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National Brain Tumor Society

The 2nd Annual International Brain Tumour Alliance "Walk Around The World for Brain Tumours"

The International Brain Tumour Alliance (IBTA) was established during the conference of the World Federation of Neuro Oncology held at Edinburgh (UK) in May 2005.

It seeks to be an alliance of the support, advocacy and information groups for brain tumour patients and careers in different countries and also includes researchers, scientists, clinicians and allied health professionals who work in the area of brain tumours.

The IBTA held its first awareness event last year during the last week of October to globally connect those dedicated to eradicating brain tumours. People are encouraged to undertake sponsored or unsponsored walks to raise awareness about brain tumours and to donate the mileage covered to the World Walk target of circling the earth three times at the Equator (75,000 miles or 120,000 kms).

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

The Brain Tumor Awareness Organization (BTAO) held a 'virtual' walk last year and pledged 25 miles. This year we bring together individuals from around the State of South Carolina and beyond to pledge their miles and their funds to raise awareness.

Although the Walk is on the International Calendar for October 26-November 1, 2008, the BTAO is pleased to participate this year with several events to raise awareness and funds for our programs. Our goal is to pledge a total of 6,000 miles (1,000 miles for each year of survival in honor of our co-founder, [Keith Houston](#))

Keith has been training through the Cancer Well-fit Program at [Sportsclub](#) of Greenville for the **LIVESTRONG** Challenge ride in Austin, TX October 25-26, 2008. He will be donating his cycling miles and a portion of the funds raised to the walk event on behalf of the BTAO.



Keith is 43 and a two time cancer survivor- 13 yr. testicular and 6 yr. brain tumor

Keith has challenged Sportsclub members to pledge fitness miles from their workout routines to the international event. Though the only miles eligible for the contribution to the IBTA initiative must be actual walked miles, the BTAO is encouraging fitness miles realized throughout any form of participation. We know that South Carolinians will raise awareness for our cause and log plenty of miles for our effort.

Keith also is excited to support the [Challenge to Conquer Cancer](#) (C3) cycling teams on their relay from "The Hills of Hincapie to the Land of Lance". He will serve the team as their medic on their fundraising journey from Greenville, SC to Austin, TX which will benefit the Greenville Hospital System Oncology Research Institute. The cyclists are members of [The Palmetto Peloton Project \(P3\)](#) which exists to promote the advancement of cancer research and advocacy efforts locally, regionally and nationally through fundraising cycling events. Over the last three years, P3's events have attracted hundreds from across the country and raised over \$330,000 for cancer research and advocacy.

The P3C3 teams have pledged their cycled miles to this International awareness event to support Keith Houston, a 13 year testicular cancer survivor and six year brain tumor survivor, who recently joined forces with the P3 as a [Greenville Army](#) leader to recruit army members and raise funds for the Lance Armstrong Foundation and support local events to further the LIVESTRONG mission.

The inaugural [Jerry Zucker Ride for Hope](#) will also be held October 26, 2008 in Charleston, SC in honor of one of its prominent citizens who lost his battle to a brain tumor in April. The cyclists will be donating their miles to the BTAO walk and raising awareness and funds for the cause. The BTAO will be sponsoring a Travelers Rest resident, Janet MacCallum and her husband to ride tandem in the event. Janet is a 22 year GBM survivor after receiving radiated cancer cells as part of a clinical trial. Janet lost both her parents to GBMs and currently has a relative in England battling a GBM. Janet will ride in their honor and she LIVES **STRONG** as the board secretary of the BTAO.

We have also challenged several area universities to donate their fitness miles to the Walk. All volunteers are encouraged to raise awareness by downloading our [awareness bib](#) and pinning it to their shirts for their awareness activity.



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 LIVESTRONG Survivorship Notebook

\$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!

Join at iGive.com 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 Goodsearch earns the BTAO one cent! Put this message in your email signatures:

Join me and Goodsearch for The Brain Tumor Awareness Organization!

Order inks through ClickInks.com!



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. [Register online](#) 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!

VOTE YELLOW!

Election time is upon us. So many issues to consider and so much change is needed. When I think about the one thing that has impacted my life and most everyone that I know, it became clear to me that cancer was on the top of my list.

Cancer is a national priority.

Ask anyone you know if they have been touched by cancer and if it became an immediate priority to them. This is what we have to do with our time, talents and tenacity- renew the war on cancer and make it a national priority.

