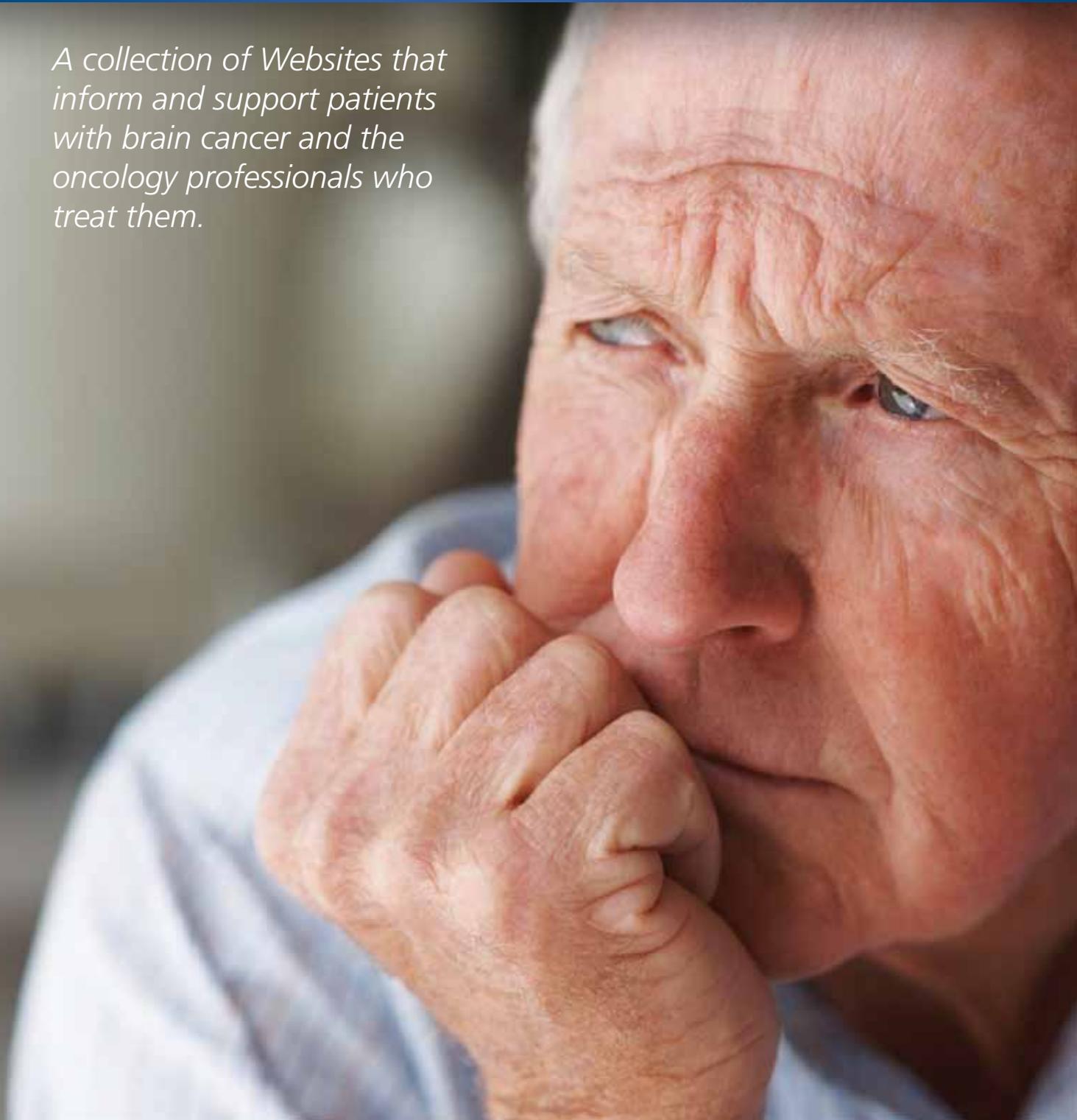


BRAIN CANCER

Resource Guide

A collection of Websites that inform and support patients with brain cancer and the oncology professionals who treat them.





TRIAL
CURRENTLY
RECRUITING

A Randomized Phase II Trial for Newly Diagnosed Glioblastoma Patients: Cilengitide in subjects with newly diagnosed glioblastoma multiforme and unmethylated MGMT gene promoter

A randomized, multicenter, open-label, controlled, phase II study investigating two cilengitide regimens in combination with standard treatment (TMZ with concomitant RT, followed by TMZ) versus standard therapy alone

MAIN INCLUSION CRITERIA

- Newly diagnosed supratentorial glioblastoma (WHO grade IV)
- Unmethylated MGMT gene promoter status
- ECOG PS 0-1
- Baseline Gd-MRI
- Stable or decreasing dose of steroids (for ≥ 5 days)

MAIN EXCLUSION CRITERIA

- Prior anti-angiogenic therapy
- Investigational agents within 30 days
- Chemotherapy within 5 years
- Prior cranial radiotherapy
- Placement of Gliadel[®] wafer
- Significant hepatic or renal impairment
- Coagulation disorder, myocardial insufficiency, peptic ulcer or another malignancy

MGMT: O⁶-methylguanine-DNA methyltransferase; RT: radiotherapy; TMZ: temozolomide

Cilengitide (EMD 121974) currently is under clinical investigation and has not been approved for use in the United States, Canada, Europe, or elsewhere. The product has not been proved to be safe or effective and any claims of safety and effectiveness can be made only after regulatory review of the data and approval of the labeled claims.

Learn More About the CORE trial

Please call 1-800-507-5284 or refer to [ClinicalTrials.gov](http://www.clinicaltrials.gov) for more information (<http://www.clinicaltrials.gov/ct2/show/NCT00813943>)

The CORE study is in collaboration with the Canadian Brain Tumour Consortium (CBTC).



From the Publisher

Finding Assistance and Support Communities on the Web

Learning that you or a loved one has a brain tumor can be overwhelming: *What kind of tumor? How is it treated? Does the treatment have side effects? How will we afford medical care?* All these questions and more may race through your mind. The organizations listed in this Resource Guide are committed to helping you find answers.

There are many different types of brain tumors, some benign and some malignant, and they occur in people of all ages, including children. Clinical research and new developments in imaging technology have advanced our knowledge of brain tumors significantly in the past decade, leading to better treatments and outcomes. Many of the Websites in this Resource Guide provide information on existing and emerging treatments and direct patients to specialists skilled in treating a particular tumor type.

Gliomas are the most common type of brain tumor. Glioblastoma multiforme, astrocytoma, oligodendroglioma, and oligoastrocytoma are all glial tumors. Of these, glioblastoma multiforme is the most prevalent and most aggressive. As a result, many of today's clinical trials are investigating therapeutic alternatives for adults and children with glioblastoma and other gliomas. Most of the groups we have featured supply information on clinical trials or help match patients with suitable trials. Others also offer skilled support staff who will address your concerns about taking part in a clinical trial.

Some organizations work solely with those caring for a child with a brain tumor. They provide emotional support and work to connect families going through similar experiences. On many of the Websites, patients' personal stories encourage new patients and their families to remain hopeful.

Although much has been accomplished in brain cancer care, much more remains to be done. The organizations in this guide and the patients who participate in clinical trials are instrumental to the progress being made on this front. For more information on clinical trials, visit www.clinicaltrials.gov.

To download a PDF of this Resource Guide, visit www.onclive.com.

American Brain Tumor Association

www.abta.org

The screenshot shows the homepage of the American Brain Tumor Association (ABTA) website. The header is dark purple with the ABTA logo on the left and navigation links for 'Health Care Professionals', 'Kids', and 'News Room' on the right. Below the header is a navigation bar with links for 'Home', 'About Us', 'Tumor & Treatment Info', 'Care & Support', 'Research Progress', 'Donate', 'Events & Meetings', and 'Act Now!'. The main content area features a large image of people's hands stacked together, with the text 'Connect with others. Begin friendships. Get informed.' and the 'Connections' logo. To the right of the image are social media icons for Facebook, Twitter, and YouTube, along with buttons for 'Sign Up for Brain Tumor News' and 'Make a Tribute Gift'. Below the image is a 'LOGIN' section with fields for 'User Name' and 'Password', and a 'Login' button. At the bottom of the page, there are sections for 'Upcoming Events' and 'Items of Interest', and a 'Brain Tumor News' section with headlines like 'House Passes Improving Access to Clinical Trials Act' and 'ABTA Announces AANS/CNS Clinical Research Award'.

ADDRESS:
2720 River Road
Des Plaines, IL 60018

CONTACT INFO:
Phone: (800) 886-2282
(847) 827-9910
E-mail: info@abta.org

HISTORY & MISSION

The American Brain Tumor Association (ABTA) is a nonprofit organization based in Des Plaines, Illinois. Founded in 1973, ABTA was the first national organization dedicated to promoting brain tumor research. ABTA offers information on a wide range of topics, from the symptoms, diagnosis, and treatment of brain tumors; to advice on finding jobs or maintaining relationships; to guides on understanding medical insurance plans. ABTA says its goal is to provide information and services to patients with brain tumors and their families, while searching for new ways to treat and prevent brain tumors.

PROGRAMS & PATIENT ADVOCACY

ABTA aids brain tumor patients and their family members through education and emotional support. One program, Connections, pairs individuals in similar circumstances as penpals to help them form friendships and learn to cope with their situations. The Sharing Hope program encourages families to share their stories with others who may be suffering, to inspire them in this difficult time. Educational materials are available over the phone, electronically, or by mail.

In addition to offering its own programs, ABTA assists people in finding services provided through other organizations. ABTA also hosts meetings for patients, advocates, and professionals a few times each year, which are designed to facilitate the exchange of information between medical experts and patients.

Every year, the ABTA holds fundraisers, such as “Brain Games” in the fall and the “Path to Progress” five-kilometer marathon in the spring. Members of the organization also provide guidance to volunteers interested in holding their own fundraising events on behalf of ABTA.

ACHIEVEMENTS & INITIATIVES

In its more than 35-year existence, ABTA has contributed millions to sponsor brain tumor research and patient services. In 2008 alone, ABTA provided more than \$2.7 million to researchers and 1.3 million resources to the patients with brain tumors. ABTA sponsors research and medical student fellowships, \$50,000 grants for small projects, and \$75,000 translational research grants.

ABTA is a member of the North American Brain Tumor Coalition and the National Organization for Rare Disorders, groups dedicated to educating Congress about brain tumors and advocating for more government funding of brain tumor treatment and research.

