

THE
Educated Patient[®]

Glioblastoma Multiforme

RESOURCE GUIDE



Presented by

cure[™]

A guide to organizations that provide information and support for patients with glioblastoma and the oncology professionals who treat them.

Cancer Therapy, Meet My Life



A novel treatment option for adult patients (22 years or older) with recurrent glioblastoma

Optune is a portable treatment option for recurrent glioblastoma. As effective as chemotherapy and with fewer side effects, Optune offers a better quality of life.¹

Ask your doctor if Optune is right for you or your loved one.

Visit Optune.com to learn more.

NovoTTF™-100A System is now

OPTUNE™

Optune is approved for the treatment of adult patients (22 years or older) with recurrent glioblastoma. For complete information regarding the device's indication, contraindications, warnings and precautions, please see the Instructions for Use (IFU) at Optune.com/Safety.

novocure™

Reference: 1. Optune Instructions for Use. Novocure 2014.

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For full prescribing information, refer to the IFU at Optune.com/Safety

INDICATIONS FOR USE

Optune™ is intended as a treatment for adult patients (22 years of age or older) with histologically confirmed glioblastoma multiforme (GBM), following histologically- or radiologically-confirmed recurrence in the supra-tentorial region of the brain after receiving chemotherapy. The device is intended to be used as a monotherapy, and is intended as an alternative to standard medical therapy for GBM after surgical and radiation options have been exhausted.

SUMMARY OF IMPORTANT SAFETY INFORMATION

Contraindications

Do not use Optune if you have an active implanted medical device, a skull defect (such as, missing bone with no replacement), a shunt, or bullet fragments. Examples of active electronic devices include deep brain stimulators, spinal cord stimulators, vagus nerve stimulators, pacemakers, defibrillators, and programmable shunts. Use of Optune together with implanted electronic devices has not been tested and may theoretically lead to malfunctioning of the implanted device. Use of Optune together with skull defects, shunts, or bullet fragments has not been tested and may possibly lead to tissue damage or render Optune ineffective.

Do not use Optune if you are known to be sensitive to conductive hydrogels like the gel used on electrocardiogram (ECG) stickers or transcutaneous electrical nerve stimulation (TENS) electrodes. In this case, skin contact with the gel used with Optune may commonly cause increased redness and itching, and rarely may even lead to severe allergic reactions such as shock and respiratory failure.

Warnings and Precautions

Use Optune only after receiving training from qualified personnel, such as your doctor, a nurse, or other medical personnel who have completed a training course given by the device manufacturer (Novocure).

All servicing procedures must be performed by qualified and trained personnel.

Do not wet the device or transducer arrays.

Do not use any parts that do not come with the Optune treatment kit, or that were not sent to you by the device manufacturer or given to you by your doctor.

Optune commonly causes skin irritation beneath the transducer arrays and in rare cases can lead to headaches, falls, fatigue, muscle twitching, or skin ulcers.

Please refer to the Optune Instructions for Use (IFU) for complete information regarding the device's indication, contraindications, warnings and precautions at Optune.com/Safety.

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www.curetoday.com

CURE™ magazine is the indispensable guide to every stage of the cancer experience. Along with CURE Media Group's many other unique and award-winning products, it has since 2002 provided information and inspiration to patients and families on the cancer journey. Continually expanding since its inception, *CURE* magazine now reflects the entire cancer continuum, including supportive care issues and long-term and late effects.

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Table of Contents

Information

- 3 About Glioblastoma Multiforme
- 6 Health, Diet, and Emotional Support

GBM Resources

- 7 American Brain Tumor Association
- 8 The Brain Tumor Foundation
- 9 The End Brain Cancer Initiative/Chris Elliott Fund
- 10 International Brain Tumour Alliance
- 11 Brain Tumor Alliance
- 12 National Brain Tumor Society
- 13 The Musella Foundation for Brain Tumor Research and Information
- 14 Tug McGraw Foundation
- 15 Voices Against Brain Cancer

General Resources

- 16 American Cancer Society
- 17 CancerCare
- 18 American Society of Clinical Oncology's Cancer.Net
- 19 Patient Advocate Foundation

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About Glioblastoma Multiforme

How Brain Tumors Develop

The central nervous system controls many functions of the human body and is composed of the brain and spinal cord.^{1,2}

The brain controls all our thoughts, emotions, and body movements. It is responsible for our memory, sight, and ability to hear, smell, and taste.^{2,3}

The brain is protected by the skull, 3 thin layers of tissue called meninges, and cerebrospinal fluid, which flows through spaces between the meninges and ventricles in the brain to act as a cushion.^{2,3}

Cranial nerves, special nerves inside the head, serve as inputs for our senses (sight, hearing, taste, balance), facial sensations, and expressions. Glial cells surround the nerve cells and support the brain's cells.^{2,3}

To understand how a brain tumor forms, it is important to understand the relationship between cell growth and cancer. Normally, cells grow and divide as needed by the body. In order for a cell to divide, all of its deoxyribonucleic acid (DNA) must first be copied. Once copied, DNA must be moved to the newly forming daughter cells (1 copy to each cell) in a highly orchestrated process (mitosis). DNA stores biological information as a code. This information is important, as the DNA's code determines the building process important to cell division.^{4,5}

Every time a cell divides, it must first replicate its DNA. If there is any damage to the DNA being replicated to form a new cell, genes responsible for the cell will try to control the division process and repair the damaged DNA. When the cell's DNA can't be repaired, old cells do not die when they normally should, and new cells grow abnormally and spread uncontrollably. These cells cluster together to form a mass of tissue known as a tumor.²

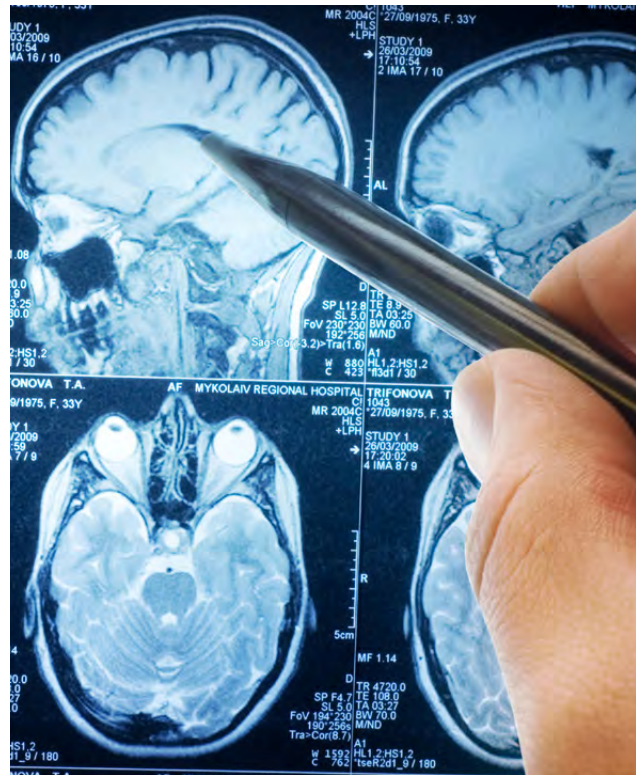
There are several types of brain tumors. They are classified according to the type of cells, or the part of the brain, in which they begin. The most common types of brain tumors, gliomas, form from the glial cells.^{2,3}

What Is Glioblastoma Multiforme (GBM)?

