A guide to organizations that provide information and support for patients with glioblastoma and the oncology professionals who treat them.
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Do not wet the device or transducer arrays.

If you have an underlying serious skin condition on the scalp, discuss with your doctor whether this may prevent or temporarily interfere with Optune treatment.

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How Brain Tumors Develop

The central nervous system controls many functions of the human body and is composed of the brain and spinal cord.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{5}

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\textsuperscript{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.
Recognizing the power of information and community support

To help ensure that patients and their loved ones understand a diagnosis of glioblastoma, and have the tools necessary to move forward with their cancer journey more proactively, video resources featuring the insight of medical experts, brain cancer advocates, real patients, and caregivers are available!

www.curetoday.com/cure-connections/brain-cancer

All About Glioblastoma: An Expert Perspective

Learn about glioblastoma and the treatment options available from Dr Joon Uhm, an associate professor of neurology and director of neuro-oncology, at the Mayo Clinic.

The Brains Behind Conquering Glioblastoma

Watch a series of videos that focus on top considerations following a diagnosis of brain cancer and hear from a patient with brain cancer.

“...It is vital to the patient, and to their treatment plan, that they have their tumor tissue saved.”

— DELLANN ELLIOTT MYDLAND
Founder and president, EndBrainCancer.org
• **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**

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**

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**

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**

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**

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 therapy**

A portable device option for adult patients (22 years or older) with GBM, 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 is intended for adult patients with newly diagnosed GBM who are also on chemotherapy after having surgery and radiation with previous chemotherapy; or as monotherapy 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.

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.

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.
Health, Diet, and Emotional Support

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 dietitian 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
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 (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
- Survivor stories
- Webcasts
- Newsletters
The International Brain Tumour Alliance (IBTA) brings together experience and expertise from all over the world with the aim of enhancing the well-being and quality of life of brain tumor patients and their families. By working together, the IBTA identifies collaborative actions across the international community and works toward its vision of a world free from the fear of brain tumors.

**Resource Checklist**

- Clinical trials information
- Resource directories
- Advocacy events
- *Brain Tumour* magazine
- E-Newsletters
The EndBrainCancer Initiative | Chris Elliott Fund
www.endbraincancer.org

The EndBrainCancer Initiative | Chris Elliott Fund is dedicated to closing the existing GAP to advanced treatments and clinical trial participation, and to providing HOPE to brain tumor patients and their families, nationally. Its goal is to extend lives, increase survivorship, and improve quality of life for patients nationally through quickly connecting patients with its network of regional experts in brain tumor treatment and research across the US, and to the best and most advanced treatment options available. The Foundation believes that IMMEDIATE ACCESS for patients with brain and other cancers where there is no effective standard treatment protocol leading to a cure, clinical trials, studies, and advanced treatments, offer the best HOPE for survival while fueling research. All services are provided free of charge to patients and their families.

Resource Checklist

- Personalized one-on-one intake process
- Direct connections/appointments to US brain tumor specialists and clinical trials
- Downloadable resources and personalized patient information packets
- Patient stories
- Disease education and awareness campaigns
- Education and outreach events
- Public health policy advocacy on behalf of brain tumor patients for new treatments/clinical trials and appropriate classification/medical reimbursement
- Social media education and outreach engagements on social media and online forums

ADDRESS:
“Direct Connect” Patient Support Services and Call Center
14959 NE 95th Street
Redmond, WA 98052

CONTACT INFO:
Phone: 800-574-5703
425-444-2215
E-mail: wecare@endbraincancer.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

**ADDRESS:**
PO Box 7607
St. Petersburg, FL 33704

**CONTACT INFO:**
Phone: 727-781-4673
E-mail: info@braintumoralliance.org
The National Brain Tumor Society is committed to improving the lives of all those affected by brain tumors, 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
- Information regarding financial support
- Tools and training for advocates
- Internet blog
- Downloadable resources
The Musella Foundation for Brain Tumor Research and Information

www.virtualtrials.com

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
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
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
- Brain Cancer Coach service
- Advocacy events
- Newsletters
American Cancer Society

www.cancer.org

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 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

**ADDRESS:**
275 Seventh Avenue
22nd Floor
New York, NY 10001

**CONTACT INFO:**
Phone: 800-813-4673
E-mail: info@cancercare.org
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
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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Do not wet the device or transducer arrays.

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nCompass™ Support

Connect to an experienced team who can answer technical questions about Optune. nCompass Support 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 glioblastoma. There is also contact information for 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.

Explore the System

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

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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