NAVIGATION & USEFUL LINKS

Links to the primary sections of the site fall below the banner at the top of ABTA’s homepage and appear on every page of the Website. Sections underneath these links describe upcoming ABTA events, news relating to ABTA, and general news on brain tumors. Those interested in attending ABTA-sponsored **Events & Meetings** will find a link to this information in the top navigation bar.

Another link takes you to the **Tumor & Treatment Info** section, which includes a featured article, provides a link to the **Brain Tumor Dictionary**, and features a long list of sublinks to various brain tumor topics. Among these are **Symptoms, How Are Tumors Diagnosed?, The Basics: Benign or Malignant?, Facts & Statistics, and Causes & Risk Factors.**

From the top navigation bar, you can find the **Care & Support** portion of the Website. This area features the **Care for the Caregiver Corner**, with tips and advice on caring for someone with a brain tumor, and another extensive list of topics, including **ABTA on Facebook, Reaching Out For Support, Financial Assistance Resources, Internet Resources, and Educating Children and Teenagers.** Visitors can also peruse past and current issues of the *Tips for Living and Coping* monthly bulletin, which discusses the emotional and social needs of brain tumor patients and survivors. Anyone who needs immediate assistance can click the large button up top for **Online Support.**



The **Research Progress** portion of the site, accessed via the home page, contains articles on the latest news in neuro-oncology. The **Act Now!** section includes information on efforts by ABTA to educate Congress about brain tumors and the importance of funding brain tumor research.

The Website has a special section just for kids, which is reached by clicking **Kids** at the top of the home page. This link opens a new page titled “ABTA Kids.” Here, kids get child-friendly definitions of complicated terms, read stories from other kids who have been treated for brain tumors, and have the opportunity to test their knowledge of brain tumors with online activities, like crossword puzzles and word finds.

American Cancer Society

www.cancer.org

The screenshot shows the American Cancer Society website homepage. At the top left is the ACS logo and the tagline "THE OFFICIAL SPONSOR OF BIRTHDAYS®". To the right, there are links for "Sign In | Register | My ACS", "Español", "Asian Language Materials", and the phone number "1-800-227-2345". A "DONATE" button is in the top right corner. Below the header is a navigation bar with links: "HOME", "LEARN ABOUT CANCER", "STAY HEALTHY", "FIND SUPPORT & TREATMENT", "EXPLORE RESEARCH", "GET INVOLVED", and "IN YOUR AREA". The main content area features a large image of a smiling child wearing sunglasses. To the right of this image is a "STAY HEALTHY" section with a "GO TO THIS SECTION" button. Below this are three columns: "HOW CAN WE HELP YOU?" with a search bar and phone number; "FREQUENTLY SEARCHED" with links to "Making Strides Against Breast Cancer", "More Birthdays", "Cancer Survivors Network", and "Statistics"; and a large colorful illustration of a head profile filled with flowers and a birthday cake. At the bottom are three featured articles: "What You Need to Know About Prostate Cancer", "Experts See Progress, Hope in Battle Against Childhood Cancers", and "Exciting New Face for the More Birthdays Movement".

ADDRESS:
National Home Office
250 Williams St. NW
Atlanta, GA 30303

CONTACT INFO:
Phone: (800) 227-2345
E-mail: Online

HISTORY & MISSION

The American Cancer Society (ACS) is a nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering through research, education, advocacy, and service. Founded in 1913 in New York City as the American Society for the Control of Cancer, it became the ACS in 1945 and has since grown to more than 3400 local offices nationwide, with more than 2 million volunteers.

PROGRAMS & PATIENT ADVOCACY

The ACS fights cancer via research, education, patient services, and advocacy. The Society's research program aims to determine the causes of cancer and to support efforts to prevent and cure the disease. It is the largest source of private, nonprofit cancer research funds in the United States, second only to the federal government in total dollars spent. To date, the Society's research program has invested nearly \$3 billion in cancer research and has funded 42 Nobel Prize winners early in their careers.

The ACS Website states that knowing the facts about cancer can save lives. What people eat and drink, how they live, and where they work can affect cancer risk. Primary cancer prevention means taking the necessary precautions to prevent these diseases. Prevention programs are designed to help adults and children make healthy lifestyle choices that continue throughout life. These programs help educate the public about cancer risks, early detection methods, and prevention. Some educational efforts include tobacco control, the relationship between diet and physical activity and cancer, sun safety, and comprehensive school health education. It also focuses on a variety of early detection programs and encourages regular medical checkups and recommended cancer screenings.

The American Cancer Society Cancer Action Network (ACS CAN, <http://acscan.org>), the advocacy affiliate of the ACS, is a nonprofit, nonpartisan organization dedicated to eliminating cancer as a major health problem. ACS CAN strives to give the community a voice by empowering patients, survivors, caregivers, and their families and friends to bring attention to cancer issues. Advocacy efforts are targeted at specific cancer-related issues, including improved access to healthcare nationwide, support for preventative screenings and services, increased government funding for cancer research, tobacco regulation, and improved quality of life for patients with cancer.

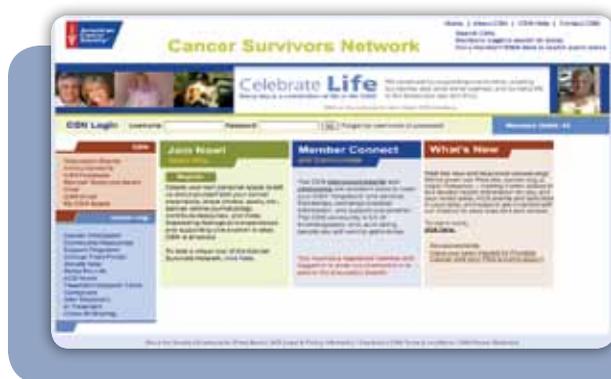
ACHIEVEMENTS & INITIATIVES

The most important cancer decisions are made in the doctor's office, but many are also made in the state legislatures, in Congress, and in the White House. The ACS coordinates work on research, education, and service initiatives to strengthen US laws, regulations, and programs. ACS also works to increase federal funding in several areas, including cancer research, and improving survival and quality of life for cancer patients, survivors, and their families. Equally important is political activism to help more people benefit from advances in prevention, early detection, and treatment, and to make it easier for patients to navigate the healthcare system.

NAVIGATION & USEFUL LINKS

Visitors to the home page are greeted with a rotation of information and images at the center of the screen. On the primary navigation bar at the top of the ACS home page, patients can connect to the [Learn About Cancer](#), [Stay Healthy](#), [Find Support & Treatment](#), [Explore Research](#), [Get Involved](#), and [In Your Area](#) sections. A guide to quitting smoking can be found on the [Stay Healthy](#) section. In [Explore Research](#), patients can find facts and figures, statistics, and information on access to health care and clinical trials. Details are also available on research programs and funding.

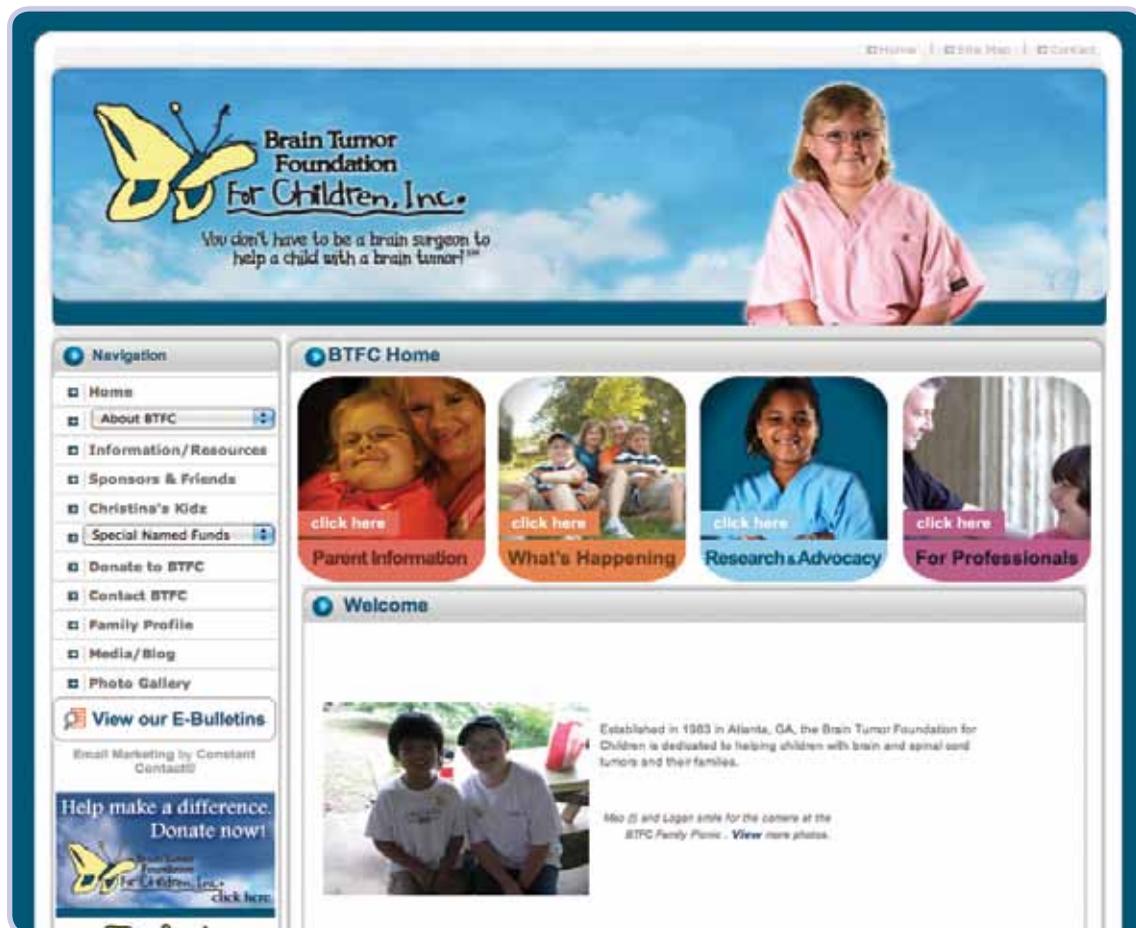
In [Find Support & Treatment](#), the [Treatment Decision Tools](#) section presents [NexProfiler™ Tools for Cancer](#), which patients can use to make informed decisions about cancer treatment. Patients can access a detailed analysis of specific conditions, uncover a statistical breakdown of treatment types, and pinpoint the exact topics that they should discuss with their doctor.



