



American
Brain Tumor
Association®

Providing and pursuing answers®

Headlines

SPRING/SUMMER 2016, VOLUME 43, NUMBER 1

In This Issue

- 2 ABTA Amps Up!
- 3 ABTA funded report reveals interesting statistics for adolescents and young adults
- 4 New driver in brain cancer cell growth
- 5 GBM AGILE
- 6 Now live: Free online Support Group Facilitator Training Program
- 7 ABTA's 2016 National Patient & Family Conference
- 8 Gingras Award winner: E. Antonio (Nino) Chiocca, M.D., Ph.D., FAANS

MAY IS
BRAIN TUMOR
AWARENESS MONTH!

Message from the President and CEO

ABTA Amps up!

The ABTA is the nation's leading organization in providing comprehensive resources that support the complex needs of brain tumor patients and caregivers as well as the critical funding of research in the pursuit of breakthroughs in brain tumor diagnosis, treatment and care.

With an enhanced presence in Washington, D.C., and strengthened influence on Capitol Hill, we are also emerging as the voice of the brain tumor community in public and health policy decisions. With the support of ABTA's volunteer advocates, recent Congressional efforts include:

Brain Tumor Awareness Month Resolution (H.Res. 679): U.S. Rep. Mike Quigley's (D-IL) introduction of a bipartisan resolution designating May 2016 as "Brain Tumor Awareness Month." This resolution was cosponsored by 29 members of Congress.

Brain Cancer Research Funding: The ABTA also worked with Rep. Quigley to spearhead a bipartisan letter in support of expanding cancers covered in the Department of Defense Peer Reviewed Cancer Research Program to include 'brain cancer.' Twenty-eight members of the House of Representatives signed the request which was sent to the House Appropriations Subcommittee on Defense. A similar letter was sent by Senator Ed Markey (D-MA) to the Senate Appropriations Subcommittee on Defense.

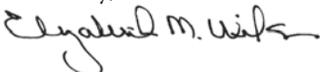
The Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act (S. 1883/H.R. 3381): The ABTA supported passage of legislation that would advance pediatric cancer research, help kids get access to life-saving care and maximize childhood cancer survivors' quality of life.

Medical Debt Relief Act (H.R. 2362/S. 2592): The ABTA joined numerous advocacy organizations in support of protection for patients and consumers struggling with medical debt. Bills are currently pending before the House Financial Services Committee the Senate Committee on Banking, Housing and Urban Affairs.

ABTA staff also met recently with members of the Vice President's Cancer Moonshot Task Force to learn more about the initiative and to provide input on brain tumor research priorities as well as the clinical experiences of brain tumor patients.

To add your voice to the brain tumor cause, visit www.abta.org/advocacy.

Sincerely,



Elizabeth Wilson, MNA
President & CEO



Board of Directors

Jeff Fougerousse, Chair
Brian Olson, Vice Chair
Carla Varner, Treasurer
Jim Reilly, Secretary
Susannah Davis
Alison Miller, MHA
Jeffery Smith
Craig Stokely
Ram Subramanian
James Zhang, M.D., M.B.A

Co-Founders

Susan Netchin Kramer
Linda Gene Goldstein



FOLLOW ME ON TWITTER @theABTACEO

Headlines

VOLUME 43, NUMBER 1

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.

Supported by Genentech

Sandy Abraham: Director,
Marketing & Communications

Phung Tran: Manager,
Marketing & Communications

 [facebook.com/theABTA](https://www.facebook.com/theABTA)

 twitter.com/theABTA

 [www.linkedin.com/company/
american-brain-tumor-association](https://www.linkedin.com/company/american-brain-tumor-association)

Please feel free to share *Headlines* with others. However, the contents are the property of the **American Brain Tumor Association**. Written consent must be obtained from ABTA before reproducing any part of this newsletter.

Copyright 2016 ABTA

American Brain Tumor Association

8550 W. Bryn Mawr Ave., Suite 550, Chicago, Illinois 60631

Toll Free General Information: 866-659-1030

Toll Free Care Line: 800-886-ABTA (2282)

Toll Free Events: 800-886-1281

www.abta.org • info@abta.org

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.

