



American  
Brain Tumor  
Association®

Providing and pursuing answers®

# Headlines

FALL/WINTER 2016, VOLUME 43, NUMBER 2

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# Message from the President and CEO



This issue of *Headlines* features a recap of the American Brain Tumor Association's (ABTA) 2016 National Patient & Family Conference which featured an expanded program focus covering information, education, research, and public policy updates on a comprehensive range of tumor types including high-grade tumors, low-grade tumors, meningioma and metastatic brain tumors.

This national conference has become the nation's largest gathering of brain tumor patients, caregivers, healthcare professionals and researchers, who come together for two days of education, support and networking opportunities.

With the unprecedented momentum underway in brain tumor research driving heightened interest in historically under-investigated tumor types, we felt this annual conference was the ideal forum for the world-renowned researchers and medical practitioners who are leading the charge to share their insights, advances and challenges directly with those who stand to benefit from them.

Working closely with program co-chairs Manmeet Ahluwalia, M.D., FACP, Cleveland Clinic Rose Ella Burkhardt Brain Tumor & Neuro-Oncology Center, and Elizabeth B. Claus, M.D., Ph.D., Brigham and Women's Hospital and the Yale School of Public Health, a dynamic roster of presenters was assembled to address current and emerging issues in brain tumor research, treatment and quality-of-life issues.

While we are only able to include highlights from select presentations in this publication, conference presenters are being featured in our monthly webinar series thus bringing this important and timely information to thousands more patients, caregivers and health care providers in the U.S. and around the world. All ABTA webinar sessions are recorded and available for viewing at our "Anytime Learning" web page.

To ensure continued momentum in brain tumor research, this fall the ABTA launched a new grant funding opportunity that fosters team science. These two-year, \$200,000 grants are intended to accelerate progress in clinical outcomes for brain tumor patients through cross-institutional collaborations. This research program is being initially funded through a matching grant from an anonymous family foundation.

It is our hope that these and other talented ABTA-funded scientists will be among esteemed presenters invited to share their scientific breakthroughs with patients and caregivers at future ABTA patient conferences.

Sincerely,

Elizabeth Wilson, MNA  
President & CEO



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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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# Returning to Work After a Brain Tumor Diagnosis

In an unexpected turn of events, ABTA Volunteer Aisha went from working as a physician assistant in a busy cardiothoracic surgical service to being on the surgical table for the removal of a benign brain tumor. Six months later — after diagnosis, surgery, paralysis, then rehab — Aisha returned to work in a new role. She was hired to teach and train future physician assistants as the assistant academic director at the University of Bridgeport Physician Assistant Institute (PAI). Recently, she was promoted to academic director at the PAI and continues to lead teaching opportunities for physician assistant students. She has also returned to clinical practice and seeing patients again, but in ways that fits her needs and abilities.

Recent studies show that eight in ten (83%) employers want to implement workplace accommodations to retain or promote a current employee, including individuals who are diagnosed with or being treated for a brain tumor or cancer.<sup>1</sup> A workplace accommodation is any change to one's

work space, schedule or other changes like technology, a shift in policy, change in job responsibility or role so that employees may enjoy equal employment opportunities.

According to Monica Bryant, Esq., chief operating officer, Triage Center, there are a range of responses from employers, including proactive use of reasonable accommodations to being unaware of their obligations.

An invaluable new publication, “**Returning to work after a brain tumor diagnosis: Accessing reasonable accommodations,**” by the American Brain Tumor Association, in partnership with the Triage Cancer Center, provides strategies for brain tumor patients, caregivers and their families to engage in an active dialogue so both the patient and employer come out winners at the workplace. This new brochure helps brain tumor patients, like Aisha, partner with their employers to discuss the options for returning to work. 



To order a free copy of the brochure, contact the ABTA at (800) 886-2282, email [abtacares@abta.org](mailto:abtacares@abta.org) or download a free copy at [www.abta.org/workara](http://www.abta.org/workara).

<sup>1</sup> Job Accommodation Network (Original 2005, Updated 2007, Updated 2009, Updated 2010, Updated 2011, Updated 2012, Updated 2013, Updated 2014, Updated 2015). Workplace accommodations: Low cost, high impact. Retrieved July 5, 2016 from <http://AskJAN.org/media/lowcosthighimpact.html>



## Giving for Tomorrow

Did you know that you can give to the ABTA through a designation in your will or as a beneficiary of your life insurance? With forethought, these types of gifts help the next generation of patients and families in need of ABTA's resources. If you would like to discuss this further, please contact Debbie Robins, Director of Development at 773-577-8781 or [drobins@abta.org](mailto:drobins@abta.org).

