



Immunotherapy: Using Your Immune System to Treat GBM

For decades, scientists have searched for ways to use the body’s own immune system to attack cancer cells, especially those that are most resistant to surgery, chemotherapy, or radiation therapy. This approach, called immunotherapy, aims to either stimulate the immune system to turn against a tumor, or to target specific pathways that regulate the normal and abnormal “conversations” among cells of the immune system. Past efforts have failed because the approaches were not selective enough and therefore ineffective, or because they provoked a more generalized immune response than desired. Often the tumor cells found a way to avoid the intended immune response altogether.

Today, new immunotherapy research offers the prospect for more strategic, intelligent, and personalized therapies that could change the treatment landscape for tumors like glioblastoma (GBM), a common and aggressive type of malignant brain tumor.

Reversing Cancer-Related Immunosuppression

Mark Gilbert, MD, professor of Neuro-oncology, deputy department chair of Neuro-oncology at MD Anderson Cancer Center, is studying how to reverse immune activities within the brain that allow tumors to grow. He explained that the blood brain barrier—so important for protecting our brains—actually blocks the body’s normal process of watching for “foreign” substances such as viruses, bacteria, or cancer cells. This suppression of immune surveillance in the brain gives cancer cells the opportunity to flourish nearly unopposed by the protective cells that would normally target these invaders.

Gaining Insight from Melanoma Studies

Recent advances in treating melanoma using a technique that blocks an “immune checkpoint” have demonstrated the power of new drugs to reverse the immunosuppression process. Learning from the melanoma studies, Dr. Gilbert and his team are developing a protocol for a large trial in

GBM patients using compounds that target a “checkpoint blocking protein” that unfairly shifts immune responses in favor of the tumor. The research team will watch for signs of effectiveness as well as “over exuberance” in the blocking, said Dr. Gilbert. This study is still being developed, but when it opens for patients, it will be found in the ABTA’s TrialConnect®, a service that links brain tumor patients with appropriate clinical trials based on the patient’s tumor type and treatment history.

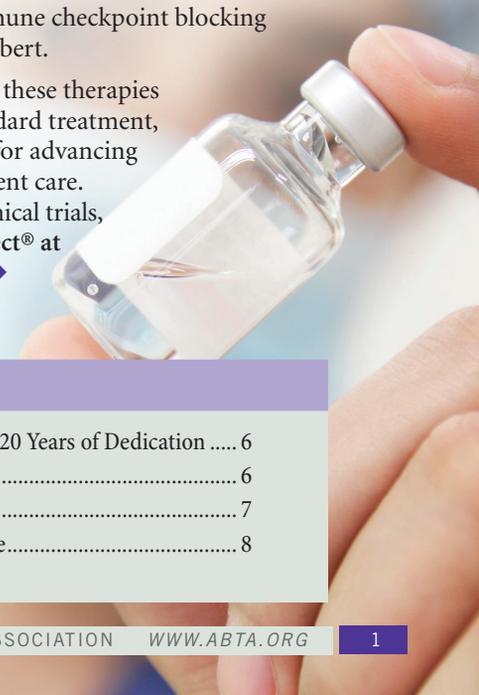
Studying the Viability of Vaccines

Another immunotherapy approach uses vaccines, alone or in combination with drug therapy, to stimulate an immune response against the tumor. Andrew Parsa, MD, chair, Department of Neurological Surgery, professor of Neurological Surgery and Neurology, Northwestern University Feinberg School of Medicine, said that renewed interest in vaccines to treat cancer comes from the ability to make the right type of vaccine for the right type of patient.

Dr. Parsa is study chair for a large NCI-sponsored trial of a vaccine (HSPPC-96) that is made from the tumor itself—research that was partially funded by the American Brain Tumor Association. Dr. Parsa and his team have shown that vaccinating a patient with antigens from his or her tumor can trigger a robust immune response to the tumor that is personalized and specific to the tumor cells, an advantage over other treatments approaches. This vaccine has the potential to be safely combined with other treatment strategies, including the immune checkpoint blocking drugs being tested by Dr. Gilbert.

While it may be years before these therapies become integrated into standard treatment, clinical trials are important for advancing medical knowledge and patient care.

For more information on clinical trials, go to the ABTA’s TrialConnect® at www.abtatrialconnect.org. ♦



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Message from the President and CEO

Every day we hear from brain tumor patients and caregivers seeking our help in understanding their diagnosis, grappling with a new and difficult vocabulary, and struggling to make life-altering decisions about their treatment options.