New Report Shows Malignant Brain Tumors are the Most Common Cause of Cancer-Related Deaths in Adolescents and Young Adults

Recognizing that adolescents and young adults with brain tumors are an understudied population, the American Brain Tumor Association funded the first in-depth statistical analysis of brain and central nervous system (CNS) tumors in this age group.

The 50-page report, published recently in the journal *Neuro-Oncology*, finds that malignant brain tumors are the most common cause of cancer-related deaths in adolescents and young adults (AYA) aged 15-39 and the most common cancer occurring among 15-19 year olds.

“When analyzing data in 5-year age increments, researchers discovered that the adolescent and young adult population is not one group but rather several distinct groups that are impacted by very different tumor types as they move into adulthood,” said Elizabeth Wilson, president and CEO of the American Brain Tumor Association.

“What’s interesting is the wide variability in the types of brain tumors diagnosed within this age group which paints a much different picture than what we see in adults or in pediatric patients.”

“For these individuals – who are finishing school, pursuing their careers and starting and raising young families – a brain tumor diagnosis is especially cruel and disruptive,” added Wilson. “This report enables us for the first time to zero-in on the types of tumors occurring at key intervals over a 25-year time span to help guide critical research investments and strategies for living with a brain tumor that reflect the patient’s unique needs.”

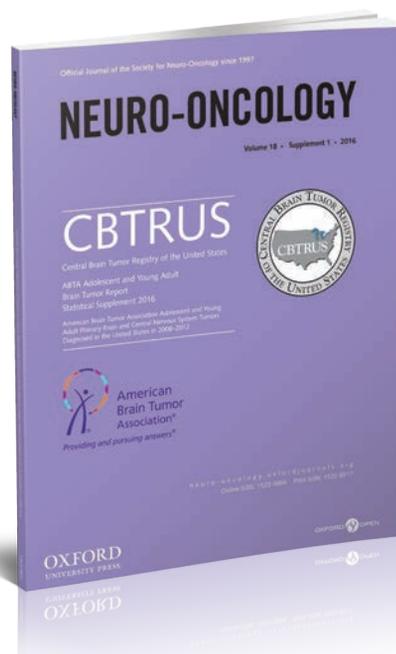
Although brain and CNS tumors are the most common type of cancer among people aged 15-19, the report shows how other cancers become more common with age. By ages 34-39 years, brain and CNS tumors are the third most common cancer after breast and thyroid cancer.

“What’s interesting is the wide variability in the types of brain tumors diagnosed within this age group which paints a much different picture than what we see in adults or in pediatric patients,” explained the study’s senior author Jill Barnholtz-Sloan, Ph.D., associate professor, Case Comprehensive Cancer Center, Case Western Reserve University School of Medicine and Scientific Principal Investigator for CBTRUS.

“For example, the most common tumor types observed in adults are meningiomas and glioblastomas, but there is much more diversity in the common tumor types observed in the adolescent and young adult population. You also clearly see a transition from predominantly non-malignant and low-grade tumors to predominantly high-grade tumors with increasing age,” Barnholtz-Sloan said.

There are nearly 700,000 people in the U.S. living with brain and CNS tumors and approximately 15 percent of these tumors occurred in the AYA population during the 2008-2012 time frame analyzed in this report. Approximately 10,617 brain and CNS tumors are diagnosed among adolescents and young adults each year and are the cause of approximately 434 deaths annually.

“The American Brain Tumor Association’s recognition of this understudied population, and their commitment to data and information sharing should be applauded,” added Barnholtz-Sloan. “There are clearly unique characteristics of the 15-39 age group that we need to more comprehensively understand and the information in the ABTA report starts that important dialogue.”



Access the full report at
[www.abta.org/about-us/news/
brain-tumor-statistics](http://www.abta.org/about-us/news/brain-tumor-statistics)

ABTA-Supported Study Suggests a New Driver for Uncontrolled Brain Cancer Cell Growth

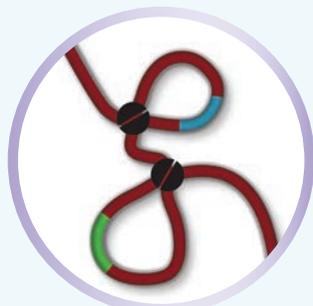
For the first time, researchers studying the structure of brain cancer DNA found an unexpected unraveling of the “loops” that are typically formed when DNA is folded into normal cells, and their findings offer a new explanation of how cancer cells can grow uncontrollably.

