



# Key Updates

Unlocking A Mystery, Increasing Survival and Hope



## Executive Sponsor's Message



This month, the world became more aware of brain tumors when Senator Edward M. Kennedy was diagnosed with a malignant glioma, one of the most serious and deadly forms of brain cancer. While the diagnosis for Senator Kennedy is quite serious and the prognosis grim, we have already seen the best of the community begin to step forward, and a highlight on the kinds of research and innovation that could help extend and save his life and so many others. We hope that there is continued rallying around the desperate need for funding into brain tumor research. This month's newsletter highlights collaborative efforts that organizations like [UnlockingBrainTumors.org](http://UnlockingBrainTumors.org) are making to fund research, and details some of the exciting treatment and research breakthroughs we are beginning to see.

-Steve Coffman,  
Survivor since 2005



## UnlockingBrainTumors.org News

•[UnlockingBrainTumors.org](http://UnlockingBrainTumors.org) has joined with **The Brad Kaminsky Foundation** and **The Musella Foundation for Brain Tumor Research and Information** to found **United Front Against Brain Tumors (UFAB)**, a coalition formed to help pool the resources of the many organizations and individuals, fighting to raise funds for brain tumor research. The group's philosophy is that there is strength in numbers, and that even the smallest organizations or individuals in the brain tumor community can play a significant role in contributing to important research efforts. Watch for more news about UFAB, also known as **The Grey Ribbon Crusade**, and consider joining our cause to maximize our collective impact.

•[UnlockingBrainTumors.org](http://UnlockingBrainTumors.org) will hold its first annual charity golf outing August 18, 2008 at Highland Park Country Club in Highland Park, IL to benefit pediatric brain tumor research. Watch our web site for more details, including how to register, how to support the event with an "In Memory Of" or "In Honor Of" sign, or sponsorship opportunities. The course is challenging but fair and we are looking for a great turnout!



## Medical Updates

•**VirtualTrials.com** links to an article in the Houston Chronicle by Todd Ackerman on noted neurosurgeon Samuel Hassenbusch. Hassenbusch, an M.D. Anderson professor of neurosurgery and a pain control expert who the article reports treated more than 500 brain cancer patients, was diagnosed with brain cancer in 2005. Following surgery and radiation, he began a treatment regimen of combining Temodar, a widely used chemotherapeutic agent, with a new vaccine which had previously only been used alone. According to the article, "In study results to be presented next week at an annual meeting of cancer doctors, Hassenbusch's treatment...significantly prolonged survival of patients with glioblastoma, the most common and aggressive brain cancer..Dr. John Sampson, a **Duke University** neurosurgeon and the principal investigator of the study, conducted at the **University of Texas M.D. Anderson Cancer Center** and Duke said "It appears very promising for a cancer where there's been little hope."

**Medical Updates** continued on page 2.

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### Around The Community

The National Brain Tumor Foundation reports that on May 21, 2008, the United States House of Representatives declared May "National Brain Tumor Awareness Month." By a voice vote, the House approved H. Res. 1124, a resolution sponsored by Representative Janice Schakowsky (D-IL), and by this action established May as National Brain Tumor Awareness Month.

A rich list of upcoming events supporting the brain tumor community can be found at ABTA's web site, [www.abta.org](http://www.abta.org), including the [4th Annual Ron Prime Golf Outing](#) (06/14/08 Bramblewood Golf Club, Holly, MI), the [3rd Annual "Gray Matters" Brunch](#) (06/14/08 Pittsburgh), [4th Annual Callie Rohr Memorial Canoe Race](#) (6/14 - 6/15/2008 Conover, WI), the [5th Annual Tom Ostoich Fundraiser](#) (6/27/08 Wicker Park Pavillion, Highland, IN), the [Sharing Hope Walk the Walk Talk the Talk](#) (6/28/08 UConn Storrs Campus, Manchester, CT), the [2008 Bank of America Chicago Marathon](#) 10/12/2008 Grant Park and the [4th Annual Brain Games](#) (11/01/2008 Westin River North, Chicago) among others.

