

# Brain S.C.A.N.-Sharing, Caring, Advocacy & News

# www.braintumorawareness.org

### Your business tag line here.resource for raising awareness and gaining support!

November 2008 Newsletter

email: subscribe@braintumorawareness.org

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# The BTAO collects 20992 miles for their Awareness Event

The Brain Tumor Awareness Organization collaborated with several fitness groups this year to encourage brain tumor awareness and fitness by collecting miles from South Carolinians for the 2008 <u>"Walk</u> <u>Around the World for Brain Tumours"</u>. Actual walk or run efforts are calculated for the IBTA event and the BTAO brought in a total of **2277** pedestrian miles!

The Brain Tumor Awareness Organization (BTAO) held a 'virtual' walk last year and pledged 25 miles and raised 25 dollars. This year was a success due to the many state residents who learned about the BTAO, the IBTA and why awareness about brain tumors is crucial to increase survival. Though our fundraising goal wasn't reached, much needed funding was provided to allow us to continue our fundraising efforts into 2009.

The <u>2007 "Walk Around the World for Brain Tumours"</u> logged 24,901 miles (40,000 kilometers) A large number of events, including 83 walks, were held in a total of 18 countries.

Although the actual Walk miles contributed to the International goal to encircle the globe are calculated on pedestrian efforts, the BTAO has decided in an effort to embrace all fitness activities that individuals may choose, the organization will collect all miles as a state initiative and encourage future walks whereby the donated miles to the IBTA event are increased. Our goal was to reach 6,000 miles (1,000 miles for each year of survival in honor of our co-founder, Keith Houston) and made it almost halfway! We want to thank the following teams:

The Palmetto Peloton Project (P3) Challenge to Conquer Cancer (C3) pledged 12208 miles Read about their journey -<u>Ride To Austin</u> Follow Keith's Journey on his <u>blog</u>.



Keith Houston (L) and Kevin Dunn ® at the LIVESTRONG Challenge in Austin Texas

The inaugural Jerry

Zucker Ride for Hope donated a total of 6480 miles.

<u>Courageous Kidz</u> pediatric brain tumor members donated 24 miles!

Golden Strip YMCA members donated 990 miles!

The <u>Sportsclub</u> of Greenville members donated 43 miles!

If you would like to sponsor or host a walk or fitness event, raise awareness and begin logging miles, please <u>register</u>.

Written by J. Houston

# The Jerry Zucker Ride For Hope

The BTAO was honored to be an exhibitor at the first inaugural Zucker Ride for Hope in Charleston, SC. It was a perfect day for a cycling event and the first visit for this Upstate resident to Daniel Island.

The area was a perfect welcome for the many supporters of this fundraising event to support the Lance Armstrong Foundation and Charleston area charities.

There were 100 cyclists and the event raised \$100,000 to make an impact on cancer in the community.

See video interviews on <u>ICYOU.com</u> Enjoy <u>pictures</u> from the ride. "We're just really trying to make Charleston a little bit more like other towns like Austin, Los Angeles, Boston where they actually have a strong cancer community that fights for awareness...you can't raise awareness in anonymity...We're known for the bridge run..the cycling community is growing by leaps and bounds in Charleston. It will give us a foot in the cancer community where we can network around the community with other cities that have cancer rides connected with The Lance Armstrong Foundation." -Michael Dennis

Fundraising Chair-BTAO

Written by J. Houston

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- Social Security 7 announces Compassionate Allowances for immediate access to Disability Benefits





All the efforts that the BTAO makes depends solely on online fundraising and donations-we need you to spread the word so we can spread the resources!

\$10 supplies a Brain Tumor Resource Guide and LIVE**STRONG** Survivorship Notebook

L

\$25 provides for internet access costs to connect to support resources and networks.

*\$75 can be applied towards a utility bill.* 

\$100 can be applied towards a mortgage or rent payment.





## Be a Brain Tumor Advocate-Raise funds online through our affiliate programs!

Currently, The Brain Tumor Awareness Organization (BTAO) is engaging in a fundraising drive until the end of the year to provide for materials and distribution costs! We need your assistance by participating in the various affiliate programs we have!

BRAIN S.C.A.N.

Join at <u>iGive.com</u> and every time you shop online, you will be making a donation to the BTAO!