American Brain Tumor Association-funded researcher William Flavahan, Ph.D., is lead author on the paper titled “Insulator Dysfunction and Oncogene Activation in IDH Mutant Gliomas” that was recently published in the journal *Nature*.

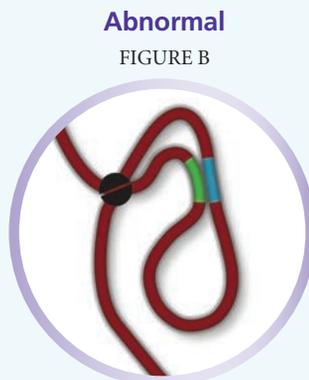
“No one has ever looked at the three-dimensional structure of DNA as a potential cancer-driving process,” said Flavahan, a postdoctoral fellow at Massachusetts General Hospital.

“No one has ever looked at the three-dimensional structure of DNA as a potential cancer-driving process,” said Flavahan, a postdoctoral fellow at Massachusetts General Hospital. “Whenever we analyze tumor cell DNA, we essentially stretch it out in a line, so it often looks similar to normal cells. However, when you look at how it’s folded inside the actual tumor cell, there is a clear difference. We identified these uncharacteristic folds that ‘turn on’ certain genes which should not be ‘turned on.’”

As Flavahan explains, each cell has about 6 ½ feet of DNA. The way a normal cell is able to function is that it folds its DNA into a series of specific loops. There are about 10,000 of these loops in the human genome. When Flavahan and colleagues began taking a closer look at this process, they found that surprisingly, the loops can be disrupted when the DNA becomes studded with marks on the DNA called methylation.



Normal
FIGURE A



Abnormal
FIGURE B

While it was already known that mutation of a gene called IDH increases methylation, scientists had not yet discovered any important genes that are “turned off” when IDH is mutated. Therefore, the importance of these IDH related methylation marks in brain tumors has not been clear, until now.



“What we ultimately found is that brain tumors with the IDH mutation lose DNA binding ability of the loop-forming protein, called CTCF. In places where CTCF should be binding and bringing the DNA loops together, there were increased levels of DNA methylation that were preventing CTCF from doing its job,” explained Flavahan. “We found that in these tumors, two or three DNA loops were merging to form bigger loops which caused genes to interact that shouldn’t be interacting.”

One of the genes being “turned on” was an oncogene, or a cancer-causing gene, called PDGFRA.

Flavahan also investigated a drug called 5-azacytidine, which can block the buildup of DNA methylation and is approved by the FDA to treat myelodysplastic syndrome. When IDH mutant cells were treated with 5-azacytidine, CTCF function was restored, the normal loop structure was reformed, and PDGFRA was turned back off.

“This is an exciting finding because it suggests that there’s a whole new way for us to look at how brain tumors are being driven. It suggests there are potential new therapies we can use to treat these tumors as well as other cancers including leukemia, bladder cancer and colon cancer,” said Flavahan. [↗](#)

Graphics illustrate the oncogene PDGFRA in blue and an activating element in DNA known as an enhancer in green. Normally they are separated in distinct loops (Figure A), but loss of CTCF binding due to DNA methylation causes the loops to merge (Figure B), allowing the interaction of the enhancer and PDGFRA, activating the gene.

Image Credit: Broad Institute Communications

Global Coalition Seeks Effective Treatments for GBM with new GBM AGILE Clinical Trial

With little advancements in the treatment for GBM, the ABTA has joined an international coalition comprised of over 130 neurosurgeons, neuro-oncologists, pathologists, imagers, basic and clinical investigators and brain tumor advocacy organizations to identify successful therapies for GBM with the launch of the GBM AGILE clinical trial.

ABTA President and CEO Elizabeth Wilson will serve as co-chair of the GBM Patient Advocacy Committee, along with Catherine Stace, CEO of the Cure Brain Cancer Foundation of Australia.

