



American  
Brain Tumor  
Association®

Providing and pursuing answers®

# Headlines

FALL/WINTER 2015, VOLUME 42, NUMBER 2

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## BEYOND THE GRADE

*The role of genetic information in understanding and treating low-grade glioma*

Significant gaps exist in understanding the causes and clinical management of glioma, the most common malignant brain tumor in the United States.

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# American Brain Tumor Association Strategic Plan

## Fiscal Years 2016 to 2018

Thanks to advances in research and technology (some funded by the American Brain Tumor Association), one-size-fits-all therapies are gradually giving way to precision medicine—sometimes known as personalized medicine—which uses molecular and genetic information to diagnose and treat tumors. Yet not all of those impacted by brain tumors have equal access to information they need and to medical innovations.

The American Brain Tumor Association Board of Directors has created a three-year strategic plan that reflects our commitment to increasing research funding; increasing the quality of information available to patients and their caregivers; increasing the number of newly diagnosed who get information they need in a timely way so they can make informed treatment decisions; and serving as the voice of the brain tumor community.

We hope that you will join us in advancing this important, life-affirming work.



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Chair, Board of Directors



**Elizabeth Wilson**  
President & CEO

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## Co-Founders

Susan Netchin Kramer  
Linda Gene Goldstein

## KEY IMPACT INDICATORS

We are committed to being the national advocate for patient-centered treatment, support services, information, and research investment for brain tumor patients and their caregivers. Our impact is measured in these ways:

- Number of scientists involved in brain tumor research**
- Research dollars we provide and influence**
- Size of our reach into the healthcare provider community**
- Growth in the number of people accessing information from the ABTA**

## GOALS

FISCAL YEARS 2016 TO 2018

- RESEARCH:** Increase career development & support for brain tumor researchers
- ADVOCACY:** Increase voice of those impacted in public and health policy decisions
- ACCESS:** Increase patient & caregiver access to information
- PROVIDERS:** Increase clinician awareness of issues faced by brain tumor patients and families
- POINT OF DIAGNOSIS:** Increase clinician use of ABTA resources
- CAPACITY:** Ensure ABTA's capacity for impact

## Headlines

VOLUME 42, NUMBER 2

**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,  
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**American Brain Tumor Association**

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# CommYOUunity™ Volunteers Step Up to Change the Stats

In spring 2015, the American Brain Tumor Association (ABTA) conducted a web-based poll of more than 2,300 patients and caregivers to gain more insight into the brain tumor diagnosis experience and to better understand what information is needed at the point of diagnosis and throughout the trajectory of the disease.

Among the findings, the ABTA learned that more information about the diagnosis and treatment options, including clinical trials, is needed at the time of diagnosis, many patients and caregivers are not being referred to additional resources for more information, and a strong percentage wished they would have known what questions to ask their healthcare team.

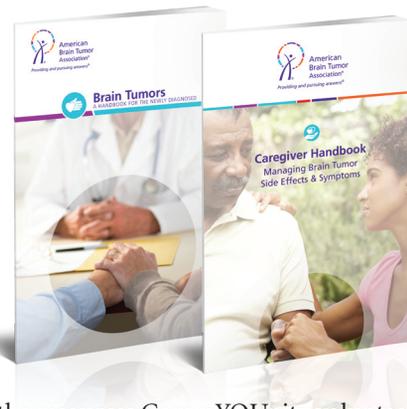
“The poll found that the information and resources are not getting to patients and caregivers at the time when it matters most. Too often we hear from patients and families that they would have made different decisions if they would have had information sooner,” said Elizabeth M. Wilson, president and CEO, American Brain Tumor Association. “Our national volunteer network, the ABTA CommYOUunity™, is motivated to ensure knowledge of and access to brain tumor advances and information are available to patients and families at the point of diagnosis and through the trajectory of the disease.”

ABTA CommYOUunity volunteers already have begun distributing informational materials to healthcare and support providers in their local communities.

“When I learned about this opportunity, it really resonated with me because I remember what it felt like to desperately search for information,” said Angela Jones, ABTA CommYOUunity volunteer from Kansas City, Mo. “This is my way of paying it forward. I’m passionate about making sure brain tumor patients and their families have the information and resources they need in the hospitals and clinics in my community.”

