Today, more hospitals and medical centers are offering, and new research is supporting, the use of complementary therapies to help minimize brain tumor and treatment side effects. While not a cure, many complementary therapies – as part of an overall treatment plan, and with the consent of your medical team – have the potential to improve overall health and life quality in brain tumor patients.

Complementary and alternative medicine (CAM) is a group of diverse medical and health care systems, practices, and products not presently considered to be part of conventional medicine, according to the National Cancer Institute (NCI). While alternative medicine is comprised of non-traditional therapies conducted in place of standard medical care, complementary or integrative practices are done in conjunction with standard – “appropriate, accepted and widely used” – medical care.

“Complementary medicine or therapies are not commonly part of Western medicine,” said Gary E. Deng, MD, PhD, an attending physician at Memorial Sloan-Kettering’s Integrative Medicine Service in New York City. “Often they have very ancient origins in other medical systems. Some appear to be safe and beneficial, and so we incorporate them into mainstream care, which is why we call them complementary medicine.”

Among the most common therapies are yoga, massage, music and art therapy and acupuncture.

Approximately 83 percent of cancer patients, and up to 34 percent of primary brain tumor patients, use CAM, often to gain “a sense of empowerment,” according to the article “Integrative Oncology as Part of the Treatment for Brain Tumors,” published in the 2009 journal Cancer Treatment and Research.

Complementary medicine allows patients to “have more control in what they can do every day for self care.”

As a result, demand for complementary therapies continues to grow, and today, nearly every major cancer center in the U.S. has a complementary or integrative medicine program, said Dr. Deng.

“Over the last five or 10 years, there has been an expansion of these programs, and they have been better incorporated into mainstream care,” said Dr. Deng. “However, there is still a lot of work to be done to demonstrate which therapies are most effective and how to best use them.”

“Do complementary therapies work? The reality is that some complementary therapies are very effective and others are not so effective,” said Scott Woodworth, a naturopathic oncology provider at Cancer Treatment Centers of America (CTCA) Midwestern Regional Medical Center in Zion, Ill.

Complementary Therapies Improving Quality of Life for Brain Tumor Patients

Making Breakthroughs from Coast to Coast

Breakthrough Spotlight: Clare Mahoney

ABTA Research Alumni Meet in Chicago

For Patients, Caregivers and Loved Ones, Answers Are Just a Click Away
40 Years Strong and Growing

Next year, the American Brain Tumor Association marks the 40th anniversary of its founding. Ours is an amazing legacy of advancing the understanding and treatment of brain tumors. Through our supportive services for patients and caregivers, collaborations with health care groups and professionals, and the funding of medical and scientific research, we have become the place where those impacted by a brain tumor diagnosis turn for the information and answers they so desperately seek.

For example, our Annual Patient and Family Conference—the most recent of which was held in Chicago this past July—offers educational sessions reflecting the complex and divergent needs and range of interests among brain tumor patients and their families. This event enables attendees the opportunity to hear from and speak with the nation’s leading brain tumor health and medical professionals about the trends they are seeing in brain tumor treatment and care, with ABTA-funded scientists about their areas of study and the potential impact their research will have on our knowledge and understanding of brain tumors, as well as others living with a brain tumor diagnosis.

Since our inception, the ABTA has supported young, talented researchers working to improve brain tumor diagnostics and treatments. Many of the scientists we have funded over the years currently lead the country’s most prestigious brain tumor centers. And the research itself has resulted in exciting new discoveries, laying the groundwork for future breakthroughs in brain tumor research and care.

Many of these individuals currently serve as ABTA scientific advisors. And it is to them that we turned to identify the next generation of researchers with the potential to significantly impact the future of neuro-oncology. Researchers attending our recent ABTA Research Alumni Collaborative Network Meeting were identified by our scientific advisors as having the potential to impact the future of neuro-oncology and the path to safer and more effective brain tumor treatments. This alumni collaborative is an important evolution of our mission to provide and pursue answers for all of those whose lives are impacted by a brain tumor. The young investigators invited to this forum explored scientific challenges, obstacles and opportunities for future research collaborations and mutual learning.