# Top Brain Tumor Experts Present New & Emerging Treatments at ABTA's Annual Meeting

For the first time in decades, advances in science and technology are changing brain tumor patients' treatment options. The ABTA's Annual Patient and Family Conference, held July 29-30, offered a unique opportunity for attendees to hear from the nation's top brain tumor experts on what these latest developments mean for them.

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**"These experts represent the best minds at the forefront of scientific and technological innovations, and we are grateful to have them convene in Chicago to share their knowledge and engage with our patients and families," said Elizabeth Wilson, president and CEO, American Brain Tumor Association.**

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Representing a wide variety of expertise, the national panel of speakers drew a record number of attendees interested in understanding how research and technological progress is fueling precision medicine, more treatment options, and improved quality of life for brain tumor patients.

## Brain-Mapping: A Path to Improved Quality of Life

The country's foremost expert on intraoperative brain-mapping, Mitchel S. Berger, MD, FAANS, Professor and Chair, Department of Neurological Surgery, University of California San Francisco, presented an in-depth session on how brain-mapping is used to maximize the amount of tumor that can be surgically removed, while minimizing risks and preserving neurological function.

As Dr. Berger explained, intraoperative brain-mapping is a highly-skilled technique used to stimulate areas of the brain around a tumor to identify function during surgery in an effort to avoid important areas like speech, comprehension and motor skills while removing as much of the tumor as possible.

For low-grade glioma (LGG) patients, Dr. Berger advocates for an aggressive approach — total resection — based on research showing that patients' overall survival and quality of life is greater than "watching and waiting". According to Dr. Berger, total tumor removal is the most effective way to control seizures which commonly impact LGG patients'



*Dr. Berger and Dr. Claus presenting at the 2016 ABTA Patient & Family Conference*

quality of life, and it has a significant effect on overall survival since LGGs tend to grow and can transform into a malignant tumor.

Dr. Berger also discussed how surgery should allow for enough tissue to be collected to confirm the tumor is low grade and to conduct molecular profiling which is essential for an accurate prognosis.

"While I advocate that we need to aggressively remove low-grade gliomas, I do so with the understanding that it must be done safely with intraoperative brain-mapping," said Dr. Berger. "I believe that neurosurgeons must recognize the advantages outweigh the risks and that we need to be moving away from a 'watch and wait' approach and toward making intraoperative brain-mapping standard of care."

## Stereotactic Radiosurgery: Targeted Treatment with Less Toxicity

Conference attendees also learned how another technological advancement — stereotactic radiosurgery — is preserving cognitive function and improving quality of life for patients with metastatic brain tumors.

Paul Brown, MD, professor of radiation oncology at the Mayo Clinic, explained that stereotactic radiosurgery is therapy that delivers targeted radiation in high doses to spare healthy tissue from the damaging effects of radiation. Because research suggests that there is no survival benefit of using whole brain radiation, Dr. Brown discussed how more centers are using stereotactic radiosurgery to treat metastatic brain tumors to lessen the toxicity to the patient, reduce the cognitive impact of treatment and, ultimately, improve quality of life.

## Immunotherapy: Science Supports its Potential

David A. Reardon, clinical director of the Center for Neuro-Oncology, Dana-Farber Cancer Institute, highlighted the potential of immunotherapy as a new treatment option for brain tumors and the need to focus more research in this area.

Dr. Reardon explained that immunotherapy is a treatment approach that takes advantage of the body's natural defense system: the immune system. There are three main types of immunotherapy treatments: vaccines, T-cell therapies and

immune check-point inhibitors. While his opinion is that there is still a tremendous amount to learn, immunotherapy research has revealed how, in some cases, brain tumors take advantage of the immune system by creating a wall around the tumor as a strategy to protect the tumor from treatment.

Through ongoing research, Dr. Reardon says that they hope to identify who will be the best candidates for immunotherapy so that brain tumor patients will experience the same success as has been shown with immunotherapy for other cancers including melanoma, lung cancer, kidney cancer and Hodgkin's disease. 

### International Low-Grade Glioma Registry: How to Get Involved

One of the most critical questions in the field of neuro-oncology today is how to best manage and treat LGG. With initial funding from the ABTA, Dr. Elizabeth B. Claus, professor and director of Medical Research, Yale School of Public Health, launched the International Low-Grade Glioma Registry to learn more about the effect of this diagnosis and the associated treatments on daily life, including the ability to work, drive, sleep, exercise or take care of oneself and/or family.

Learn more about this research study and how you can participate at [www.abta.org/LGGRegistry](http://www.abta.org/LGGRegistry).

View a webinar with Dr. Claus about the registry at [www.abta.org/anytimewebinars](http://www.abta.org/anytimewebinars).