**42%**

**42% of brain tumor patients, caregivers and long-term survivors wished they would have known the questions to ask their healthcare team**



Among the resources CommYOUunity volunteers are providing are publications titled *Brain Tumors: A Handbook for the Newly Diagnosed* and *The Caregiver Handbook*. These comprehensive publications cover information about how to navigate those critical first hours and days following a diagnosis, including questions to ask your doctor.

“There is nothing like this out there,” added Jones. “After receiving a brain tumor diagnosis, every patient and caregiver needs to be given these handbooks.”

While CommYOUunity volunteers are providing resources to healthcare professionals in local markets across the country, the ABTA’s *Brain Tumors: A Handbook for the Newly Diagnosed* and *The Caregiver Handbook* are also available online with the ABTA’s vast array of educational resources at <http://www.abta.org/brain-tumor-information/publications/>.

**To learn more about how to get involved in this volunteer opportunity in your community, go to [www.abta.org](http://www.abta.org).**

**60%**

**60% of brain tumor patients, caregivers and long-term survivors reported that they were not referred to resources for more information, with a majority citing they need more information about treatments options, including clinical trials.**



## Beyond the Grade

### *The role of genetic information in understanding and treating low-grade glioma*



Significant gaps exist in understanding the causes and clinical management of glioma, the most common malignant brain tumor in the United States.

“One of the biggest questions in neuro-oncology today is how to best manage low-grade glioma,” said Elizabeth B. Claus, MD, PhD, attending neurosurgeon and director of Stereotactic Radiosurgery in the Department of Neurosurgery at Brigham and Women’s Hospital. Dr. Claus also is a professor and director of Medical Research at the Yale School of Public Health and has focused her research on the genetic and epidemiology of such tumors.

Traditionally, gliomas have been classified by the World Health Organization (WHO) as grade I to IV based on histology and clinical criteria. Adult grade II tumors (Low-Grade Gliomas or LGG) are typically diagnosed in patients between ages 25-55 years and have included astrocytomas, oligo-astrocytomas (mixed gliomas) and oligodendrogliomas.

Researchers recently developed a new molecular genetic method to reclassify such gliomas based on three glioma tumor alterations: TERT promoter mutation, IDH mutation and co-deletion of 1p and 19q. This classification method generated five glioma subgroups: triple-positive (containing all three alterations), IDH mutant only, IDH and TERT mutant, triple-negative and TERT mutant only. Each group has unique clinical features (such as specific ages at diagnosis) as well as specific additional tumor and inherited genetic alterations.

“Although a very exciting advance in glioma research,” says Claus, “these new studies included primarily patients with high grade (grade III/IV) glioma and only a small number (n=311) of LGG patients. Emerging data strongly suggest that distinct tumor and inherited genetic variations underlie different glioma subtypes highlighting the need to identify and collect data on a larger cohort of ‘pure’ LGG patients.”

### Using Registries for Research

When performing such research, epidemiologists generally use population- or hospital-based registries to identify

patients. However, the use of such registries to identify and enroll large numbers of patients with less-common diseases such as LGG is expensive and labor-intensive given the need to include registries over many geographic regions. In addition, patients who live in areas without registries are often not included. Collaboration with patient communities and use of the internet represents a cost- and time-efficient solution to these challenges.

### Developing a LGG Registry

The ABTA has provided initial funding for Dr. Claus to build an international LGG patient registry using web-based methods to identify, consent and collect clinical/ biological data for at least 2,000 LGG patients.

“The data Dr. Claus will collect through this registry will provide valuable insights into better understanding low-grade gliomas and ways to improve treatment,” said Nicole Willmarth, PhD, chief science officer, American Brain Tumor Association.

The intent of the patient registry is to use the data collected in a study to determine inherited and non-inherited genetic variants associated with risk of LGG. Dr. Claus also plans to look at response to treatment and clinical outcomes for these patients.

“Discovery of inherited and tumor differences may help to better define the timing and selection of appropriate treatment for these patients,” Dr. Claus explained. “The patient registry is an important first step to advance our understanding and hopefully guide development of targeted therapies for LGG. We also hope to gain insight into concerns that these patients might have regarding quality of life as well as their needs regarding information on their tumor and its treatment.”

### Interested in learning more about Low-Grade Gliomas?

Join us for a free webinar on February 16 (1pm-2pm CT) when Dr. Claus will provide the latest information about LGG and her research.

# ABTA Funds Nearly \$1Million in Innovative Brain Tumor Research

## 2015-2017 ABTA Basic Research Fellowships

The American Brain Tumor Association Basic Research Fellowships are two-year, \$100,000 grants supporting postdoctoral fellows conducting brain tumor research.