The [Survivorship: During and After Treatment](#) section features information on staying active and healthy during and after cancer treatment, including nutrition information and individualized survivorship care plans for monitoring and maintaining health. In [Stories of Hope](#), patients with cancer can find inspiration and support in stories about others whose lives have been touched by the disease. The Website presents a long list of stories categorized according to topic or type of cancer. The [Find Support Programs and Services in Your Area](#) section also offers a link to the [Cancer Survivors Network](#), an online support program where members can create personal Web pages to share cancer experiences, photos and audio, start a blog, or contribute resources. This network also provides discussion boards and chat rooms so patients can share what they have learned or experienced with other members.

Brain Tumor Foundation for Children, Inc.

www.braintumorkids.org



HISTORY & MISSION

The Brain Tumor Foundation for Children, Inc. (BTFC) was founded in 1983 in Atlanta, Georgia, as the first nonprofit organization in the United States dedicated to helping children with brain and spinal cord tumors. The stated mission of BTFC is to offer financial aid, emotional support, and information to the families of these children. BTFC also funds research for the treatment and prevention of brain cancer and seeks to raise public awareness of the condition. BTFC's annual Flight of the Butterflies spring gala, the J. Smith Lanier & Co. Charity Golf Classic, and William's Walk & Run have helped raise public awareness of pediatric brain tumors.

ADDRESS:
6065 Roswell Rd
Suite 505
Atlanta, GA 30328

CONTACT INFO:
Phone: (404) 252-4107
Fax: (404) 252-4108
E-mail: info@braintumorkids.org

PROGRAMS & PATIENT ADVOCACY

BTFC offers several programs and services for children with brain tumors and their family members. One such service is the Butterfly Fund, which provides financial support for families who are struggling to afford their household bills because of medical expenses or to pay for medical items their health insurance does not cover. BTFC also provides two \$2,500 educational scholarships per year for survivors of pediatric brain and spinal cord tumors through the Larry Dean Davis Scholarship Fund (limited to Georgia residents at this time).

In addition to financial aid programs, BTFC hosts various events for patients to have fun and make friends. The Boating Bonanza, Fishing Extravaganza, and Holiday Party take place annually, and numerous picnics and emotional support groups take place year-round. There is also an annual fall Celebration of Life luncheon for families that have lost a child to brain cancer.

ACHIEVEMENTS & INITIATIVES

Every year, BTFC sponsors thousands of dollars in research efforts with the money it has raised. In 2008, it awarded three research grants to medical professionals in the field of neuro-oncology, including \$25,000 to Dr. Kevin Schooler and \$50,000 each to Dr. Donald Durden and Dr. Erwin Van Meir.

In 2000, BTFC's Butterfly Fund was available only to families in the state of Georgia, but through concerted efforts to find financial support for the initiative, the BTFC has been able to extend this service to families in eight southeastern states. Last year, BTFC gave \$282,000 in financial aid to 206 different families. BTFC's contributions to research have increased as well, a trend the organization hopes to continue.

NAVIGATION & USEFUL LINKS

On BTFC's Website home page, a navigation bar on the left contains links to the primary sections of the site. This bar is present on every page. Selecting **Support Programs** on the drop-down menu brings you to a page with brief descriptions of the services BTFC offers, including instructions on signing up for the Parent E-mail List. This allows parents of children with brain tumors to seek support from BTFC or other parents on the list.

The **Research** link on the drop-down menu opens a page displaying some of the most recent research grants given out by BTFC, with detailed information on who received the grants and what projects were funded. Clicking on **Information/Resources** calls up a list of other brain tumor



advocacy organizations that may offer information or services BTFC does not provide. This includes Websites that supply information on available clinical trials.

Under **Stories of Hope**, patients and their families can read stories from other parents on their child's brain tumor type or they can submit their own for inclusion on the site. A similar section, called **Our Angels**, allows parents to share remembrances of their children who have succumbed to their disease.

Visitors can sign up to have the *Butterfly Bulletin* sent to their home as well as view archived issues online. They can also sign up to receive BTFC's electronic E-Bulletins delivered via e-mail. The **Media/Blog** displays different news articles related to BTFC and its efforts to increase awareness of brain tumors.

At the bottom of the home page, you can select the link to join BTFC's Facebook community, which has more than 6,000 members. If you are interested in volunteering with BTFC, a list of needs and an application can be found in the **Volunteer at BTFC** section, accessible from the drop-down menu on the left navigation bar.

Children's Brain Tumor Foundation

www.cbtf.org

The screenshot shows the homepage of the Children's Brain Tumor Foundation (CBTF). At the top, there is a navigation bar with links for Home, Login, Register, and a search box. Below this is a banner featuring the organization's logo and a group of children, with a prominent "DONATE NOW!" button. A secondary navigation bar includes links for ABOUT, BLOG, LEARN, FIND CONNECTIONS & SUPPORT, SUPPORT US, PROFESSIONALS, EVENTS & ACTIVITIES, and CONTACT, along with social media icons for Twitter, Facebook, and RSS. The main content area is divided into several sections: a large introductory text block about the foundation's mission, a "Jenna's Corner ONLINE COMMUNITY" login section with fields for Username and Password, and three columns of links for LEARN, FIND CONNECTIONS & SUPPORT, and SUPPORT US. Below these are sections for the CBTF Blog, Latest News, and Upcoming Events, each with a list of recent or upcoming items.

ADDRESS:
274 Madison Ave, Suite 1004
New York, NY 10016

CONTACT INFO:
Phone: (866) 228-4673
E-mail: info@cbtf.org

HISTORY & MISSION

The Children's Brain Tumor Foundation (CBTF) was founded in 1988 by families and physicians concerned about the lack of knowledge and treatment for brain tumors, especially for children. Its motto is "hope and help every day." The long-term mission of CBTF is to improve treatments and quality of life for children with brain and spinal cord tumors by promoting research and increasing public awareness, and the short-term mission involves providing support and education for patients and their families.

PROGRAMS & PATIENT ADVOCACY

CBTF extends several services to children with brain tumors and their caregivers. It sponsors annual teleconferences that allow parents to receive valuable knowledge from experts in the field of neuro-oncology without having to leave their homes or their sick child. The conferences are free, and individuals who register get instructions, a schedule, packets of information on the conference topic, and details of the services CBTF provides. The CBTF Website houses downloadable recordings of previous teleconferences.

One of the more original resources CBTF provides is a free children's book called *Parker's Brain Storm*. Written by medical student Jennifer A. Moliterno, the book is a tale about Parker the bear cub, who undergoes surgery for a brain tumor. The story helps parents answer questions their child has about a brain tumor diagnosis or treatment and can be ordered at the CBTF Website. CBTF also offers its own *Resource Guide*, written by parents, survivors, and professionals for parents of a child with a brain or spinal cord tumor.

CBTF sponsors several activities for children and families dealing with a brain tumor diagnosis. These events help them build a network of relationships with others who are enduring, or have endured, a similar situation. This might include a free weeklong stay for the family at Camp Sunshine, a service offered exclusively by CBTF; or, for children hospitalized for brain tumor treatment, a trip to the Big Apple Circus to be a kid for a day, rather than a patient.

Through the Case Advocacy program, CBTF works directly with families to ensure that they are receiving all services to which they are entitled. Caregivers can also call the support line at (866) 228-4673 to speak with a pediatric neuro-oncology social worker.

ACHIEVEMENTS & INITIATIVES

Since its inception, CBTF has awarded more than \$5 million in research grants and more than \$600,000 in Quality of Life grants. CBTF is part of the Brain Cancer Funders Collaborative, a group of eight organizations united in fighting brain cancer. CBTF was a founding member of the Alliance for Childhood Cancer, which represents more than 25 patient advocacy groups and research organizations, and the North American Brain Tumor Coalition. It is also a charter member of the LIVESTRONG Young Adult Alliance.

NAVIGATION & USEFUL LINKS

On entering the site, visitors can find the primary navigation bar along the top of the site and a list of upcoming events to the right. Selecting **Find Connections & Support** brings up a page with links to an **Online Community**, **Events & Activities**, and **Family 2 Family**, which connects family volunteers with families who need support. Another unique site feature is **Memorial Quilt**, available under the **CBTF Loss, Grief, and Bereavement Support Services** section, where caregivers construct virtual "quilt squares" to memorialize a loved one. Each square opens a personalized Web page about the special child.

The **Learn** section includes areas for people at different stages of dealing with a brain tumor diagnosis, like **In Treatment** and **After Treatment and Survivorship**. At **CBTF Publications**, visitors can access printable versions of everything CBTF publishes. Here, you can sign up to have the newsletter, which is published three times a year, sent to you via e-mail. The **Advocacy** portion of the Website under the **About** section outlines how one becomes an advocate and provides a brief summary of CBTF's own advocacy efforts. Under the **Support Us** section is a link to **Justin's Hope Fund**, which designates contributions for the Children's Brain Tissue Tumor Consortium—six children's hospitals that share tissue samples to help speed the process of finding a cure. On the top navigation bar, on any page, users will find links to CBTF's profiles on Facebook and Twitter.



Lance Armstrong Foundation

www.livestrong.org

LIVESTRONG GET HELP TAKE ACTION WHAT WE DO WHO WE ARE DONATE SHOP BLOG LOG IN

We fight to improve the lives of people affected by cancer. Search

JOIN US

SHOW YOUR SUPPORT AND CELEBRATE LIVESTRONG DAY ON 10.02.10

HOST OR ATTEND AN EVENT

GET HELP

Need support for yourself or a loved one? We can help you handle the challenges and changes of cancer survivorship, head-on.

- GET ONE-ON-ONE SUPPORT
- LEARN ABOUT CANCER
- FIND MORE RESOURCES
- EN ESPAÑOL
- SEE ALL >

TAKE ACTION

Find out how you can get involved in the fight against cancer with LIVESTRONG — online or on the streets.

- VISIT LIVESTRONG ACTION
- FIND TEAM LIVESTRONG EVENTS
- LEARN ABOUT LIVESTRONG LEADERS
- SEE ALL >

HISTORY & MISSION

The Lance Armstrong Foundation (LAF), also known as LIVESTRONG, was created in 1997 by famed bicyclist and Tour de France winner Lance Armstrong while he was undergoing treatment for testicular cancer, which had spread to his lungs and brain. LAF is not dedicated to fighting any one form of cancer, but to all cancers. LAF has posted its mission on the Website as a “manifesto” that outlines its many goals; although too lengthy to include here, it is definitely worth a read. In essence, LAF’s objectives include helping anyone with any type of cancer fight it from the time of diagnosis to the end, whenever that may be. LAF supports patients with cancer in multiple ways, advocating for patients’ rights and funding research into better treatments and possible cures.

