respiratory functions, he endured an endotracheal tube and remained in the intensive care unit at Westmead for several weeks.

While he was hospitalized, Jane and I spent all our waking hours and then some with Sean. We smiled and laughed.

We read to him. We watched TV with him. We washed and massaged him. It was only in those few hours between midnight and dawn that we allowed grief full reign. Then we cried and moaned and prayed. It was only away from Sean that we (me mostly) updated friends and family with grim news. With our ten-year-old daughter Sophie still hundreds of miles away, it was me who was forced to stumbly explain everything to her on the telephone.

Jane became the chief caregiver, the nurturer. I became the provider, the one who spoke to doctors, who shopped and paid bills. We discovered the intended and true roles of men and women.

Eventually, with the help of his wonderful doctors, nurses and technicians, Sean began to get better. By the time he was ready to go home to Woolgoolga he was eating mush, moving all limbs a little and saying a few words. Once home, he improved even more. Soon he could walk/limp with a walker, pat his dog, read his train books, eat most solids, and even convey his philosophical ideas with ever longer, smile-inducing sentences. They were good times, those between times. We, Jane and I, and perhaps Sean knew what was coming but we put it to one side. We went to the beach, we swam in the town pool, and we watched videos together. We even planned a holiday.



In the days leading up to Christmas 1999, Sean began to complain, as before, of leg weakness. Jane and I avoided speaking of this ominous shadow for a time. We had to act when the leg weakness became scream-inducing pain.

Sean woke on Christmas Day unable to walk. We aborted planned festivities and spent the day in Coffs Harbour Hospital. "Sean's symptoms are neurological," we were told eventually. We knew they were but that didn't soften the blow.

We tried to embark on a curtailed holiday but it didn't work. By the dawn of the new millennium, we were in Westmead again. This time the MRI told of secondary deposits, meningeal seeding, radiation growths, and spinal metastases. Jane and I found it hard to recover from this attack on our emotions. For Sean we had to. For a few days we did. Even after all he and we and they did, in some cases, such as Sean's, nothing can stop a primary brain stem tumor in a child.

Sean died at home on January 13, 2000, just into the new century. He missed it, this century.

Our grief began the day of Sean's diagnosis. I wrote a whole book about our *before* and *after* lives, and I still cannot explain grief satisfactorily. All I can tell you is that grief is life changing and all encompassing. But it can be harnessed.

(continued on page 6)

Sean's Story (continued from page 5)

I began writing within days of Sean's death. I didn't stop until "Can I Take My Panda Daddy?" was published some five years later. I have never completely understood my motives for becoming an author at the expense of my son's death. Partly, I know, I did it for love. But there were other reasons. Just as Jane hid her emotions away and began planting flowers so there would always be blooms for Sean's grave, I transferred my parental duties to pens and keyboards. I became a writer out of a desire to tell the world about Sean and of his and our journey, but also to continue the fatherly role I began on September 4, 1995 when our much-loved bundle of joy was born. Later, the more I wrote and tearfully rewrote, the more I realized our story could benefit others--other parents and those in the caring professions, for example. Much later, I realized my words meant that Sean would not only live on but that he could make an impact on the world beyond what his short life and early death, however tragic, did.

I suffer still from grief. Recently our little boy, Sophie's brother, should have turned ten. For some reason this missed birthday affected me more than most previous ones had. Perhaps the double figures, the pre-teen number, subconsciously implied he was gone for good. I don't know. Whatever the case, I know I miss my beautiful boy now more than I would the sun if it ceased to shine and I know, for that reason alone, I would not wish a brain tumor on anyone.

Greg and his family live in Woolgoolga, a small town on the mid-north coast of NSW. He trained as a registered nurse in 1980 and works as a medical/palliative nurse at Grafton Base Hospital. He loves being with his family, surfing, reading, writing, listening to music and gardening. His wife Jane is a primary school teacher. They share a daughter, Sophie. This family hopes that those who read, Can I Take My Panda Daddy? or the article will understand the many obstacles these courageous children face and the journeys a family may share.

Can I take My
Panda Daddy?



We will report on the seventh annual Run with the Saints event, in memory of Lauren Lockard; and the second Geoff Cornman Memorial Golf Classic in our next issue.