### Here's a list of our 680+ stores

Giving gifts of quality are a great way to spread awareness and raise funds. Check out:



Watkins Vanilla Extract, Black Pepper and Cinnamon are just a few of the classics!

Every <u>Goodsearch</u> earns the BTAO one cent! Put this message in your email signatures:

Join me and <u>Goodsearch</u> for The Brain Tumor Awareness Organization!

Order inks through ClickInks.com!

# Current Fundraiser

Seasonal gifts and stationery products, great gadgets and more earn the BTAO 50%!

The Entertainment Book- A savings book to save you 50% off most restaurants and activities plus the benefit of additional printable discounts, offers and benefits through online access, also your online membership\_features nationwide 50% off discounts on everything from restaurants, hotels and family activities to groceries, dry cleaning and car repair.

Recycle used printer cartridges and cell phones... easy to collect counter top box. <u>Register online</u> today to benefit the BTAO!

View the list of our qualifying cartridges and cell phones.

Please consider your end of the year gifting. The Brain Tumor Awareness Organization is a 501 c 3 non-profit organization. Donate through Paypal

### Become a Grey Ribbon Campaign Sponsor!

We can raise awareness in South Carolina during Brain Tumor Awareness Month in May of 2009. With your help, we can raise funds and provide support for brain tumor survivors in our communities!

# Donation items needed for MissionFish Auction

Do you have an item that you would like to donate? Would you like to place it up for auction? Did you know that you can benefit The Brain Tumor Awareness Organization through an online auction?

Ebay provides for non-profits a way to collect auction items from sellers and conduct online auctions. <u>MissionFish</u> to donate, sell or buy items that benefit The Brain Tumor Awareness Organization.

Sellers can set their price, choose what % they want to contribute to our organization and MissionFish handles the rest for a small fee. All transactions are secure and guaranteed through PayPal, which allows you to send and receive money using an email address. MissionFish provides a great online promotion tool to enable non-profits to reach beyond their physical boundaries to supporters from around the world.



# To sell your item:

Visit <u>Ebay</u> and choose the Sell tab Click on the <u>Start Selling</u> tab Select a Category Find a matching category Choose a listing form>More Listing Choices Scroll to the bottom of this form Choose "select a nonprofit that you love" Type in The Brain Tumor Awareness Organization Choose % that you want to benefit BTAO And you are done!

# "Heads Up To Heroes" \* Daring \* Surviving \* Thriving

Jennifer was diagnosed in November 2003 with a brain stem tumor, shortly after the birth of her first son. She chose to fight and not give into this horrible disease. Dying was not an option! Since that day, she had seen multiple physicians across the country, completed 23 rounds of chemotherapy and under went Cyber Knife Radio Surgery. Prior to her diagnosis, she was working full time as a nurse and still longs for the day when she can return to work.

She began her volunteer work back in high school when she volunteered as a candy striper with the American Red Cross. Then went on to volunteer teaching CPR classes and working in their office. She is still in the mind set of helping others and volunteers as the facilitator for on line support groups and at the Wellness Community. Since her diagnosis, she has been involved in helping set up local fund raisers to benefit brain tumor research. She is also waiting for training to become a Cyber Knife Ambassador for St. Louis University Hospital in St. Louis Missouri.

Her situation is unique from others. She has experienced cancer from ALL aspects. From being a nurse for oncology patients, to being a patient herself and being a caregiver/advocate for her grandmother and numerous friends.

Jennifer is currently working with Senators in Missouri to pass legislation for a brain tumor awareness license plate. We should have more information about the license plate by December 1st. This license plate initiative is one that needs to happen in every state so that we can raise awareness nationwide. The more initiatives we have started by May 2009, the more success as an awareness community we can have!

"Prior to diagnosis I was working full time as a nurse and long for the day when I can return to work. But then again, I wouldn't really want a nurse with a brain tumor taking care of me!! I was very surprised at the lack of awareness.

I have tried to maintain my positive attitude, except when I could not, and feel that has helped me through out the past 5 years. I am still in the mind set of helping others and am a volunteer facilitator for the young adult brain tumor and adult brain stem glioma online support groups. Since my diagnosis I have been extremely involved in helping set up local fund raisers for brain tumor research. Starting in March, I will be teaching classes twice per month at a local cancer center also. I am very involved in my son's parochial school with organizing new fundraisers.