ADDRESS:
2201 E. Sixth Street
Austin, TX 78702

CONTACT INFO:
Phone: (877) 236-8820
(866) 673-7205
E-mail: Online

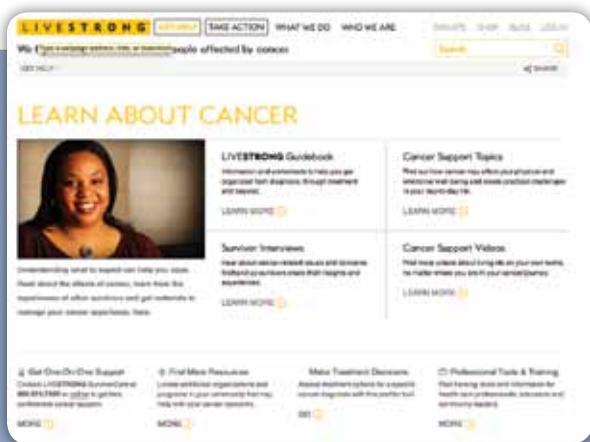
PROGRAMS & ACHIEVEMENTS

By now, everyone recognizes the yellow LIVESTRONG wristbands, which LAF introduced in 2003; LAF sold more than 47 million in the first year alone, raising more than \$6 million for cancer research. Since LAF's inception, the organization has raised more than \$250 million to sponsor research and education. It has contributed to more than 550 cancer research institutes and awarded numerous grants.

LAF wants patients to slow down, breathe, and regain control over their lives. LAF believes cancer care does not end when treatment ends, and it has established a network of LIVESTRONG Survivorship Centers to coordinate services for survivors.

The Foundation also provides a one-on-one support program, which patients or their clinicians can request. The program pairs a patient with an advisor, who offers counseling, aids in locating nearby resources, and addresses concerns patients may have with finances, employment, or insurance. The advisor can also help connect the patient with suitable clinical trials. Services are available in English and Spanish.

Last year, LAF announced plans to go global. To launch this initiative, LAF held a global summit in August 2009, inviting leaders, organizations, and advocates from across the globe to discuss the urgent need to decrease cancer deaths.



NAVIGATION & USEFUL LINKS

The motto at the top of the colorful site reads, "We fight to improve the lives of people affected by cancer." Like Lance Armstrong, the LAF Website is energetic and dynamic. It actually consists of a network of LIVESTRONG sites addressing various aspects of the organization. At [Who We Are](#), you can read [Lance's Story](#), which encourages other young people with cancer to "live strong" and follow their dreams.



Visitors to the home page are greeted with a rotation of information and images at the center of the screen. Other items on the home page include regularly updated headlines related to cancer and summaries of LAF blog posts. Despite the tremendous amount of resources at the site, visitors will find it easy to find the information they seek. The top has a short navigation bar, and pointing to any link unrolls a list of subsections. Scrolling over [Get Help](#) displays a menu of resources for cancer survivors, such as the [Get One-On-One Support](#) section and the [Learn About Cancer](#) section, which includes the worksheets and guidebook. The [Find Clinical Trials](#) link in the [Get One-on-One Support](#) section helps patients locate clinical trials, using the LIVESTRONG Cancer Clinical Trial Matching Service. [Make Treatment Decisions](#) provides patients with access to Cancer Profiler Tools. After registering, patients can summon up information on the latest treatment options based on their particular cancer type.

LAF challenges everyone to [Take Action](#). This might be through [Grassroots Fundraising Events](#), posting on the [LIVESTRONG blog](#), or participating in the [LIVESTRONG Challenge Series](#).

Musella Foundation

www.virtualtrials.com

Home | Learn About | Find A Treatment | Virtual Trial | Interact | Resources | About Us

Clinical Trials and Noteworthy Treatments for Brain Tumors

Presented by The *Musella Foundation*
For Brain Tumor Research and Information

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Please Click On The Above Banner For More Details

Newly Diagnosed Brain Tumor (Brain Cancer) Patients and First Time Visitors

- Brain Tumor Guide for the Newly Diagnosed- a FREE 48 page online book covering what you need to know NOW!
- Important News: Subscribe to our FREE Brain Tumor Blast
 - The Remarkable Story of virtualtrials.com - published in *Brain Tumour - World Edition*
 - ***** Successful Phase III Clinical Trial Results Reported For Novocure's Novel Medical Device For Treatment Of Recurrent Glioblastoma
 - ***** Long-Term Follow-Up of DCVax®-Treated Brain Cancer Patients Shows 33% of Patients Reached 4-Year Survival and 27% Have Reached or Exceeded 6-Year Survival (8/3/2010)
 - ***** ImmunoCellular Therapeutics' ICT-107 Vaccine Demonstrates 80 Percent Survival at 2 Years in Phase I Study of Newly Diagnosed Glioblastoma Patients
 - Generic Temodar Available in the UK!
 - ***** New Videos added to our video library about the Novocure treatment, vaccines, personalized medicine and much more!
 - ***** FDA Approves Avastin for Brain Tumors
 - ***** The Efficacy of Temozolomide (Temozar) In Vitro and in Patients with Newly Diagnosed Glioblastoma Multiforme (GBM) is Enhanced by Adjuvant Exposure To Alternating Electric Fields
 - ***** New theory on cause - and way to treat Glioblastomas: Click [HERE](#) and [HERE](#) and [HERE](#) for 3 articles about it!

ADDRESS:

1100 Peninsula Blvd
Hewlett, NY 11557

CONTACT INFO:

Phone: (888) 295-4740

Fax: (516) 295-2870

E-mail: musella@virtualtrials.com

HISTORY & MISSION

The Musella Foundation was founded in 1998 by Al Musella, DPM, who remains president of the organization. In 1993, Dr. Musella established the first forum for brain cancer on CompuServe, a network for professionals in education that preceded the World Wide Web explosion, when his sister-in-law received a brain tumor diagnosis. At the forum, he posted a list of every type of brain cancer treatment offered at major hospitals in the United States, including trial drugs. Dr. Musella presented his ideas to the National Cancer Institute, and his original list became the inspiration for ClinicalTrials.gov, an online database of clinical trials.

Today, the Musella Foundation is a nonprofit organization seeking to improve the quality and length of life for patients with brain tumors until a cure is discovered. To accomplish this, the Foundation funds research and clinical trials and offers information and advice to patients with brain tumors and their families.

PROGRAMS & PATIENT ADVOCACY

The Musella Foundation directs most of its funds toward grants for research to discover new treatments for brain tumors or to improve existing ones. Every year, the Foundation contributes tens of thousands of dollars toward this purpose. Although the organization does not offer many direct support resources for patients and families, its Website serves as a clearinghouse for a plethora of useful information on brain tumors, trials, treatments, support groups, and more. Musella staffs a hotline at (888) 295-4740 from 10 AM to 9 PM EST, seven days a week, for people with questions about trials.

Musella is a founding member of the Grey Ribbon Crusade, a group of organizations dedicated to fighting brain cancer. Musella is also a member of the International Brain Tumor Alliance.

ACHIEVEMENTS & INITIATIVES

For its efforts in fighting brain tumors through research and computer technology, the Musella Foundation has been endorsed by many organizations and received numerous awards, including the Best of the Planet People's Choice Award. In June 2009, Dr. Musella received the Voices Award for "dedication and charitable giving to brain cancer research and support" from Voices Against Brain Cancer. He also received the 2009 Tim Gullikson Spirit Award. This year alone, Musella Foundation has awarded more than \$180,000 in grants for various investigations into brain tumor treatments.

NAVIGATION & USEFUL LINKS

The Musella Foundation served as the origin for a database of clinical trials, and it continues to channel many of its efforts along those lines. The **Virtual Trial** section, accessed from the top navigation bar, is used to compile data on brain tumor treatments and their effectiveness based on patient reports from around the world. To participate in this long-term project, patients must register via the **Join** link, then provide specified medical records and agree to update their medical data once a month.

Mousing over **Learn About** at the top brings up a drop-down menu linking to information on all aspects of brain tumor care. The **Guide for the Newly Diagnosed** is a free 48-page downloadable book that covers everything a patient with a new brain tumor diagnosis needs to know. You can also click on **Noteworthy Treatments** to access a long list of links on available treatments, supplemented with expert opinions or

trial results. The **Learn About** section also includes an extensive **Frequently Asked Questions** link with patient-submitted questions and a **Dictionary** of brain tumor terms. **Survivor Stories** features first-person accounts from people who survived a brain tumor.

Find a Treatment allows patients to search for available trials **By Tumor Type**, **By Geographical Location**, or by treatment method. You can also use **Trials Matcher**, which connects visitors to **emergingmed.com**, a separate site that helps registered participants locate suitable trials.



The **Video Library**, found under **Interact**, is a popular feature at Musella. It contains presentations by medical experts that can be viewed online; some are also available for iPhone use. **Interact** also brings up a link to the Musella Foundation's **Newsletter**; the **Brain Tumor Blast**, which has articles on the latest happenings in neuro-oncology research. This is also where you can sign up for the **Daily Brain Tumor News Blast**, to get links to new relevant articles.

People looking for support can find a list of **Online Support Groups** under the **Resources** tab. Musella's group, the **Temodar (Brain-Temozolomide) Group**, is for all caregivers and patients, regardless of the patient's type of treatment. Medical professionals also participate in this e-mail-based chat service. Under **Resources**, you can review a list of **Brain Tumor Centers** or search the **Doctor/Hospital Address Book** for a specific provider. The Musella Foundation maintains an online **Memorials** section, where families who have lost a loved one to brain cancer can submit a slide show to be displayed on the Website.

National Brain Tumor Society

www.braintumor.org

The screenshot shows the homepage of the National Brain Tumor Society. At the top, there is a navigation bar with links for 'Login', 'Online Community', 'About Us', 'Careers', 'Be Successful', 'Contact Us', 'Site Map', and 'RSS'. Below this is a search bar and contact information: 'Patient Services: 800 934 2873' and 'Toll-free: 800 770 8287'. A green navigation bar contains links for 'Patients, Family & Friends', 'Get Involved', 'Giving', 'Research', 'Donate', 'News', and 'Events'. The main content area features a large image of four people in orange shirts with the text 'Join our community' and 'Be part of one of our many national events'. Below this is a section for 'Latest Brain Tumor Research News' with two articles: '9/28 Mayo Clinic-TGen-Arizona Cancer Center Study Finds Gene...' and '9/26 New Brain Tumor Treatment Design Advance for Speech-Language Pathologists and Audiologists'. There are also sections for 'Upcoming Events' (Boston Brain Tumor Walk, October 2, 2010) and 'Latest Brain Tumor News' (Highlights from the NBTS Annual Meeting). On the right side, there is a 'Stay Connected' section with a sign-up form and three informational buttons: 'Brain Tumor Information', 'Resources & Support', and 'Get Involved'.

