



American
Brain Tumor
Association®

Providing and pursuing answers®

Headlines

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A Brain Tumor Diagnosis Changes Your Perspective.

Being diagnosed with a brain tumor makes you look at your world, and what's important in it a little differently...

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Message from the President and CEO

Science is telling us that every brain tumor is as different as the individual diagnosed. While we're seeing scientific and medical advances in the field, the brain is a complicated structure and brain tumors are confounding for the scientists studying them, for the clinicians treating them, and for the patients and families and friends whose lives are disrupted and forever changed by them.

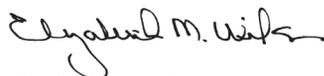
To better understand the diagnosis experience, the ABTA conducted a web-based poll earlier this spring. Findings from more than 2300 respondents, consisting of patients, caregivers and long-term survivors, show that for many, information about their diagnosis and treatment options is lacking. Consider:

- Sixty-seven percent had a few days or less to make treatment decisions.
- Forty percent did not feel they had sufficient information to make informed decisions.
- Sixty-eight percent cited physician recommendations as most influencing their treatment decisions.
- Sixty percent reported that they were not referred to resources for more information, with a majority of those specifically citing treatment options, including clinical trials.
- Forty-two percent wished they would have known the questions to ask their healthcare team.
- Forty-four percent turned to the Internet for more information.

To close these information gaps, the ABTA has created new and robust sections on our website with content tailored to meet the needs of the newly diagnosed and their caregivers. We have also produced two new publications, *The Caregiver Handbook* and *Brain Tumor Basics*, with each available in print and in downloadable formats. We are also working with health care professionals and providers across the country to distribute these materials and develop a comprehensive web-based brain tumor center resource listing.

In addition, the ABTA CommYOUUnity™, a network of volunteers working with us at the grass roots level, is mobilizing to help make more readily known the information and support services available locally and through the ABTA.

It is our hope that future poll results will show that brain tumor patients have the information and support they need at the point of diagnosis and throughout the trajectory of the disease.



Elizabeth M. Wilson, MNA
President & CEO

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Headlines

VOLUME 42, 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.

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Caring for the Caregiver

The ABTA Caregiver Resource Center Now Available

The American Brain Tumor Association (ABTA) recently went live with its online Caregiver Resource Center created specifically for brain tumor caregivers by brain tumor caregivers. The extensive online center provides comprehensive information and resources to help caregivers anticipate, prepare for and better cope with the unique needs of caring for someone with a brain tumor throughout the trajectory of the disease.

Needs and Support

Studies have shown (*see sidebar*) that due to the neurological symptoms that can accompany a brain tumor diagnosis, brain tumor caregivers often need more support than caregivers for other types of cancer. In many situations, caregiving is a full time job where the caregiver assumes additional roles, including: medical researcher, financial manager, patient advocate, and communicator.

“Just as a patient’s needs change over time, so do the roles and responsibilities of the caregiver,” said Elizabeth Wilson, ABTA President and CEO. “We designed this center with that in mind, understanding that caregivers’ needs for support and information will vary, so we hope caregivers will check back often for information about how to care for their loved one, but just as important, how to take care of themselves.”

Center Resources

The ABTA interviewed several caregivers who shared their experiences and suggested what information would have been helpful to them. The Caregiver Resource Center combines caregiver advice with information from clinical experts to provide tools and resources to navigate the caregiving continuum. Available online 24/7 at www.abta.org/caregiver, caregivers can watch video messages from caregivers who already have been through the experience, and learn more about:

- Understanding your role as caregiver
- Impact on the Family
- Communicating with Children
- Getting the Help you Need
- Physical and Psychological Symptoms
- Safety at home
- Tips for Family and Friends
- Navigating the Health Care System

“As a caregiver for my husband, I know first-hand the challenges caregivers face when caring for someone with a brain tumor,” said Kristin Gray. “I’m proud to have provided input for this new resource for caregivers, and hope many caregivers take advantage of what is here because they are not alone, the ABTA is here to help.”



Study Evaluates Caregivers Quality of Life

In a recent study published in the journal *Neuro-Oncology Practice*, researchers in France aimed to assess the impact of gliomas on caregivers’ quality of life compared to other cancer caregivers.