Kyle's Heroes Golf Classic



Kyle's Heroes was established by the family and friends of Kyle Killeen after he was diagnosed with a pediatric brain tumor in the spring of 1999. The Kyle's Heroes has raised significant funds to support research for pediatric brain tumors. The 2005 event marks the seventh annual Kyle's Heroes

Golf Classic, hosted by the Killeen family on Monday, September 19, 2005 at the Jumping Brook Country Club in Neptune. It was a fabulous event raising \$15,000 for research.

This highly supported event included golfing, a raffle auction with incredible items, and a delicious buffet dinner. The attendees enjoyed the special entertainment provided by a group of bagpipers.



The Childhood Brain Tumor Foundation is grateful to Kyle and his family, the excellent sponsors, and all of the supporters who help us make a difference by contributing. The golfers enjoyed a beautiful day.

Also, in the spring of 2005, Kyle's Heroes and the Childhood Brain Tumor Foundation were beneficiaries of a wine tasting held at the Town and Country Fine Wine Shop.

An appreciation message from Kyle to event supporters, his family, and friends.

"I speak for myself and others like me, especially the kids, who seem to have a normal life but inside feel different. Your sacrifice and gifts are greatly appreciated by all of us."

WORKPLACE GIVING

Thank you to those who choose us as their charity!
CBTF

- Combined Federal Campaign;
- Children's Medical Charities of America (National); and
- United Way

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. **For next year's campaign we will be in Children's Medical Charities and will have a new designation number.**

Thank you to our friends and supporters at Exxon Mobil, Lockheed Martin, GXS, IBM, and NASD. Also, thank you to Fannie Mae for gift matching.

Remembrances

Morris Berger
 John Boyles
 Jeff Brown
 Kelley Bula
 Ria Dicker Butler
 Barbara W. Byrum
 Charles Byrum
 Catherine Cason
 Ryan Caspar
 Laira Caverly
 Josetta Chiang
 Shirley Coleman
 Geoffrey Cornman
 Web Daniels
 Tommy Donzelli, Jr.
 Shawn Edwards
 Clay Eich
 Barbara Waxman Fiduccia
 Daniel Fiduccia
 Doyle Garrett
 Frank Giacini
 Ian Hahn
 Dennis Hanlon
 William Hanlon
 Katie Harris
 Rebecca Hatef
 Salmaan Hava
 David Hayes
 Leah Lorberbaum
 Jonathan Hicks
 Erica Holm
 Tara Houston
 Joyce Hutton
 John Russell Irvin
 Kristi Johnson
 David Keith
 Amy Kruppenbacher
 Rebecca Lilly
 Lauren Lockard
 Margie Kane
 Emily Mau
 Willard Maddox
 Gianna Mason
 Araminta Mustafa
 Bernard Miller
 Hannah Miller
 Al Nirenberg
 George Nuzzo



The world's been turning
 Today is calling
 Your friends are waking
 It's time for work and playing
 Rise with the bluebirds
 Shine with the sun
 Shine like a pearl
 Rise and show your love around the world
 Now it's time to rise and shine

- -Raffi

In memory of Russ Irvin, selected by his parents.

*Left: CBTF's Founder's son, John Russell Irvin,
 fondly known as Russ.
 December 1986~February 17, 2006*



*Rebecca Joy Hatef (age 7)
 January 5, 2006*

This is Rebecca's favorite song.

"If You Can Dream" Disney Princesses

There is a world where hopes
and dreams will last for all time

A wondrous place to go, you'll
know it when your heart finds it
Hearing our song as
old as rhyme

Hold my hand we're gonna fly
What a magic ride and just
a kiss away

If you can dream
The wish we're making on a star
is coming true
The colours of the wind will lead
my heart right back to you

Cause if you can dream
Reflections in a diamond sky
come shining on through
Romance will always be so new
And love will save the day
If you can dream.