ADDRESS:
124 Watertown Street, Suite 2D
Watertown, MA 02472

CONTACT INFO:
Phone: (800) 770-8287
(800) 934-2873
E-mail: info@braintumor.org

HISTORY & MISSION

The National Brain Tumor Society (NBTS) is a nonprofit organization formed in 2008 through the merger of the National Brain Tumor Foundation and the Brain Tumor Society, two organizations established in the 1980s to lobby for more brain tumor research and better treatment access. The stated mission of NBTS is to improve the lives of those affected by brain tumors while searching for a cure. The organization believes in supporting patients through every step of their journey, from diagnosis through treatment to end of care and survivorship. NBTS has two major offices in the United States, one on each coast.

PROGRAMS & PATIENT ADVOCACY

NBTS offers many services for patients with brain tumors and their caregivers, giving them the information and emotional support they need during this difficult time. In addition to sponsoring support groups across the nation, NBTS helps match patients according to age and tumor type with others who have shared a similar experience.

NBTS understands that caring for a loved one with a brain tumor can be challenging. The group provides services specifically for caregivers, including educational materials and workshops.

NBTS also offers financial help and assists patients and families with navigating the complex provisions of their insurance policies. NBTS provides these services, available in English and Spanish, through Patient Services, at (800) 934-2873. Every year, Patient Services handles more than 10,000 phone calls and email requests for assistance from patients and their families.

Throughout the year, NBTS hosts fundraising events, such as Brain Tumor Walks and Races for Hope, at locations throughout the United States. NBTS also assists people interested in organizing their own event.

ACHIEVEMENTS & INITIATIVES

In 2008, NBTS contributed more than \$4.5 million to brain tumor research, including funds designated specifically for pediatric conditions. NBTS also dispersed more than 40 research grants in 2008, focusing on two specific areas: comprehensive molecular profiling and developmental neurobiology.

Every year, NBTS hosts a meeting in the Washington, DC vicinity that unites patients, medical professionals, scientists, and volunteers. During these meetings, NBTS recognizes active members of the brain tumor community, awards research grants, and encourages government legislators to increase funding for brain cancer research.

NAVIGATION & USEFUL LINKS

On the home page of the site, visitors are greeted with a large banner bearing the NBTS logo and its slogan: "Leading through research and support." This page includes continuously updated active sections on [Upcoming Events](#) and the [Latest Brain Tumor News](#). The green navigation bar at the top links to the various sections of the Website.



At [Patients, Family & Friends](#), you can read about tumor types, treatment options, and available support services and access on-demand Webcasts/teleconferences. A panel of buttons on the left expands on the information in each category. For example, [Information About Brain Tumors](#) includes the [Brain Tumor FAQ](#), a [Glossary](#), and [Brain Anatomy](#), which leads visitors to an illustrated [Interactive Tour of the Brain](#). Patients can [Find a Treatment Center](#), located under the [Treatment Information](#) section, or click on [Find Support](#) to join the interactive [NBTS Online Community](#). Here, patients with brain tumors and their families and caregivers can share stories and find emotional support.

The site offers multiple ways for visitors to learn about the research projects NBTS supports. Clicking [Research](#) in the green navigation bar at the top explains grants and research programs, including the [Pediatric Research Initiative](#), accessible from the [Research Programs](#) button on the left, which also outlines collaborations between NBTS and various groups.

The [News](#) page explains how to sign up for the NBTS monthly e-mail newsletter (also available using the [Stay Connected](#) button) and contains links to archived newsletters. Enlisting people to [Get Involved](#) is one of the goals of NBTS. This section details upcoming advocacy events taking place across the nation. You can also learn how to host a fundraising event of your own for NBTS.

National Cancer Institute

www.cancer.gov

The screenshot shows the National Cancer Institute website homepage. At the top, there is a red header with the NCI logo, the text "National Cancer Institute", "U.S. National Institutes of Health | www.cancer.gov", and a search bar. Below the header is a navigation menu with links for "NCI Home", "Cancer Topics", "Clinical Trials", "Cancer Statistics", "Research & Funding", "News", and "About NCI".

The main content area features a large banner for "Progress Against Prostate Cancer" with the text "Our Knowledge is Evolving" and "Understanding Prostate Cancer". Below this are several sections:

- Quick Links:** Includes links for "Director's Page", "Dictionary of Cancer Terms", "NCI Drug Dictionary", "Funding Opportunities", "NCI Publications", "Advisory Boards and Groups", "Science Serving People", and "Español".
- Types of Cancer:** Lists "Common Cancer Types" (Bladder Cancer, Breast Cancer, Colon and Rectal Cancer, Endometrial Cancer, Kidney (Renal Cell) Cancer, Leukemia, Lung Cancer, Melanoma, Non-Hodgkin Lymphoma) and "All Cancer Types" (A to Z List of Cancers, Cancers by Body Location/System, Childhood Cancers, Adolescents and Young Adults, Women's Cancers).
- Clinical Trials:** Includes "Search for Clinical Trials", "What is a Clinical Trial?", "Clinical Trial Results", and "Educational Materials".
- Cancer Topics:** Lists "What is Cancer?", "Treatment", "Prevention, Genetics, Causes", "Screening and Testing", "Coping with Cancer", "Smoking", "Cancer Health Disparities", "NCI Fact Sheets", and "Physician Data Query (PDQ®)".

On the right side, there are three smaller promotional boxes: "NCI Cancer Bulletin", "NCI Budget Analysis Tool", and "The Nation's Investment in Cancer Research". At the bottom right, there is a box for "RECOVERY ACT AT NCI".

HISTORY & MISSION

The National Cancer Institute (NCI) was authorized under the National Cancer Act of 1937 and is part of the National Institutes of Health (NIH). It was formed with the purpose of conducting and supporting cancer research, reviewing and approving grants for promising research projects, gathering and analyzing cancer research from across the globe, and training healthcare professionals in the proper diagnosis and treatment of cancer. The creation of the National Cancer Program by the National Cancer Act of 1971 expanded NCI's focus to support other programs and research projects involving cancer prevention, rehabilitation, and continued care for patients with cancer and their families. Today, NCI is the world's leading funder of cancer research.

ADDRESS:
6116 Executive Blvd.
Suite 300
Bethesda, MD 20892-8322

CONTACT INFO:
Phone: (800) 422-6237
E-mail: Online

PROGRAMS & ACHIEVEMENTS

Since its establishment, NCI has allocated billions of dollars to cancer research and awarded tens of thousands of research grants. NCI has funded the research of at least 20 Nobel Prize winners. One of its most important projects to date is the launching of The Cancer Genome Atlas in 2005 with the National Human Genome Research Institute, also part of NIH. The Cancer Genome Atlas plans to map genetic changes for at least 20 cancers in the next two years.

Although NCI is not a patient advocacy organization, it offers a range of useful services and tools for patients and their loved ones. Specialists at NCI's Cancer Information Service helpline at (800) 4-CANCER answer questions on a range of cancer topics, including the latest treatments and clinical trials. NCI's biweekly e-Newsletter, *The NCI Cancer Bulletin*, provides the latest cancer research news, including findings from major research journals, detailed articles and reports, information on new clinical trials, and legislative updates related to cancer and health care. NCI also has its own YouTube channel, which patients can follow to view various cancer-related videos.

Another valuable resource offered by NCI is its massive publications library. These publications can be ordered through the mail, downloaded and printed, or viewed online at no cost. They come in a variety of forms, including CDs/DVDs, pamphlets, fact sheets, and more. The hundreds of publications listed on NCI's Website can be searched by cancer type, subject, and target audience. Over 100 of these are also available in Spanish.

NAVIGATION & USEFUL LINKS

NCI's busy home page is compartmentalized to facilitate visitor navigation. A Quick Links box in the upper left-hand corner of the Website provides access to a [Dictionary of Cancer Terms](#), the [NCI Drug Dictionary](#), and the volumes of cancer information found in [NCI Publications](#). On the primary navigation bar at the top of the home page, patients can connect to the [Cancer Topics](#) section. Under [Common Cancer Types](#), you can select [Cancers by Body Location/System](#) and [Brain](#) to go directly to sections on adult and pediatric brain tumor types. Or, you can select [All Cancer Types](#) for an [A to Z List of Cancers](#).

Whatever cancer type you select, the menu bar at the top stays the same. It includes a tab for [Clinical Trials](#), a section that includes several clinical trial-related tools and articles. [Find a Clinical Trial](#) lets patients search the more than 8,000 NCI-sponsored clinical trials that are

accepting new patients. [Educational Materials About Clinical Trials](#) contains a number of articles explaining the purpose and process of clinical trials. Links to clinical trial information are also available on the bottom of the page, some specific to the type of cancer.



In the right column of each cancer's page, the [Related Pages](#) and [General Cancer Resources](#) sections include links to similar disease states or articles that address a range of subjects applicable to patients with all cancer types, such as [Educational Materials About Clinical Trials](#) and [Complementary and Alternative Medicine](#). There is also a [Coping with Cancer](#) section, with guides on [Managing Physical Effects](#), [Managing Emotional Effects](#), and [Finding Healthcare Services](#).

The small NCI Cancer Bulletin box in the home page's right-hand column allows visitors to subscribe to NCI's biweekly newsletter. A small row of links appearing at the bottom of every page includes [Contact Us](#). Here, visitors can access NCI's Cancer Information Service helpline or use the [LiveHelp Online Chat](#) service, which allows visitors to have a confidential online chat with an NCI cancer information specialist.

NCI's Adult Brain Tumor page can be accessed through [Cancer Topics](#), [Cancers by Body Location/System](#), and selecting [Brain](#). The page begins with a brief definition of the disease and current-year estimates of new diagnoses and fatalities. Directly below this information is a link to NCI's booklet on the disease, [What You Need To Know About™ Brain Tumors](#). The remainder of the page consists of various links sorted by category that connect to articles on treatments, prevention and risk factors, clinical trials, related literature, research, and statistics. Several of these sections include pages with information pertaining to brain tumors in children.

National Coalition for Cancer Survivorship

www.canceradvocacy.org

login en español online store contact us search

NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

About Us Find Resources Take Action Community Donate

We speak FOR ALL CANCERS. FOR QUALITY CARE. AS SURVIVORS.

The power of survivorship.
The promise of quality care.