According to the research, caregivers of glioma patients showed increased burden scores and lower scores for leisure time. Compared to other cancer patients, glioma patients have higher rates of dependent status and their need for assistance with activities of daily living—including dressing, laundry, shopping, and transportation—seem to be a primary cause of caregiver exhaustion.

“It’s a caregiver’s nature to put their own needs last, but it’s important that they put some effort into thinking about their own wellness,” said Elizabeth Wilson, ABTA President and CEO. “I encourage caregivers to visit our new online Caregiver Resource Center to get guidance on managing stress and seeking support and help from others.”

CEO Charts ABTA Future with Launch of the ABTA CommYOUUnity™

As the convergence of science and technology ushers in an unprecedented era of a more personalized approach to brain tumor treatment and care, ABTA President and CEO Elizabeth Wilson is committed to ensuring that knowledge of and access to these advances are available to brain tumor patients and families through the launch of the first nationwide brain tumor volunteer network. Wilson shares her vision, goals and what the ABTA CommYOUUnity™ means to the brain tumor cause.

Q: What is your vision for the ABTA CommYOUUnity™?

A: When we were founded more than 40 years ago, there was an absence of information and resources about brain tumors, their treatments and prognoses. There was also very limited, if any, coordination of brain tumor research funding. While the ABTA has contributed to research that has advanced brain tumor treatment and care, as well as the development of patient and caregiver educational programs, materials and supportive services, we know that this information is not reaching patients soon enough and, often, not at all.

The ABTA CommYOUUnity™ is patient-centric by design and intended to bring together the resources necessary to achieve a greater understanding of the brain tumor diagnosis and treatment options. We also want to make known the supportive services available locally and through the ABTA that can assist patients and families in making informed medical decisions as well as the life style adjustments necessary as an outcome of either the tumor itself, its treatment or, as is often the case, both.

The ABTA's mission is to advance the understanding and treatment of brain tumors in an effort to improve, extend and, ultimately, save lives. Through the ABTA CommYOUUnity™, we will be able to more fully deliver on the mission by reaching more people, in more places, in more meaningful ways.

Q: How will the ABTA CommYOUUnity™ address some of the current challenges facing brain tumor patients and caregivers?

A: No one is prepared for this diagnosis. If there is a shared theme that runs through the brain tumor diagnosis experience it is the initial shock. For all but a tiny percentage, there is no family history, and as far as we know, no way of preventing a brain tumor.



All too often patients and caregivers tell me how they might have made different decisions if only they would have known about the ABTA and its resources sooner. It is my hope that through the ABTA CommYOUUnity™, when a family learns, “it’s a brain tumor,” they will know they are not alone and that there is a place where they can turn for information and support. And if and when they’re ready, that there is the opportunity to become more involved in efforts to support others struggling with the diagnosis.

Q: How do you see the ABTA CommYOUUnity™ driving the ABTA's growth moving forward?

A: The ABTA CommYOUUnity™ is about the patient and caregiver experience and a more comprehensive approach to delivering the educational and supportive resources they need. The volunteer network structure supports local and regional programming efficiency, flexibility and growth. It provides consistency in opportunities available locally, regionally and nationally. We’ve built in flexibility to the volunteer opportunities offered so that they are appealing to both groups and individuals and reflect preferences in individual interests, levels of responsibility and time commitments. The ABTA CommYOUUnity™ is a more effective and efficient approach to delivering on our mission and we believe the foundation of a sustainable growth strategy.

continued

Q: Five years from now, what do you hope people will say about the ABTA CommYOUUnity™ and what it has achieved?

A: In five years, I hope the ABTA CommYOUUnity™ will have had a transformational effect on both the ABTA as an organization and the greater brain tumor community. The shift to becoming a national volunteer advocacy organization is a fundamental change in how the ABTA will fulfill its mission. By bringing together all of those engaged in advancing the understanding and treatment of brain tumors, the ABTA can positively impact the current brain tumor experience and influence efforts at the local, regional and national levels to improve, extend and, ultimately, save lives. 