Glioblastoma multiforme (GBM), a type of glioma, is the most common type of malignant (cancerous) brain tumor in adults.²

GBM tumors are fast growing and very aggressive. They spread rapidly throughout the brain and mix with healthy brain tissue, making the complete removal of these types of tumors very difficult. However, GBMs rarely spread beyond the central nervous system.²

When a GBM tumor grows back after initial treatment, it is called recurrent GBM. It is common for GBM to recur. Unfortunately, this type of tumor is not usually curable.⁶



However, it is important for you to consult with your healthcare professional about your prognosis and understand the treatment options that are available to you.

GBM Risk Factors^{2,6}

The cause of a GBM tumor is unknown. There is no way to prevent a GBM from forming. However, it has been suggested that the following factors may increase a person's risk for developing a brain tumor:

- **Radiation exposure:** Exposure from past radiation therapy has been suggested as an environmental risk factor for brain tumors. Most radiation-induced brain tumors are caused by radiation exposure to the head when used to treat other types of cancer. Often, this risk factor is seen in scenarios where patients received radiation to the brain as a child for the treatment of leukemia. In this case, brain tumors usually develop 10 to 15 years after treatment.
- **Exposure to vinyl chloride:** In some studies, exposure to vinyl chloride, a chemical used to manufacture plastics, has also been suggested as an environmental risk factor for brain tumors.

- **Genetic syndromes:** Genetic syndromes including tuberous sclerosis, types 1 and 2 neurofibromatosis, von Hippel-Lindau disease, Li-Fraumeni syndrome, Gorlin syndrome, and Turcot syndrome have been linked to brain tumors.

It is important to understand that a risk factor does not guarantee that you will develop a brain tumor. Furthermore, radiation exposure is the only factor of those listed above proved to increase the risk for developing a brain tumor.

Symptoms of a GBM Tumor^{2,6}

A patient's symptoms will vary depending on the area of the brain affected and the size of the tumor. However, the most common symptoms of a GBM tumor include:

- Headaches
- Frequent nausea and vomiting
- Loss of appetite
- Loss of or blurred vision
- Hearing and speech problems
- Trouble with balance and walking
- Weakness
- Unusual drowsiness or change in activity level
- Changes in personality, mood, ability to focus, or behavior
- Seizures

These symptoms are caused by increased pressure of the tumor onto adjacent structures within the brain, and by direct invasion and damage to the structures. Headaches, especially those that occur frequently in the morning and go away after vomiting, are the most common symptom of a brain tumor. Increased intracranial pressure is the cause of headaches linked to brain tumors, however, not the cause of the other symptoms mentioned above.

How a GBM Tumor Is Diagnosed^{2,6}

A GBM tumor is often diagnosed after a patient begins experiencing symptoms of a brain tumor and visits their healthcare professional. Several testing procedures are available to help diagnose and monitor a GBM tumor. Some of these testing procedures may be used in combination with one another to help determine a patient's prognosis.

Physical exam

Your physician will review your medical history and discuss your current symptoms with you. During this exam, he or she will perform a series of tests to review

your reflexes, muscle strength, eye and mouth movement, coordination, alertness, and other functions. These tests help check for signs of a brain tumor. Your physician may also refer you to a neurologist, a healthcare professional who specializes in nervous system diseases. A neurologist can perform more specialized testing to help assess your medical condition.

Imaging tests

Your healthcare professional may suggest an imaging test such as a computed tomography (CT) scan, magnetic resonance imaging (MRI) scan, or a positron emission tomography (PET) scan to help detect a brain tumor.

- **CT scan:** A CT scan may also be helpful for determining a brain tumor. During this procedure, a machine attached to a computer takes a series of pictures from different angles. These images can be combined to create a detailed photo. In some instances, a contrast medium (dye) may be injected through a vein to make the pictures more vivid and easy to read. A CT scan is usually the first test performed. If results reveal anything suspicious, a MRI scan is often performed.
- **MRI scan:** MRI scans are considered very helpful when searching for brain tumors. During this procedure, strong magnets and radio waves are used to make a series of detailed pictures of the brain and spinal cord. These images show up on a monitor to be examined. A contrast material called gadolinium is injected into a vein before the procedure to help brighten the images and make them easier to read.
- **PET scan:** During a PET scan, a small amount of a non-chemically-reactive substance is injected into the body. The substance is absorbed by any organs or tissue that produce abnormal energy (a possible sign of cancer), and a scanner detects the substance and takes detailed pictures of the body.

Brain biopsy

A brain biopsy is commonly performed after a specialist has reviewed the results of a patient's imaging scan. During a biopsy, a sample of tissue is removed from the tumor and sent to a lab for examination. At the lab, a pathologist, a doctor who specializes in evaluating cells, tissues, and organs to help diagnose a disease, will examine the tissue under a microscope for abnormalities.



The 2 types of brain biopsy exams are:

- **Stereotactic biopsy:** Performed when an imaging test reveals that a tumor is located deep in the brain, in a spot that makes the tumor difficult to remove. During this procedure, a computer and a 3-dimensional scanning device are used to locate the tumor and guide the removal process of the tissue.
- **Open biopsy:** This type of biopsy is performed when an imaging test reveals that a tumor may be removed surgically. During an open biopsy, the part of the skull above the tumor is removed during an operation called a craniotomy.

Treating a GBM Tumor

Your prognosis, as determined by your healthcare professional, will help your healthcare professional determine how to treat your GBM tumor. As there are several treatment options available, and many may be used alone or in combination with one another, it is important to understand your treatment options and speak with your healthcare professional before beginning therapy.