Every day, 500 people are diagnosed with a brain tumor. They join more than 600,000 who are living with the fear, frustration and uncertainty a brain tumor diagnosis brings. Because when it comes to brain tumors, we don’t know who, we don’t know when, and perhaps most frustrating of all, we don’t yet know why.

For the past 40 years, the ABTA has been a leader in the pursuit of answers to these questions. Whether you are a brain tumor patient or survivor, a family member, caregiver or friend, know that as long as questions remain and there are answers to be pursued the American Brain Tumor Association is here for you.

Elizabeth M. Wilson

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Headlines

**Volume 39, 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.
ABTA-Commissioned Study Sheds New Light on Metastatic Brain Tumors

While assessing the future needs of brain tumor patients, the American Brain Tumor Association recognized the importance of including those with metastatic brain tumors into our projections. Over time, the estimates of the size of this group have varied from 70,000 to more than 400,000, so the ABTA commissioned a study to look into the incidence rate of metastatic brain tumors. 

Because they are sometimes confused, it is important to note the difference between the term “incidence” and “prevalence.” Incidence refers to the number of people newly diagnosed in one year. Prevalence is the number of people living with a disease at any given point in time.

Studying the incidence of metastatic brain tumors is important because almost the majority of all brain tumors are metastatic tumors – those that begin as cancer elsewhere in the body and move to the brain. The remainder, which still represents a significant number – 66,000 per year – are primary brain tumors, which begin in the brain and stay in the brain. Each represents clinical treatment challenges.

“It is also important to note the fact that treatments and diagnosis of primary site cancers have changed with time, and published data may not reflect these new trends.”

As people diagnosed with cancer live longer, more effective treatments become available, and more of America moves into age ranges at higher risk for cancer, it is important that the brain tumor community understand the true number of people with the potential to be impacted by metastatic brain tumors. This information is necessary for the strategic, advance planning of brain tumor diagnostics, clinical care, research and support initiatives at hospitals, medical centers, and universities across the country.

A research team, lead by Faith Davis, PhD, at the University of Alberta in Edmonton, began to explore the available data. Their work was supported by an American Brain Tumor Association contracted grant to the Central Brain Tumor Registry of the United States.

The results of their study, which appear in the September 2012 issue of Neuro-oncology, project the likelihood of people diagnosed with cancer in 2007 developing a metastatic brain tumor during their lifetime.

The research team used the expected incidence of brain metastases from primary cancer sites (such as lung, kidney, melanoma, breast, and colon, among others) and applied them to cancer incidence data from the Center for Disease Control (CDC) and Surveillance Epidemiology and End Results (SEER) registries. The fifteen primary cancer sites used in these projections were felt to represent almost 80% of all cancers occurring in 2007.

The authors conservatively estimated that among this specific group of people – 1,194,282 patients – almost 70,000 of them would be diagnosed with new brain metastases in their lifetime. That is about 6% of people who are diagnosed with cancer at a primary site, would be expected to develop brain metastases at some time during their life.

“Some of the high estimates of metastatic brain tumor rates are based on autopsy studies performed in the 1970s and ‘80s that are not necessarily clinical or symptom based,” said Dr. Davis. “We have estimated the number of brain metastasis likely to occur over the lifetime of new cancer cases diagnosed in 2007 and recognize these are on the low range of estimates.”

Almost 20% of all primary site cancers were not evaluable for inclusion, which excluded more than 303,644 additional cases of cancer. It is also important to note the fact that treatments and diagnosis of primary site cancers have changed with time, and published data may not reflect these new trends.

These estimates from the study place metastatic brain tumors at approximately twice the incidence of primary brain tumors.

In some ways, the study provided unanticipated results. With improved survival, one might expect people with cancer who lived longer to be at higher risk of developing brain metastases. In reality, the data indicated that the site of the primary cancer and the initial treatment may be greater influences on risk, and this risk may change as the effect of newer treatments is observed and treatment patterns change. The study also found select subgroups of patients who seemed to have higher estimates of brain metastases than other ages. For example, those with breast cancer who are aged 50-59, seemed to have a higher rate of brain metastases than other subgroups.