## World Health Organization classification of brain tumors

### *Genetic information now a key component for classifying brain tumors*

For the first time since 2007, the World Health Organization (WHO) has reclassified central nervous system tumors. This means that the way tumors are classified will now combine genetic information of the tumor in conjunction with histology (the way the tumor looks under a microscope). At the 2016 ABTA annual meeting, Dr. Kenneth Aldape of Princess Margaret Cancer Centre, Toronto General Hospital, shared how this milestone event enables a more precise diagnosis and an opportunity to translate findings into clinical trials.

View a webinar with Dr. Aldape about the WHO classification at [www.abta.org/anytimewebinars](http://www.abta.org/anytimewebinars).

### *What's new?*

#### **A more accurate diagnosis**

Incorporating both the genetic information and histology of the tumor allows for a more objective and detailed approach to classifying a tumor. For example, two tumors may look the same when viewed under a microscope but when their genetic makeup is examined, there are clear differences in the tumors. A diagnosis that includes molecular information, where available, is better able to inform your clinician about your tumor by offering a more precise diagnosis.

#### **A better treatment plan**

This new layered diagnosis based on histology and molecular definition will hopefully allow clinicians to better predict which treatments the tumor is more likely to respond to and the best overall treatment plan for the patient. The hope is that the WHO classification that combines genetic information will "fine tune" the diagnosis and treatment of brain tumors as well as facilitate clinical, experimental and epidemiological brain tumor studies. 

# ABTA Funds Promising Researchers and Impactful Projects



Funding research is critical to advancing the understanding and treatment of brain tumors. Since 1976, the ABTA has awarded nearly \$30 million in research funding.

Every year, the ABTA awards research grants through a multi-step competitive process. This thorough process allows for projects to be reviewed by a panel of expert scientists and fully vetted before the grant is awarded.

Past grant recipients, particularly early-career investigators, have stated that an ABTA grant is a valued credential that has helped them to get further funding and has had a significant impact on their careers. 

For more information about the grant funding opportunities, visit: [www.abta.org/grants](http://www.abta.org/grants)

I am dedicated to improving lives of brain tumor patients through direct patient care and focused glioma research. When I am in the clinic or the lab, I frequently think to myself that this is a dream for me to be doing what I am doing.

Funding from the ABTA over the years has been part of this good fortune that has played a critical role in my success. This has included the Basic Research Fellowship and numerous other grants which always seemed to provide critical timely funding allowing my lab to get off the ground. For these reasons, I am always grateful toward the ABTA and all that they have done and continue to do for brain tumor patients and researchers.

Perhaps more importantly, these awards have helped me gain the confidence necessary to work in this most challenging of diseases. I will never forget the phone call I received from the ABTA which notified me that I was the recipient of a Basic Research Fellowship and how it meant that I, like other awardees, was destined to make a significant impact in the brain tumor area. That belief and expectation from the ABTA has been a driving force in my career.

— Albert Lai, MD, PhD, Assistant Clinical Professor of Neuro-Oncology, University of California, Los Angeles

*ABTA grant recipient and 2016 Co-Chair of the ABTA Alumni Research Network (AARN) Meeting*

## Congratulations to the 2016 Research Grant Recipients



### 2016 Discovery Grantees

Anita Bellail, PhD, Henry Ford Health System, Detroit, MI  
Peter LaViolette, PhD, Medical College of Wisconsin, Milwaukee, WI  
Josh Neman, PhD, University of Southern California, Los Angeles, CA  
Vivian Gama, PhD, Vanderbilt University, Nashville, TN  
Xi Huang, PhD, The Hospital for Sick Children, Toronto, Ontario  
Jiangbing Zhou, PhD, Yale University, New Haven CT



### 2016-2017 Basic Research Fellowship Grantees

Christopher Alvarez-Breckenridge, MD, PhD, Massachusetts General Hospital, Boston, MA  
Lan Hoang-Minh, PhD, University of Florida, Gainesville, FL  
Giedre Krenciute, PhD, Baylor College of Medicine, Houston, TX  
Francisco Puerta-Martinez, PhD, MD, Anderson Cancer Center, Houston, TX  
Zhaohui Wang, PhD, Duke University, Durham, NC



### 2016 ABTA Medical Student Summer Fellowship Grantees

Abdul-Kareem Ahmed, Brigham and Women's Hospital, Boston, MA  
Raymond Chang, Weill Cornell Medical College, New York, NY  
Patrick Flanigan, University of California San Francisco, San Francisco, CA  
Tyler Lazaro, Massachusetts General Hospital, Boston, MA  
Adela Wu, Johns Hopkins University School of Medicine, Baltimore, MD

