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CBTF:

20312 Watkins Meadow Drive
Germantown, Maryland 20876
Toll free: 877-217-4166
phone number: 301-515-2900

Check Out Our Website!

<http://www.childhoodbraintumor.org>

Adult Survivor Explores Coping as a Process

Lazarus (1993) defines "coping as a process," which encompasses "ongoing cognitive and behavioral efforts to manage specific demands that tax the resources of a person." In relation to life-threatening illness, Taylor (1989) asserts, "coping that enhances and focuses on the positive is important for maintenance of health."

My diagnosis with two brain tumors thirteen years ago was a shock. How could this be, I wondered? For so long the fact that there was "no" tumor had afforded me a sense of comfort and security which helped me through some of the most trying neurological sagas (related to hydrocephalus) of my childhood. But this all changed one spring day in 1989 with the news that I had two brain tumors.

The first surgery was two months before I was supposed to leave for college with a second, more complicated procedure following two weeks later. Expecting a straightforward chain of events, my neurosurgeon anticipated that I would be off to school in a matter of weeks following the surgeries. It did not take long for anyone, except me, to realize that such a course was not meant to be. Finally, one week before my scheduled departure for college it all sank

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Kate Lund enjoying a day of boating.

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Cerebellar Mutism

Cerebellar mutism was first reported in 1979 by Hirsh after a posterior fossa tumor resection. In the past, cerebellar mutism was thought to be an uncommon problem. However, there have been increasing numbers of case reports and literature reviews that indicate that cerebellar mutism may be significantly more common than previously thought. The reason for this increase of reports is unclear but may be due to neurosurgical advances that allow more aggressive tumor resection.

The complication of cerebellar mutism, also known as syndrome of mutism of subsequent dysarthria or posterior fossa syndrome with cerebellar mutism, is rarely mentioned to parents during the consent for surgery of a posterior fossa tumor. When it occurs parents are often scared and confused by this unexpected new problem their child is experiencing. Frustration may be heightened by the lack of information written at a level for parents at a time when they have been thrust into probably the worst nightmare of their life. The questions are many: How did this happen? Will it get better? How long will it take to improve? What is the natural course of this problem? Will my child talk normally again? Can I talk to any other parent who has been dealt this hand?

The basics:

Definition:

This is a symptom complex including decreased or absent speech, irritability, hypotonia (low muscle tone), ataxia (unsteadiness and decreased coordination) and the inability to coordinate voluntary movements most commonly seen after surgery in the posterior fossa region of the brain. Mutism is considered a severe incoordination of the volitional motor aspects of speech.

Onset of Mutism:

The mutism may be immediate or delayed. Virtually all cases of mutism will occur within the first week of surgery - 50% within the first two days. It is not uncommon for the child to speak a few words after surgery and then the next day unable to produce words.

Length of Mutism: Mutism has been e-

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Adult Survivor Explores...(continued from page 1)

in. Not only was I not getting out of bed unassisted, I was not leaving for college. Beyond this point, however, I would let nothing sink in. I had been conditioned early in life as a result of my hydrocephalus to push through each episode and sometimes each moment as if a separate entity. Subconsciously, I knew that in order to cope with these tumors, and ultimately to survive I could not become consumed by any single element of this new and difficult situation. In this article, I will discuss the ways I have coped with my brain tumor diagnosis both past and present. I will also highlight the ways these coping strategies have shifted over time, illustrating the idea that coping is a fluid process, which typically changes based on developmental, situational and/or environmental factors.

I always have been committed to maintaining a high level of physical fitness and overall wellness. This did not change with my diagnosis. In fact, fitness, although modified, by the physical limitations imposed by surgery and associated treatments, quickly became my primary coping strategy. I was extremely determined to maintain as much physical, body-based integrity as possible. This was not easy, as I could barely walk unassisted and my sight was severely compromised. Nonetheless, I lived for my daily walks around my parent's circular driveway, as they provided me with an outlet for my masked emotions, as well as some sense of well-being and health. Along with physical activity, denial also helped me to cope. I worked very hard to keep reality at bay, as I wasn't yet interested in what these tumors might mean. At least I tried to make myself believe I wasn't interested.