“Continued on page 9
Woodworth, a licensed Neuropathic physician, spoke at the American Brain Tumor Association (ABTA) Patient and Family Conference in July.

“Can complementary therapies cure brain cancer? There is no current evidence that shows complementary therapies cure brain cancer,” said Woodworth. “Can some complement traditional medicine and improve symptoms? Absolutely. We have proof and research to support that.”

The National Center for Complementary and Alternative Medicine (NCCAM) divides CAM into five groups:

- **Whole medical systems**, such as Traditional Chinese Medicine (TCM), including acupuncture.
- **Mind-body medicine**, such as imagery, hypnosis, meditation, tai chi or prayer, and therapies that use creative outlets such as humor, art, music or dance therapy.
- **Biologically based substances** found in nature such as herbs, foods, vitamins, dietary supplements and herbal products.
- **Manipulative and body-based practices** including chiropractic, osteopathic manipulation and massage.
- **Energy therapies** involve the use of energy fields, such as biofield therapies and bioelectromagnetic-based therapies. While not scientifically proven, energy therapies such as qi gong combine movement, meditation and controlled breathing to improve circulation and control of “qi” (life force).

Among the more commonly utilized and accepted complementary therapies is acupuncture, which may minimize or eliminate treatment-induced nausea in brain tumor patients, without constipation, a common side effect of anti-nausea medication.

“If you have nausea because you were taking your conventional medication, and it’s making you badly constipated, you could supplement magnesium or even acupuncture,” said Mary Hardy, MD, medical director for Simms/Mann-UCLA Center for Integrative Medicine at the University of California, Los Angeles’ Jonsson Comprehensive Cancer Center. “That’s a great example of how complementary therapies work.”

Dr. Hardy also prescribes a combination of vitamin B, glutamine, acetyl carnitine and alpha lipoic to brain tumor patients to minimize the effects of peripheral neuropathy (damaged nerves).

Some of the movement-based therapies, such as tai chi, “help improve flexibility and balance,” said Dr. Deng. This is especially important for brain tumor patients who may have difficulty moving arms and legs before or after surgery. And for patients experiencing anxiety, depression and fear, mind-body therapies “can help make patients more resilient mentally, and aim to help them get more in touch with the present instead of worrying about the future.”

In addition, recent research studies have found that music, creative art and massage therapies can decrease stress and anxiety in brain tumor patients.

Newer studies on complementary therapies include research published in the 2010 *Journal of Neurosurgery* that found that the use of electroacupoint stimulation may prevent postoperative nausea and vomiting in patients following brain surgery, and a 2011 study in the journal *Cancer* that found that boswellia serrata, also known as frankincense, may significantly reduce cerebral edema (swelling) in brain tumor patients.

“Perhaps if this research (on boswellia serrata) continues, patients might require less steroids,” which is currently the standard treatment for edema, said Dr. Hardy. However, “it’s not clear yet if the treatment will protect memory loss.”

“Now that you’ve heard about this research, it doesn’t mean that you should go to the store and buy boswellia,” said Dr. Hardy. “You have to have someone advise you. Is this the one that you have had tested? Is this right for me?”

Some complementary and alternative therapies can actually harm patients, especially if they are taken or administered without doctor approval. Patients and clinicians should consider the quality of the research, and whether or not the therapy is appropriate for patients’ brain tumor type.

For example, the use of dietary supplements, such as St. John’s Wort with chemotherapy and vitamin E is not recommended for brain tumor patients, according to Dr. Hardy in her article, “Dietary Supplement Use in Cancer care: Help or Harm,” appearing in the 2008 journal *Hematology Oncology Clinical North America.*
Proper nutrition plays an important role throughout the course of your brain tumor journey. “Nutrition therapy” should be a part of your health care plan for managing treatment side effects, as well as part of life after treatment as you try to become well again.

Going through treatment can have a serious impact on your body. Although surgery, chemotherapy and radiation are all tools to help treat your brain tumor, they have a variety of side effects that range in severity. Nutrition therapy allows you to utilize food to minimize side effects of your treatment and make you feel as well as possible.