“It’s an honor to work in partnership with a global consortium that is boldly pursuing effective therapeutic strategies for a disease in which the five-year survival rate is unacceptably low and has not changed in decades,” said Wilson. “The international scope of this trial offers a real opportunity to recruit a significant number of patients, and with the inclusion of molecular profiling, move us closer to making precision medicine a reality for GBM patients.”

Considered an “adaptive” trial, GBM AGILE is designed to be a “learning environment” that allows the response of each patient to inform the ongoing conduct of the trial.

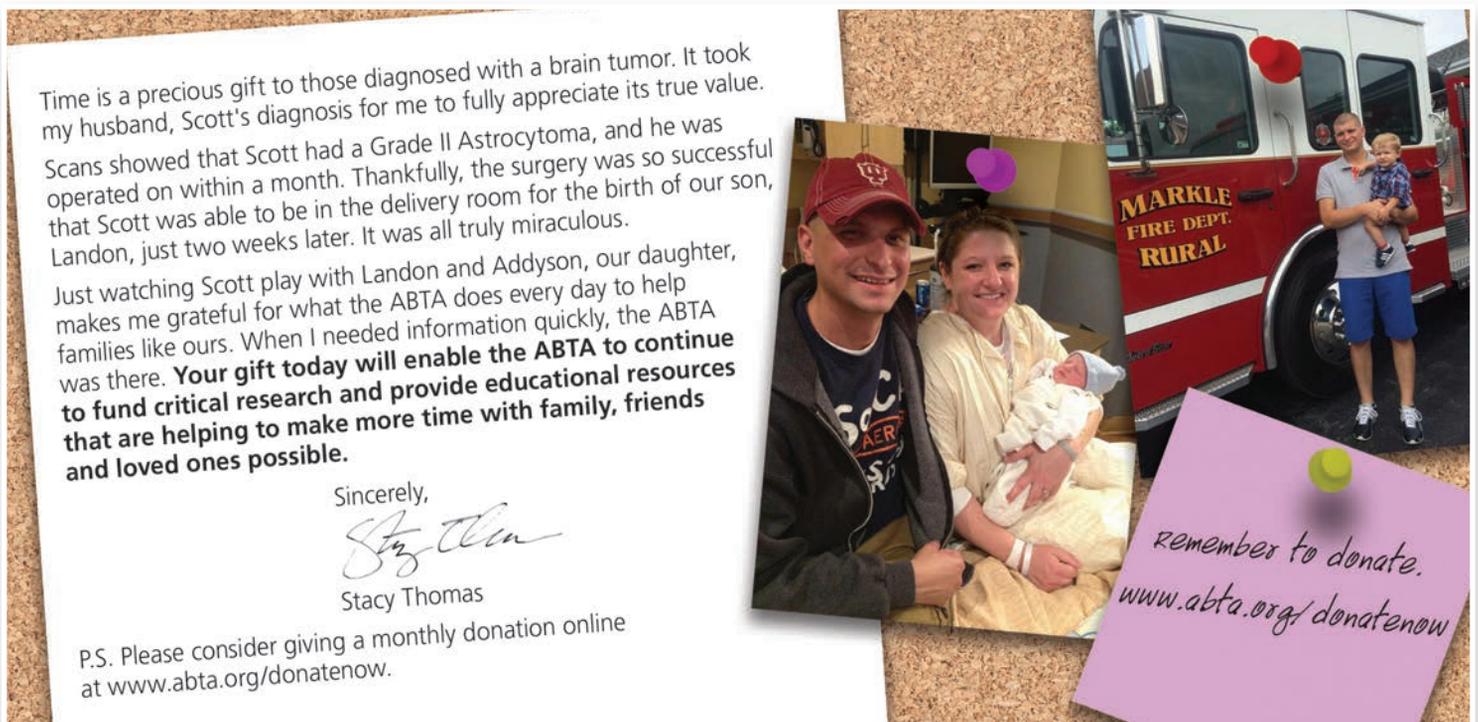
One of the major barriers in identifying effective drugs for GBM is the lack of validated biomarkers. This trial will address that by incorporating biomarkers to divide GBM patients into subclasses to more rapidly and efficiently test single agents and combinations of drugs and biologics.