Despite multiple setbacks, this mix of physical activity and denial enabled me to cope and maintain a generally positive outlook during the year following my initial diagnosis. Once I had recovered enough to resume activities of daily living and left home for college, coping became more challenging. I was increasingly preoccupied with thoughts and worries about the tumors and my health. Not a day passed when I did not think about these issues. As a result, I increased my emphasis on fitness to help me cope with these looming worries. Throughout college, I spent countless hours in the pool, swimming laps, rode my bike long distances and ran on the side. Additionally, I became interested in nutritional healing and worked hard to shape my diet according to these principals.

During this time, however, I never lost sight of how fortunate I was to have regained enough physical strength to engage in these activities. At the same time, challenges remained and I still did not consider myself as physically able as my peers. Nonetheless, I somehow developed an identity on campus as a "fitness guru." Most of my peers had no idea about my medical history or the ordeal of the previous year. They just viewed me as a fit, fun girl who loved life as a typical college student. While this assessment was largely true, there was clearly much more to the story. It would take years for me to feel comfortable sharing this part of myself with those I did not know well. Still, my new identity was a welcome change. Growing up with

hydrocephalus made it difficult to escape other's perception of me as a "sick child." Being viewed in the opposite way was refreshing.

Despite my improving health and fitness, I still could not shake my fears and questions related to the tumors. I needed additional strategies to work through these issues. However, I still resisted the idea of facing my many feelings and emotions buried beneath my now healthy, fit exterior. While I realized these feelings were impacting me day-to-day and were consuming a tremendous amount of energy to keep at bay, I still wanted to avoid them.

In time, I became involved with various brain tumor causes and advocacy projects, which, in many ways, also helped me to cope. Meeting others with similar experiences was empowering and helpful on many levels. The work also provided me with a sense of purpose and meaning, not present in my job as a publicist. During this time, I also decided to change careers and become a psychotherapist. My goal in making this move was to find work which would be intrinsically satisfying for the long-term. Once I made this decision, I had no choice, but to get more in touch with my brain tumor experience and explore the many associated emotions and feelings. If I did not fully know and understand my own inner-world, I could not become an effective therapist.

Working through these feelings and emotions enabled me to begin integrating my brain tumor experience more fully into my overall sense of self. Until this point, most of these issues were compartmentalized and separate from the rest of me. The energy required to keep these aspects of myself off my emotional radar was intense. I found bolstering my coping arsenal with strategies, which added balance to my life and enhanced my physical and emotional condition helpful during this ongoing process of integration. Over time, I have experimented with and incorporated multiple alternative healing modalities into my still active lifestyle. Thus far, I have found massage, principles of nutritional healing, reflexology and meditation the most useful in coping with the many challenges of living beyond a brain tumor.

Clearly, a brain tumor diagnosis can present significant challenges, uprooting the normality of life and relationships across the lifespan. Nonetheless, it is possible to cope with and manage related issues, while maintaining quality of life through diagnosis and treatment. However, it is important to note here that coping is a highly individual process and what works for one person may not work for another. Since all brain tumor experiences are inherently different, it is necessary to experiment with different ways of coping in order to find an effective and comfortable strategy.

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Kate Lund is a licensed clinical social worker and is working on a doctorate in clinical psychology. She lives in Massachusetts with her husband Ted.

Cerebellar Mutism (continued from page 1)

ported to last as short of six days and as long as 52 months. There have been no cases reported where a child with cerebellar mutism did not get return of functional speech.

Incidence: Review articles have published the statistic that approximately 8% of children undergoing posterior fossa surgery for tumor will develop a degree of cerebellar mutism.

Factors associated with the development of mutism:

Posterior fossa surgery for tumor- Overwhelmingly mutism of cerebellar origin has been reported with surgical intervention in the posterior fossa for tumor. However, there are other etiologies reported in the literature including posterior fossa trauma, cerebellitis (inflammation of the cerebellum), cerebellar hemorrhage, embolic events, and Arterio-Venous Malformations (AVM's).

