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2008 brought many discoveries...funding woes...2009 brings need for more awareness

As 2008 draws to a close, we reflect upon the many issues that drew attention to the issues facing brain tumor survivors and their families.

During Brain Tumor Action Week in May, the House of Representatives passed a resolution proclaiming May as "National Brain Tumor Awareness Month". For those of us in the brain tumor advocacy community, this was a success, the first unifying initiative allowing us a vehicle to gain more awareness in our respective communities and engage in fundraising efforts for various programs and research.

The shock that reached across the nation and around the world, was when we learned of Senator Kennedy's diagnosis of a brain tumor just a week following the House decision. Senator Kennedy has been a supporter of The Brain Tumor Society which calls Massachusetts home and it was good to see the love and support of a community so affected by this disease, reach out to someone in need. This happens on a daily basis within list serves, online support groups, and on-site groups each time someone new finds themselves on this journey. In this election year, there weren't any politics involved when it came to encouraging another everyone is faced with the same tough choices regarding treatment and quality of life. Robert Novak, a Washington journalist, called on Senator Kennedy for advice when he also found himself diagnosed with a brain tumor.

David Bailey, a 12 year GBM survivor and musician, recently underwent surgery for a recurrence and yet

is still encouraging the members of the brain tumor community with his words of healing and faith as he looks ahead to survival.

Many conferences have been held this fall to share the hope of what science has to offer brain tumor patients-Neuradiab, DC-Vax, Gliadel, and most recently LabCorp who announced their discovery on detecting initial changes in the DNA of the brain cells when it begins to convert to cancer. With each advance made, we recognize the importance of increasing awareness and funding so that more can access the science that may impact their journey. We continue to champion for a semi-postal stamp to raise awareness and funds for not only brain tumors but all brain research so that it may gain the overall support of those that both support and benefit from the research that translates across various programs at the National Institutes of Health and increase the likelihood of its introduction and passage through Congress. We believe that the time is now to provide a fundraising tool for the public to provide their support just as the Breast Cancer Research Stamp has.

As we move forward into 2009, we extend our support and prayers for their continued response to treatment, and commit to the effort to raise awareness so that funding can increase research, support, awareness and advocacy efforts-all resulting in the reduction of burden on patients, survivors and families.

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Methylation is a chemical change in DNA that adds methyl groups to proteins in genes. Methylation in the MGMT gene promoter is

common in brain cancers and predictive of response to therapy, according to a LabCorp press release.

"DNA methylation is a key gene regulation mechanism in cancer. Lab tests to determine methylation status of specific genes in various cancers are important and differentiating additions to our menu of oncology services," said Dr. Andrew J. Conrad, LabCorp's chief scientist and global head of clinical trials. "The addition of this test to our menu of

oncology services continues our leadership in personalized medicine and gives oncologists a new tool to help guide patient care."

LabCorp's Esoterix Clinical Trials Services division was also selected by OncoMethylome as one of its preferred subcontractors for MGMT methylation testing services for clinical trials.

Visit [Virtual Trials](#) for more brain tumor news .



George Pocheptsov Auction to benefit The Brain Tumor Awareness Organization

The Minds In Motion Gala and Silent Auction will be held on April 4th at the Westin Poinsett Hotel prior to the Spring production of "Don Quixote" presented by The International Ballet at The Peace Center

Through the end of the year, you can preview and purchase one of his paintings online at MissionFish.

Visit www.braintumorawareness.org for more details.

The proceeds from the sale of this painting will benefit The International Ballet and The Brain Tumor Awareness Organization.

The Minds in Motion Arts Scholarship Program is provided for brain tumor survivors and matches them with local artists for a therapeutic arts program. Initial funding for this program will be provided through this auction.

Advertisement for George Pocheptsov auction featuring text about the event, artist information, and a colorful painting of a woman with wings.

"Heads Up To Heroes" Daring ❖ Surviving ❖ Thriving

Skyla was diagnosed on August 17, 2004 with a very large and inoperable tumor in the left thalamus region of her brain. She was ten years old at the time. What was once a normal life was gone, and Skyla, her parents and sisters started the long, adventurous journey into their "new normal" life of living with a brain tumor.

For two years, Julie searched for another mom who was living in the shoes that she was currently wearing. The hopes of finding someone who had 'been there, done that' sent her into two years of searching and researching for others with a common tumor in an uncommon location. A chance meeting with a mother in California started Julie's life as an advocate for families living similar brain tumor lives.

Over the last few years, Julie has become quite active in the brain tumor community. Starting an online support group and joining forces with Courageous Kidz,

a group based in Charleston, South Carolina aimed at making days brighter for children who are fighting all types of cancer. Between family, friends and her brain tumor family, Julie has reached out to many who have found themselves faced with the harsh reality of living with a brain tumor. She has devoted her life and time to helping others find the support that is needed. From insurance to second opinions, every day is met with Julie talking and researching on behalf of those who are in need. There are not enough hours in the day to get everything done that she wants, but no one ever gets set aside.