I learned what the definition of [VOTE YELLOW](#) is at the [LIVESTRONG Summit](#) in Ohio this past summer:

Vote Yellow (vōt • yel-ō)

1. n. An expression of choice made by 12 million cancer survivors and their loved ones.
2. v. To declare one's opinion that our leaders should make cancer a national priority.
3. n. A philosophy believing it unacceptable to lose 560,000 Americans to cancer each year.
4. n. LIVESTRONG™

Editorial by J.Houston

Reference-www.livestrong.org

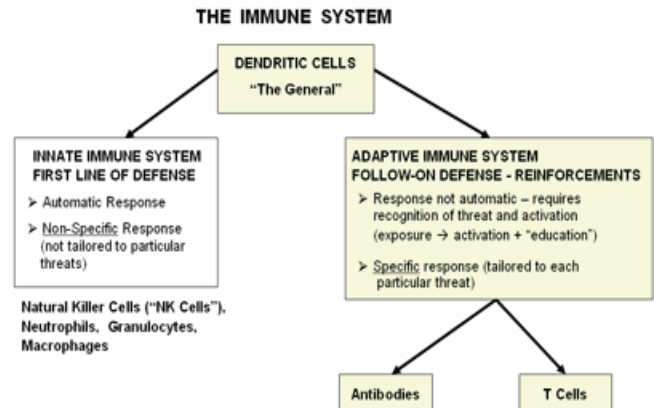
Long-Term Phase I and Phase I/II Trial Data Continue to Show Striking Improvement In Survival of Brain Cancer Patients Who Receive DCVax®-Brain

DCVax®-Brain is a groundbreaking personalized vaccine that takes a patient's own immune cells and trains them in the laboratory to attack the biomarkers from that patient's own tumor cells. The 10-day manufacturing process produces several years of personalized vaccine for a patient, making DCVax®-Brain an "off-the-shelf" product for that patient throughout the treatment period. DCVax®-Brain is administered as a simple injection under the skin, similar to a flu shot, and is not toxic as chemotherapies are.

The most recent data provides an update for the period since December 31, 2007, concerning both disease progression and overall survival. During that period, only one of the nineteen patients experienced disease progression (at 59.5 months), and only one patient died (at 37.8 months). The long term data from these clinical trials shows that more than 80% of the patients who received DCVax®-Brain showed a clinical response. In contrast, the typical response rates for cancer drugs are in the range of 20 to 25% of patients, and have been as low as 13% of patients with some approved cancer drugs.

[Read more...](#)

Source – Northwest Biotherapeutics



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“Heads Up To Heroes” Daring ❖ Surviving ❖ Thriving

Mary Lowe is a three time cancer survivor-thyroid, brain and breast. Mary became paralyzed in 2000 but after a long fight, she regained the use of her hands and put them back to use, accompanied with her passion, to change the landscape of support within the area of Wenatchee, Washington. Still experiencing difficulty in her neck, and watching carefully 2 benign tumors on the left side of her thyroid, she shares the message that she is a miracle but then so is everyone. Most everyone in the brain tumor community came to own a piece of Mary Lowe's legacy through a collection of works called "I Have This Day" submitted by famous individuals, brain tumor internet group members and Wenatchee residents. This collection serves as a fundraiser for support programs in the Wenatchee area.

She along with Karen Pell a cancer patient and Betsy Tontini, mother of a son survivor of cancer) started "[Our House](#)". It is a home providing residency for 8 patients during chemo and radiation.

Betsy came to Karen and I and talked about the need for patients who lived up by the border or down by Moses Lake who would often stop their treatment due to the fact they just could not keep going having treatment as they would be getting so sick on the way home. So we joined together, found volunteers, money etc. and there started the first "Our House". After several years we sold it and built a larger home which Betsy's husband did much of the overseeing of the building. Sadly also during the time of building Betsy joined Karen and I with the horrid

word of cancer, and sadly hers was terminal. We had a wonderful party in our new house (dedicated to Betsy) to say "goodbye". It was not a sad party but a joyous one and she ran the whole thing. When it was her final time she went to Heaven listening to our CD called "Going Home" produced free with even Willie Nelson doing "Amazing Grace with Mary Lowe."

Mary Lowe's Milestones:

1993-started first cancer [support group](#) in Wenatchee

1994-received the "Coping Heroes" group honor award by the Richard Block Foundation for "Our House"

2000-received the Tim Gullikson Spirit Award. Autism Support Group at church

"The Mary Lowe House" dedicated in her honor

The Story behind the photo...

(as told by Mary Lowe-edited by J. Houston)

"Three years ago it was the time for Lance's walking/running/biking event in Portland. My closest ever friend Sandy Beardsley (Louise) was truly dying. I put Louise because two years prior to that she and I had gone on a wonderful trip to Moab Utah where Thelma and Louise was filmed. (I was Thelma!) The trip was one of a lifetime and we were even up with the actual car. So "Louise" said she was going to do the LIVESTRONG walk. Needless to say hospice and the doctors said something a LOT different. Well finally a doctor friend had an RV and he drove Dan (her husband, Sandy and I) in the RV ... we were invited to where Lance would do



Sandy Beardsley, Mary Lowe and Lance Armstrong at the LIVESTRONG Challenge in Portland, Oregon

the opening ceremony...Lance arrives and SANDY takes over –she kept him there 10+ minutes. Then Lance started the opening ceremony, the bikers went off, then they called Sandy to come and start the walkers. Sandy turns to me, and says..."you said I would be doing this in a wheelchair but I am going to walk the last 17 steps." We come to the end, she slowly gets up, starts to take the steps and the WHOLE place comes to a halt. The press goes crazy. When the day was over (5 pm) we went to the RV and Sandy started her journey home."