- Children- Most cases involve children. Although there have been reports of mutism in patients in their eighth decade of life.
- Midline tumor location
- Cerebellar vermal incision
- Large or very large tumor size- A size greater than 5cm with medulloblastomas appears to increase the risk.
- Medulloblastoma- This tumor type appears to be increasingly associated with mutism although it has also been reported to occur with ependymomas, choroid plexus tumors, astrocytomas and rhabdoid tumors.

Pathophysiology: The exact reason for cerebellar mutism has not been agreed upon. Recent reports believe that there is focal decreased cerebral and cerebellar blood flow leading to decreased cell functioning in particular areas. Specifically, decreased blood flow to the dentate-thalamic-cortical pathway may cause these cells not to function as well. Single photon emission computerized tomography (SPECT) studies have lent support to this theory. It is not thought to be an emotional problem where the child is unwilling or too angry or depressed to talk.

The speech: Speech always returns with cerebellar mutism. Rarely, some children have their speech come back almost all at one time. For example, one day few sounds and then next "one, two, three, four I declare a thumb war". More commonly the communication comes back more slowly with more spontaneous sounds first (laughing and crying) followed by sounds (such as fffff). If a child had not been able to communicate in a nonverbal way due to severe hypotonia (such as with head nods, gestures, or communications boards), this type of nonverbal communication usually precedes speech.

Speech virtually always becomes functional for communication, however it may not be the same as before surgery. The speech may be hypernasal, monotone, high pitched (helium voice), slower and sparser. The child may have difficulty initiating an answer and speak less than before. The stress

patterns of speech (prosody) may also be off.

Some children will never return to a normal voice and are left with residual deficits in prosody (the melody or normal stress patterns of speech), initiation and vocal quality. It should be noted that children undergoing posterior fossa surgery may have speech disturbances of a similar nature even without mutism. This is often referred to as cerebellar speech.

Intervention: Children with cerebellar mutism are usually seen by a speech-language pathologist whose job may include:

- Assisting in devising a form of nonverbal communication
- Explaining the usual course of cerebellar mutism and what to expect in the recovery. For example, asking a child to speak when they do not have the motor ability just leads to frustration for both the parents and children.
- Practicing tongue and lip movements before speech returns
- Practicing and suggesting volitional blowing tasks (Harmonicas, recorders, party favors, blowing bubbles are some of the most common. Straw games such as blowing the paper off a straw, blowing bubbles into liquid, and blowing cottonballs off a table are favorites among many kids)
- Assessing speech and language skills
- Giving suggestions to parents to aid in recovery of function such as, singing or taping songs at a very slow speed as a way for the child to practice the intonation differences and other speech skills.
- Starting a nursery rhyme and having the child complete it.
- Giving a picture and having the child tell a story
- Having the child do something and then explain what they did.

Other problems:

- Posterior fossa syndrome - This refers to the irritability, hypotonia, and ataxia which may or may not be accompanied by mutism. Some of these children will also suffer from a hemiparesis as well. Rehabilitative services, including physical therapy and occupational therapy, are usually given. Cerebellar mutism has not been reported without the other finding of posterior fossa syndrome in the face of tumor resection
- Feeding difficulties - Some children have such severe problems with the coordination of oro-facial movements that they are unable to chew and swallow. Return of voluntary movements of the tongue (to stick it out and move to side to side) precede the ability to eat. Children who have been affected this severely often need tube feeding, especially when radiation therapy and chemo-

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Cerebellar Mutism (continued from page 3)

therapy is given at the same time as the child is trying to regain the ability to eat. The decreased appetite, nausea and vomiting may not allow the child who is just regaining these skills to get enough nutrition on their own.

- Cortical blindness-like syndrome - Very uncommonly a child will develop a problem in which the eyes can see but the brain is not interpreting images. Thus, the patient is essentially blind since the brain is not processing visual input. This is frequently referred to as cortical blindness. This may be more common than reported as the vision usually returns before the mutism improves. Unless it is checked for or the child asked at a later time, this may not be noted.
- Neuro-cognitive Issues - Some clinicians believe that children who have experienced cerebellar mutism may also experience greater neuro-cognitive deficits. This question has not been answered but investigations are now underway in some institutions.