Surgery^{2,6}

GBM tumors are fast growing and very aggressive. They spread rapidly throughout the brain and mix with healthy brain tissue. For this reason, complete removal of these types of tumors with surgery is very difficult.

Although surgery is not effective for curing a GBM tumor, it may be used to retrieve a biopsy sample, to remove as much of the tumor as possible, to help prevent or treat possible complications from the tumor, and to help relieve symptoms.

Chemotherapy^{2,6}

Chemotherapy uses drugs to destroy cancer cells. Chemotherapy drugs can be administered orally as a pill, capsule, or liquid, or intravenously by injection. To treat GBM tumors, a dissolvable wafer may be used to deliver a drug directly to the tumor site after the tumor has been removed by surgery.

Radiation therapy^{2,6}

Radiation therapy is commonly used together with chemotherapy as first-line treatment after surgical resection to help destroy any remaining tumor cells with high-energy beams. It may be suggested as your main treatment if surgery is not a good option or to help prevent or relieve symptoms.

Tumor Treating Fields therapy⁷⁻⁹

A portable device option for adult patients with recurrent GBM, recently approved by the US Food and Drug Administration, uses alternating electric fields to help slow down or stop the division of cancer cells. This treatment option is intended for adult patients with recurrent GBM after treatment with chemotherapy, radiation, and surgery.

Additional types of treatment

GBM tumors are very difficult to treat effectively for long periods of time. Although GBM tumors are currently difficult to cure, additional types of treatment options, including supportive care agents and options available through clinical trials, may be appropriate for you.²

Your healthcare professional may recommend that you take drugs to help control seizures, fluid buildup, or swelling of the brain. Although these drugs will not directly treat your GBM tumor, they may help reduce symptoms caused by the tumor or treatment, and may improve your quality of life.^{2,6}

Clinical trials are studies that test potential treatments on volunteers to help researchers determine if a treatment is beneficial in the management of a particular medical condition. Participation is commonly suggested as a possible option for cancer patients. If you are considering a clinical trial, it is important for you to understand and discuss your options with your healthcare professional. He or she can also advise you on how to search for local clinical studies, and how to select an appropriate study.^{2,6}

Health, Diet, and Emotional Support²

There are steps you can personally take to help manage your cancer diagnosis and cope with treatment side effects. Adjusting to a life with a GBM tumor may include making changes to your diet and lifestyle. The following information provides suggestions to help you stick to your treatment plan and manage the side effects associated with treatment; although it is important to consult your healthcare professional before beginning anything new.

Rest and Exercise

During treatment, fatigue is common. However, there is evidence that suggests that cancer patients who are physically active during and after cancer treatment consistently experience improved muscular strength, an increased amount of energy, an improved quality of life, and lower levels of depression.

If beginning or continuing an exercise program after a recent diagnosis with a GBM tumor, be sure to discuss your plans and the intensity of the intended workout with your healthcare professional. He or she can help you determine a safe and effective exercise program. You may also decide to find a workout buddy, someone who will exercise with you and support you when you need it.

When planning an exercise routine, start slowly. Any little activities will add up and can produce positive results on your health. Begin with short periods of exercise and create time for intermittent breaks. Increase the length and intensity of your workout as you feel more comfortable.

While it is important to incorporate exercise or physical activities into your daily living, it is also important to pay attention to your body and rest when you need to. Listen to your body and understand that it is okay to feel tired and decide to relax.

Diet

Along with your exercise regimen, you should be sure to eat nutritious foods while undergoing treatment. Maintaining a healthy weight and diet can be beneficial to your long-term health.

During treatment, you may experience side effects that make eating properly difficult. Your sense of taste may change, you may feel nauseated, or you may experience fatigue or a change in body weight.

To help you cope with any side effects from treatment, you should try to snack often. Consume small portions every 2 to 3 hours instead of 3 large meals per day. It is common for your body to rely on extra calories and proteins during treatment. If you feel challenged to practice healthy eating habits, you may want to consider speaking to a dietician or nutritionist. Remember that it is important to speak to a professional before planning any special diet.

Emotional Support

During and after treatment, you may experience many different emotions. It is important to understand that these feelings are normal, but it is also important to manage these emotions rather than dwell on them. Your attitude makes a difference when facing cancer.

To help you manage your emotions, you should discuss your diagnosis, thoughts, concerns, and emotions with friends, family, your caregiver, or a healthcare professional. In addition, you may want to consider seeking support from a local support group, spiritual group, or online support community.

In this guide we've included a number of website resources to help you find additional support. Starting on page 7, you will find information about advocacy groups for GBM tumors and brain cancer. The resources in this guide can help you learn more about GBM tumors and the treatment options and support available to you.

References

1. Dugdale DC. MedlinePlus® Medical Encyclopedia website. Central nervous system. <http://www.nlm.nih.gov/medlineplus/ency/article/002311.htm>. Updated April 18, 2013. Accessed March 27, 2015.
2. Brain and spinal cord tumors in adults. American Cancer Society website. <http://www.cancer.org/acs/groups/cid/documents/webcontent/003088-pdf.pdf>. Updated January 7, 2015. Accessed March 27, 2015.
3. What you need to know about brain tumors. National Cancer Institute website. <http://www.cancer.gov/publications/patient-education/brain.pdf>. Published May 2009. Accessed March 27, 2015.
4. What is DNA? Genetics Home Reference website. <http://ghr.nlm.nih.gov/handbook/basics/dna>. Accessed March 27, 2015.
5. Handbook: help me understand genetics: how genes work. Genetics Home Reference website. <http://ghr.nlm.nih.gov/handbook/howgeneswork.pdf>. Accessed March 27, 2015.
6. Adult brain tumors treatment (PDQ). National Cancer Institute website. <http://www.cancer.gov/cancertopics/pdq/treatment/adultbrain/Patient/page1/AllPages/Print>. Updated February 13, 2015. Accessed March 27, 2015.
7. Considering Optune: learn more about this treatment option. Novocure Ltd; 2014.
8. Medical devices: NovoTTF-100A System - P100034. US Food and Drug Administration website. <http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/DeviceApprovalsandClearances/Recently-ApprovedDevices/ucm254480.htm>. Updated September 6, 2013. Accessed April 2, 2015.
9. National Comprehensive Cancer Network. NCCN Clinical Guidelines in Oncology: central nervous system cancers. Version 2.2014. www.nccn.org. Accessed March 27, 2015.