For more information about ABTA CommYOUUnity™ and how you can volunteer, go to www.abta.org/commYOUUnity

Opportunities to get involved in CommYOUUnity™



Advancing the understanding and awareness of brain tumors



Connecting those impacted by a brain tumor for peer support and inspiration



Fundraising to provide vital resources to patients and families, and fund critical research



Educating and facilitating within the brain tumor community

A Brain Tumor Diagnosis Changes Your Perspective.

Being diagnosed with a glioblastoma makes you look at your world, and what's important in it, a little differently.

When I was first diagnosed, my husband immediately wanted to know how long I had, while I wanted to learn all I could about different treatment options. We often turned to the American Brain Tumor Association (ABTA) website for answers on clinical trials, new treatment options and general brain tumor information.

Your gift to the ABTA will help to fund critical research and provide patient support and resources. Your support also allows the ABTA to launch new programs such as the ABTA CommYOUUnity™, a nationwide volunteer network that engages and connects members of the brain tumor community.

It's so easy to feel isolated in this fight – sometimes it feels like no one understands how we feel or what we are going through. The ABTA makes sure that no one has to face this diagnosis alone. Please consider making a donation to the ABTA today, so families like mine can find the information and support they need.

Thank you,

Kelli Woodstock
Mother, wife, sister, daughter, brain tumor patient



Visit www.abta.org/donatenow or use the envelope in this newsletter to make a donation.

Hope in a Life with Trials

Mary and Angelo Vayas are no strangers to challenge. They married young, started a business, and had two little boys born just 19 months apart. When the pressure of juggling a business while raising a young family became too much, they divorced.

Years later, they remarried, celebrated the birth of their third son, and went on to build a successful restaurant chain while raising their three boys.

“Angelo is a successful entrepreneur, and everything was running smoothly, until a few days before our youngest was leaving for college. We knew something wasn’t right,” recalls Mary.

August 2013

For about two weeks, Angelo complained of a bad headache in the morning. Mary attributed the symptoms to the stress her husband had been under with the passing of his father and wasn’t overly concerned.

“It wasn’t until I noticed Angelo carrying a notepad with my name and our boys’ names for his reference that I knew something was wrong and had to get him to a neurologist,” she said. “Sitting with Angelo during an MRI, I saw a terrible look on the technician’s face and she said, ‘I’ve called your neurologist; your husband has a brain tumor and you need to go to the ER.’”

Recalling those moments, says Mary, “It was scary. I had no idea this was what they were going to tell us; it was completely unexpected.”

In shock, Mary says the only option doctors offered to treat Angelo’s GBM was standard treatment involving surgery, chemotherapy, and radiation. She remembers leaving the office feeling numb.

“I believe that we have to be our own advocates, so I began researching as much as I could, scouring the Internet, including the ABTA’s website, for information about treatments, doctors and brain tumor centers.”

Months passed and clear scans offered signs of hope, but Mary was cautiously optimistic. “I read that GBMs come back and they come back with a vengeance,” she said.

June 2014

When Angelo’s scan showed his tumor had recurred, Mary knew that standard treatment wasn’t the route for them.

“We wanted to be as aggressive as we could, and throw everything possible at this beast. I began asking about clinical trials knowing we wanted something cutting-edge.”

They sought treatment at John Theurer Cancer Center at Hackensack University in New Jersey.

“Once we decided to be a part of a clinical trial, we had a lot of treatment choices to consider,” she said. “I never once felt that Angelo was a guinea pig and would have made the same decisions for myself.”

Angelo enrolled in the HSPPC-96 (Heat Shock protein-peptide) vaccine trial with three arms. Patients received Avastin®, Avastin® with the vaccine or the vaccine alone; Angelo received the vaccine alone.

Mary says he handled the trial well, and they can’t say enough about the care they received.

“We are getting the best possible, personalized care which makes a ton of difference when you are going through something so difficult,” she said. “Throughout the entire clinical trial experience we felt informed, supported and safe.”

September 2014

Scans showed tumor progression, so Angelo began taking Avastin®.

“What’s interesting is that the area where the vaccine was made looked better on the scans, but other areas seem to be resistant to the Avastin®,” she said. “I wasn’t disheartened that the vaccine didn’t work, it’s hard to say because these tumors change.”