Recurrence of Cerebellar Mutism:

There are no reports in the literature of a recurrence of cerebellar mutism with subsequent surgeries.

Other resources: Other resources available to parents include the Cerebellar Mutism/Posterior Fossa Listserv at <http://groups.yahoo.com/group/cerebellarmutism> or the American Speech-language-Hearing Association at www.asha.org.

Permission given by author for use by the Childhood Brain Tumor Foundation. Written by Dr. Loice Swisher, parent, and co-authored by Dr. Peter Phillips.



The Childhood Brain Tumor Foundation will announce research funding for 2002 in our next newsletter. We thank all of our supporters that contribute to our efforts. Thank you to all of our Medical and Scientific Advisors for the time dedicated to the review process.

Brain Tumor Action Week May 5-11, 2002

The North American Brain Tumor Coalition (NABTC) is a network of charitable organizations dedicated to eradicating brain tumors. Brain Tumor Action Week was held May 5-11, 2002. On May 7, 2002 NABTC held an Educational Day for families, friends and patients at the Hotel Washington. Speakers included: Dr. Howard Fine, Dr. Jeffrey Wisoff, Anita Nirenberg, BSN, MS, Dr. Jeffrey Sherman, and Dr. Richard Pazdur

On May 8, 2002 brain tumor advocates throughout the United States brought a united message to Congress. Amongst the messages delivered were Implementation of the Brain Tumor Progress Review Group (PRG) report, the Benign Brain Tumor Registries Amendment Act and the Patients' Bill of Rights.

Advocates asked Members of Congress to include language in the Appropriations Bill directing the National Cancer Institute (NCI) and the National Institute of Neurological Disorders and Strokes (NINDS) to finalize the implementation plan for the PRG. In addition, they asked that the Institutes report back to Congress by the end of 2002. For additional information about the Brain Tumor Progress Review Group Report check the NCI and the NINDS websites.

Advocates discussed the Benign Brain Tumor Cancer Registries Amendment Act with members of Congress. Patients and families encouraged their Representatives to co-sponsor H.R. 239, a bill that has strong bi-partisan support. Passage of the Benign Brain Tumor bill will ensure a nationwide count of all brain tumors, therefore, representing the true incidence rate. Benign is a misleading term for brain tumors and their course is not always so "benign."

Another topic addressed was the lack of progress on a Patients' Bill of Rights. Brain tumor patients need to be guaranteed access to clinical trials, specialty care, continuity and quality of care.

NCI RESOURCES AND INFORMATION

NCI Cancer Facts

The NCI Cancer Facts are a collection of fact sheets that address a variety of cancer topics. Fact sheets are frequently updated and revised based on the latest cancer research. Fact sheets also include information about NCI such as NCI's Cancer Centers Program and how to designate donations to NCI. Many NCI Cancer Facts are also available in Spanish, and are available in PDF format or in an HTML web-based format.

<http://cis.nci.nih.gov/fact/index.htm>

The Fabric of Life



A year ago had I been required to select a type of cloth to symbolize my life, I might have chosen a white quilt – an unblemished canvas upon which I carefully embroidered each experience of my existence. Every potential intricate design analyzed to see whether it would blend into the master plan. Every strand of floss inspected prior to use. Every stitch precisely placed. And why shouldn't it be that way? After all, I had gone

after all my goals – and had attained them all. I had excelled at the academic path and became an emergency physician. I had a great job, a wonderful husband, a house, two cars, and a beautiful daughter. The perpetual plotting of my life's course had seemed to have paid off.

On December 3, 1999, my husband and I took our five year old daughter for a "reassurance MRI". Over the previous month she had had four bouts of vomiting – three of which were associated with chocolate. With one of those episodes, she had complained that her forehead hurt. To an ER doc, headache and vomiting may equal a brain tumor, especially when it is your own kid. I had felt foolish going to our pediatrician for such trivial symptoms. What are the odds that my kid would have a brain tumor when only a little more than 2,000 children a year in the United States are diagnosed with brain tumors. It was silly to even consider the possibility that my perfect life would be messed up by such an event.