As for Skyla, well she is an inspiration all in her own. Her fearless look at life and her refusal to allow a brain tumor to control allows others to see what they should hope to be. Skyla is always smiling, even when times are bad, and leans upon her faith, her friends and her family, for the guidance that she needs to maintain her positive point



Skyla -

"always smiling, even when times are bad, and leans upon her faith"

of view. Skyla has endured three solid years of chemotherapy, countless MRIs, five regrowths, and three major surgeries, yet nothing has slowed her down. While some moments in time are scheduled around appointments and treatments, she has never allowed her brain tumor to schedule her life.

"We have had a lot of fun with our brain tumor diagnosis. We get to see what life is actually worth. Whereas a lot of people are too busy going through their lives without ever stopping to think about how precious life actually is. We've had a lot of fun. A lot of hard times, but a lot of fun." Julie M. Long "It's all good. Life is dandy and good." Words O' Wisdom by Skyla

Mark Your Calendars

January 23-26, 2009	Sharing Hope: Tumor Talk	Florida Brain Tumor Assn.
March 6, 2009	10th Annual Corporate Challenge for Hope	Children's Memorial
March 9, 2008	Once in a Lifetime Gala/ Auction	Cincinnati Music Hall Ballroom
April 4, 2008	Minds in Motion Gala/Auction	Brain Tumor Awareness Organization
April 10, 2008	Together in Hope Candlelight Vigil	Miles For Hope



Auditory Relay: This Month's Features

[Auditory Relay](#) is the section of our website where you can listen to "aud-casts", podcasts,

Teleconference on [Treatment Advances for Malignant Gliomas](#) with Dr. Howard Fine held on Dec. 2, 2008 is a part of the [12th Annual Teleconference Series](#) hosted by The National Brain Tumor Society.

Dr. Fine is currently chief of the Neuro-Oncology Branch at NCI's Center for Cancer Research, and of the National Institute of Neurologic Disorders and Stroke. His research interests include tumor angiogenesis, therapeutic gene transfer, and neural stem cell biology.

Read his [biography](#) on the National Cancer Institute Center for Cancer Research website.

[Nanoparticles Aim Drugs Directly at Tumors](#)— presented by EarthSky Science Podcasts

[Complementary and Alternative Therapies for Cancer Symptoms](#)— podcast by Mayo Clinic

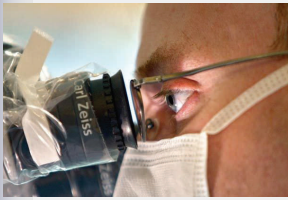
[For Caregivers: Coping with a Loved One's Cancer During The Holidays](#)

[For Caregivers: Coping with Holidays, Special Occasions and Birthdays, Throughout the Year](#)

-podcasts by CancerCare



Dr. Howard Fine



Foltz peers into a magnifier during surgery to remove a patient's brain tumor at Swedish Medical Center/Cherry Hill.

JOHN LOK / THE SEATTLE TIMES

"The human brain, then, is the most complicated organization of matter that we know."

-Isaac Asimov



Can weather technology determine tumor growth patterns?

Brain-cancer center at Swedish maps tumors to design treatment

"Brain cancer remains one of the deadliest diseases, but local neurosurgeon Dr. Greg Foltz is tapping into the science and biotech that Seattle is famed for in his quest for better treatments and a cure. Already, the work is leading to personalized treatment plans based on genetic analysis of every tumor."

Seattle's only nationally recognized brain-cancer program is at Seattle Children's, so the city seems an unlikely place for those trends to converge. But a pianist-

turned-neurosurgeon at Swedish Medical Center is on a mission to boost the city's standing by tapping into the science for which Seattle is renowned.

"We're sitting in one of the great technology centers of the world," Dr. Greg Foltz said. "Why not use that to advance the treatment of this devastating disease?"

Foltz was playing piano for the St. Louis opera and headed for The Juilliard School 14 years ago when a

friend's daughter died of brain cancer. Stunned to learn how little could be done for patients at that time, he gave up music for medical school.

Now, as head of the new Center for Advanced Brain Tumor Treatment at Swedish, Foltz, 45, has forged a coalition with local research centers and biotech firms. They apply cutting-edge tools to the treatment of patients and work toward better ways to fight the disease.

Read [full story](#) in The Seattle Times

Brain Tumor Drug Derived From Herpes Virus Passes Next Hurdle

An anti-brain tumor agent developed from a genetically engineered herpes simplex virus has been shown to be safe when given in two doses and injected directly into the brain of patients with malignant glioma. New research from UAB (University of Alabama at Birmingham) published online in *Molecular Therapy*, also showed that

the drug, G207, appeared to prompt an immune response in patients and showed signs of actively pursuing and killing cancer cells.

UAB researchers studied six patients with recurrent glioblastoma multiforme, one of the most deadly forms of brain cancer. G207 was injected directly into the tu-

mors, which were surgically removed several days later. More of the drug was then injected directly into the brain in the cavity where the tumor had been removed. No major adverse effects were observed, which was the primary goal of the study.

Read [full article](#) at *Medical News Today*.