SIGN UP FOR NEWS enter your e-mail go

SURVIVOR PROFILES
Anne Willis, Ewing's sarcoma survivor
"I'm thankful to have found an oncology team that is so helpful, but I wish I'd had a treatment summary and survivorship care plan the day I finished treatment."
Read More | Leave a Comment | Submit Your Story

IN THE SPOTLIGHT

The National Coalition for Cancer Survivorship Applauds Introduction of ALERT Act
September 29, 2010
Cappe-Patlone Cancer Care Bill Would Institute Cancer Care Planning

What's happening with health care reform?
September 27, 2010
Recent news articles provide helpful summaries of which health insurance changes took effect starting last week.

Register for Tuesday's Free Advocacy Webinar
September 20, 2010
Learn to make an impact with your cancer story and effect change in "The Media and the Message: How to Use to the Media to Raise Awareness and Get Action" (821, 2:30-3:30 p.m. EST)

More NCCS News | More Community News

Call for Better Cancer Care!
Support CCCIA
Call Now!

NCCS CANCERVERSARY
JOIN OUR BLOG

Diagnosed with cancer?
Get the free tools you need >>

Journey Forward
giving Survivors as they move ahead
GET A PLAN >>

ADDRESS:
1010 Wayne Ave.
Suite 770
Silver Spring, MD 20910

CONTACT INFO:
Phone: (301) 650-9127
(888) 650-9127
Fax (301) 565-9670
E-mail: info@canceradvocacy.org

HISTORY & MISSION

Founded in 1986, the National Coalition for Cancer Survivorship (NCCS) claims to be the "oldest survivor-led cancer advocacy organization in the country." NCCS wants to change the perception of individuals with cancer from victims to survivors, encompassing every step of the cancer journey, from diagnosis to post-treatment. NCCS believes family members, friends, and caregivers of people with cancer also deserve the moniker of cancer survivor. NCCS advocates for federal laws to ensure that all Americans with cancer receive quality care and have their rights respected. NCCS also works for legislative changes to see that the needs of cancer survivors are met. Another component of the mission espoused by NCCS is to provide patients with access to medically accurate information and tools to guide them in their care decisions.

PROGRAMS & PATIENT ADVOCACY

NCCS was one of several patient advocacy organizations that came together in 1993 to form the Cancer Leadership Council, which meets monthly to discuss public policies related to cancer. This was followed by the first National Congress on Cancer Survivorship in 1995.

In 1998, NCCS organized “The March...Coming Together to Conquer Cancer” event, bringing 250,000 supporters to the nation’s capital. That same year, NCCS introduced the Cancer Survival Toolbox, which has since been used by more than 500,000 people.

ACHIEVEMENTS & INITIATIVES

NCCS staff members are actively involved in policy discussions concerning cancer at the highest level. They serve on committees convened at the Institute of Medicine and work with ASCO in planning Cancer Quality Alliance meetings. NCCS has contributed to many legislative efforts on behalf of cancer survivors, including the Office of Cancer Survivorship, created in 1996 at the National Cancer Institute; the Health Insurance Portability and Accountability Act; and the National Cancer Policy Board. To expand its legislative reach, NCCS launched Cancer Advocacy Now! in 2004, which now has more than 25,000 members.

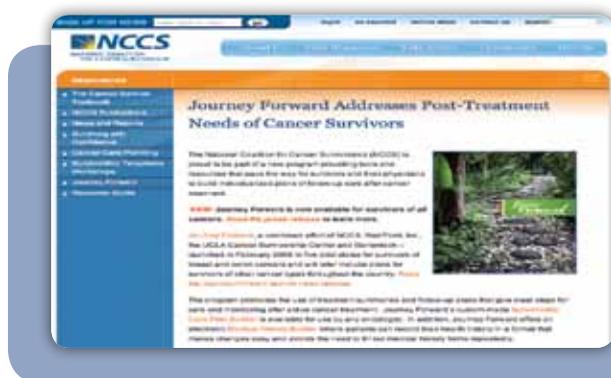
Every spring, NCCS and other organizations jointly host a three-part teleconference series that address survivorship concerns. Thousands of people from all 50 states call in to the teleconference. In addition, NCCS hosts the Rays of Hope Awards Gala annually in Washington, DC, to recognize groups and individuals for their efforts to improve life for cancer survivors.

NAVIGATION & USEFUL LINKS

Many visitors to the site appreciate the **Cancer Survival Toolbox**. This award-winning audio program, available in Spanish and Chinese, is found under the **Find Resources** tab in the top menu bar, or you can order the CDs by following the **Get the free tools you need** link toward the bottom of the home page.

Also under **Find Resources** is a list of **NCCS Publications**. Download free guides such as *What Cancer Survivors Need to Know About Health Insurance*, *Teamwork: The Cancer Patient’s Guide to Talking with Your Doctor*, and *Self-Advocacy: A Cancer Survivor’s Handbook*. Other brochures discuss patients’ employment rights.

To the left of every subsection, you will find a menu with additional options. **News and Reports** features headlines of recent cancer news. **Survivorship Telephone Workshops** contains Podcasts of each year’s NCCS teleconference on survivorship. NCCS believes strongly in the importance of developing a written plan for every patient. The **Cancer Care Planning** page (also available from the **Find Resources** tab) outlines care plans and links to sites that discuss this important step. Selecting **Journey Forward** from the side menu or the bottom of the home page takes visitors to an overview of a newly launched initiative from NCCS and its partners. The Journey Forward Website, at www.journeyforward.org, provides tools to help survivors design a care plan.



Under **Community** from the navigation bar at the top of the main page, you can learn more about the NCCS community of cancer survivors. Read their stories at **Survivor Profiles** or **Share Your Story**. NCCS is working to enhance opportunities for site visitors to connect with one another and provide each other with support. The **Cancerversary** blog is available via a link under **Community** or from the bottom of the home page. Midway down on the main page of the site, visitors can register to receive news from NCCS about its efforts.



North American Brain Tumor Coalition

www.nabraintumor.org

The screenshot shows the homepage of the North American Brain Tumor Coalition. At the top, there is a green header with the organization's name. Below this is a navigation menu with links to Home, Action, News & Events, Health Policy, Become An Advocate, Who We Are, Member Organizations, Brain Tumor Facts, and Contact Information. The main content area features a mission statement: "OUR MISSION: The North American Brain Tumor Coalition is dedicated to improving the prognosis and quality of life for brain tumor patients. The Coalition educates policymakers, and advocates for increased research into brain tumor treatments, causes and rehabilitation." Below the mission statement are three columns of content. The first column, titled "Advocate", includes a photo of an elderly couple and text about providing informed representation. The second column, titled "Be Informed", includes a photo of a group of people holding hands in a field and text about providing current updates. The third column, titled "Collaborate", includes a photo of a group of people huddled together and text about providing a myriad of patient and family support options. Each column has a "Find out more" button. At the bottom left of the screenshot, there is a "NABTC RSS" link.

HISTORY & MISSION

The North American Brain Tumor Coalition (NABTC) is a consortium of brain tumor organizations working in concert to achieve their goals of increasing public awareness and funding for brain tumor research, treatment, and rehabilitation. Formed in 1993, the NABTC includes American and Canadian members. Among the participating organizations are the American Brain Tumor Association, the National Brain Tumor Society, the Children's Brain Tumor Foundation, and the Michael Quinlan Brain Tumor Foundation.

Primary missions of NABTC are ensuring that the government is well informed when it comes to brain tumor issues and advocating for bigger research budgets and easier access to treatments for patients. NABTC lists one of its main goals as improving treatment methods and the quality of life for patients with brain tumors until a cure can be found.

ADDRESS:
2446 39th Street NW
Washington, DC 20007

CONTACT INFO:
Phone: N/A
E-mail: info@nabraintumor.org

PROGRAMS & PATIENT ADVOCACY

NABTC focuses primarily on advocacy efforts, rather than providing services and support programs, which its individual members handle. All the members of NABTC sponsor their own fundraisers, events, and services, and NABTC is more than happy to help you locate these resources. In 1997, NABTC sponsored the first Brain Tumor Action Week, which has become a yearly event dedicated to increasing awareness of the serious effects of brain tumors on patients and their families.

NABTC, along with other cancer societies, reacts to any policy proposals affecting the lives of those with brain tumors and even initiates its own proposals. It is pressing Congress to pass healthcare reform that gives all Americans access to good medical care. NABTC also developed the Principles of Quality Care for Brain Tumor Patients, a list of measures its members feel any new system should incorporate.

ACHIEVEMENTS & INITIATIVES

NABTC has accomplished a great deal in its efforts to assist patients with brain tumors and scientists in the neuro-oncology field. NABTC was largely responsible for passage of the Benign Brain Tumor Cancer Registries Amendment Act in the United States. This act requires the National Program of Cancer Registries to collect data on benign brain tumors as well as malignant, making more accurate and detailed data available to researchers.

NABTC works with other advocacy groups to lobby for complete Medicare coverage of clinical trials and cancer treatments, better coverage of cancer drugs, and abolishment of the two-year waiting period for Medicare coverage. NABTC also hopes to secure increased funding for brain tumor research through the National Institutes of Health and works with Congressional representatives and senators to maintain funding for clinical trials and existing research programs.

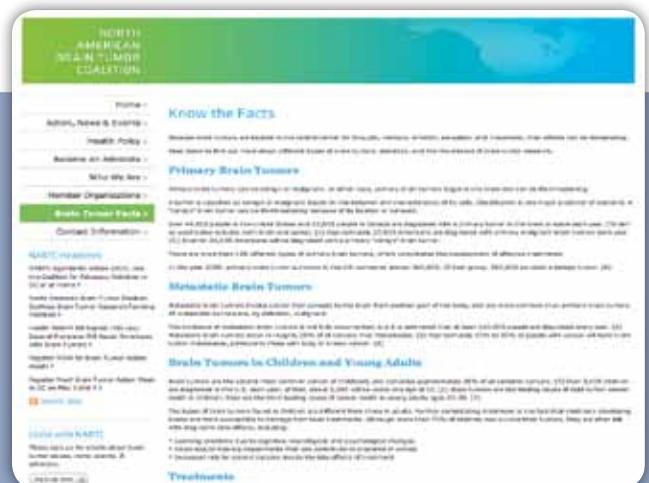
NAVIGATION & USEFUL LINKS

The NABTC Website is simple to navigate. Links on the left-hand navigation bar are, for the most part, self-explanatory. Clicking on [Action, News & Events](#) brings up the most recent articles pertaining to NABTC, brain tumor research, or government health policies. This page also contains archives of previous articles, organized into subcategories like [Action Items](#), [Advocacy Positions](#), [Brain Tumor Research](#), and [Health Care Reform](#).