“Good nutrition during cancer treatment provides adequate energy to fuel the body to fight cancer, promote healing and to maintain a healthy weight,” says Cassandra Vanderwall, MS, RD, CPT. “Healthful eating also gives the body a bountiful source of vitamins, minerals and antioxidants, which play a critical role in maintaining healthy processes in the body, supporting the medical treatment and bolstering the immune system.”

Vanderwall explains the three main energy sources for maintaining weight are:

• Carbohydrates
• Proteins
• Healthy fats

Carbohydrates should make up about half of your daily intake, including:

• Simple carbohydrates (fruit)
• Complex carbohydrates (like whole grain pastas and whole grain breads)

Vanderwall continues to say that lean proteins support immune system and essential hormones and enzymes. Lean proteins include:

• Lean beef
• Skinless poultry
• Fish
• Low-fat dairy
• Soy
• Legumes

Finally, healthy fats can be easily incorporated into parts of meals, healthy snacks or supplements. These include

• Olives and Olive oil
• Avocados
• Omega-3’s (including walnuts, almonds, and fish oils)

If you’re having a hard time eating well-balanced meals due to side effects from treatment or the tumor itself, nutrient deficiencies may be a concern. Malnourished individuals are often at a higher risk for complications. Although supplements are an option, speak with a registered dietitian about what foods may work best to make you feel well and help achieve your goals. They may be able to offer

recipes for easy to make (and easy to eat) meals, like soups with lean meats and vegetables. You can also talk to your doctor about options for supplements, and which ones would be best for your needs. Do not start taking anything, including vitamins or supplements, without consulting a doctor first.

Nutrition is also an important factor after your treatment has ended. Positive nutrition-related lifestyle changes can help you to achieve a better quality of life. General guidelines for healthy eating include eating a plant based diet (strive for 5 fruits and/or vegetables a day), limit high fat foods and alcohol, maintain a healthy weight, and try to achieve 30 minutes of activity per day.

“Positive nutrition-related lifestyle changes can help you to achieve a better quality of life.”

Most importantly, whether you’re in treatment or on the road to recovery, only do what you can handle. Make sure to stick with things that make you feel better and listen to your body.

“Cancer is a life-changing diagnosis and often turns a person’s world upside down,” says Vanderwall. “I encourage my patients to be gentle with themselves during this process and remind them that what they eat is something they can control. It is in this kind consideration that patients are able to choose what is healthiest for themselves in each moment.”

To find a registered dietitian in your area, visit the Academy of Nutrition and Dietetics web site at www.eatright.org.
Whether you are a walker, casual jogger or endurance runner, in 2013, you can make breakthroughs with the ABTA.

Join us at one of our family-friendly 5K events, or challenge yourself by participating in an endurance event.

To register and learn more about the Breakthrough for Brain Tumors 5K Run & Walk, visit www.breakthroughforbraintumors.org.

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Complementary Therapies Improving Quality of Life for Brain Tumor Patients: continued from page 4

Also, “caution should be urged when dietary supplement use substitutes for or delays the start of conventional care,” said Dr. Hardy.

Dr. Woodworth warned that while therapies, such as acupuncture, “can be very effective when they are offered by qualified practitioners,” today, “there are varying degrees of regulation in complementary medicine. There are lots of practitioners out there saying they have training in these therapies and they actually don’t. Therefore, some patients can get less than proper treatment and will not have a good result.”

Instead, brain tumor patients should first seek out the best medical care available, and then “use these therapies to modify, improve efficacy and reduce side effects,” said Dr. Hardy.

“I would encourage people to talk to their physicians about [their interest in these therapies], and in general people don’t. A lot of patients pick these therapies because it makes them feel like they’re doing something on their own behalf. However, if you’re an older cancer patient, and you’re thinking about using these therapies, and your renal and liver functions are not as efficient as if you were prime adult age,” caution is warranted, as there could be an increased risk for bleeding, or interactions with other medications.

Dr. Hardy said she asks patients to outline their goals, whether they want to improve their general outlook, treat depression or relieve symptoms.