1. Sampurna Chatterjee, PhD, Massachusetts General Hospital and Harvard Medical School, Boston, Mass.
2. William Flavahan, PhD, Massachusetts General Hospital, Boston, Mass.
3. Hernando Lopez-Bertoni, PhD, Hugo W. Moser Research Institute Kennedy Krieger, Baltimore, Md.
4. Megan Muroski, PhD, University of Chicago, Chicago, Ill.
5. Richard Phillips, MD, PhD, Memorial Sloan-Kettering Cancer Center and Rockefeller University, New York, N.Y.
6. David Raleigh, MD, PhD, University of California San Francisco, San Francisco, Calif.

## 2015 ABTA Discovery Grants

The American Brain Tumor Association Discovery Grant is a one-year, \$50,000 award supporting high risk/high impact projects that have the potential to change current diagnostic or treatment paradigms for either adult or pediatric brain tumors.



1. Amanda Garner, PhD, University of Michigan, Ann Arbor, Mich.
2. Santosh Kesari, MD, PhD, University of California San Diego, La Jolla, Calif.
3. Martina Malatesta, PhD, University of California San Francisco, San Francisco, Calif.
4. Braden McFarland, PhD, University of Alabama at Birmingham, Birmingham, Ala.
5. Renee Read, PhD, Emory University, Atlanta, Ga.
6. Andrew Venteicher, MD, PhD, Massachusetts General Hospital, Charlestown, Mass.
7. Jennifer Yu, MD, PhD, Cleveland Clinic, Cleveland, Ohio

## 2015 ABTA Medical Student Summer Fellowships

The American Brain Tumor Association Medical Student Summer Fellowship program is a 10-12 week mentoring-focused summer program, intended to motivate talented medical students to pursue a career in neuro-oncology research.



1. Vyshak Chandra, Massachusetts General Hospital, Boston, Mass.
2. Maxwell Cooper, Cleveland Clinic, Cleveland, Ohio
3. Ramita Dewan, National Institutes of Health, Bethesda, Md.
4. Michael Hadler, University of North Carolina at Chapel Hill, Chapel Hill, N.C.
5. Jaeho Hwang, Dana Farber Cancer Institute, Boston, Mass.
6. Jacob Miller, Cleveland Clinic, Cleveland, Ohio
7. Panayiotis Pelargos, David Geffen School of Medicine at UCLA, Los Angeles, Calif.
8. Kristen Scheitler-Ring, University of Missouri School of Medicine, Columbia, Mo.
9. Aditya Sengupta, Brigham and Women's Hospital, Boston, Mass.
10. Nickpreet Singh, Hospital of the University of Pennsylvania, Philadelphia, Pa.





## Breakthrough Your Way

The American Brain Tumor Association (ABTA) recently launched *Breakthrough Your Way*, a new program that provides tools and resources for people who would like to turn their passions and interests into a fundraiser to benefit the ABTA.

For the Kessler family, it was a fundraiser that focused on celebrating their son, brother, and husband Gavin's incredible life that was cut short in 2006 because of brain tumor. After he died, family and friends began hosting the *Kessler Cruise for a Cure* that has been an annual event for the last 10 years.

"Gavin loved Chicago and boating in Lake Geneva, so we thought a chartered cruise on the Chicago River and Lake Michigan was a perfect tribute," said Kimberly Jarvis, Gavin's sister. "Every year, about 100 people gather to remember Gavin and raise money for the ABTA."

The *Kessler Cruise for a Cure* has raised over \$85,000 to date. 

**To learn more about creating a fundraiser in your community, go to [www.btyourway.org](http://www.btyourway.org).**



**Breakthrough**  
your way American Brain Tumor Association

## Wanting to be like everyone else

Eight-year-old Malak enjoys all the typical things that third grade girls do, even while battling a brain tumor.

Diagnosed when she was just three-years old, Malak doesn't remember much about life before her diagnosis. Her father Sager says, "She is the sweetest, most kind little girl wanting to be just that, a little girl, but she has to deal with issues beyond her age that accompany a brain tumor diagnosis."

Malak attended the ABTA's National Patient and Family Conference last summer with her father to meet the researchers investigating new therapies to help people of all ages with brain tumors. When asked if she enjoyed being at the conference, Malak spoke like a true eight-year old when she said, "I would rather be riding my bike!"