So, we waited in the MRI suite over an hour while our daughter underwent her "45 minute scan." When the neurologist came in to inject dye at a time that we were supposed to be done, I asked in my steadiest voice I asked, "Can you tell us something?" The response – "Yes mom, it is a posterior fossa tumor."

Those words were like a knife plunging right through the fabric of my "white quilt" life. The walls seemed to be closing in. My palms were sweaty. My heart rate doubled. It seemed I couldn't breathe. A brain tumor! How could this be? How could this happen to us. My life would never be the same. An unmistakable gash tore through the center of the fabric of my life.

Fortunately, sometimes stronger parts of the psyche come to rescue one in the darker hours. Thus, the doctor part reiterated those few memories from lectures in medical school. Kids are resilient. Their brains are more plastic and can handle things better than adults. Kids rehab well. The gaping

hole could be fixed. There would always be a mark left. It would take a little longer until I could continue embroidering the measured pattern of my life, but we could get back on track.

Little things frayed the edges enlarging the chasm. There was the medical equipment at the bedside "just in case" she deteriorated and need an emergency hole drilled in her head to relieve the increasing pressure. There were the nurses who shined a blinding flashlight in my daughter's eyes hourly through the day and night. The sedation "unmasked" the problems this mass was causing my child. The next morning her coordination was so bad that she could no longer walk alone. There was my baby yelling on the way to the operating room, "It's my tumor and I want to keep it." It was hard, perhaps the most difficult ordeal that would ever happen in my life, but we could get through it.

Of course, when there is a mass there is always the possibility that it could be malignant, that it could be cancer. And whenever someone's brain has been insulted by having someone else's fingers poking and prodding around, there is the likelihood of some complications. Despite knowing this, nothing could have prepared me for the double whammy out of surgery. It was a medulloblastoma; in other words – cancer. And the surgery had devastated my child. Within 48 hours, I had been told three phrases that a mother never wants to hear. Your child has a brain tumor. Your child has cancer. Your child is entirely disabled.

My beautiful, strong-willed child was blind, mute, unable to swallow, incontinent, and paralyzed on the right side. Her right eye was turned all the way into her nose and the right side of her face drooped so that the saliva that she could not swallow dribbled down her chin. Her muscles had no tone. She could not even hold her head up. She was unable to follow even the simplest command. The only things she could do were hear, smell and breathe. By some cruel twist of fate, my little girl still had the normal thinking powers of a five year old with all the silence fears and unspoken questions.

It didn't end there. My scarred, disabled child became a medical device kid – a permanent shunt was placed. We would never, ever be able to leave this experience behind us. The shunt would be a constant reminder. She would be tattooed. The radiation had the potential to make her short, sick and stupid. Then, there was the chemotherapy!

I stared at the pile of rags my "white quilt" life had become. It had been destroyed. I looked at the shredded pieces and I did not want them. It did not want this life. It didn't seem salvageable. After all, didn't we learn anything from Humpty-Dumpty?

Sometimes, things are just impossible to fix. Nevertheless, others had hope and came to help try to put the pieces back together again. The first one to try to sew the tattered fragments was the neurosurgeon.

"Mom, it will get better," he would say.

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Late Effects in Long-Term Survivors of Childhood Cancer

On Saturday, June 1, 2002 the Long Term Survivor Conference (LTSC) was held at the National 4-H Center. The conference was sponsored by Children's National Medical Center and made possible in part by the Ronald McDonald House Charities of the Greater Washington, DC. The Childhood Brain Tumor Foundation was pleased to provide sponsorship toward the informative conference. The purpose of the LTSC was to educate patients and families about medical problems that can develop as late effects of treatment of childhood cancers. Late effects are related to the type of cancer, treatment, age at treatment and length of treatment.