“I try to avoid throwing everything at them,” said Dr. Hardy. “It’s really useful to have them get the basics first.” First, patients should be “comfortable and as stable psycho-socially as possible.” Then, “get your pain managed, and make sure you’re eating as much as you can. If you’re losing weight, that’s not a good sign.”

“Definitely, there’s a lot of demand from patients for complementary medicine,” said Dr. Deng. “On the other hand, the information out there available to patients can be of very mixed quality. We try to guide patients in taking advantage of helpful therapies and avoiding harmful ones, using our professional knowledge.”

“I think research on complementary therapies is increasing, there is much less resistance to it, and people can get real benefits from mind-based and other supportive therapies,” said Dr. Hardy. “Be proactive and ask about them.”

Other resources:
- Oncology Association of Naturopathic Physicians: www.oncanp.org
- The National Certification Commission for Acupuncture and Oriental Medicine: www.nccaom.org
- The Office of Cancer Complementary and Alternative Medicine (OCCAM) at the National Cancer Institute: www.cancer.gov/cam.

Breakthrough Spotlight: Clare Mahoney

“It is necessary, therefore it is possible.”

These words, found in a fortune cookie, inspired Clare Mahoney to join the American Brain Tumor Association’s Team Breakthrough running and endurance team, to run 26.2 miles and cross the finish line of the Bank of America Chicago Marathon on October 7, 2012, and to raise more than $2,800 for the ABTA in the process.

At one point in her life, Mahoney thought running a marathon would be an impossible task for her to complete. But recently, her brother was diagnosed with a brain tumor. And that was when the fortune cookie’s words, which she kept taped to her desk, truly sank in: running while fundraising for the ABTA became necessary, and was therefore possible.

“I am not the type of person you look at and think, ‘wow, she must be a good runner,’” said Mahoney. However, she joined Team Breakthrough “to prove to myself that the things we resolve as impossible need to be challenged with courage and confidence in the inherently gigantic power that resides in each of us. I am capable of running a marathon, people with brain cancer are capable of surviving, a cure to brain cancer can be found, and it all begins with believing in ourselves.”

If you’re interested in being part of Team Breakthrough this season, visit www.abtateambreakthrough.org to learn more.

Clare Mahoney
John L. Villano, MD, PhD, another member of the research team, states, “As new treatments become available for primary cancers, it is increasingly important to monitor their effect on the development of metastasis. Additionally, as treatments for metastasis improve it will become more important to understand the relationship between occurrence and prevalence of these tumors.”

The study has significant implications to those projecting clinical and administrative support resources for those with both primary cancers and metastatic disease. As access to care evolves to reflect current trends in treatment, a significant part of the population will be accessing neuro-oncology cancer care at some point in their care continuum. Understanding how many patients, and which demographics, will need to utilize this care could enhance proper support needs for this patient group significantly.

“We would hope that the clinical data on brain metastasis will improve over time so that estimates like this will also improve,” says Dr. Davis. “These data provide a baseline to begin to understand the pattern of brain metastasis in the United States.”

If you or a loved one has a metastatic brain tumor, please visit www.abta.org to download a copy of our Metastatic Brain Tumors publication, or call our CareLine at 800-886-ABTA (2282).

To learn more about the research projects supported by the ABTA, visit www.abta.org/advancing-research.
For Patients, Caregivers and Loved Ones, Answers Are Just a Click Away

A brain tumor diagnosis turns lives upside down. Whether you need help from the American Brain Tumor Association, or help from friends and family members, we’re able to provide the resources you need to start pulling the pieces together. And it all begins at www.abta.org.

The ABTA’s website is a digital hub of information—from caregiver help, to tumor and treatment information, to support groups near you. Our website has the programs and information you need to become empowered, organized and supported.