Clicking on [Health Policy](#) from the home page takes visitors to a page outlining NABTC's current advocacy goals. This area also contains links to the House and Senate Websites, where you can find contact information for your elected officials or learn about legislative efforts underway. One of NABTC's most important collaborations is with the 30 patient advocacy organizations that make up The Cancer Leadership Council, which visitors to the Website can learn more about by following this link. [Accomplishments](#) opens a page with a timeline of the results of NABTC's efforts throughout its 16-year existence and important milestones in the history of brain tumor research.

To learn more about the roles other organizations play as part of the NABTC, click on [Member Organizations](#). In addition to a breakdown of the various contributions these organizations make, the section provides each one's contact information and links to their Websites (several of which are included in this Resource Guide). Although the NABTC site does feature a [Brain Tumor Facts](#) area, many of the member sites provide information that is more comprehensive and offer financial or emotional support services.

Advocacy is a major component of what NABTC does, and the organization encourages you to [Become An Advocate](#), outlining things you can do to support people with benign and malignant brain tumors. While you are at the site, be sure to sign up to receive e-mails about NABTC's ongoing efforts through [Unite with NABTC](#).



Pediatric Brain Tumor Foundation

www.pbtfus.org

ADDRESS:
302 Ridgefield Court
Asheville, NC 28806

CONTACT INFO:
Phone: (800) 253-6530
(828) 665-6891
Fax: (828) 665-6894
E-mail: pbtfus@pbtfus.org

HISTORY & MISSION

The Pediatric Brain Tumor Foundation (PBTf) is a nonprofit organization founded in 1991 that is dedicated to helping children with brain tumors and their families. The goals of PBTf are to find a cure for and prevent childhood brain tumors through supporting medical research and to provide assistance to children with brain tumors and their families. PBTf also strives to increase public awareness of children with brain cancer and the importance of helping them.

PROGRAMS & PATIENT ADVOCACY

PBTF offers several helpful services, especially educational information. It publishes a number of booklets filled with brain tumor facts and enough information to answer any questions parents may have about a child's brain tumor diagnosis. The booklets, available at no charge in English or Spanish, also address concerns like what to ask your medical team. The organization also developed the Informed Parent and Survivor Internet Conference Series, a selection of online broadcasts from parents, survivors, and professionals who work with children with brain tumors.

In addition to sponsoring medical research, funds raised by PBTF go toward direct help for patients. Families can e-mail familysupport@pbtfus.org to connect with a PBTF family support program manager. PBTF has also established a scholarship program for students who have survived brain tumors. In the first six months of 2009, PBTF awarded a total of \$264,000 to 236 young adults living with a brain tumor diagnosis.

ACHIEVEMENTS & INITIATIVES

PBTF has contributed more than \$44 million toward brain tumor research and patient support since opening its doors in 1984. In addition to providing research grants to neuro-oncology professionals, PBTF awarded founding grants to the medical journal *Neuro Oncology* and helped fund creation of the Brain Tumor Registry of the U.S., the country's largest brain tumor database. Today, PBTF is the largest sponsor of pediatric brain tumor research outside of the U.S. government.

Alongside the National Cancer Institute, PBTF helped fund a workshop on a new treatment protocol for atypical teratoid rhabdoid tumors. PBTF has also teamed up with the Alliance for Childhood Cancer to advocate for patients' rights by raising public and government awareness of their cause.

NAVIGATION & USEFUL LINKS

At the top of PBTF's brightly colored homepage is a navigation bar connecting to the four primary sections of the Website. Scrolling over these displays a dropdown menu of each section's subcategories. Under **Families**, which has sections for **Parents**, **Siblings**, and **Survivors**, the **Family Support** link takes you to a page containing some of PBTF's useful and unique services. Here, you can download information booklets on different types of brain tumors or access the archives for the **Informed Parent and Survivor Internet Conference Series**. These internet conferences, which can be viewed online or ordered at no charge on CD-



ROM, feature survivors, family members, and medical experts offering input on topics ranging from how clinical trials work to reentering school after a child is diagnosed with a brain tumor. The final subsection, **Medical Information**, includes a downloadable form called **Your Child's Medical History**, designed to be shared with your child's physician, and information on clinical trials.

PBTF has established a special **Survivors** area of the Website designed for children and young adults who have completed treatment. **Feelings** talks about emotional concerns, like depression or post-traumatic stress; and **Your Body** talks about the physical aspects. **Stories of Hope** is where survivors of childhood brain tumors share their stories. It can be especially helpful for adolescents and teens to read stories from their peers on life after treatment.

The **Medical Community** section of the site contains news on the latest medical breakthroughs in brain cancer. The **Research** subsection includes **Pediatric brain tumor facts** and **Research news**, with links to scientific articles from PBTF-funded research. **Clinical Trials** lists resources that help connect patients to available trials. **Ways to Help**, the fourth major section of the site, offers suggestions for volunteering and provides a searchable list of fundraising events in your area. PBTF publishes two newsletters, *The Helping Hand* and *The Caring Hand*, and you can sign up for these using the link at the top right corner of the home page. From the home page, you can also sign up for the PBTF Facebook community.

Pediatric Low Grade Astrocytoma Foundation

www.fightplga.org

The screenshot shows the PLGA Foundation website. At the top left is the PLGA Foundation logo with the tagline "Unite to fight children's brain tumors". To the right is a "Donate" button. Below the logo is a navigation menu with tabs for "About PLGAs", "Ways to Help", "Our Community", "Medical Research", "Resources", and "PLGA Foundation". The main content area features a large article titled "A Children's Brain Tumor Cure" with text about fundraising and a "Meet the kids that inspire us" link. Below this is a section for a 2010 event: "2010 EVENT RAISES \$350K AND STILL GROWING", describing the "Annual Geared Up for Kids Ride and Family Fun Festival". Another section titled "2009 GRANTS INCREASE MOMENTUM FOR PLGA RESEARCH!" discusses funding for 5 new grants. On the right side, there are sections for "Recent Updates" (listing research news), "Accredited by" (showing logos for Heroes of Hope, HON @ CDBI, and RBCSB), and "Shop with Purpose" (explaining the partnership with We-Care).

HISTORY & MISSION

The Pediatric Low Grade Astrocytoma (PLGA) Foundation is the first nonprofit organization dedicated to helping families with children fighting PLGAs. PLGAs are the most common type of brain tumor found in children, and they have a fairly high survival rate compared to other brain tumor types. Because of this, PLGAs are not at the top of the priority list for most cancer research funding. If a PLGA recurs, however, today's treatments can be deleterious to a child, putting them at risk for impaired physical growth and mental health. The mission of the PLGA Foundation is to fund research on safer treatments for PLGAs and other brain tumors. The organization also seeks to increase awareness of the condition and unite the PLGA community.

ADDRESS:
98 Random Farms Drive
Chappaqua, NY 10514

CONTACT INFO:
Phone: N/A
E-mail: contact@fightplga.org

PROGRAMS & PATIENT ADVOCACY

The PLGA Foundation helps organize parents and family members in advocating for more government resources to fund PLGA research. The group also helps interested individuals organize fundraising teams or hold events to raise money for PLGA research.

The PLGA Foundation belongs to several collaborative organizations committed to promoting brain tumor awareness and research. It is a founding member of the Grey Ribbon Crusade and belongs to the International Brain Tumor Alliance.

ACHIEVEMENTS & INITIATIVES

Since the PLGA Foundation was established in 2007, it has raised more than \$6 million to promote its causes. This has been used to support at least a dozen research projects on treatments for childhood brain cancer. In addition, the Foundation coordinated more than \$2 million in donations to establish a research department at the Dana-Farber Cancer Institute in Massachusetts that focuses specifically on developing new treatments for children with PLGAs. The group also gave a multi-year grant to Johns Hopkins for the “PLGA: Dedicated Tumor Banking and Establishment of Cell Lines and Xenografts” project.

In June 2008, the PLGA Foundation and the Brain Tumor Society co-sponsored a symposium at the annual International Symposium on Pediatric Neuro-Oncology conference. This symposium, attended by more than 500 researchers and medical experts, was the largest gathering ever held to discuss PLGAs.

NAVIGATION & USEFUL LINKS

The PLGA Foundation’s Website uses top and side navigation bars. Clicking any of the tabs at the top opens a new page with a side bar listing further options for exploring the site. Selecting [About PLGAs](#) in the primary navigation bar brings you to a page with basic information on PLGAs. The subsections in this section, such as [Brain Tumor Types](#) and [Brain Tumor Locations](#), are particularly useful in helping visitors understand the various brain tumor diagnoses. For those unsure of where to start or who want to learn more about how the Foundation can help, [For Newly Diagnosed](#) explains the organization’s mission and includes links to areas of the site where visitors can find support. [Common Questions](#) is a great place to start if you are unsure of where to find the information you need. Many patients will find the pages on [Treatment Options](#) helpful, as well as the areas designated for [Clinical Trials](#) and [Complications](#).

The bottom link in the side bar is [Video Gallery](#), which lists numerous videos from survivors, survivors’ parents, or pediatricians offering advice and information.

[Our Community](#) in the top navigation bar opens a page detailing how to join the Foundation and listing ways to help the organization achieve its goals. You can share information about the PLGA Foundation with friends and family by [emailing them a PLGA postcard](#). The [PLGA Teams](#) subsection lists fundraising efforts established on behalf of specific children and tells you how to set up your own team. [Stories of Inspiration](#) is a place for young survivors or their parents to share poems, videos, or essays on their struggle with PLGA. This section helps patients and caregivers recognize their shared struggle with others who have PLGA and encourages them to remain hopeful.

For those interested in learning about new discoveries on PLGA and research efforts underway, [Medical Research](#) has sections on [PLGA-Sponsored Projects](#), [Other Projects](#), [New Abstracts](#), and [Research Meetings](#). [Resources](#) provides links to a variety of patient support services, including [Info on Children’s Specialists & Programs](#), [Other Pediatric Brain Tumor Groups](#), [Sibling Resource Networks](#), and [Financial Support](#). This section also includes links to [Find Us on Facebook](#) and [Follow Us on Twitter](#), which are some of the PLGA Foundation’s latest efforts to increase awareness of PLGA and the organization.