Jennifer Gutierrez with son Alex and husband Ernesto

My situation is unique from most others I have met. I have experienced cancer from ALL aspects. I was the nurse taking care of oncology patients. Then became a patient myself. I have also been a caregiver/advocate to my grandmother, aunt, uncle and numerous friends. Now that I am feeling "better" I am eager to make a difference and give back as much as I can to our cause. I say our cause since we are all in this together. We have to be a united front to make a difference and have our voice be heard. The knowledge I would gain from the LIVE**STRONG** Summit could be brought back here to St Louis and shared within my community."

> by Jennifer Gutierrez Edited by J. Houston

# Specialty License Plates Can Raise Awareness and Funds

You know the one, the tag on the car in front of you that gives you something to think about...like DC's license tag that says "Taxation without Representation" which left several people scratching their head for a while until you learned that they aren't an official state so they don't have a voice in Congress.

Now *imagine*... if you pulled up behind a car and saw a grey ribbon and it also had the slogan "**Grey Ribbon Awareness**" and when you saw it, you knew everything about what it stood for and what an impact it makes for research funding, support services and community programs.

Though each state's requirements vary and some direct the money to state organizations or agencies, it is an initiative that has begun in the State of Virginia.

The supporters of this initiative did have a bill introduced HB5024 but since the Commonwealth of Virginia required that 350 prepaid plate registrations be collected before the plate became a reality, it makes it a difficult goal. Visit www.braintumorawarenessplate.com The bill was tabled in 2007 with 2008 being the look forward for further action. As of this writing, the author is unsure of the current status.

As mentioned in the Hero article above, Jennifer Gutierrez is giving it a go at the Missouri Legislature to make it happen in her home state. We think that since Missouri is known as the "Show Me State" this could be a great win should she succeed. So the BTAO decided to lend its affiliates some support for these type of initiatives and set up a section on our website where you can register online for your Brain Tumor Awareness specialty plate and if we can meet the number of signatures so that we can recruit an affiliate to be the point person to walk it through their state's legislature...so be it. The BTAO isn't collecting any monies but simply a signature list for support within each state. We will update you as to how many supporters sign up for such a plate. After all, our first National Brain Tumor Awareness Month is May 2009! We are only just beginning!





It's a matter of time...

# Mark Your Calendar:

Pocheptsov Preview/ <u>Nutcracker Ballet</u> Dec. 20-21,2008

# **Feleconference on Gliomas**

Dr. Howard Fine Dec. 2nd, 2008

CancerCare Caregiver Telephone Workshop Coping with the Holidays

Pediatric Brain Tumor Foundation Radiothon



La Vie en Musique



Waiting for a Kiss



Time Tunnel

## BRAIN S.C.A.N.

# BTAO announces Arts Auction and Gala in honor of George Pocheptsov

The Brain Tumor Awareness Organization is proud to present George Pocheptsov to South Carolina through an arts auction and gala planned for two locations in the Spring of 2009.

The Greenville event will be in conjunction with the <u>International Ballet</u> Spring performance of "<u>Don Quixote</u>" April 4th, 2009 at The Peace Center. A silent auction and reception will take place prior to the performance to introduce George, his mother Dubrava and his work.

The Charleston event is to be announced.

George's works will be on display at the Peace Center during the International Ballet performance of <u>'The Nutcracker'</u> December 20-21st, 2008.

The International Ballet was founded by professional Ukrainian dancers in the Upstate and conducts a student exchange program between the Ukraine and the United States to showcase international talent in Kiev and Greenville.

The Houstons have been involved with the International Ballet (IB) for the last 5 years when their daughter joined the ballet company and Keith became their productions manager. Due to the Ukrainian background and international talent that both the members of IB and George Pocheptsov share, it was their vision to bring them together in a benefit event to support both non-profits. George's connection to the mission of The BTAO is due to the loss of his father to a brain tumor when he was only 3 years of age. The proceeds from the Greenville Auction and Gala event will benefit the International Ballet and The Brain Tumor Awareness Organization (BTAO).