Please consider donating to the ABTA today. Your gift will support critical research projects and important resources, such as the Caregiver Resource Centers (Adult and Pediatric), which help caregivers navigate a diagnosis and its impact on the entire family.



Visit [www.abta.org/donatenow](http://www.abta.org/donatenow) or use the envelope in this newsletter to make a donation.





# Olympic Trials Hopeful Going the Distance to Raise Awareness

With her sights set on the Olympic Trials, competitive marathoner Jill Howard never gave much thought to her ability to run until unexpected fatigue suddenly prevented her from pounding the pavement.

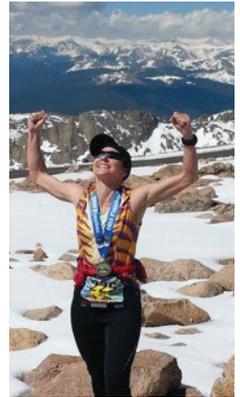
“After running 90 miles one week, followed by a 10K-race personal record, my body shut down and wouldn’t allow me to run for more than 10 minutes for the next two years,” recalled Howard. “Every time I tried to get back on the saddle, my body would protest and send me to the couch for days with debilitating fatigue.”

After two years of misdiagnosis and of being sidelined from the sport, doctors finally discovered a baseball-sized brain tumor. “I didn’t know if I’d be able to walk straight again, let alone run.”

Less than a year after surgery, Howard qualified for the 2016 Boston Marathon. “I wouldn’t give up, and now I run with a joy and never-ending gratitude that fuels me,” she said. “It’s one reason I’m devoted to helping others by volunteering for the American Brain Tumor Association (ABTA) CommYOUunity™. I want to offer hope and encouragement to others faced with this diagnosis. By sharing my story, I hope I can help others.”

Howard attended the ABTA’s National Patient and Family Conference last July and participated in a workshop for ABTA CommYOUunity volunteers about how to share their story and help raise awareness of brain tumors.

Not one to lose any ground, Howard already shared her story and secured coverage from the Denver Post, KUSA-TV (the NBC affiliate in Denver), KOA-radio, RunnersWorld.com and Runner’s World in which she was selected as a semifinalist in their cover search contest. 



To learn more about how to become a volunteer for the ABTA CommYOUunity in your area, visit [www.abta.org](http://www.abta.org).

## IN EVERY STEP, A STORY.

The BT5K Breakthrough for Brain Tumors Run & Walk is the American Brain Tumor Association’s signature fundraising event. Join us in a city near you in 2016! Register at [www.bt5k.org](http://www.bt5k.org)

**CHICAGO**  
Sunday, April 24

**MICHIGAN**  
Saturday, May 7

**COLUMBUS**  
Saturday, June 4

**TAMPA BAY**  
Saturday, March 26

**LOS ANGELES**  
Saturday, April 9



## 2015 NATIONAL PATIENT & FAMILY CONFERENCE

### National Patient and Family Conference Empowers Attendees

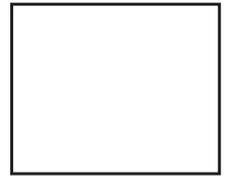
Over the course of two days, more than 230 people convened in Chicago for the ABTA’s National Patient and Family Conference held July 24-25.

If you weren’t able to be there, learn more and check out our highlights video and photos at [www.abta.org/2015conference](http://www.abta.org/2015conference).



American  
Brain Tumor  
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A snapshot of hot topics

## What's TRENDING



### FDA Approves Optune for Newly Diagnosed

In recent news, the FDA approved Optune — a device that delivers Tumor Treating Fields (TTFields) — to be used in combination with the chemotherapy drug Temodar® for newly diagnosed GBM patients. The approval was based on a study of 695 patients that demonstrated improved progression-free and overall survival in those receiving Optune in combination with Temodar® compared to treatment with Temodar® alone. The FDA initially approved Optune in 2011 only for the treatment of recurrent GBM.

### Stem Cell Agency Invests Nearly \$20 Million in GBM Clinical Trial

CIRM, California's stem cell agency, awarded \$19.9 million to ImmunoCellular Therapeutics to carry out a Phase III clinical trial in people with newly diagnosed GBM using a vaccine made from the patient's own immune system. ImmunoCellular plans to recruit about 400 patients at 120 clinical trial sites in the US, Canada and Europe.

An ABTA CommYOUity™ volunteer will be serving on the advisory committee and will be providing valuable input from the patient perspective.