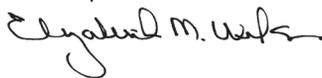
And every day we are reminded that a brain tumor diagnosis is the start of a journey no one expects to take. Caregivers who contact us feel unprepared and ill-equipped to navigate the complexities of their loved one's illness, the recommended course of treatment, and the health care system. They turn to us for more detailed information on treatment side-effects and the overall progression of the illness; they want to know what to expect and when; they're looking for local resources and suggestions on where to go and how to ask for help; they're seeking guidance on how to talk to their employer, and about how much and how best to share information with their children.

They're also looking for ways to connect with, learn from and support each other. As one member of our *Connections* online support community recently shared, "This site has been a huge resource for me, full of love, support, practical advice and understanding. Some days I can't bear to look at it, to see the reality of the disease. Other days, I need to know the reality—and the experience of others."

This issue of *Headlines* features additional members' experiences on *Connections*—just one of the many ways in which the ABTA is—every day—providing reassurance, comfort and support to those coping with a brain tumor diagnosis. The issue also includes inspiring stories of Ohio resident, Wildlife Correspondent, and ABTA supporter Jack Hanna; the ABTA's 2014 Joel A. Gingras Award recipient and brain tumor survivor Lynne Adams; and medical student Saman Sizdahkhani, whose childhood exposure to two separate and unrelated adult brain tumor diagnoses is leading her to fulfil her dream of becoming one of only 200 women neurosurgeons in the U.S.

Further inspiration can be found in our observance of Brain Tumor Awareness Month this May. This annual national designation is an opportunity for us to come together as a community to promote greater understanding of the disease and advocate for safer, more effective treatments. It's also an opportunity for us to spotlight the tributes and triumphs of all of those impacted by a brain tumor diagnosis. To share your story and be inspired every day this month, visit www.abta.org/BTAM, and follow us on Facebook (www.facebook.com/theABTA) and Twitter (www.twitter.com/theABTA).

Sincerely,



Elizabeth M. Wilson, MNA
President & CEO



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Headlines

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Our mission: The mission of the American Brain Tumor Association is to advance the understanding and treatment of brain tumors with the goals of improving, extending and, ultimately, saving the lives of those impacted by a brain tumor diagnosis.

We do this through interactions and engagements with brain tumor patients and their families, collaborations with allied groups and organizations, and the funding of brain tumor research.

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American Brain Tumor Association

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Headlines, the American Brain Tumor Association's newsletter, is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician(s), utilizing your specific medical information. Inclusion in an ABTA newsletter is not a recommendation of any website, product, treatment, physician or hospital.

Ohio's State of Leadership: Research, Fundraising and Awareness

Home to eight U.S. Presidents and the first man to walk on the moon, Ohio has a history of leading the country and exploring new frontiers. It's no different when it comes to providing and pursuing answers for brain tumors.

Since 1978, the ABTA has funded 28 researchers in Ohio who have played a major role in unraveling the mysteries of cancer stem cells and their possible link to the development of brain tumors. Ohio researchers also explored new frontiers in the development of gene therapies—a technique in which scientists engineer viruses and genes to be therapeutic or to carry drugs to the tumor.

Idea Exchange

For the continued success of research like this, free exchange of ideas and strong partnerships between basic research and clinical teams is necessary. Cleveland Clinic's Justin Lathia, PhD, assistant staff, Department of Cell Biology, served as the co-chair of the ABTA's inaugural Alumni Research Network (AARN) meeting. The AARN is a unique forum that encourages ABTA-funded research alumni to share knowledge, experiences and insights on research direction, and the role of research in treatment.

"The benefits of this network already are coming to light as collaborations have formed and multiple investigator teams are now working together. These teams are working on basic research projects as well as rapidly integrating laboratory science with clinical trials which will accelerate the development of the next generation of brain tumor therapies," Lathia said.

A Movement Afoot



While researchers look in the lab for answers, Ohioans are pounding the pavement to raise awareness and critical funds. On June 14, more than 1,000 runners and walkers are expected to participate in Ohio's inaugural Breakthrough for Brain Tumors 5K Run & Walk in Columbus to raise more than \$100,000.

Janet W. Bay, MD, FAANS, vice president and lead physician, Neuroscience, at OhioHealth has been instrumental in organizing this day of celebration and commitment which OhioHealth has generously supported as the event's presenting sponsor. All funds raised will support vital brain tumor research and comprehensive services for those living with a brain tumor. To register, visit www.bt5k.org or call 800-886-1281.