Reflecting on the decision to participate in a clinical trial, Mary says she has little regret.

“I’m not suggesting that everyone place their faith in clinical trials because they are trials, so you aren’t guaranteed the outcome you’re hoping for,” she said. “For us, a clinical trial felt right. If people like my husband don’t participate in trials, then we’re never going to find better treatment options. If my husband doesn’t benefit from this, then we hope someone else will.” ✨



Learn about available clinical trials with ABTA’s free clinical trial matching service Trial Connect™ at www.abta.org.





Mary Vayas Amps Up with Dr. Oz



“Angelo and I believe in giving back as much as we can,” said Mary Vayas. “I didn’t hesitate to share our story when a producer in our community asked me to be on Dr. Oz because we need to do more to raise awareness of brain tumors and funding for brain tumor research.”

The Dr. Oz Show aired Mary and Angelo’s love story on December 12, 2014.

“Raising awareness and fundraising is something in this whole cancer experience that I feel like I have control over,” she added.

“I can’t control what this brain tumor is doing to Angelo, but I can control how I fight it with fundraisers and encouraging others to donate.”

“I think Angelo and I are pretty good citizens, and we’ve felt a lot of pride in doing things to help others. A brain tumor can’t take that away from us.” ✧



ABTA CommYOUity™ Peer Support Network

“When my husband was diagnosed with a Grade III Astrocytoma, a mutual friend connected me to another young mother in my city whose husband also had a brain tumor and we formed an instant bond. At the time, it was mindboggling to think that there could possibly be another family in the world doing the same thing, let alone in my neighborhood. Connecting with another caregiver was one of the most enriching and inspiring experiences I had through my husband’s diagnosis and treatment. Through the ABTA’s CommYOUity™ Connect program, I hope to be able to share and foster that experience for others.”

— Tracy Koski,
ABTA Community™ Connect Peer Mentor



Tracy with her son Emmett, and late husband Paul.

PHOTO CREDIT: MICHELLE TANNER

ABTA CommYOUity™ Connect is a peer support network that matches individuals seeking support with someone who has already gone through a similar patient or caregiver experience. The ABTA screens and provides training for all volunteer mentors whose support can range from a single phone call to lasting friendships. Mentors also help patients and caregivers take full advantage of all the resources the ABTA has to offer.

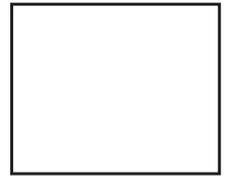
“A strong support system is one of the most important factors in navigating life with a brain tumor. While our friends and family were incredibly helpful, I always felt like nobody else could ever ‘get it,’ and in attempt to keep life feeling normal, I wasn’t ever fully comfortable discussing all the challenges of caregiving with everyone,” added Koski. “The ABTA’s CommYOUity™ Connect program will provide a lifeline of support from someone who has been there, and I believe that connecting with one another and sharing experiences will fill a critical gap in our support networks.” ✧

If you are interested in being a peer mentor, or would like to be paired with a mentor who has been through a similar experience, please visit www.abta.org/commYOUity.



American
Brain Tumor
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2015 NATIONAL PATIENT & FAMILY CONFERENCE Providing & Pursuing Answers: Advances in Research, Treatment and Care

Friday – Saturday, July 24 – 25
Renaissance Chicago O’Hare Suites Hotel

Join us at our annual conference where esteemed experts from leading brain tumor treatment centers will discuss the latest advancements in brain tumor research, treatment and care.

Conference attendees are encouraged to participate in informational sessions and to network with health care professionals and researchers.

2015 PROGRAM HIGHLIGHTS

- Researchers and doctors will highlight treatment advances in surgery, radiation, chemotherapy and immunotherapy
- Physicians will present the latest treatment options and symptom management techniques based on tumor type
- Health care professionals will discuss:
 - managing cognitive and personality changes in patients with brain tumors
 - coping with common symptoms of brain tumors, such as fatigue and seizures
 - strategies for caring for the caregiver
- Brain tumor patients and family members will lead a panel discussion about living with a brain tumor

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



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