The program was coordinated by Revonda Mosher. After Gregory Reaman, MD, Chairman of the Children's Oncology Group (COG) welcomed attendees, Wendy Hobbie, RN, MSN, CPNP, gave the keynote speech including a general overview of late effects and stressing the importance of regular follow-up in a comprehensive late effect clinic. Interactive workshops presented educational topics including: Osteoporosis in Survivors, Dr. Tosi; Infertility and Reproductive Technology: Options for Cancer Survivors, Drs. Byrne and Stillman; Cognitive Late Effects, Dr. McCabe; Dental Effects in Childhood Cancer, Dr. Ng; and Endocrine Effects, Dr. Guttman-Bauman. The topics were of great interest to attendees. It was reported that the estimated overall survival rate is 70% for the cancer survival rate in children. 1:1000 adults between ages 20-29 years is a long-term cancer survivor. Clearly conferences such as this are beneficial to patients.

The afternoon session included a Survivors Panel, facilitated by Lynn Hardesty, LCSW with panelists Cindy Baliles, Karin Brown, Fio Carmelino, Sheila Milam Savoy, Michael Schoenfeld and James Turner; and the Life Issues Professional Panel, moderated by Gilbert Smith, Esquire, joined by panelists Dr. McCabe, Grace Powers Monaco, Esq. and Barbara Hoffman, JD. The panels were very interactive. Gib Smith provided the story of his life post treatment and spoke of his passion and commitment to giving back. All survivors expressed that surviving cancer has given them a perspective that has had an incredible impact on their lives, a heightened appreciation level for life. The professional panelists provided information about education, employment and insurance issues and pursuit of ones rights.

The LTSC was an excellent conference held in conjunction with National Cancer Survivor Week. It was our pleasure to support such an informative conference.

Information on Long Term Survivors clinics in your area may be obtained by calling Revonda Mosher, MSN, CPNP at (202) 884-3568 or by e-mail at rmosher@cnmc.org.

The Dan Fiduccia Spring Biathlon

In the early morning of April 28th, CBTF, in conjunction with The Capitol Sea Devils and The Madeira School hosted the 8th annual Spring Biathlon. Unlike the past seven years where we absolutely stunning weather, we had to deal with a constant chilly downpour!! Initially, we considered canceling the race, but the amazing participant turnout spurred us on!! Unfortunately, for safety reasons we had to shorten our run from 5k to 3k, eliminating the "popular" woods section of the run. Bummer. As usual, participants could either compete as individuals or as a team. Although, the weather kept many of our race-day signees away, we still had approximately 100 participants. Despite the rain, everyone had a great time.

Winners this year included Luke McCarthy and Krisen Moores as the overall male and female winners respectively. Other winners include E.B. Kuhn (14-UF), Caroline Gignoux, (15-19F), Naomi Sullivan (20-29F), Tricia Lang (30-39F), Cindy Deugo Carlyle (40-49F), Rosemary Craighill (50+ F), Sean Whipkey (14-UM), Drew Neuhaus (15-19M), Jason Goyanko (20-29M), Jeff Cundiff (30-39M), Jose Santos (40-49M), David Conover (50+M), Sarah Reynolds/David Hahn (M/F Relay), Warren Kohm/Paul Bundick (M/M Relay), and Anita Meginn/Joanne Reker (F/F Relay).

Before and after the race (inside the Hurd Sports Center of course), participants feasted on bagels, various juices and fruits, Snickers, hot dogs and assorted donuts. A fond thank-you to our many generous snack contributors, including DrinkMore, Neal's Bagels, and Safeway. A special thanks to The Capital Sea Devils, The Madeira School, Yvonne Soghomonian, Susan Lyon, Lynn Chiang, Liz and Keith Irvin, Lyn Hellmann, Pat McGeehan, and Warren and Jane Harvey for all their help. Thank you to all participants and the rest of the volunteers for their time and efforts. Race results are posted at www.childhoodbraintumor.org. Can't wait to see you next year!



Left: Dedicated athletes on the run course.



Right: Gib Smith presenting medals.

Casino Party 2002

The Childhood Brain Tumor Foundation held its 6th Casino Party fund-raiser at the Barns at Wolf Trap in Vienna, Virginia on April 20, 2002. The evening included musical entertainment by long time supporters, Redline, and guests enjoyed the casino with black jack and craps, a silent auction, dinner buffet, and open bar. Exquisite floral designs were donated by Flowers by Anne of Mt. Airy.