American Brain Tumor Association

www.abta.org

The American Brain Tumor Association was the first and is now the only national organization committed to funding brain tumor research and providing support and education programs for all tumor types and all age groups.

ADDRESS:
 8550 West Bryn Mawr Avenue
 Suite 550
 Chicago, IL 60631

CONTACT INFO:
Phone: 800-886-2282
 773-577-8750
E-mail: info@abta.org

For more than 40 years, the American Brain Tumor Association (ABTA) has had the distinction of being the first (and now, only) organization dedicated to funding research and providing comprehensive resources for all tumor types and all age groups. The mission of the ABTA 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. Patients are the core of the ABTA's research program, which includes the funding of new drug development, personalized medicine, targeted therapies, vaccines, and immunotherapy, as well as improving survivorship.

Resource Checklist

- ✓ Downloadable resources
- ✓ "Listen to this page" features
- ✓ Adolescent and pediatric brain tumors information
- ✓ Information for caregivers
- ✓ Research funding programs
- ✓ Patient and caregiver conferences
- ✓ Monthly e-news
- ✓ ABTA CareLine

The Brain Tumor Foundation

www.braintumorfoundation.org

The screenshot shows the homepage of the Brain Tumor Foundation. At the top left is the logo, a colorful arc of lines. To its right are links for 'Select Language', 'Contact Us: (212) 265-2401', and a 'keyword search' box. Below the logo is the text 'BRAIN TUMOR FOUNDATION' and the tagline 'BRINGING TOMORROWS OF HOPE'. A navigation menu includes 'ABOUT US', 'EDUCATE YOURSELF', 'NEWS', 'EVENTS', 'RESOURCES', 'SUPPORT GROUPS', and 'DONATE'. The main content area is divided into three columns. The left column features a 'NEWSLETTER SIGNUP' form with fields for first name, last name, and e-mail address, and a 'SIGN UP!' button. The middle column has a heading 'NO ONE SHOULD FACE THIS BATTLE ALONE' and text describing the BTF as a non-profit organization that guides and supports patients, families, and caregivers. It also mentions the BTF's partnership with the TCS New York City Marathon. The right column is titled 'LATEST NEWS' and lists three recent news items: 'Team BTF Finished Strong In Their Fight Against Brain Tumors', 'Lazer, Aptheker, Rosella & Yedid Philanthropy Supports the Brain Tumor Foundation', and 'Chemotherapy After Radiation Improves Outcomes For Brain Cancer Patients'.

ADDRESS:

25 West 45th Street
Suite 1405
New York, NY 10036

CONTACT INFO:

Phone: 212-265-2401

The Brain Tumor Foundation (BTF) was founded in 1998 by Patrick J. Kelly, MD, FACS, a professor of neurosurgery at New York University School of Medicine, to tend to the financial, social, and emotional needs of patients with brain tumors. BTF offers support and guidance to patients through its many programs and services, which include support group programs, medical referrals, peer matching programs, and educational materials.

Resource Checklist

- ✓ Downloadable resources
- ✓ Insurance tips
- ✓ Resource directories
- ✓ Internet forum
- ✓ Survivor stories
- ✓ Advocacy events
- ✓ Newsletters

The End Brain Cancer Initiative/ Chris Elliott Fund

www.endbraincancer.org

The screenshot shows the homepage of the Chris Elliott Fund. At the top left, it says "CHRIS ELLIOTT FUND" with the tagline "Bringing HOPE to the lives of brain tumor patients & their families". Navigation links include HOME, ABOUT, GET INVOLVED, PATIENT SUPPORT, EVENTS, and BLOG. The main logo features a green sprout with three leaves above the text "Chris Elliott Fund Providing National Patient & Family Brain Tumor Support" and "endbraincancer®". Below the logo is a photo of two women, with a caption: "Gender can affect Cancer Prognosis and Outcomes. Dellann Elliott Mydland with Dr. Paula Johnson, renowned expert in women's health issues, at the 2014 Women's Health Summit in Boston MA." To the right of the photo is a search bar and a "Make Your Gift Today" button. Below that is a "CONTACT US" section with the phone number 1-800-574-5703, a note about a line update, and a "Sign-up for our E-mail Newsletter" button. At the bottom right, it says "THANK YOU TO OUR VERY SPECIAL 2015 CORPORATE SPONSORS" and features the "novocure" logo.

ADDRESS:

Brain Tumor Patient Support Services
and Call Center
14959 NE 95th Street
Redmond, WA 98052

CONTACT INFO:

Phone: 800-574-5703

E-mail: wecare@endbraincancer.org

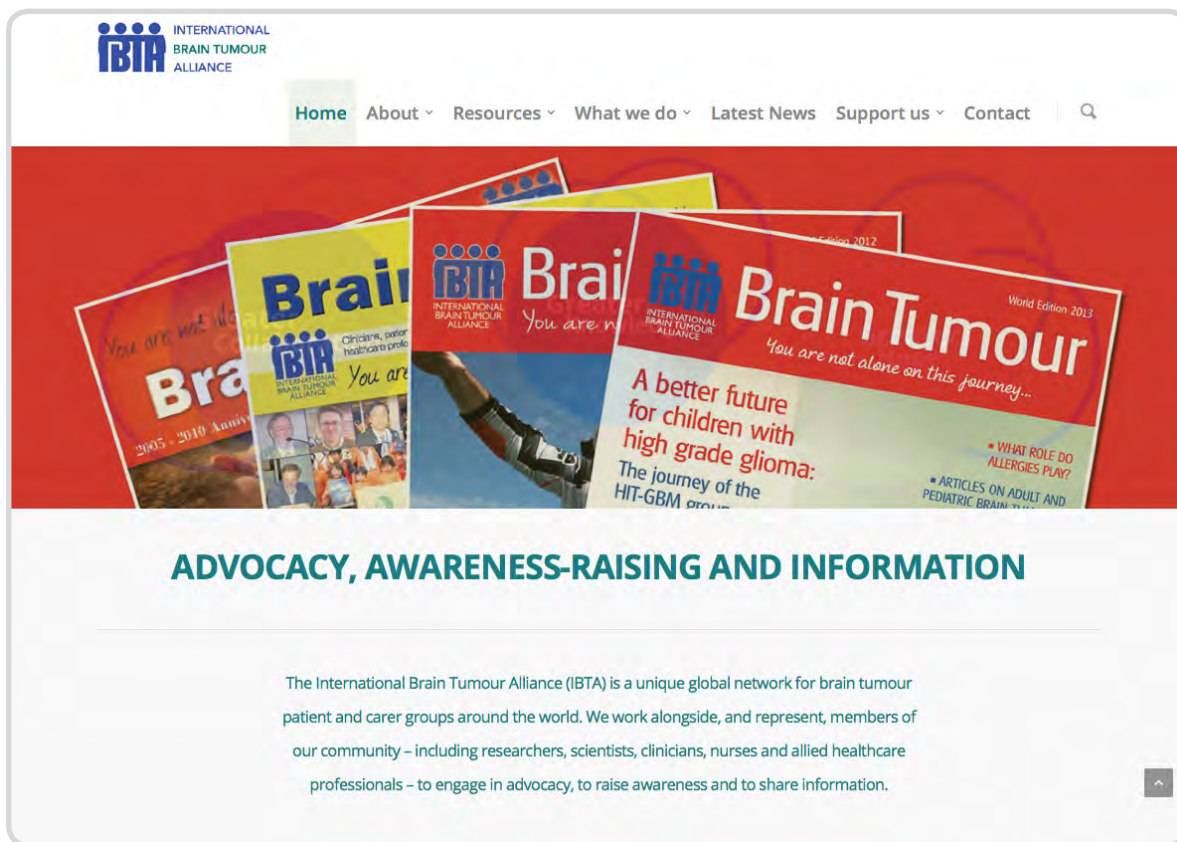
Enhancing lives and empowering patients by ***closing the existing gap*** from initial diagnosis to immediate and expanded access to advanced treatment, clinical trials, and critical care, the End Brain Cancer Initiative/Chris Elliott Fund is committed to curing brain cancer. To help reach this goal, the organization provides personalized support to patients with brain tumors and their family members. Specifically, the Chris Elliott Fund assists patients so that they can receive immediate access to advanced treatment options, healthcare specialists, and support programs. The organization also educates the general public about brain tumors and brain cancer and advocates issues of national public health policy that impact the lives and welfare of patients.