In the book we have produced "I Have This Day" I wrote my story of Thelma and Louise. It is the only story or piece we ever have had edited by a professional. Also we contacted Susan Sarandon who wrote a wonderful letter to Sandy and it is in with the story notes.



Dr. Darell Bigner

1937– The Brain Tumor Program at Duke was founded

2007-70 years as the largest & most successful program in the country.

1974– Dr. Allan Friedman joins BTC

1980– Dr. Henry Friedman joins BTC

Read a [Q & A](#) with Dr. Allan Friedman and Dr. Henry Friedman



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.



Darell Bigner awarded the Zuelch Prize-Germany's Most Prestigious Award for Neurological Research

DURHAM -- Darell Bigner, director of The Preston Robert Tisch Brain Tumor Center at Duke, has been awarded the Zuelch Prize, Germany's most prestigious award for basic neurological research.

Monoclonal antibodies developed in Bigner's laboratory are in late stage multi-institutional clinical trials in patients with malignant brain tumors. Promising responses and survival increases are being observed.

Bigner has been at Duke for 41 years, except for two years spent at the National Institutes of Health. In addition to serving as the director of the Preston Robert Tisch Brain Tumor Center, he is the Edwin L. Jones Jr. and Lucille Finch Jones Cancer Research Professor and director of the Pediatric Brain Tumor Foundation Institute at Duke.

He is considered one of the world's leading authorities on brain tumors. He has published more than 500 full-length manuscripts, books, chapters, and reviews on brain tumors. His research focuses on the cause and improved diagnosis and treatment of malignant brain tumors in adults and children.

The Zuelch Prize, awarded annually since 1990, is named in honor of the former director of the department of neurology at the Max Planck Institute for Brain Research in Cologne, Germany, where Bigner studied in the early 1970s. The Zuelch Prize carries an award of \$36,710.

Source– [Duke BTC News](#)

Intro to Cancerbill.org

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 be updated via email and can lend your support to see it passed.

Upload your video story or share your photo to accompany your story– [Here](#) 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. [Find out more about CancerBill.org](#) and the [partners](#) involved in this effort.

A Caregiver's Bill of Rights

by Jo Horne

I have the right:

To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.

To seek help from others even though my loved ones may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

To get angry, be depressed, and express other difficult feelings occasionally.

To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.

To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.

To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer need my full-time help.

To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

Source-Today's Caregiver-Caregiver.com

Study highlights benefits of end-of-life conversations for patients, caregivers

[Dana-Farber Cancer Institutes Researchers](#) have found that contrary to prior beliefs, discussions between patients and providers regarding the subject of end-of-life issues can actually improve quality of life for the patient.

Often an uncomfortable area due to the emotional stress factor, these end-of-life issues were thought to increase a patient's anxiety and therefore impact their overall well-being while undergoing treatment.

On October 8th 2008, the study was published in the *Journal of the American Medical Association* and the results showed that patients who had engaged in end-of-life discussions didn't report increased anxiety or depression over those that hadn't participated in such discussions. In fact, those that had recalled the conversations about these issues, were more inclined to present a level of acceptance regarding their terminal prognosis and expressed the desire for "comfort care" over life-extending therapies.

"This study extends our understanding of the end-of-life experience," says senior author Holly Prigerson, PhD, study principal investigator and director of Dana-Farber's Center for Psycho-Oncology and Palliative Care Research. "To the best of our knowledge, it is the first to show how care received affects the dying patient's quality of life, and the first to show that a patient's health care and quality of life near death significantly influence the adjustment of his or her bereaved survivors."

The 332 patients were part of Coping with Cancer, a six-year longitudinal study of more than 600 adult terminally ill cancer patients and their caregivers recruited between 2002 and 2008.

Preliminary results were announced this past June during the American Society of Clinical Oncology's annual meeting.

Source-EurekAlert.org



Caregiving Support Sources:
[AlzOnline](#)

[National Family Caregivers Assn.](#)

[Family Caregiver Alliance](#)

[Brain Tumor Caregivers](#)



The doctor-patient relationship can make all the difference in one's response to treatment, outcomes and end-of-life care.

The Brain Tumor Awareness Organization

Contact us:
news@braintumorawareness.org
www.braintumorawareness.org

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:
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[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 be 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 [Caregiver Training](#) Workshops at centers across the U.S.

TBTS offers unique opportunities for individuals to connect such as the [Patient and Caregiver Support](#)

Network: [The Storybee](#)—a story telling website partner and [Lotsa Helping Hands](#)—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'