Tug McGraw Foundation

www.tugmcgraw.org

TUG MCGRAW FOUNDATION

HOME - SEARCH - HELP NOW - EMAIL TO A FRIEND

“Ya Gotta Believe”

About Us | Team McGraw | Quality of Life Research | Grants | News/Events | Get Involved | Resources | Give Today | Online Store

“Ya Gotta Believe”-- The Tug McGraw Foundation was established in 2003 to enhance the quality of life of children and adults with brain tumors and in 2009 expanded programs to include Post-Traumatic Stress Disorder, (PTSD), and Trauma Brain Injury, (TBI). We collaborate and partner with other organizations so that we can accelerate new treatments and cures to improve quality of life in areas of physical, social, emotional, cognitive, and spiritual impact of those debilitating conditions.
[Learn more](#)

SUBSCRIBE TO THE TMF NEWSLETTER

WHAT'S NEW

Team McGraw 45 T-SHIRT
Wear Your Support in “Team McGraw” Style!
\$20.00 DONATE TODAY >>

September 17, 2010 - **“LEGACY OF PRIDE” BRINGS CANCER AWARENESS, WESTERN TRADITIONS TO EUROPE, PREMIERING IN LONDON**
BREAST CANCER AWARENESS MONTH, TUG MCGRAW FOUNDATION HONORED BY OCTOBER TOUR LAUNCH.
[To Read the full press release, click here.](#)

September 14, 2010 - Grammy-award winning musician, Tim McGraw, and renowned chef, Michael Chiarello, will bring their talents to the Tug McGraw Foundation's annual event to raise awareness for individuals battling brain tumors and other neurological conditions.

MISSION in action

Now On Sale!
The Tug McGraw Foundation presents:
An Evening with Tim McGraw and Friends Honoring Those Who Make a Difference
Saturday, November 13, 2010
Yountville, CA
[To Purchase, Click Here.](#)
[To Learn More, Click Here.](#)

ADDRESS:
P.O. Box #45
Yountville, CA 94599

CONTACT INFO:
Phone: (707) 933-6445
Fax: (707) 676-4398
E-mail: info@tugmcgraw.org

HISTORY & MISSION

The Tug McGraw Foundation was founded in 2003 by professional baseball player Tug McGraw after his diagnosis of brain cancer. After surgery, physicians gave McGraw 3 weeks to live, but he survived 9 months. Realizing that many face this disease without access to the outstanding medical care he was fortunate enough to receive, McGraw established the organization to fund research and increase awareness of brain cancer. His goal was to make patients' lives better as researchers hunt for a cure. A unique aspect of the Foundation is its focus on the needs of caregivers, in addition to patients.

PROGRAMS & PATIENT ADVOCACY

The Tug McGraw Foundation makes a determined effort to improve the quality of life for patients with brain tumors. It recently sponsored the Brain Tumor Quality of Life Research Summit, bringing 28 researchers, clinicians, and advocates together to discuss quality-of-life concerns. This conference was important, because much of today's brain tumor research focuses only on how to let patients live longer, not better.

In keeping with McGraw's love of sports, the Foundation sponsors numerous athletic events throughout the country with the Team McGraw program. Team McGraw trains amateur athletes to participate in various sporting events—competitive and noncompetitive—to raise funds. This includes marathons, bowling tournaments, and more. The first time Team McGraw entered an event, 32 members ran the 2007 ING New York City Marathon and raised more than \$280,000.

The Foundation also works with other organizations, such as various chapters of Big Brothers, Big Sisters, and sporting associations to promote its youth partnership program. Together, the groups have developed scholarship programs for youth and student athletes, such as the Hits for Tug's Team, to reward young people who work to improve their communities.

ACHIEVEMENTS & INITIATIVES

In 2004, the foundation helped establish the Tug McGraw Center for Neuro-Oncology Quality of Life Research, under the umbrella of the Brain Tumor Center at Duke University in Durham, North Carolina. The Tug McGraw Foundation takes a unique approach to funding research, collaborating with other organizations to support various projects. Joining forces allows the awarding of larger grants to projects that show great promise.

The Tug McGraw Foundation recognizes how hard caregivers work to assist their loved ones undergoing treatment for brain cancer. The Foundation awards grants not only to research brain tumor treatments but also to conduct research on caregiver issues. The Tug McGraw Foundation and the National Brain Tumor Foundation recently established a \$30,000 grant for research designed to improve caregivers' ability to provide high-quality care. The Foundation also gives an annual award to a caregiver who has provided outstanding care.

NAVIGATION & USEFUL LINKS

The Tug McGraw Foundation Website is easy to navigate, greeting visitors with a picture of the legendary baseball player in action on the field. Clicking [Team](#)



[McGraw](#) takes you to information on the Tug McGraw Foundation's athletic fundraisers, an important component of the Foundation. In this section, you can [Sign Up for Team Newsletter](#), which tracks Team McGraw's events and achievements; find [Applications](#) to join a team; and visit the [Message Board](#) to chat with Team members. You can also find information on joining the Team's Facebook page.

Several resources can be found under the [Under Quality of Life Research](#) section. Patients can review a report from the recent summit, find links and information on [Clinical Trials](#), and learn about the [Tim McGraw Scholarship](#) for a Duke University graduate who plans to attend medical school, in particular to study oncology.

Patients and their families are most likely to be interested in the [Resources](#) section of the Website. The [Heroes](#) link on the left provides stories from or about notable people who had brain cancer, such as the late columnist Robert Novak and golfing professional Todd Dempsey. Other stories are from everyday heroes who accomplished extraordinary things as they struggled with this difficult disease. The section for [Caregivers](#) includes a list of the [Top Ten Caregiving Tips](#) and information on the [Caregiver of the Year Program](#). [Resource Links](#) is exactly as it sounds—a list of links to a multitude of resources for patients and caregivers. This includes national and regional organizations and cancer treatment centers, recommended [Books and Publications](#) for adult and pediatric patients, and inspirational sites.

Clicking the [News/Events](#) link in the top navigation bar brings you to an archive of news related to brain cancer and the Tug McGraw Foundation. Articles can be sorted by [Foundation News](#), [Brain Tumor News](#), and [Press Releases](#).

Additional Resources



A Day of Sunshine

www adayofsunshine.org

A Day of Sunshine provides a service for patients with cancer or anyone who has undergone chemotherapy or radiotherapy. The service sends a team to patients' homes at no cost to clean and provide the patient with a makeover, a pedicure, and a manicure. This can help relieve stress for a patient struggling with the side effects of cancer treatment.



Brain Tumor Resource and Information Network

www.brainsite.org

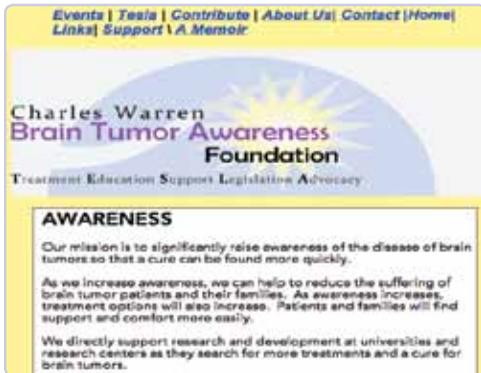
The Brain Tumor Resource and Information Network is a nonprofit volunteer organization committed to raising public awareness of benign brain tumors and brain cancer. It also funds research and supports patients with brain tumors. The site contains various educational resources, including a list of recommended books for patients to read.



Central Brain Tumor Registry of the United States

www.cbtrus.org

The Central Brain Tumor Registry of the United States is a nonprofit corporation that collects data on benign and malignant brain tumors. The goal is to advance research by allowing investigators to share important data. The site contains charts and tables on brain tumor data and a glossary of medical terms, making it a useful resource for patients and healthcare professionals alike.



Charles Warren Brain Tumor Awareness Foundation

www.charleswarrenfoundation.org

The Charles Warren Brain Tumor Awareness Foundation is dedicated to promoting public awareness of brain tumors. The organization hopes that raising awareness and funding research efforts will help researchers discover a cure sooner. The Website offers easy-to-read information on brain tumors and treatments and lists support services offered by other organizations.



Chris Elliott Fund for Glioblastoma Brain Cancer Research

www.chriselliottfund.org

The Chris Elliott Fund for Glioblastoma Brain Cancer Research is a Website-in-progress. It contains information and resources specifically for patients with glioblastoma. The organization holds fundraising events, including an annual golf tournament, and offers online educational resources.



Connecticut Brain Tumor Alliance

www.ctbta.org

The Connecticut Brain Tumor Alliance is a regional organization dedicated to raising awareness of brain tumors and offering support to patients in Connecticut dealing with a brain tumor diagnosis. The site contains facts on brain tumors and information on available treatments. The Connecticut Brain Tumor Alliance hosts multiple fundraisers, including a golf tournament, an annual dinner, and a raffle.



Kortney Rose Foundation

www.thekortneyrosefoundation.org

The Kortney Rose Foundation was founded in memory of Kortney Rose Gillette by her mother after Kortney passed away from brainstem glioma. The Website contains information on pediatric brain tumors, a list of fundraising events sponsored by the Kortney Rose Foundation and other organizations, newsletters, and a photo gallery. The site also contains a video archive of news related to the Kortney Rose Foundation.



Michael Quinlan Brain Tumor Foundation

www.mqbtf.org

The Michael Quinlan Brain Tumor Foundation is an organization based in Louisville, Kentucky. It is a member of the North American Brain Tumor Coalition. The Michael Quinlan Brain Tumor Foundation supports regional patients with a brain tumor diagnosis. It sponsors local support groups, provides an online care and support blog, and furnishes downloadable educational resources.



San Diego Brain Tumor Foundation

www.sdbtf.org

The San Diego Brain Tumor Foundation was created to help those in San Diego with brain tumors by offering financial and emotional support. Its Website includes a fundraising events calendar, an online memorial section, and an "in honor of" subsection. The organization sponsors a support group for patients, families, and friends that meet monthly.



Southeastern Brain Tumor Foundation

www.sbtbf.org

The Southeastern Brain Tumor Foundation is a nonprofit organization based in the southeastern United States. This Foundation sponsors support groups in this region for people with brain tumors and their families. The Foundation also hosts an annual Race for Research fundraising event. The Website features news archives and photo galleries from these events.



Students Supporting Brain Tumor Research

www.ssbtr.org

The Students Supporting Brain Tumor Research is a Website that helps different schools and collegiate organizations sponsor fundraising events to raise money for brain tumor research. Events include walk-a-thons and silent auctions, and the Website streams YouTube videos of these events.



Tumor Free

www.tumorfreesite.com

With a goal of helping to educate patients and their caregivers, the Tumor Free Website compiles resources from many other Websites and organizations in easy-to-navigate lists. These resources include information on diagnosis and treatment, tips for caregivers, options for financial or emotional support, and helpful books and links.