# ABTA Marathoner Fueled by Honoring Dad's Legacy

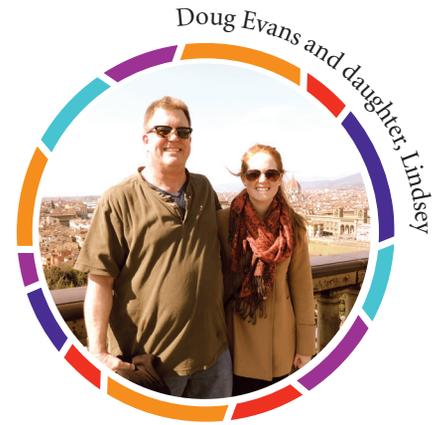
Doug Evans would call his daughter, Lindsey, every week to tell her how great he felt, even though he struggled to manage his metastatic brain tumors — tumors that occurred years after the treatment of malignant melanoma (skin cancer).

He was just a high school student when he was diagnosed with and treated for skin cancer. Decades later, his doctor found three large brain tumors after Doug experienced severe headaches and sleeplessness. Lindsey feared that he had only days or weeks to live, but he fought for a year before passing away this past February.

When her dad was first diagnosed with his brain tumors, Lindsey completed her first marathon. Lindsey trained for her next marathon and raised funds with ABTA's Team Breakthrough, endurance training program, in his honor and to keep his positive attitude alive.

"My dad was always really proud of his kids, and he loved telling everyone I was a marathon runner," said Lindsey. "Participating in the marathon made me feel like I could do anything, and gave me a sense of control of my life as I watched my dad get sicker and sicker."

On October 9, Lindsey joined 91 runners on the ABTA's Team Breakthrough at the 2016 Bank of America Chicago Marathon. For Lindsey, it was important to compete in the marathon for her dad and to support the patients and families who are going through a similar situation her family experienced. ✨



## Facts about Metastatic Brain Tumors

Cancer patients are living longer through advanced treatments, and as a result, metastatic brain tumors are increasingly diagnosed among cancer patients

Metastatic brain tumors are the most common brain tumor in adults

The incidence begins to increase in those ages 45–64 years and is highest in people over 65 years of age.



Join us for one of our nationwide 5K run & walks.

- Dallas** Saturday, March 4, Amphitheater at Oak Point Park
- Tampa** Saturday, March 25, Al Lopez Park
- Chicago** Sunday, April 23, Soldier Field Stadium Green
- Denver** Saturday, May 6, Great Lawn Park
- Michigan** Saturday, May 13, Kensington Metropark
- LA** Sunday, May 21, Fairplex
- Columbus** Saturday, June 3, Arch Park McFerson Commons Park

[www.BT5K.org](http://www.BT5K.org)



Now recruiting runners for the 2017 Bank of America Chicago Marathon!

Participate in endurance events across the country.

- New York City Half Marathon Sunday, March 19
- Chicago Bank of America Shamrock Shuffle Sunday, April 2
- Indy Mini Marathon/5K Saturday, May 6

[www.abtateambreakthrough.org](http://www.abtateambreakthrough.org)



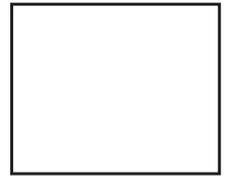
Twenty-year old Matt Tifft is a NASCAR driver for the Joe Gibbs Racing team and a brain tumor survivor who recently returned to the track to race against brain tumors. Visit <http://www.matttifftracing.com/shop> to learn more and purchase an ABTA #TifftStrong shirt.





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## Living Every Day with a Reason to Succeed



*Kevin and his son, Alexander*

At 17, Kevin joined the Army. The military gave him direction, discipline, and a reason to succeed every day. He experienced many tours of duty; however the most important — and least expected — tour of duty was a personal one. Fighting a brain tumor.

In March of 2015, Kevin went to the hospital because he was having strange sensations on the right side of his body. MRI results showed an acoustic neuroma the size of a peach. A few days later he had the first of three surgeries.

He kept looking ahead and at the end of his recovery, he volunteered at a BT5K near him. He passed out water at the finish line and then joined CommYOUUnity™, the ABTA's nationwide volunteer network.

Like his experience in the Army, Kevin believes we are given a reason to succeed each day. Please join Kevin in his fight against brain tumors. Together we can look forward to a future with a greater understanding of brain tumors and an arsenal of more effective treatment options.

Your donation today could help us to meet a challenge given to us by an anonymous family foundation. They are matching dollar-for-dollar, eligible donations raised through this campaign. Please visit [www.abta.org/donatenow](http://www.abta.org/donatenow) or use the included envelope to donate today. 