CAREGIVER ASSISTANCE
When a loved one receives a brain tumor diagnosis, caregivers may find themselves deluged by offers of assistance from friends, family members and colleagues. But even a simple request such as “What can I do to help?” can sometimes cause even more stress. Where do you begin? How do you make sure that the help being offered is the help you actually need? It can be overwhelming. The ABTA’s new MyCaringLink service, powered by Lotsa Helping Hands, can help you to organize your needs and to keep track of the tasks you need help with. Start a MyCaringLink community and you’ll be able to keep a sharable calendar in which you can post requests for assistance—rides, cooking, babysitters...all those important day-to-day commitments that need to get done. Now when a friend asks what they can do, you can simply point them to your MyCaringLink calendar where they can see a list of your specific needs. MyCaringLink pages also have a personal blog capability that you can use to update friends and loved ones of the patient’s status throughout their treatment.

INFORMATION AND RESOURCES
After a diagnosis—your own or that of someone you love—you probably have many questions of your own. The American Brain Tumor Association’s newly-redesigned publications, including About Brain Tumors: A Primer for Patients and Caregivers, are available to help you understand tumor types, treatment methods and more. Our full line of publications, resource sheets and educational tools are all available for download at www.abta.org.

SUPPORT GROUPS
No matter how much information you process, sometimes just talking to someone who understands can be the best support. That’s why the ABTA has a list of support groups nationwide listed on our website. Our Support Group Listings page allows you to sort groups by state to find one near you. Groups are available not only for brain tumor patients, but also for caregivers and family members.

Whether you need information, help, or support, it’s just a call or click away with the ABTA. Visit us online at www.abta.org or call our CareLine at 800-886-ABTA (2282).

Have you purchased your American Brain Tumor Association Holiday Cards yet?
Send a holiday greeting, available in a variety of sentiments, while helping to support the ABTA. Order cards online at www.easyholidaycards.org/ABTA. Questions? Call us at 866-659-1030.
This year, one such breakthrough came in a most unusual package: our canine companions. Through American Brain Tumor Association-funded research, dogs diagnosed with naturally-occurring meningioma brain tumors – the most common brain tumor in dogs and humans – were treated with a personal vaccine, designed to utilize the dog’s own tumor cells to trigger its immune system. The data suggests that the vaccine is better than either surgery alone, or surgery and radiation, and will hopefully lead to human clinical trials.

In another significant breakthrough, reported in the March 2011 issue of the journal *Nature Medicine* as one of the “most relevant recent discoveries in cancer research,” ABTA-supported research discovered a genetic mutation associated with brain tumors, called IDH1. The mutation presents a springboard for new approaches to diagnosis and treatment.

As the first national organization committed to funding brain tumor research, the ABTA has funded generations of researchers, many of whom lead brain tumor programs at some of the nation’s most prestigious institutions, influence research trends and mentor the next generation of leaders.

For brain tumor patients and caregivers, though, a breakthrough can also be something far more immediate and personal – a calm, reassuring voice of an ABTA Care Consultant on our CareLine; a welcome response to an email sent in the middle of a restless night; vital information available online in a time of desperate need. At every step, we assist patients and caregivers to make breakthroughs in their understanding — helping to inform their choices in treatment, care and recovery. The ABTA is the only national organization that provides this invaluable patient and caregiver support.

Breakthroughs aren’t the end. Each one has opened pathways to new thinking, better understanding and more effective treatments. Through your generous gift, the American Brain Tumor Association will continue to lead the way in making breakthroughs — both in labs and in lives.

We thank you for your generosity.

To donate, visit www.abta.org or use the envelope in this newsletter.
ABTA Webinar Series Provides Convenient Online Learning

Covering important topics ranging from tumor type overviews to cutting-edge treatments to quality of life concerns, the American Brain Tumor Association’s free webinar series offers a unique opportunity to learn from the nation’s leading brain tumor experts in the comfort of your home or office. And every webinar is recorded and archived online at www.abta.org for viewing that fits your schedule. Upcoming webinars include:

January 10, 2013 at 12 p.m. Central time
**Coping with Caregiver Stress**

February 26, 2013 at 2 p.m. Central time
**Multidisciplinary Approaches for Treating Pediatric Tumors**

March 29, 2013 at 2 p.m. Central time
**Understanding Palliative Care**

To register, or to view archived presentations, visit the “Understanding Brain Tumors” section of www.abta.org.