### Beneficiaries

We are continuing our support of beneficiaries and researchers with targeted identification of those foundations whose mission may best align with our goals. This month, we are pleased to announce several areas of support. Our first annual charity golf outing, to be held August 18th, will benefit pediatric brain tumor research. Separately, we are also pledging support to **BrownBagForACure.org**, an organization dedicated to raising funds for pediatric brain tumor research. And with our co-founding of **United Front Against Brain Tumors (UFAB)**, we are pleased to announce our contribution to a \$20,000 donation (1/3 donated by UnlockingBrainTumors.org) to Emory University for brain tumor research.

If you have recommendations on foundations that we might approach and who you feel might be interested in our efforts, contact [steve@unlockingbraintumors.org](mailto:steve@unlockingbraintumors.org)



### Partners

UnlockingBrainTumors.org continues to believe that by partnering with other like minded organizations, we can work together to achieve a greater, faster and more lasting impact. We are pleased about the upcoming launch of **United Front Against Brain Tumors**, in conjunction with **The Brad Kaminsky Foundation (tbkf.org)** and **The Musella Foundation For Brain Tumor Research & Information**. While each group continues to operate independently to continue its stated mission, we all have an opportunity to expand our collective "footprint" by pooling resources for larger scale and rapid funding. We are committed to gaining representation in all 50 states, with members having a full say on how contributed research funds are allocated. We also continue to reach out to other foundations around the country about opportunities to work together, or to lend our assistance to help them reach their goals. Our model is about helping to raise funds for any important research efforts within the community, and we intend to be flexible to provide the maximum support we can.

### Medical Updates *continued from page 1.*

- The trial's big surprise was that the chemotherapy didn't stop the vaccine from prompting a strong immune response and instead enhanced it. Because chemotherapy kills patients' white blood cells, it is usually considered incompatible with vaccines or, as they're also known, immunotherapy". For more detail, see the article at The Houston Chronicle at <http://www.chron.com/disp/story.mpl/headline/metro/5804850.html>
- A company in Washington, **Advanced Medical Isotopes**, reports it is developing a new isotope treatment that could help thousands of individuals affected by brain tumors, including the recently diagnosed Senator Edward Kennedy. VirtualTrials.com links to an article from KNDO that explains the problem with some tumors, like Senator Kennedy's is "the fingers that sprout off it into the brain. Doctors can often remove the main mass, but those fingers are almost impossible to get or treat". The article reports that the firm is working to produce Astatine-211, a potentially life saving treatment for inoperable brain tumors. "The still being developed isotope could potentially target only the cancerous cells surrounding the brain, allowing doctors to treat patients without damaging vital brain tissue..." "Particularly the inoperable tumors which allows you to basically radiate brain tumors for example and make some progress on those," said Bill Stokes, a company founder. Stokes says the treatments aren't there yet, but promising research shows astatine could be the solution".

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Feedback/Contact Us

We'll soon be expanding our volunteer opportunities, to reflect a growing area of needs as we ourselves grow, launch more fundraising events and need to continue expanding our reach. If you'd like to volunteer in our upcoming golf event on 8/18 or have interest in organizing a wine tasting event to raise funds for our group similar to the one we conducted in April, please contact [mike@unlockingbraintumors.org](mailto:mike@unlockingbraintumors.org) for more information!

Whether you have a preferred beneficiary or project, level of involvement, or simply want to help our team in whatever area possible, we'll make it easy for you to do just that. *We're looking to expand our use of volunteers and partners, so if you have ideas or suggestions, please let us know!*

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How to Support Us

This summer, please consider supporting our golf event, either through participating, a memorial or tribute sign, or becoming an event sponsor. Please visit our site for more details.

Your financial support, either one-time or ongoing, or helping to arrange for UnlockingBrainTumors.org to become a corporate beneficiary, is invaluable to our core mission to raise funds and redistribute them to our beneficiaries, and therefore, directly to research. We also have a need for volunteers who can support UnlockingBrainTumors.org in any number of ways, including fulfillment of fundraising campaigns, event support, marketing, speaking events and other channels. Even linking to [www.unlockingbraintumors.org](http://www.unlockingbraintumors.org) from your site will help to raise awareness for our organization and support our community.

For more information, please contact Steve at (616) 335-9050 (office) or (312) 375-8346 (cell).



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Newsletter content submission is due the 1st of each month. Send content to Mike Tancredi, [Mike@unlockingbraintumors.org](mailto:Mike@unlockingbraintumors.org)

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