ABTA Support Spans the State

From the southwest corner in Cincinnati to the shores of Lake Erie in Cleveland, Ohioans have come together for town hall meetings and roundtable discussions to learn more about the ABTA, its services and resources for people of all ages and all tumor types. Attendees shared their ideas

for educational meetings, as well as their need for support and services in their area.

"I was thrilled to be a part of these discussions. After losing my husband to a brain tumor, I became so passionate about wanting more families who are facing a brain tumor diagnosis to have access to resources and know about the services that the ABTA can offer," said Sue Gessner, BT5K Columbus event committee volunteer and Cleveland resident. "It's my mission to motivate and inspire others to get involved and support the ABTA because this is the organization that is making a difference in families' lives."

In every corner of the state and in every sense, Ohioans are supporting the ABTA. As political lore claims that this state can determine presidential elections, time will tell whether Ohio will find the answers so many in the brain tumor community seek. ♦

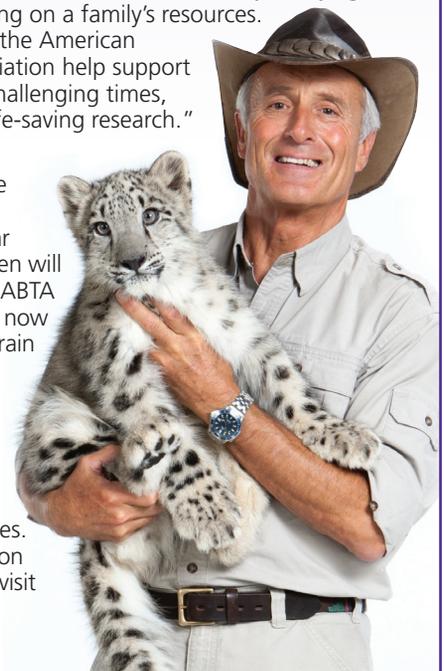
Wild About Raising Awareness

Wildlife Correspondent and Ohio resident Jack Hanna, best known for his appearances with animals on *Good Morning America* and the *Late Show with David Letterman*, is lending his support to the American Brain Tumor Association. Hanna, father to three daughters, understands how overwhelming a brain tumor diagnosis can be, which is why he's committed to raising awareness of the support and services available from the ABTA.

At the age of 2, Jack's youngest daughter, Julie, was diagnosed with leukemia and went through chemotherapy, cranial radiation, and bone-marrow treatments. Though Julie's leukemia has been in remission for many years, she has also battled benign brain tumors—the first while she was in college and again in 2011.

"Having a child with a brain tumor is not only terrifying for a parent—but taxing on a family's resources. Organizations like the American Brain Tumor Association help support families through challenging times, while also doing life-saving research."

Across the U.S., 700,000 people are living with a brain tumor, and this year alone, 4,300 children will be diagnosed. The ABTA was the first and is now the only national brain tumor organization dedicated to funding research and providing comprehensive resources for patients and families. For more information or to get involved, visit www.abta.org.



“No One Knows What it’s Like”

Two women, one diagnosis, and a growing support community

The ABTA’s online support community *Connections* knows her as *AGBecky*, but to family and friends, she is mom; she is an antique dealer; she is Becky Loske from Elburn, Ill.

Nearly 600 miles and one time zone away in Buffalo, N.Y., *RobinMB*, also a mother, a wife and college professor found herself facing the same situation as *AGBecky* at nearly the same time—their husbands had been diagnosed with one of the most common and aggressive types of malignant brain tumor, glioblastoma (GBM).



By [RobinMB](#)
Reply
10:09 pm

I completely understand where you are coming from. My husband was diagnosed with GBM in Feb. '12. He just finished 4 treatments of Avastin, and he is scheduled for an MRI on Feb. 22. I am so nervous.

“It all happened so fast, and it was so overwhelming,” recalls Becky. “It was surreal stepping out of my ‘busy mother-of-three’ life and stepping into a whole different world where I felt no one knows what it’s like.”

Going by her screen name, *RobinMB*, Robin Bobowicz, shared similar feelings when she first heard her husband’s diagnosis. “My husband and I were a team. We were married for 33 years; he was the picture of health, and out of nowhere he is diagnosed with glioblastoma,” shares Robin. “It was an isolating experience until I found the ABTA’s *Connections*.”