George was born in Philadephia, Pennsylvania in 1992 to Ukrainian parents. When George was 11 months old, his father became ill with a brain tumor. He died in 1995 at the age of 40. Though he was just a toddler, his mother gave him a pencil and some paper to keep him busy. At 17 months he drew a remarkable replica of an antique car parked across the street. At an age where most children has barely graduated from finger painting, George was drawing jesters, pregnant women and four-headed giraffes, all in luminescent colors. he began to paint 6 months before he began to talk. For many experts, George is, without question, a child prodigy. This man has a unique an exceptional talent. George has appeared in many leading magazines, including TIME, People, Parents, U.S. Art,

Art and Antiques, Art News Architectural Digest, Southern Living, Spirit of Carolina, Wilmington and many others. He has also made appearances on the Oprah Show, Good Morning America, The John Walsh Show, The Today Show, Ripley's Believe It Or Not, Later Today Show, The Rob Nelson Show, The Amanda Show, and Nickelodeon. Today, at 15, George is often hailed by the press as a young Picasso or Chagall, and his paintings sell for up to \$100,000.

During the last eight years, George has been commissioned to do paintings for Colin Powell, Celine Dion, Michael Jordan and Alan Ducasse. He was commissioned to do 3-D paintings for the Camera Museum in London and the United Nations' 60<sup>th</sup> Anniversary Show. Internationally, George has been featured on television programs in England, France, Korea, South Africa, Holland, Russia, Japan, and the Ukraine.

Recently, George has been selected as North Carolina's for the official commemorative art for the <u>62<sup>nd</sup> annual NC Azalea Festival.</u> The documentary film about George, "**Brush** 

*With Destiny"* won an Emmy Award and was produced by Michael Cogdill, Greenville WYFF Channel 4 anchorman.

George was welcomed by Greenville previously when he benefited the Ronald McDonald House through the donation of one of his paintings. He recently benefited Duke Hospital and generated \$60,000 through his art alone for their program.

Recently, George was featured on WCNC-TV and shared with viewers his amazing talents and extensive works.

If you are interested in displaying George's paintings during the holidays at an affair, please contact Julie Houston or call at 864-836-4609.

"We know that this is an honor and a privilege to be able to showcase George's art in South Carolina and would welcome other venues to share this opportunity with." -J. Houston

President-BTAO

If you are interested in assisting with our benefit, please <u>contact us</u>. We welcome donated items to add to this auction to provide funding for programs and resources for brain tumor patients.

# Bradmer sponsors physician panel to raise awareness of brain cancer treatments

TORONTO, Nov 05, 2008 / PRNewswire-FirstCall via COMTEX/ – TSX: BMR Bradmer Pharmaceuticals Inc., a biopharmaceutical company dedicated to the development and commercialization of cancer therapies, announced today that it is participating in a GBM (glioblastoma multiforme) Awareness Day as a co-host with Voices Against Brain Cancer. The event will take place on Wednesday, November 12, 2008, at the Four Seasons Hotel in New York City. The panel discussion will begin at 4:15pm ET. Dr. Alan M. Ezrin, President and Chief Executive Officer of Bradmer will present the Company's Neuradiab(TM) therapy, and an expert panel of physicians will discuss current trends and therapeutic advancements in the treatment of GBM, the most common and most advanced form of brain cancer.

The expert panelists include:

Steven Rosenfeld, M.D., Columbia University Medical Center (Moderator)

Henry Friedman, M.D., Duke University Medical Center

Keith Black, M.D., Cedars-Sinai Medical Center

Pamela New, M.D., Methodist Neurological Institute

Joycelyn Speight, M.D., Ph.D., University of California, San Francisco, Medical School

David A. Reardon, M.D., Duke University Medical Center

Michael R. Zalutsky, Ph.D., Duke University Medical Center David M. Bailey, Patient Advocate

The event will be broadcast live via a webcast presentation accessible from the Company's website

at <u>www.bradmerpharma.com</u>. Please connect at least 15 minutes prior to the start time to ensure adequate time for any software download that may be required to join the webcast. The webcast will be archived for 30 days on Bradmer's website.