Resource Checklist

- ✓ Free Care Coordinators
- ✓ Direct connections/appointments to brain tumor specialists
- ✓ Downloadable resources and personalized patient information packets
- ✓ Patient stories
- ✓ Advocacy events
- ✓ Internet blog
- ✓ Newsletters

International Brain Tumour Alliance

www.theibta.org



ADDRESS:
PO Box 244
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KT20 5WQ
United Kingdom

CONTACT INFO:
E-mail: chair@theibta.org

The International Brain Tumour Alliance (IBTA) is an alliance of support, advocacy, and information groups for brain tumor patients and caregivers across the world. Additionally, the IBTA team includes researchers, scientists, clinicians, and healthcare professionals who specialize in brain tumors.


Resource Checklist

- ✓ Clinical trials information
- ✓ Resource directories
- ✓ Advocacy events
- ✓ *Brain Tumour* magazine
- ✓ E-Newsletters


Brain Tumor Alliance


www.braintumoralliance.org

Home About Get Involved Events Gallery Facts Contact Us f t DONATE NOW +

 brain tumor alliance

Through our work, we aim to raise awareness and funds for brain cancer research while helping those suffering with a brain tumor have a better quality of life.



 Upcoming Events

Every three minutes, someone is being diagnosed with a brain tumor. That is a staggering 200,000+ people a year. With so many people being affected by this disease, we need your help and support to raise awareness. To do so, we invite you to join us for one of our exciting events across the nation. You can register, donate, or volunteer at any cancer run or walk events in

January 25, 2015	Texas Hold'Em
February 21, 2015	Orlando, FL
March 21, 2015	Pasadena, CA
April 4, 2015	Denver, CO

ADDRESS:

2561 Nursery Road
Suite D
Clearwater, FL 33764

CONTACT INFO:

Phone: 727-781-4673
E-mail: info@braintumoralliance.org

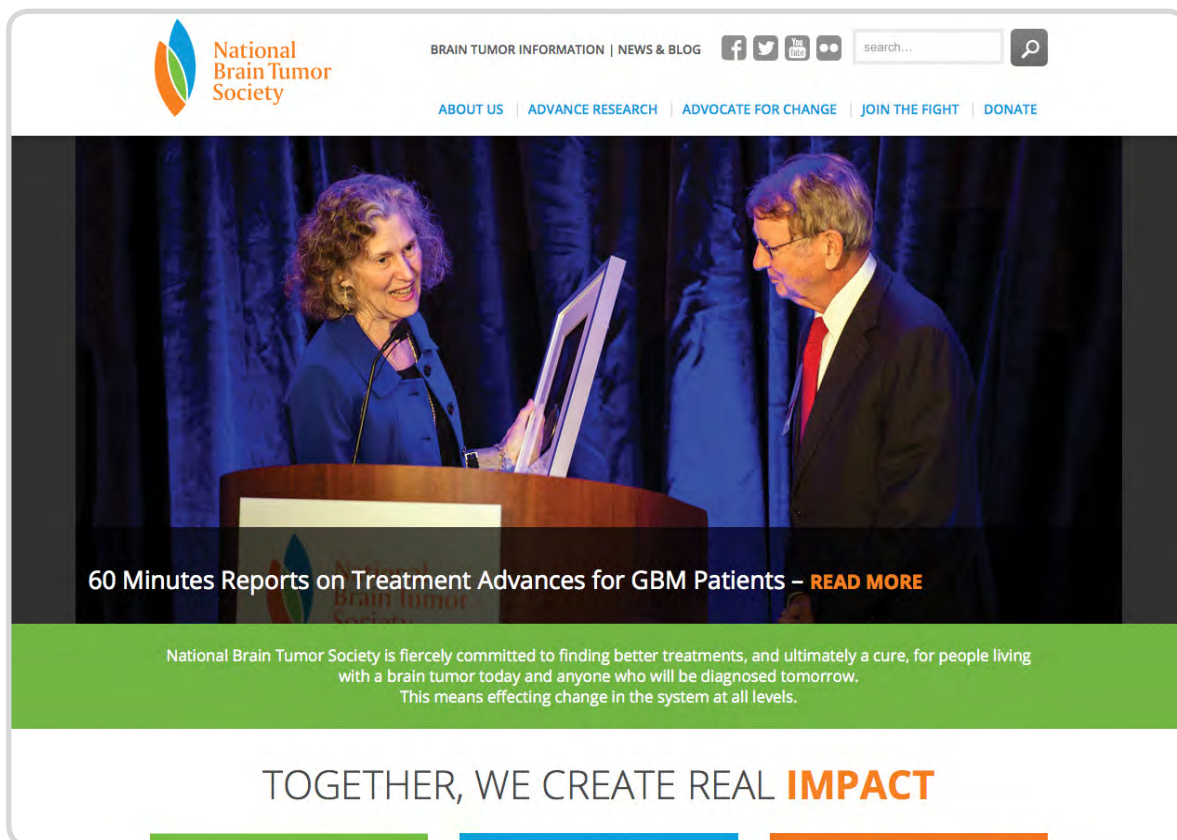
The Brain Tumor Alliance is a foundation that shares a mission to raise awareness and help provide funding for tumor research and clinical trial programs. In addition to its advocacy efforts aimed to improve cancer treatment and patients' quality of life, the group provides travel assistance to qualified patients.