Understanding Brain Tumor Growth Through Applying Weather Forecasting

Researchers and students from St. Joseph's Hospital and Medical Center and Arizona State University's Math Department are applying weather forecast technology to model and track the growth patterns of brain tumors.

The technology allows researchers to study various growth patterns of brain

tumors and apply treatment parameters to determine the best option for patients. It will forecast how a patient's tumor may grow with different treatment scenarios, help physicians make a much more informed prognosis and be used as a patient consulting tool.

The research study began when Barrow and ASU researchers Mark Preul, Yang Kuang and Eric Kostelich

used data from a collection of normal brain images to create a life-like recreation of the brain. They positioned a virtual tumor in the brain image and applied intricate math formulas used in weather forecast technology to predict how the tumor would grow.

Read [full article](#) at *Science Daily*

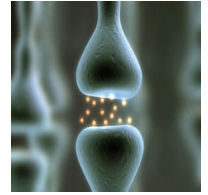
Mechanism In Cells That Generate Malignant Brain Tumors May Offer Target For Gene Therapy

Researchers at Cedars-Sinai Medical Center's Maxine Dunitz Neurosurgical Institute who first isolated cancer stem cells in adult brain tumors in 2004 have now identified a molecular mechanism that is involved in the development of these cells from which malignant brain tumors may originate. This could offer a target for scientists seeking treatments that would kill malignant brain tumors at their source and prevent them from recurring.

Normal stem cells are "immature" cells that have the potential to become any of several types of cells. Cancer stem cells have the same multi-potent and self-renewing properties, but instead of producing healthy cells, they propagate cancer cells. Theoretically, if these "mother cells" can be destroyed, the tumor will not be able to sustain itself. On the other hand, if these cells are not removed or destroyed, the tumor will continue to return despite the use of existing cancer-killing therapies.

Glioblastoma multiforme is the most malignant form of tumor that develops in the brain, but not all glioblastomas are identical. Subgroups are comprised of cells originating from different brain tumor stem cells with unique genetic characteristics that use different signaling pathways in their development and growth. The Cedars-Sinai researchers are building genetic "profiles" of these cancer stem cells and the tumors they appear to produce.

Read [full article](#) at *Medical News Today*.



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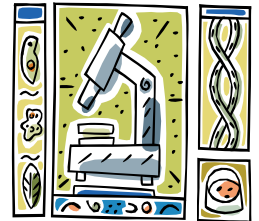
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New Biomarkers For Brain Tumor Discovered

Researchers in the US and The Netherlands have discovered that cancer cells from a deadly type of human brain tumor called glioblastoma release tiny sacs containing proteins that traverse the brain-blood barrier and contain genetic material that could be used as biomarkers in new diagnostic tools and perhaps as new targets for treatments too.

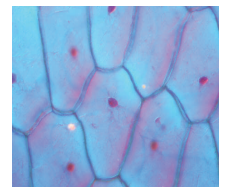
The study, which was published online on 16 November in the journal *Nature Cell Biology*, was the work of lead author Dr Johan Skog, who works in the laboratory of co-author Dr Xandra Breakefield, at the Neuroscience Centre of Massachusetts General Hospital (MGH), which is part of Harvard Medical School, and colleagues from other parts of Harvard Medical School and the Cancer Center Amsterdam.

Using blood samples from glioblastoma patients, Skog, Breakefield and colleagues found that the glioblastoma cells released tiny blood-borne sacs called microvesicles or exosomes that carry a range of proteins and tumor-associated RNA.

Some of these glioblastoma microvesicles or exosomes contained the cancer genes EGFRvIII and miRNA-21 that cause cells to proliferate, leading the researchers to suggest that they may serve as new biomarkers or drug targets for this deadly form of cancer.

"Exosomes also may someday be used to deliver therapeutic molecules to the site of a tumor," Skog added.

Read [full article](#) at *Medical News Today*



The Brain Tumor Awareness Organization

Want to be a news correspondent for BTAO?

Contact us and we will put you in our newsroom!

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

Editors - J. Houston; C. Galloway

Contact us:
news@braintumorawareness.org

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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

Caregiving and Coping during the Holidays

For many caregivers the holiday season gives rise to stress, frustration and anger, instead of peace and good will.

Caregivers may feel resentful towards other family members who they feel have not offered enough assistance. Managing care for someone who has a cognitive impairment may leave caregivers feeling that they will not be able to participate as fully as they would like in family gatherings. Already feeling overwhelmed with caregiving tasks, stressed-out caregivers may view traditional holiday preparations as more of a drain of precious energy than a joy.

This article by the Family Caregiving Alliance presents several points to consider during this busy time of year:

- An opportunity for communication
- Holiday Greetings and a brief note
- Let sleeping dogs lie?
- Be clear about your energy level
- Accept the need to adapt
- The visit room
- Share your wish list
- Schedule one-on-one time
- Reflect on the rewards
- A little thank you goes a long way

The American Brain Tumor Association offers great tips in [“Coping with the Holidays”](#)

Happy Holidays



**from the
Brain Tumor**

Awareness Organization



[click on notes for Holiday treat](#)