About Glioblastoma Multiforme Glioblastoma multiforme (GBM) is the most common and most advanced form of brain cancer with approximately 30,000 new cases diagnosed each year in the world's seven largest healthcare markets. Unlike many other solid tumors, GBM tumors do not metastasize, but cause symptoms and often death through invasion of nearby tissues and impairment of brain function. The current standard of care, consisting of surgery, radiation and adjuvant chemotherapy (temozolomide), extended average overall patient survival from 53 to 64 weeks. About the GLASS-ART Trial(TM) ( www.glassarttrial.com) The Phase III GLASS-ART Trial derives its name from its description: GBM Locoregional Agent Survival Study - Antitenascin Radiolabeled antibody Therapy Trial. The study is designed to determine the survival benefit derived from, and safety of, adding Neuradiab to the current standard of care therapy for patients diagnosed with primary glioblastoma multiforme. The randomized trial will enroll up to 760 patients at leading treatment centers across the United States. Additional information on the trial can be found at www.glassarttrial.comor at www.clinicaltrials.gov and then by searching the term "Bradmer" or the study identifier NCT00615186. About Neuradiab(TM) Neuradiab is a monoclonal antibody, conjugated to radioactive iodine, used to treat glioblastoma multiforme (GBM), the most common and most advanced form of

brain cancer. Neuradiab delivers tumor-killing radiation specifically to residual brain tumor cells after surgery, with minimal impact on normal brain tissue. During the course of development at Duke University, over US\$60 million in research grants and related support has produced a series of Phase I and Phase II clinical trials on Neuradiab and other closely related technologies. Approximately 200 brain cancer patients, including over 160 with GBM, have been treated with the Neuradiab therapy regimen, and survival benefits have significantly exceeded historical controls in each completed trial. Neuradiab has been formerly referred to in literature as 131-I anti-tenascin monoclonal antibody 81c6. GBM tumors typically have infiltrating edges that are very difficult to completely remove with surgery. The Neuradiab therapy is delivered directly into the surgical resection cavity in a separate procedure after the initial surgery. Neuradiab delivers a concentrated level of radiation specifically to the remaining cancer cells by targeting tenascin. Tenascin is a protein over-expressed in 99% of GBM cells but absent from normal brain cells.

# About Bradmer Pharmaceuticals Inc. (<u>www.bradmerpharma.com</u>)

Bradmer Pharmaceuticals is a biopharmaceutical company focused on the development and commercialization of new and innovative cancer therapies. Bradmer's lead clinical candidate. Neuradiab, was developed at Duke University Medical Center as a proprietary therapy for a particularly aggressive form of brain cancer, glioblastoma multiforme. Bradmer has initiated enrollment in a Phase III multi-center clinical trial of the licensed treatment. Neuradiab has been granted Orphan Drug Status by both the U.S. Food and Drug Administration and the European Medicines Agency, Bradmer Pharmaceuticals Inc.'s common shares have not been registered under the Securities Act of 1933, as amended (the "Securities Act") or any state regulatory agency in the United States. The resale or transfer by a U.S. investor of such common shares of Bradmer Pharmaceuticals Inc. is subject to the requirements of Rule 904 of Regulation S of the Securities Act or such other applicable exemption thereunder, and other applicable state securities laws. Except for historical information. this press release may contain forward-looking statements, which reflect the Company's current expectation regarding future events. These forward-looking statements involve risk and uncertainties, which may cause but are not limited to, changing market conditions, the successful and timely completion of clinical studies, the establishment of corporate alliances, the impact of competitive products and pricing, new product development, uncertainties related to the regulatory approval process and other risks detailed from time to time in the Company's ongoing quarterly and annual reporting.

Watch the Webcast.

SOURCE Bradmer Pharmaceuticals Inc. (not pictured-Dr. Pamela New)



Keith Black, M.D.



Joycelyn Speight, M.D., Ph.D.



David A. Reardon, M.D.



Michael R. Zalutsky, Ph.D



Henry S. Friedman, M.D.



**David Bailey** 

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# Young Adult Resources





LIVESTRONG ANCE ARMSTRONG FOUNDATION

Young Adult Podcast Series at LIVESTRONG.org







The Kennedy-Hutchison bill is the first time ever in history that 7 Democrats and 7 Republicans have come across the aisle to address healthcare reform.



We are neither pediatrics nor geriatrics, we have unique needs- medically, socially, and economically.

However, the rights and dignity of adolescent and young adults are equal and vital to all individuals.

> We deserve to have our beliefs, privacy, and personal values respected.

> > Access to care is a right, not a privilege.

Our rights, as we perceive them to be and intend to preserve them, are:

1. The right to be taken seriously when seeking medical attention to avoid late diagnosis or misdiagnosis, and entitlement to separate and confidential discussions regarding our own care.

2. The right to affordable health insurance, as well as early detection tests unhindered by insurance or socioeconomic status.