Beyond increasing the numbers of agents tested and the speed of the screening process, effective therapies can progress quickly and more cost-effectively to “graduate” from GBM AGILE to a confirmatory Phase III trial. Similarly, agents that do not work can be dropped from the trial more efficiently and quickly.

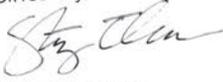
GBM AGILE is being led by the the National Biomarker Development Alliance (NBDA), a non-profit organization created as part of the Research Collaboratory at Arizona State University (ASU). The trial aims to begin patient enrollment in 2016. 



For more information about the GBM AGILE trial, go to www.abta.org/agile.



Time is a precious gift to those diagnosed with a brain tumor. It took my husband, Scott's diagnosis for me to fully appreciate its true value. Scans showed that Scott had a Grade II Astrocytoma, and he was operated on within a month. Thankfully, the surgery was so successful that Scott was able to be in the delivery room for the birth of our son, Landon, just two weeks later. It was all truly miraculous. Just watching Scott play with Landon and Addyson, our daughter, makes me grateful for what the ABTA does every day to help families like ours. When I needed information quickly, the ABTA was there. **Your gift today will enable the ABTA to continue to fund critical research and provide educational resources that are helping to make more time with family, friends and loved ones possible.**

Sincerely,

Stacy Thomas

P.S. Please consider giving a monthly donation online at www.abta.org/donatenow.

remember to donate.
www.abta.org/donatenow

LEADING BY EXAMPLE

ABTA Launches Support Group Facilitator Training Program

Juston Tankersley may likely be the most positive, uplifting person you would ever meet, but he says that wasn't always the case. After surviving a difficult surgery to remove a grade III anaplastic oligodendroglioma, Juston says he experienced severe depression until he turned to the ABTA for help.

"That one call to the ABTA changed my life," he says. "They talked with me and sent me resources that helped tremendously. At that time, our hospital didn't have a neuro-oncologist let alone a support group, so I remember feeling lost and alone until I called."

Recently, Juston was one of the first to complete the ABTA's new Support Group Facilitator Training Program.

"The training was phenomenal, and I would encourage others to participate and become facilitators so that more people have access to support groups closer to home," said Juston. "A brain tumor diagnosis doesn't mean that you have to stop living, and as support group facilitators, we can be that light, that force that encourages others to lace up their boots and go."

The ABTA is committed to partnering with health care professionals and volunteers like Juston across the country to ensure education, information and support are available to brain tumor patients and caregivers locally.

"We understand the healing that takes place when patients and families connect with and support each other, so developing this comprehensive training program was a real priority to expand the ABTA's reach and increase the availability of support groups nationwide," said Vince Rock, MSW, program manager, American Brain Tumor Association.

The online training program is offered free of charge and was created by highly credentialed experts from top U.S. brain tumor treatment centers. Open to health care professionals and volunteers, the four-course program covers:

- Side Effects of Brain Tumor Treatments
- Neuropsychological Issues Relating to Brain Tumors
- How to Help Caregivers Cope
- The Basics of Organizing and Facilitating a Brain Tumor Support Group

Upon completion, nurses are eligible for 4 CEUs through the American Association of Neuroscience Nurses (AANN), and social workers are eligible for 4 CEUs through the National Association of Social Workers (NASW). 



"A brain tumor diagnosis doesn't mean that you have to stop living, and as support group facilitators, we can be that light, that force that encourages others to lace up their boots and go."



To learn more about this training opportunity or to find a support group near you, go to www.abta.org or call the ABTA CareLine 800-886-ABTA (2282).

2016 NATIONAL PATIENT & FAMILY CONFERENCE

Precision Medicine & its Impact on Brain Tumors: Low Grade, High Grade & Metastatic



NEW
VENUE
IN 2016!