Midway through the evening two children, Joe Sanford and Eric Richardson, were honored for the spirit and courage they have shown while undergoing treatment. They each received a special gift basket. Mary and Ryan Sanford graciously accepted Joe's gift basket for him as he was unable to attend. They also read Joe's well wishes to Eric on his special night. Eric and Joe's siblings all received a special gift for being supporters of their brothers! Todd O'Brien added to the evening festivities by presenting a check for \$2,300 from a fund-raiser he held in honor of his dear friend, Joe. Todd's fund-raiser was well supported by St. Patrick's Parish, Rockville, Maryland, Brooke Grove Elementary School, Olney, Maryland and by family and friends. Todd spoke eloquently of Joe and the special friendship they share.

Toward the end of the evening after the casino closed, Dr. Roger Packer and Jeanne Young presented awards from the Childhood Brain Tumor Foundation and the Central Brain Tumor Registry to Delegate Jean B. Cryor and her aide Kathleen Clough recognizing their dedication to passage of the Benign Brain Tumor Legislation HB-636. Kathleen Clough described the efforts and teamwork that proved most effective in successful passage of the bill. She also stated that to her knowledge it was one of the fastest bills passed through the Maryland State Legislature. Redline, as always, provided great music throughout the evening and ended the evening with everyone on the dance floor rock'in out to the bands well known rendition of Bruce Springsteen's Rosalita.

The Childhood Brain Tumor Foundation thanks the volunteers, sponsors, committee members, and attendees that made the event a huge success. We look forward to the next Casino Party in the fall of 2003.

Joe Sanford, diagnosed with medulloblastoma in September 1999, passed away on June 19, 2002. He was 10-years-old. Joe touched the lives of many and he will be greatly missed.



Above: Attendees keeping Black Jack dealer, Mark, busy.



Honored guests and siblings.



Left: Dr. Roger Packer and Kathleen Clough.



Top left: Group shot

Bottom left: Redline friends

Right: Efram Cherrick and Bernice Packer



Left: Theresa Santelli, Jane Young, and Esther Whitten



Todd and Eric



More photos on page 8

Fabric of Life (continued from page 5)

"Will it really?" was my plea.

With a calm and steady voice the answer came, "Yes mom, it will."

Unfortunately, stitches for the spirit sometimes are not usually as strong as surgical sutures for the body. Thus, he would have to redo his work everyday.

Then others came – each offering their own patch to help repair the damage. Family totally rearranged their lives to be with us and give us rest. Co-workers took up the slack for two months of missed shifts without a single complaint. Friends brought in meals so that we wouldn't have to have "hospital food." Therapist gave us encouragement. Nurses and doctors gave us hope. Total strangers let me pour out my heart in the cafeteria. Presents and prayers came from all over.

Each interaction brought its own patch. These patches had richness in textures, colors, sizes and designs. The way they fit together made other patterns of their own. A new quilt was created – a patchwork quilt.

It is a year later though I still have a great job, a wonderful husband, a house, two cars, and a beautiful daughter; but my life will never be the same. I'm told the fear of recurrence will lessen, but it never goes away. It will be a harder life for my girl than I dreamed for her. On the other hand, I now secretly smile that my daughter can have a temper tantrum and run into her room screaming, "it's not fair". I look forward to our weekly "family dates" and am thrilled to be able to get up at 8AM Saturday morning to take her to ballet. I practice random acts of kindness more often. Thus, some of my patches are even sewn there by myself.

Today, I look at my quilt. It was not at what I had expected. However, I must admit I love my Patchwork Quilt. It has given me the chance to feel the entire spectrum of emotions, the chance to see the resilience of life, and the chance to experience the goodness of people. With each patch, I see someone who has touched my heart and healed my soul.

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More Casino Party photographs



Lanigan, Ryan, Malcolm and Doyle, P.C. Charity Golf Tournament

Thank you to Lanigan, Ryan, Malcolm and Doyle, P.C. for choosing the Childhood Brain Tumor Foundation as one of the recipients for the 2002 annual golf tournament. This year the event was held at the Montgomery Country Club on Monday, May 13, 2002. This event marked their 10th anniversary for holding the charitable golf tournament.

