

Key Updates

V1 #1 December 2007



Unlocking A Mystery, Increasing Survival and Hope

Executive Sponsor's Message



Welcome to the inaugural issue of *KeyUpdates*, the monthly newsletter of UnlockingBrainTumors.org! If you're reading this, it's because you're already part of our community, whether as an interested party, a volunteer, a donor, or someone else touched by a brain tumor. Our goal is simple: to raise public awareness about this terrible disease, and in turn, to raise funds that we can quickly channel to our beneficiaries who can rapidly put it to work. The goal of *KeyUpdates* will also be simple – to provide you with some quick information about what we're up to at UBT, as well as other members of the community, including coverage of medical advances, our partner organizations and our beneficiaries. Welcome!

UnlockingBrainTumors.org News



UnlockingBrainTumors.org has been extremely busy! Even with our former business leader, Steve Coffman

at the helm, it's been a very busy few months launching the organization. Key accomplishments since UnlockingBrainTumors.org was formed include registration and approval of our 501(c)3 status, development of our logo and identity, creation of a suite of documents to share with you and other interested parties, launch of our initial web site, unlockingbraintumors.org and its successor, and a variety of other behind-the-scenes operation. So much has been completed so quickly, however, that we're able to fully focus on the mission at hand even sooner – raising awareness about brain tumors and the significant need for funding. We've been aided every step of the way by some of the world's leading medical specialists, and comprehensive cancer centers, and **The Musella Foundation**, and continue to benefit from their support and counsel each day.

Medical Updates



Al Musella writes: "Following a letter writing campaign and meetings with Medicare, the **Musella Foundation** was successful in reversing a Medicare decision that would have neglected to include

payment for Gliadel (the wafers implanted into the brain when a tumor is removed - which slowly release chemotherapy) in their massive proposed overhaul of the payment system. Having Medicare remove payment would mean loss of access to this potentially life saving treatment (it reduces the risk of dying over 3-4 years by 27% in patients with high-grade malignant gliomas), as the hospitals wouldn't even be allowed to charge you for it or offer it.

The next crisis Musella is working on is how to pay for the expensive new treatments being tested, such as Avastin and CPT-11, which now costs up to \$600,000 per year. We are also working on trying to figure out what the optimal length of time is to be on Temodar after radiation (and it probably isn't the standard 6 months).

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Stories:

UnlockingBrainTumors.org is soliciting your stories of survival, of hope, or of memories of a loved one who lost their brain tumor battle. Our goal is to continue to bring a human face to this disease by sharing inspiring stories and personal remembrances of our community members. Please visit www.unlockingbraintumors.org and click on "Stories" to submit your story.

www.unlockingbraintumors.org

Around The Community



- The **American Brain Tumor Association** has a full slate of 2008 events listed at its site, including the “**Table of Twelve**” event coinciding with ABTA’s 35th Anniversary. See www.abta.org.
- The **Pediatric Brain Tumor Foundation** reports that one of its research grant recipients, Mario Capechhi, Ph.D., of the University of Utah School of Medicine, has won the **2007 Nobel Prize for Physiology or Medicine**. See www.pbtfus.org
- The **Tug McGraw Foundation** has posted some holiday tips for caregivers or family members that you may find useful. See http://www.tugmcgraw.org/news/caregiver_tips.asp

Beneficiaries

The **Musella Foundation For Brain Tumor Research & Information**, Operated by Al Musella, is our organization’s lead beneficiary. The Musella Foundation is a non-profit organization dedicated to improving the quality of life and survival times for brain tumor patients by using computer technology to index brain tumor clinical trials, streamline the flow of information, organize the brain tumor community and raise money for brain tumor research. It operates www.virtualtrials.com, and has worked tirelessly and successfully to bring attention to clinical trials, patient outcomes, research, letter writing campaigns for expanded treatment options, and a great many other contributions to the community.

Al has alerted us that **The Florida Brain Tumor Association** and **The H. Lee Moffit Cancer Center and Research Institute** present “*The Bridge To Hope*” - a conference for survivors, friends and health care professionals, January 18-19, 2008, in Tampa, FL. For more information or to register, visit: <http://www.fbta.info/register.html>

Partners



In addition to its lead beneficiary, we will also work closely with leading members of the brain tumor community, including **The International Brain Tumour Alliance, The American Brain Tumor Association, The Brain Tumor Society, the National Brain Tumor Foundation, the Pediatric Brain Tumor Foundation** and many others. Additionally, the foundation will align with and enjoy support from leading experts in the field, from some of the nation’s finest medical systems and comprehensive cancer centers.

Medical Updates *continued from page 1.*

Another pet project of the **Musella Foundation** is the microbeam radiation project being done at **Brookhaven National Lab** by Dr Dilmanian. This is a new form of radiation that potentially may work better and have fewer side effects, and as such may be able to be used over and over again if the tumor recurs. This is especially important in children, whose brains are more sensitive to radiation. This is in an early stage, currently working on rats only. The process involves many small experiments figuring out how best to administer the radiation and to build up enough data to support winning a large NIH grant to complete the development. We didn’t have enough

money to fund it ourselves, so I asked other brain tumor organizations to join with me to fund them together. With the help of **Lauren’s First** and **Goal Foundation** and the **Have a Chance Foundation**, we funded a few experiments. I am now trying to raise money to fund a few more. We need to raise money quickly to keep the experiments going and keep the researcher focused on brain tumors.

Musella is negotiating right now to test an alternative treatment called Ruta-6. This is the most popular - and perhaps the most promising – alternative treatment for brain tumors, yet we have no scientific data on it.”

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Feedback/Contact Us



For more in-depth discussions or to get involved in this very important cause, please call, write or visit us.

You'll find that it's easy to help, and that your help will quickly be operationalized. Whether you have a preferred beneficiary, 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. www.unlockingbraintumors.org
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How to Support Us



We can use your support in a variety of ways.

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 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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