3. The right to be offered fertility preservation as well as current information and research regarding ongoing and

potentially lifelong effects of cancer treatment that would affect our fertility.

4. The right to be informed about available clinical trials and given reasonable access to them.

5. The right to untethered access to adolescent and young adult cancer specialists and, when requested, a second opinion regardless of insurance or geographic location.

6. The right to access a social worker or caseworker who is well-versed in adolescent and young adult cancer specifics.7. The right to "generationally applicable" psychosocial

support. 8. The right to have our insurance and position as a student or employee protected by law while dealing with our cancer in order to minimize discrimination.

9. The right to clear explanations regarding the long-term side effects of our disease and its treatment, and to be offered all available and applicable physical reconstruction and rehabilitation options.

10. The right to have all of our treatment options explained to us in full detail, to have our questions answered, and to receive clarification when requested so that we can be an active part of our own care.

Preserve our potential.

Visit <u>www.seventyk.org</u> and sign the petition today! Source-www.seventyk.org

# Intro to Cancerbill.org

Adolescent and Young Adult Cancer Bill of Rights

### What is Cancerbill.org?

Senator Kennedy and Senator Hutchison are renewing the war on cancer and introducing legislation that will take a comprehensive approach to addressing the human cancer experience-from prevention to diagnosis to treatment and cure.

The cancer advocacy community has formed a partnership to facilitate easy access to information about this bill as it progresses as well as opportunities for you to write to your U.S. Senators and Representatives encouraging their support for its passage.

### Why?

1 in 3 women and 1 in 2 men will be diagnosed with cancer in their lifetime. We have made great advances in knowledge, research and treatments have increased survival but it isn't enough.

#### Get Involved

The website provides easy ways to share your story with policymakers, tell others how to get involved, or contact Congress with your concerns.

### Why Take Action?

Change is driven by people and organizations who commit to making a difference and engaging others in the process. When this important legislation is filed, you will updated via email and can lend your support to see it passed.

#### Upload your video story or share your photo to accompany

**your story**–<u>Here</u> you can deliver why renewing the war on cancer is important to you! Let your voice be heard and encourage your friends and family to participate-when we unite, we make a difference!The Kennedy-Hutchison cancer bill will modernize the war on cancer by reinvigorating the country's commitment to research, prevention, treatment, and quality care for people with cancer. Here are the types of undertakings the bill is expected to include:

- Significantly enhancing research efforts through increased funding to the National Cancer Institute, incentives for private investments in research, and programs encouraging collaboration among government and private researchers;
- Raising participation in clinical trials, which currently stands at only five percent of adults with cancer, even though clinical trials often represent the best treatment options;

Investing in programs to promote healthy behaviors that are known to decrease cancer risk, such as smoking cessation and healthy nutrition;

- Improving access to early detection and care, including developing ways to expand access to screening and treatment for underserved, uninsured, and underinsured populations;
- • Helping patients navigate the healthcare system and better coordinating their care;
- Addressing a workforce shortage in oncology by encouraging more doctors and nurses to enter the oncology field.

By taking a comprehensive approach to the complex issues surrounding cancer, this bill may be the most far-reaching cancer legislation of the 21st century and one of the greatest opportunities we have as a nation to win the war on cancer. <u>Find out more about</u> <u>CancerBill.org</u> and the <u>partners</u> involved in this effort.

## Lotsa Helping Hands- a service of the Brain Tumor Society

# What does Lotsa Helping Hands provide?

In literally minutes, a Coordinator can <u>create</u>, freeof-charge, a private and secure Lotsa Helping Hands web community, define volunteer activities using the supplied templates, and begin inviting members to the community. Through an intuitive interface that requires no training, volunteers can then easily view and sign up for any number of available tasks, review their current commitments, and be confident they won't forget any assignments as the system automatically sends out email reminders of upcoming obligations.

Community members also have access to the community's private message boards, photo galleries, resource sections for sharing relevant web links Lotsa Helping Hands

and documents, and even a Well Wishes wall. Any number of custom community sections can be created by the Coordinators to enrich the flow and sharing of information within the community, keeping all members, near and far 'in the loop'.

295.00

View the <u>slideshow</u> to see how this online tool can streamline your caregiver tasks.

Source - The Brain Tumor Society

## **Compassionate Allowances by Social Security Disability Determination**

Social Security has an obligation to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards.