By [agbecky](#)
Reply
8:23 am

My circumstances are very similar to yours. My husband received his GBM diagnosis on 12/7/11, had surgery 12/9, did chemo and radiation during January through March of this year. He is also doing very well right now. He has been back to full-time work since late May. We’ll be driving back to Mayo Clinic tomorrow for his monthly checkup and to pick up his next round of clinical trial chemo pills.

Connections is the ABTA’s online support community that has joined 4,000 patients, families, friends and caregivers seeking support and inspiration 24/7. Unlike social media outlets such as Facebook or Twitter, *Connections* offers a



more private setting where members join for many of the same reasons people attend a face-to-face support group: to ask questions of their peers, to provide updates on their personal situations, and to gain confidence in and comfort through talking with others who may be traversing a similar brain tumor journey.

***Connections* offers a more private setting where members join for many of the same reasons people attend a face-to-face support group.**

Neither Becky nor Robin had ever tried any form of social media prior to joining *Connections*, but it was through the ABTA’s online support community that they found each other, and the support, information, and strength that comes from knowing that they were not alone.

“Becky inspired me to keep moving, to keep going,” said Robin. “After reading her posts, I felt like I could breathe again.”

From the inspirational to the mundane, both women say *Connections* covered the spectrum of issues they were facing. Questions they considered too “trivial” to ask their doctors, “*what do you feed your husband during chemo when everything tastes metallic?*” were met with an outpouring of suggestions that worked for others who had already been through chemotherapy. Nagging questions that woke them in the middle of the night? They posted them on *Connections*.



By [RobinMB](#)
Reply
10:09 pm

Not to worry! It is very common to discharge patients 2 days after brain surgery. My husband had two craniotomies at different hospitals. Both hospitals released him after 2 days. I was so glad to have him home with me, and he was happy to be home. Dorothy knew what she was talking about when she said, “there’s no place like home.” Enjoy every minute with your loved ones.

*NOTE: The individuals featured in this story provided their permission to share their experiences and their posts, so others will feel comfortable seeking *Connections* as a safe and compassionate environment for support.*

“At 2 a.m., *Connections* is there and there is a lot of compassion from others who are walking in your shoes,” said Becky. “It’s hard to explain how you become invested in each other’s lives even though you have never met, but everyone is so open and so real, and you’re really in it together. It became my lifeline.”

“It’s hard to explain how you become invested in each other’s lives even though you have never met, but everyone is so open and so real, and you’re really in it together. It became my lifeline.”

As Becky and Robin’s support for each other strengthened, so did their friendship. Becky’s husband lost his battle last October after 22 months. Two months later, Robin lost her husband in December. They talk about meeting in person this summer to reflect not only on where this brain tumor journey took them, but to celebrate where they are today.

“I’m sharing my experiences and sharing my posts so more people will turn to the ABTA. It is a safe place to say how you’re feeling, and it gives you hope when you feel hopeless,” said Robin.

Robin still goes on *Connections* every day. “If I can help just one person with the knowledge that I gained, or be the support that they need, then it’s what I’m here to do. I cannot imagine having gone through this journey without Becky and without the support I found from the compassionate people on *Connections*.” ♦



Connections FAQs

Q: I have never participated in social networking or an online community. Is it difficult to join *Connections*?

A: It is easy to sign-up at the ABTA’s website www.abta.inspire.com. Here you will create a screen name and password to get started.

Q: How will my privacy be protected?

A: You control the privacy setting for every part of your profile and each discussion and journal entry that you post. The ABTA strongly recommends that you not use your real name or e-mail address as your screen name because your screen name is public, which means anyone on the Internet can see it.

Q: Is there a moderator? What are the guidelines for participation?

A: Yes, ABTA’s licensed health care professionals serve as the moderators. Like all support groups, members share the responsibility to create a supportive and kind place where respect and acceptance is mutual.

Q: Is it free? What are the fees?

A: ABTA’s *Connections* online support community is free of charge. Through generous donations, the ABTA is proud to offer this safe place for patients, caregivers, families and friends to interact with each other, and provide support and inspiration.

If you have any questions about *Connections* or would like to learn more about ABTA resources and support available, please call our CareLine 800-886-ABTA (2282).



“I’m not a techie, but *Connections* is really user-friendly and it provided the support and information I didn’t find anywhere else.”

— BECKY LOSKE

Brain Tumor Survivor Honored for 20 Years of Dedication

Throughout the years, the American Brain Tumor Association has been supported through countless acts of generosity. Year after year, we're amazed as we see members of our community who, through their philanthropy, discovery, or patient care and support, embody our mission. The Joel A. Gingras, Jr. Award was established to honor these individuals, organizations or groups, whose consistent support advances the ABTA mission and brain tumor community.