Resource Checklist

- ✓ Travel assistance for patients
- ✓ Brain tumor information
- ✓ Clinical trials information
- ✓ Advocacy events
- ✓ Internet news room

National Brain Tumor Society

www.brainumor.org



The screenshot shows the top navigation bar of the National Brain Tumor Society website. On the left is the logo, which consists of a stylized brain icon in blue and orange, followed by the text "National Brain Tumor Society". To the right of the logo is the text "BRAIN TUMOR INFORMATION | NEWS & BLOG" and a row of social media icons for Facebook, Twitter, YouTube, and LinkedIn. Further right is a search bar with the placeholder text "search...". Below the navigation bar is a main content area featuring a photograph of a woman in a blue jacket speaking at a podium, with a man in a suit standing next to her. Below the photo is a green banner with the text "60 Minutes Reports on Treatment Advances for GBM Patients – READ MORE". Below the banner is a white box with a green border containing the text: "National Brain Tumor Society is fiercely committed to finding better treatments, and ultimately a cure, for people living with a brain tumor today and anyone who will be diagnosed tomorrow. This means effecting change in the system at all levels." At the bottom of the white box is the slogan "TOGETHER, WE CREATE REAL **IMPACT**".

ADDRESS:

55 Chapel Street
Suite 200
Newton, MA 02458

CONTACT INFO:

Phone: 617-924-9997

The National Brain Tumor Society describes itself as “The largest nonprofit dedicated to the brain tumor community in the United States” and shares a mission to help patients find better treatment options and work toward a future cure for brain tumors. To help achieve this goal, the organization fosters nationwide collaboration with private-sector, government, and academic programs that share involvement in cancer research efforts.

Resource Checklist

- ✓ Brain tumor information
- ✓ Resource directories
- ✓ Information for caregivers
- ✓ Clinical trials information
- ✓ Treatment center directory
- ✓ Tools and training for advocates
- ✓ Internet blog
- ✓ Downloadable resources

The Musella Foundation for Brain Tumor Research and Information

www.virtualtrials.com

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

Clinical Trials and Noteworthy Treatments for Brain Tumors

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

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The Brain Tumor Center At Duke
- Roberta Hayes, Ph.D.
New York, NY
- Gil Lederman, MD
Radiosurgery New York
- Mark Levin, MD

Please Sign the Petition!
Help us convince Medicare to pay for the Optune™ (Novocure) System!

Sponsored By

Today, doctors have **NEW TOOLS** for dealing with abnormal growths in the brain and that means **MORE CHOICES** for people like you.
Visit MyBrainTumorOptions.com to learn more.

Please Click On The Above Banner For More Details

Introduction

- The Musella Foundation For Brain Tumor Research & Information, Inc is a 501(C)3 nonprofit public charity dedicated to helping brain tumor patients through emotional and financial support, education, advocacy and raising money for brain tumor research.
- This site was last updated on: 04/03/2015 3:52 PM . Click [HERE](#) to see what was added!

Newly Diagnosed Brain Tumor (Brain Cancer) Patients

- Checklist for Newly Diagnosed Brain Tumor Patients. START HERE!**

Search: Search

ADDRESS:
1100 Peninsula Boulevard
Hewlett, NY 11557

CONTACT INFO:
Phone: 888-295-4740

The Musella Foundation for Brain Tumor Research and Information was founded in 1998 by Al Musella, DPM. Following his sister-in-law's brain tumor diagnosis, Musella established a forum for brain cancer on CompuServe, a network for professionals in education. At the forum, he presented a list of every type of brain cancer treatment offered at major hospitals in the United States, including trial drugs. This list later became an inspiration for ClinicalTrials.gov, an online database of clinical trials. Today, the foundation is dedicated to helping brain tumor patients by providing support, education, and advocacy initiatives. Additionally, the foundation raises money to help advance brain tumor research.

Resource Checklist

- ✓ Brain tumor information
- ✓ Copay assistance program
- ✓ Clinical trials information
- ✓ Resource directories
- ✓ Survivor stories
- ✓ Video library
- ✓ Newsletters

Tug McGraw Foundation

www.tugmcgraw.org

NEWS & EVENTS | RECEIVE OUR NEWSLETTER | SEARCH | LOGIN / SIGN UP

TUG MCGRAW
FOUNDATION

Working together to enhance quality of life for those affected by brain-related trauma and tumors. "Ya Gotta Believe"

DONATE SHOP TMF

About Us | Our Projects | Brain Tumors | PTSD | TBI | Support TMF

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"Ya Gotta Believe"

Making "Believe" Real
SUPPORT THE FOUNDATION >>

1 2 3 4 5 6

LATEST AND GREATEST

What is RSS? RSS

60 Minutes Follows Brain Cancer Patients at Duke University

March 29th, 2015

Tug McGraw was treated at Duke by this incredible team. We are proud to share this very special 60 Minute Story on Duke's efforts in battling one of the deadliest forms of cancers. Glioblastoma-the brain cancer that took Tug's life.

Songwriters Round
FRANKLIN THEATRE
PURCHASE TICKETS

MARINE CORP 10K
Registration

Register for

ADDRESS:
PO Box 45
Yountville, CA 94599

CONTACT INFO:
Phone: 707-947-7124
E-mail: info@tugmcgraw.org

The Tug McGraw Foundation was founded in 2003 by professional baseball player Tug McGraw after his diagnosis of brain cancer. Realizing that many face this disease without access to the medical care that he was fortunate enough to receive, McGraw established the foundation to help provide resources and support, foster understanding and awareness, and stimulate research collaboration to improve the quality of life for patients with brain-related trauma and tumors.