Friday – Saturday, July 29 – 30 • Westin O’Hare

6100 North River Road, Rosemont, IL 60018

FEATURED SPEAKERS

Manmeet Ahluwalia, M.D., FACP
(Cleveland Clinic), Program Planning
Co-Chair

Elizabeth B. Claus, M.D., Ph.D.
(Brigham and Women’s Hospital and
Yale University School of Public Health),
Program Planning Co-Chair

Kenneth Aldape, M.D.
(University Health Network,
Toronto General Hospital)

Mitchel S. Berger, M.D., FACS, FAANS
(University of California, San Francisco)

E. Antonio Chiocca, M.D., Ph.D., FAANS
(Brigham and Women’s Hospital,
Dana-Farber Cancer Institute)

David A. Reardon, M.D.
(Dana-Farber Cancer Institute)

2016 PROGRAM HIGHLIGHTS:

- Physicians will present the latest precision medicine treatment options and symptom management techniques for low-grade glioma, high-grade glioma and metastatic brain tumors
- Researchers and doctors will highlight treatment advances in neurosurgery, radiation and immunotherapy
- Health care professionals will discuss:
 - The International Low-Grade Glioma Registry
 - Resources for returning to work
 - The World Health Organization (WHO) re-classification of glioma
 - Strategies in caring for the caregiver
 - Healing and finding support
- A special session for the newly diagnosed will cover how to navigate the early days of a brain tumor diagnosis and what information patients, families and caregivers would need to know in order to be empowered with information and resources to make informed decisions throughout their treatment and care.

SPACE IS LIMITED — REGISTER TODAY!

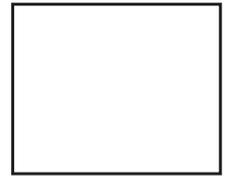
To register, visit www.braintumorconference.org or call 800-886-ABTA (2282).





American
Brain Tumor
Association®

8550 W. Bryn Mawr Ave., Suite 550
Chicago, Illinois 60631



Register today for the ABTA's National Patient & Family Conference.
July 29-30 at the Westin O'Hare.

www.braintumorconference.org



2016 Joel A. Gingras Award to be Presented to Antonio (Nino) Chiocca, M.D., Ph.D.

The American Brain Tumor Association (ABTA) bestows the prestigious Joel A. Gingras (JAG) Award annually to an individual, organization or group that through philanthropy, advocacy, discovery or patient care, has made a major impact on the ability of the ABTA to achieve its mission. In 2010, the award was established in honor of the Joel A. Gingras, Jr. Memorial Foundation, which has raised more than \$1.7 million for the ABTA.

The 2016 JAG award will be presented to Nino Chiocca, M.D., Ph.D., chair of the Department of Neurosurgery and co-director of the Institute for the Neurosciences at Brigham and Women's/Faulkner Hospitals, at the ABTA's National Patient & Family Conference, held July 29-30, in Chicago.

"Dr. Nino Chiocca's career is an example of the promise and potential of early career scientists who go on to make valuable contributions to the field after receiving early funding through the ABTA's research fellowship program — a program that the JAG Fund has supported for more than 25 years," said Elizabeth M. Wilson, president and CEO, American Brain Tumor Association.

Dr. Chiocca received his first grant from the ABTA in the early 1990s. He was researching "Experimental Therapy of Human Glioma Mediated by Glial-Specific Herpes Simplex Virus Mutants". That \$50,000 Fellowship grant supported his work on

an experimental therapy — work that continues to this day and which will move into a clinical trial this fall.

Throughout his career, he has mentored five ABTA-funded early-career scientists, served as an ABTA Scientific Advisor and participated as the keynote speaker and expert panelist at the ABTA's Alumni Research Network's annual meeting.

Dr. Chiocca is the Harvey W. Cushing professor of Neurosurgery at Harvard Medical School and surgical director at the Center for Neuro-Oncology at the Dana-Farber Cancer Institute. Esteemed neuro-surgeons and researchers like Dr. Chiocca will be presenting at the ABTA's National Patient & Family Conference in July. Register today at www.braintumorconference.org. 



Left to Right:
Dr. Nino Chiocca,
Johnathan Gingras
(JAG Fund President),
Elizabeth Wilson (ABTA
President & CEO), Dr.
Steven Brem (previous
award recipient), Nicole
Willmarth (ABTA Chief
Science Officer)