This year, the ABTA is proud to present the Joel A. Gingras, Jr. Award to the Butler Family Foundation Trustee Lynne Adams.



As a brain tumor survivor, Lynne understands the challenges of navigating the disease as well as the health care system for both patients and caregivers.

The Foundation has been a leader in funding the ABTA's extensive line of educational publications and, more recently, corresponding web content.

"I have been free of my tumor for this long, and I know how fortunate I am," said Adams. "Our funding and support of the ABTA is our expression of that gratitude."

Since 1994, The Butler Family Foundation has been a dependable supporter of numerous programs designed to support and inform brain tumor patients and caregivers as they struggle to cope with and adjust to their brain tumor diagnosis.

"The Butler Family Foundation's 20 years of consistent support of the ABTA, while largely anonymous, has contributed greatly to our ability to offer and build upon patient services," said Elizabeth M. Wilson, ABTA president and CEO.

In addition to their strong support of patients and caregivers, Lynne also stewarded anonymous Foundation sponsorship of the ABTA's annual patient and caregiver conference, which Lynne faithfully attends each year. It is at this year's conference that Adams will be presented with the 2014 Joel A. Gingras, Jr. Award.

The ABTA's annual conference is the ABTA's mission in action, with patients, caregivers and health care professionals coming together from around the nation to learn from and with each other about the advancements in brain tumor research, treatment and care.

This year's conference, "*Providing and Pursuing Answers: Advances in Brain Tumor Research, Treatment & Care*," will be held on July 25-26 at the Renaissance Chicago O'Hare Suites Hotel in Chicago. To learn more, visit www.braintumorconference.org. ♦

How Will You Breakthrough?

There are so many ways to get involved with the ABTA. From attending one of our educational webinars or our annual conference, to participating in an event or fundraiser, our events bring patients, families and health care professionals together. Join us as we make breakthroughs for patients and families. Here's what we have coming up:

Webinars

- May 22 "Genomics and its Relevance to Brain Tumors"
- June 5 "Radiotherapy for Pediatric Brain Tumors and Late Effects of Radiotherapy in Children"
- June 18 "Brain Cysts: A Treatment and Care Update"
- July 15 "Low Grade Gliomas in Children"
- August 13 "Living with a Brain Tumor"
- Sept. 10 "Risk Factors, Treatment Options and Future Advances"
- October 8 "Ketogenic Diet for Brain Tumor Patients"

To RSVP for any of our free educational webinars, visit www.abta.org/brain-tumor-information

Annual Patient & Family Conference

- July 25-26 "Providing and Pursuing Answers: Advances in Research, Treatment and Care"
Chicago, IL

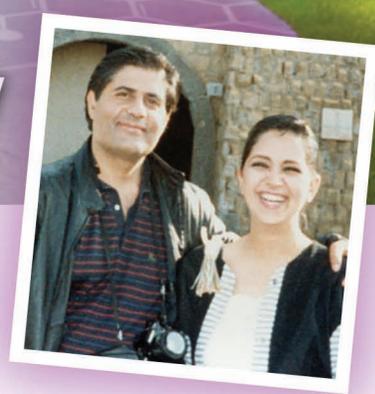
To register, visit www.braintumorconference.org

Walks, Runs and More

- May 31 Sandy SMILES Memorial 5K & Family Fun Walk
South Park, PA
- May 31 2014 Sharing Hope Walk: Walk the Walk, Talk the Talk — Storrs, CT
- June 10 Hands Across the River Golf Outing
West Hartford, CT
- June 13 Thomas C. Ellis 5K Trail Run & 1 Mile Walk
Broadview, OH
- June 14 Columbus BT5K, presenting sponsor: OhioHealth
Columbus, OH
- June 21 Rock 'n' Roll Seattle Marathon & Half Marathon
Seattle, WA
- June 28 In Memory Of...5K Run & Walk
Indiana, PA
- July 27 San Francisco Marathon & Half Marathon
San Francisco, CA
- Sept. 7 Chicago Half Marathon
Chicago, IL
- Oct. 11 Dallas BT5K
Dallas, TX
- Oct. 12 Bank of America Chicago Marathon
Chicago, IL
- Oct. 19 Nationwide Children's Hospital Columbus Marathon
Columbus, OH
- Nov. 8 New York City BT5K