Compassionate allowances are a way of quickly identifying diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal objective medical information. Compassionate allowances will allow Social Security to quickly target the most obviously disabled individuals for allowances based on objective medical information that we can obtain quickly.

Commissioner Astrue has held two Compassionate Allowance public outreach hearings. The first was on rare diseases and the second was on cancers. A third hearing on brain injuries is planned for November 18, 2008.

The initial list of Compassionate Allowance conditions was developed as a result of information received at public outreach hearings, public comment on an Advance Notice of Proposed Rulemaking, comments received from the Social Security and Disability Determination Service communities, and the counsel of medical and scientific experts. Also, we considered which conditions are most likely to meet our current definition of disability.A modest 50 conditions have been selected for the initiative's rollout. The list which follows may expand over time.

Initial List of Compassionate Allowance Conditions

Included are:

Astrocytoma - Grade III and IV

Glioblastoma Multiforme (Brain Tumor)

Additional information about how compassionate allowances are processed

Source-www.ssa.gov

#### Editor's Note:

It is encouraged that if you have been diagnosed with either of the above brain tumor types and have not received your benefits OR been previously denied, that you contact your caseworker and inform them that you qualify under the Compassionate Allowances ruling. Also, it is encouraged to ask how this affects the timeline for benefits and payments disbursement for your individual case. This suggestion isn't to replace any legal advice as each individual's case is unique but with this new ruling occurring this month, it may be helpful to your caseworker to have it the ruling brought to their attention on your behalf.



Connecting with others during your journey:

**CarePages** 

Caring Bridge

RealityCharity.com

T.H.E. BRAIN TRUST

## The Group Loop

ر <u>The Wellness</u> <u>Community</u>

LIVESTRONG Survivorcare

National Brain Tumo Foundation on Facebook

Brain Tumor Society on Facebook

**BTAO on Facebook** 



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# The Brain Tumor Awareness Organization

Contact us: news@braintumorawareness.org Phone: 555-5555

Want to be a news correspondent for BTAO?

Contact us and we will put you in our newsroom!

Read our newsletter online: www.braintumorawareness.org/ scan.html

 Subscription Options:

 Subscribe
 Unsubscribe

 Update
 your email address or information

The Brain Tumor Awareness Organization was founded by a patient and a caregiver, to provide an interactive resource community. This community will provide access to resources and be enhanced by an advocacy network who uses it to raise awareness and provide support. Bringing talents together in a web community will empower survivors and advocates to provide valuable assistance to those new on this journey-simply by sharing this website! Become a state affiliate and you can host your own web page within this community, update your events here, and raise awareness and funds for your community!

Join today and help us develop this advocacy network!

www.advocate.braintumorawareness.org

# The National Brain Tumor Foundation and The Brain Tumor Society Merge

If you have visited either organization's website lately, you will see that there is something exciting on the horizon.

Two brain tumor organizations are merging and will bi-coastal in their operations. The organization will be known as **The National Brain Tumor Society.** 

The National Brain Tumor Foundation (NBTF) (www.braintumor.org) began in California and The Brain Tumor Society (TBTS) (www.tbts.org) began in Massachusetts in the 1980s by families who experienced the loss of children to brain tumors.

Collaboration strengthens any cause and these two fine organizations will bring together their respective programs and services to better serve those affected by brain tumors.

NBTF provides some great services such as online teleconference series to keep you informed about the latest treatments and also hosts <u>Caregiver</u> <u>Training</u> Workshops at centers across the U.S.

TBTS offers unique opportunities for individuals to connect such as the <u>Patient and Caregiver Support</u>

<u>Network</u>; <u>The Storybee</u>-a story telling website partner and <u>Lotsa Helping Hands</u>-a volunteer coordination online calendar service.

All of these programs have made significant differences in survivors. Both organizations are dedicated to increase research funding and to improve the quality of life for brain tumor patients across the nation.

Many resources are available to download, order or view online. If you are looking for more personalized support, you can contact them directly:

NBTF 1-800-934-2873

TBTS 1-800-770-TBTS (8287)

Look for the new identity for National Brain Tumor Society will debut in late 2008.

Source :http://www.braintumor.org/GeneralMenu/



# synergy:

'the interaction or cooperation of two or more organizations, substances, or other agents to produce a combined effect greater than the sum of their separate effects'