Submitted by Rebecca's parents

Audrey Petersen
 Eric Richardson
 Jay Rowley
 Nicole Ringes
 Andrew Rypien
 Joseph P. Sanford
 Lynda Santelli
 Amy Schiller
 Simon Schoenfeld
 Luke Shahateet
 Steven Sliwerski
 Brennen Smith
 Lisa Soghomonian
 Teresa Stargel
 Jaime Vanderheyden
 Swetha Vasudevan
 Matthew Wierzbicki
 Ian Hammond Williams
 Ben Zell
 David Zucker
 Mary Waugh
 Josie Wynn

Brain Awareness Week is held mid-March annually.

The Society for Neuroscience and Dana Alliance have partnered since 1995 to support brain awareness. A series of events are held around the world to increase awareness about the brain and various disorders. For example, the Brain Bee is a popular awareness tool successfully implemented by teachers, scientists and students. Visit www.sfn.org/brainfacts for information about brain facts.

Brain Tumor Action Week will be held May 1-7, 2006.

The North American Brain Tumor Coalition (NABTC) is a network of charitable organizations dedicated to eradicating brain tumors. Activities that are scheduled by the NABTC and are due to take place in Washington, D.C.

*The Childhood Brain Tumor Foundation appreciates the continued support shown everyday by our contributors.
Together, we will make a difference.*



Our CFC / UW designated number will be different for the 2006 campaign. We will be in Children's Medical Charities. Always check the number, changes are expected again for the 2007 campaign.

Thank you for your support!
The Childhood Brain Tumor Foundation, Inc.



Donation form or to be added to our mailing list.

Enclosed is my contribution of \$: _____
 In Memory of: _____
 In Honor of: _____
 On the occasion of: _____
 General donation: _____
 Please send remembrance card to:
 Name: _____
 Address: _____
 City/State/Zip: _____
 Optional Phone: _____
 Please make checks payable to:
 The Childhood Brain Tumor Foundation
 20312 Watkins Meadow Drive
 Germantown, Maryland 20876
 telephone: 301- 515-2900 toll free: 877-217-4166
 Charge my: ___MasterCard ___Visa
 Card# _____ exp. ____/____
 Note: minimum charge donation is \$20
 Name: _____
 Address: _____
 City/State/Zip: _____
 Optional Phone: _____
 Optional E-Mail: _____
 Donations also accepted through our secure Give Button.
 American Express is only accepted via our Give Button on our
 Web site: www.childhoodbraintumor.org
 Your donation is tax-deductible.

Our mission is to support and fund basic science or 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 by funding vital research. initiatives.

CBTF has a website!

visit us at:

<http://www.childhoodbraintumor.org>

Thanks to Tim Ratliff, Web Master.

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 to the Childhood Brain Tumor Foundation reporting a contribution, stating they will match the contribution. We return the form to the employer with the proper acknowledgment and information required.

If you would like to receive our newsletter publications or other information, please notify us with your contact information.

**National Cancer Institute
The Facing Forward Cancer Survivor Series**

--Life After Cancer Treatment

--Ways You Can Make a Difference in Cancer

Visit www.cancer.gov/publications or call 1-800-4-CANCER

Vehicle Donation Program



Vehicle Donation Program

CBTF now accepts vehicle donations. Donate online or call 866-332-1778 and designate the Childhood Brain Tumor Foundation as your charity of choice.

QUICK FACTS FOR DONATING

You are eligible for an itemized TAX DEDUCTION. The service is totally free and includes convenient pick-up of your car, truck, or RV anywhere in the U.S.

Find out details by checking the Foundation Web site; [Http://www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

A big thank you to those who have donated cars!!

Bequests, Planned Giving and Trusts

Through a trust, bequest, or planned giving you can contribute to furthering the future research and programs of the Childhood Brain Tumor Foundation. By including the Childhood Brain Tumor Foundation in your estate planning you can minimize your taxes.

CBTF now accepts donations via **stock securities** through Bank of America Investment Services, Inc. **Contact our Broker, Steven P. Burroughs at the new phone number 301-493-2893.** Another opportunity for donating stock securities is offered online through our Give Button.

Thank you to all who have donated through stock securities. Please call us if you have any questions.

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Thank you to our bulk mail team.

Thank you so much to the **Rocking Moon Foundation** for donating printing costs for our newsletters, brochures, and our book of compiled articles and stories. The Rocking Moon Foundation also covers the mailing costs for the newsletter.

Past newsletter editions are posted in color on our Web site: www.childhoodbraintumor.org