Resource Checklist

- ✓ Extensive information about the brain
- ✓ Information for caregivers
- ✓ Resource directories
- ✓ Advocacy events
- ✓ Internet forum
- ✓ Newsletters
- ✓ Downloadable resources

Voices Against Brain Cancer

www.voicesagainstbraincancer.org

Monday April 06, 2015

Our mission is to find a cure for brain cancer by advancing scientific research, increasing awareness within the medical community and supporting patients, their families and caregivers afflicted with this devastating disease.

Donate Now

Home About Us Board Programs Granting Events Volunteers In Memory Sponsors Contact Us Donate

Thank you to everyone who came out to the Inaugural Join The Voices! Miami Run/Walk on March 8th.

Become a Volunteer

Support Groups

Brain Tumor Facts

Find us on Facebook

Voices Against Brain Cancer

44,035 people like Voices Against Brain Cancer.

Recent Updates

The Inaugural Join The Voices! Miami Run/Walk on March 8th was an incredible day and raised close to \$100,000! Thank you to the 700+ people who came out to support VABC.

Interested in joining VABC's 2015 TCS New York City Marathon Team? Please click here to fill out a survey and we will contact you regarding our available spots.

ADDRESS:
1375 Broadway
3rd Floor
New York, NY 10018

CONTACT INFO:
Phone: 212-340-1340
E-mail: info@voicesagainstbraincancer.org

The Voices Against Brain Cancer (VABC) Foundation is committed to finding a cure for brain cancer. The foundation works to reach this goal by contributing to scientific research, increasing awareness within the medical community, and by supporting patients, their families, and caregivers. The growing VABC medical advisory board includes doctors and researchers from across the United States who review grant requests submitted to the VABC and recommend those that are most likely to provide results and help cure brain cancer.

Resource Checklist

- ✓ Brain tumor information
- ✓ Resource directories
- ✓ *Raise Your Voice* comprehensive guide
- ✓ Advocacy events
- ✓ Newsletters

American Cancer Society

www.cancer.org

Sign In Register Sign Up for Email Español Asian & Pacific Languages f + Twitter YouTube

American Cancer Society THE OFFICIAL SPONSOR OF BIRTHDAYS® JOIN THE FIGHT AGAINST CANCER DONATE

there is so much to live for.

How can we help you? search cancer.org SEARCH Live Chat 800-227-2345

Home Learn About Cancer Stay Healthy Find Support & Treatment Explore Research Get Involved Find Local ACS

What Personalized Medicine Means for Cancer
More so now than ever, when doctors decide how to attack a cancer, they are arming themselves with a wealth of knowledge about the molecular and genetic makeup of their patient's tumor.

Minority Cancer Awareness
Every April the American Cancer Society works with other organizations to raise awareness about cancer among minorities in honor of National Minority Health Month and National Minority Cancer Awareness Week, celebrated this year April 5-11.

Donate Now to Save Lives
There's still so much to live for. Donate to Relay For Life to help the American Cancer Society finish the fight against this disease.

ADDRESS:
250 Williams Street NW
Atlanta, GA 30303

CONTACT INFO:
Phone: 800-227-2345

The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem. The society's international mission is concentrated on capacity-building in developing cancer societies and on collaborating with other cancer-related organizations throughout the world in carrying out shared strategic directions.

Resource Checklist

- ✓ Brain tumor information
- ✓ Clinical trials information
- ✓ Tips for coping
- ✓ Information for caregivers
- ✓ Stories of hope
- ✓ Recent news

CancerCare

www.cancercare.org

JOIN A SUPPORT GROUP
and find strength and support online,
on the phone or face-to-face

Calendar at a Glance

APR 13	Connect Education Workshop Healthy Eating and Managing Weight Changes During Cancer Treatment
APR 15	Connect Education Workshop Emerging Therapies in Hodgkin and T-Cell Lymphomas
APR 21	Connect Education Workshop Precision Medicine: Implications for the Treatment of Prostate Cancer
APR 22	Fundraising Event 2015 CancerCare Gala New York, NY
APR 28	Connect Education Workshop Medical Update on Ovarian Cancer

[View Calendar of Workshops & Events »](#)

Welcome

A cancer diagnosis turns a person's world upside down—emotionally, physically and financially. CancerCare® can help.

We provide telephone, online and face-to-face counseling, support groups, education, publications and financial and co-payment assistance. Professional oncology social workers offer personalized care, and all of our services are free of charge.

Explore our website to learn more, and call us at 800-813-HOPE (4673).

Featured Program

HELP FAMILIES TALK ABOUT CANCER

pillowtalk
CONVERSATIONS ABOUT CANCER

The Comfort Pillow Activity can help you better communicate with your loved ones about cancer. [Order your free Pillow Talk Care Package today!](#)

Quick Links

From Our Blog

ADDRESS:

275 Seventh Avenue
22nd Floor
New York, NY 10001

CONTACT INFO:

Phone: 800-813-4673
E-mail: info@cancercare.org

CancerCare provides free professional support services to anyone affected by cancer, including patients, caregivers, children, loved ones, and the bereaved. The organization helps more than 100,000 people annually face the crisis of cancer, and the website has become a leading online resource for cancer information, with more than 1 million unique visitors last year.

Resource Checklist

- ✓ Free counseling
- ✓ Limited financial assistance
- ✓ Free community programs
- ✓ Patient stories
- ✓ Podcasts
- ✓ Free publications
- ✓ Connect Education Workshops

American Society of Clinical Oncology's Cancer.Net

www.cancer.net

ASCO and Cancer.net are trademarks of the American Society of Clinical Oncology.

The American Society of Clinical Oncology (ASCO) patient information website, Cancer.Net, provides the expertise and resources of ASCO, a leading voice of the world's cancer physicians, to cancer patients and those who care for and about them. Cancer.Net believes that well-informed patients are their own best advocates and are invaluable partners for physicians. For this reason, Cancer.Net provides timely, comprehensive information to help patients and family members make informed healthcare decisions.