To register for any of our events, visit www.abta.org/get-involved

A Scientist's Story



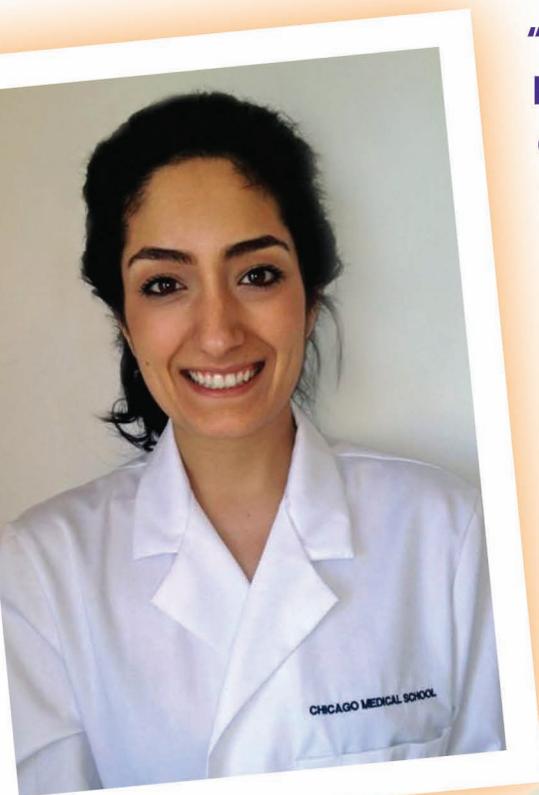
Saman's Aunt Naghme
and Uncle Alan

Dedication to Her Dream

When other six-year-old girls were playing hopscotch or dreaming of becoming a princess, Saman Sizdahkhani dreamed that one day she would be a neurosurgeon. Her fascination with the brain began at a tender age when her aunt was diagnosed with a brain tumor. Saman recalls feeling mesmerized by how the brain worked and how suddenly something within the brain could change.

"I remember how my family spoke about my aunt's neurosurgeon, how they adored him, and from those early experiences, I learned what a neurosurgeon was," Saman said. "A year or so later in the second grade, it became very real to me what a brain tumor diagnosis meant. My best friend's father passed away only a year after a brain tumor diagnosis. It was then that I knew in my heart I wanted to be a neurosurgeon."

Touched not once, but twice by a brain tumor diagnosis, Saman's curiosity and fascination with the inner workings of the brain intensified. Seventeen years later, as a second-year medical student at Chicago Medical School, she craved the opportunity to do her own brain tumor research under the direction of renowned neurosurgeon Roberta Glick, MD. Saman applied for the ABTA Medical Student Summer Fellowship and was awarded a \$3,000 grant to spend a summer doing what she longed to do—conducting brain tumor research.



"This funding from the ABTA is incredibly meaningful because in giving me the opportunity to pursue my dream, I hope to help people diagnosed with a brain tumor live to fulfill theirs," she said. "Without a doubt, this

funding is critical to moving ideas and knowledge forward, and I know in my lifetime we will discover new therapies that will change the way we view a brain tumor diagnosis—we will make it happen."

Today, there are only about 200 women neurosurgeons in the United States. In many ways, Saman represents the future and the ABTA's commitment to engaging bright young researchers who have the potential to change our understanding of the causes, effects, diagnosis and treatment of brain tumors.

Please donate today!
Visit www.abta.org/mypath
or use the envelope in this
newsletter.



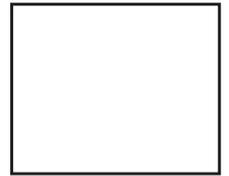
**American
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2014 Patient & Family Conference
Providing & Pursuing Answers:
Advances in Research, Treatment and Care

Friday – Saturday, July 25 – 26
Chicago, IL



American
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Join us for our annual conference to learn about the latest advances in brain tumor research, treatment and care. Patients and caregivers are invited to attend. During the conference, attendees are encouraged to participate in informational sessions and network with each other.

Esteemed researchers and physicians will deliver presentations addressing how science and technology are impacting the development of new treatments and advancing strategies to minimize treatment side effects.

2014 Program Highlights

- Brain tumor-specific breakout sessions
- Symptom management tips and strategies
- Integrative medicine, nutrition, and ketogenic diet information
- Legal and financial matters to consider
- Strategies for successful caregiving

Space is limited – register today!

To register, visit
www.brainumorconference.org
or call 1-800-886-ABTA (2282).