The golfers left the course for a short break during a thunderstorm and then resumed playing when the storm passed. At the end of the day a dinner reception was held at the Montgomery Country Club. Sponsors were recognized and many door prizes were given to the attendees.

Again, many thanks to Lanigan, Ryan, Malcolm, and Doyle, P.C. for including CBTF as one of the charities.



NIH State-of-the-Science Conference on Symptom Management in Cancer: Pain, Depression and Fatigue

The National Institutes of Health (NIH) will convene a State-of-the-Science Conference on Symptom Management in Cancer: Pain, Depression and Fatigue, on July 15-17, 2002. NIH Consensus Development Conferences bring together biomedical investigators, practicing physicians, consumers, and representatives of public interest groups to evaluate state-of-the-art scientific information and resolve controversial issues in clinical practice. http://consensus.nih.gov/news/upcoming/cancer/cancer_info.htm#overview This conference will be webcast live. Visit the NIH Videocast website <http://videocast.nih.gov/> for a live webcast of the conference, beginning at 8:30 am on July 15, 2002. Click on "Today's Events," and select "Symptom Management in Cancer." Viewing the webcast requires RealPlayer software which can be downloaded free of charge from the NIH Videocast website.



Remembrances

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



*Joseph Sanford
May 11, 1992–
June 19, 2002*

The Sanford family would like to convey their deep appreciation to the Childhood Brain Tumor Foundation for their support of Joe and all those who supported the Foundation in Joe's honor over the past several years.

If You Could See Where I Have Gone

If you could see where I have gone,
The beauty of this place,
And how it feels to know you're home,
To see the Saviors' face.
To wake in peace and know no fear,
just joy beyond compare.
While still on earth, you miss me yet,
you wouldn't want me there,
If you could see where I have gone.
If you could see where I have gone,
had made the trip with me,
You'd know I didn't go alone.
The Savior came with me.
When I awoke, He was by my side,
and reached out his hand,
Said, "Hurry Child you're coming home
to a grand and glorious land,
Don't worry over those you love,
for I'm not just with you,
And don't you know, with you at home,
they'll long to be here too".
If you could see where I have gone,
And see what I've been shown,
You'd never know another tear
or ever feel alone.
You'd marvel at the care of God,
His hand on every life,
And realize he really cares,
and bears with us each strife,
And that he weeps when one is lost.
His heart is filled with pain,
But oh! the joy when one comes home,
a child is home again.
If you could see where I have gone,
could stay awhile with me,
Could share the things that God has made,
to grace eternity.
But no, you could never leave,
once Heavens' joy you'd known,
You couldn't bear to walk earth's path,
once Heaven was your home.
If you could see where I have gone,
you'd know we'll meet someday,
And though I'm parted from you now,
that I am just away.
So, thank you family, thank you friends,
for living for the Lord,
For teaching me to love Him,
To trust Him and His word,
And now, that I'm at home with Him
secure in every way,
I'm waiting here at Heaven's door,
To greet you some sweet day.

Anonymous

With Love from Joe's family

*In Loving Memory of
Jonathan Littleton Forbus, Jr.*

Thank You

Thank you for being our son.
Thank you for looking down
and saying "They are the ones."

You did more in your four short years;
and with so few tears,
Then many do in eighty years.

No matter what challenges you faced;
you always had a smile
upon your angelic face.

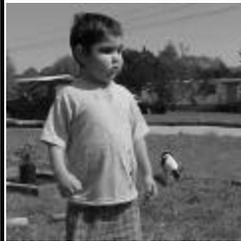
You made us proud to be your parents;
with your strength that was so
apparent.

Thank you for being our son:
For looking down and saying
"THEY ARE THE ONES"

*In Memory of
Kelly Marie Pendleton*

Should you go first and I remain
One thing I'll have you do
Walk slowly down that long, long path
For soon I'll follow you
I'll want to know each step you take
That I may walk the same
And someday down that lonely road
You will hear me call your name
Yes, you will hear me call your name.

Anonymous



Jonathan

*Fond memory brings the light of other
days around me.*

Thomas Moore