Resource Checklist

- ✓ Brain tumor information
- ✓ Tips for coping
- ✓ Information for caregivers
- ✓ Resource directories
- ✓ Financial information
- ✓ "Find an Oncologist" database
- ✓ Internet blog

ADDRESS:
2318 Mill Road
Suite 800
Alexandria, VA 22314

CONTACT INFO:
Phone: 888-651-3038
571-483-1780
E-mail: contactus@cancer.net

Patient Advocate Foundation

www.patientadvocate.org/gethelp

The screenshot shows the Patient Advocate Foundation website. At the top, the logo features the letters 'PAF' in a stylized font with a lighthouse icon, followed by 'Patient Advocate Foundation' in orange and blue text. Below the logo is the tagline 'Solving Insurance and Healthcare Access Problems | since 1996'. A navigation bar includes links for 'DONATE', 'Get Help', 'Healthcare Reform', 'Resources', 'Events', 'Meet PAF', 'En Espanol', and a search box with a 'GO' button. The main content area features a large image of a woman with a thoughtful expression. To the left of the image are vertical banners: 'Participate in our Legacy Campaign', 'We are here for you', and 'Helping educate you about your insurance options'. To the right is a quote from Ruth, Missouri: 'I was so anxious over losing my insurance and my case manager stayed with me through the ups and downs and made sure I was settled with solutions and a good plan. I don't know what I would have done without her.' Below the image are four vertical banners: 'Taking the confusion out of complex enrollment forms', 'Finding financial help for medication co-pays', 'Taking the questions out of the disability process', and 'Identifying care options for the uninsured'. Below the main image are four sections: 'Patient Services' (describing arbitration and mediation services), 'Educate' (offering direct access to resources), 'News' (listing recent posts like 'PAF Launches New Co-Pay Assistance for Hepatitis B Patients'), and 'Facebook'. Each section has a dropdown menu for further filtering.

ADDRESS:

Headquarters
421 Butler Farm Road
Hampton, VA 23666

CONTACT INFO:

Phone: 800-532-5274

Patient Advocate Foundation (PAF) offers assistance to patients who receive a diagnosis of a life-threatening or debilitating disease and are in active treatment. PAF case managers assist patients with issues specific to insurance, job retention, access to care, and debt crisis matters.

Resource Checklist

- ✓ Downloadable resources
- ✓ Resource directories
- ✓ Clinical trials information
- ✓ Information for uninsured patients
- ✓ Copay assistance
- ✓ Toll-free helpline

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(NovoTTF™-100A System)

www.Optune.com

Treatment for Recurrent Glioblastoma

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City

State Zip Code

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SUBMIT

Cancer Therapy, Meet My Life™

See what Optune can mean for you

Discover Optune
Take a closer look at the system components.

Patient Videos
See real users share their experiences.

Optune
Discover the science behind Tumor Treating Fields

Treatment for Recurrent Glioblastoma

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Explore the System

Optune Components

The complete system includes a portable electric field generator, transducer array, rechargeable battery and dock.

Living with Optune

Find out what to expect from this novel therapy.

Learn More

Explore the System

Visit the interactive video gallery in this section to explore the features and components of Optune.

Treatment for Recurrent Glioblastoma

Intended for US audiences only.

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Patient Journey Videos

See the science

Understand how the therapy destroys cancer cells.

Watch video

Patient Journey Videos

Hear the experiences of Optune patients by selecting to watch their patient journey videos highlighted in this section.

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OncLive.com

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Introducing Cancer Therapy, Meet My Life™

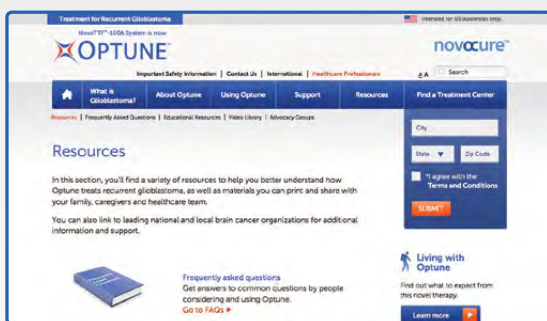
See what Optune can mean for you

novocure™



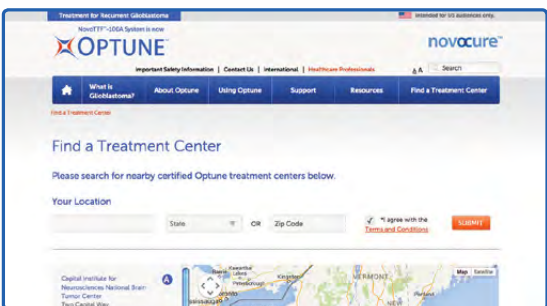
Support

Connect to a team of professionals who can answer technical questions about Optune. The experienced customer care team also assists and supports patients with information regarding financial assistance and insurance coverage for Optune.



Resources

Access a library of videos and downloadable resources to help you better understand how Optune treats recurrent glioblastoma, and connect with leading national and local brain cancer organizations for additional information and support.



Find a Treatment Center

Use this tool to search for nearby certified Optune treatment centers.

Indications For Use

Optune™ is intended as a treatment for adult patients (22 years of age or older) with histologically confirmed glioblastoma multiforme (GBM), following histologically- or radiologically-confirmed recurrence in the supra-tentorial region of the brain after receiving chemotherapy. The device is intended to be used as a monotherapy, and is intended as an alternative to standard medical therapy for GBM after surgical and radiation options have been exhausted.

Summary of Important Safety Information

Contraindications

Do not use Optune if you have an active implanted medical device, a skull defect (such as, missing bone with no replacement), a shunt, or bullet fragments. Examples of active electronic devices include deep brain stimulators, spinal cord stimulators, vagus nerve stimulators, pacemakers, defibrillators, and programmable shunts. Use of Optune together with implanted electronic devices has not been tested and may theoretically lead to malfunctioning of the implanted device. Use of Optune together with skull defects, shunts, or bullet fragments has not been tested and may possibly lead to tissue damage or render Optune ineffective.

Do not use Optune if you are known to be sensitive to conductive hydrogels like the gel used on electrocardiogram (ECG) stickers or transcutaneous electrical nerve stimulation (TENS) electrodes. In this case, skin contact with the gel used with Optune may commonly cause increased redness and itching, and rarely may even lead to severe allergic reactions such as shock and respiratory failure.

Warnings and Precautions

Use Optune only after receiving training from qualified personnel, such as your doctor, a nurse, or other medical personnel who have completed a training course given by the device manufacturer (Novocure).

All servicing procedures must be performed by qualified and trained personnel.

Do not wet the device or transducer arrays.

Do not use any parts that do not come with the Optune Treatment Kit, or that were not sent to you by the device manufacturer or given to you by your doctor.

Optune commonly causes skin irritation beneath the transducer arrays and in rare cases can lead to headaches, falls, fatigue, muscle twitching or skin ulcers.

Please see the Optune Instructions for Use (IFU) for complete information regarding the device's indications, contraindications, warnings and precautions at Optune.com/Safety.

