

Brain Tumors: **Unlocking A Mystery,** **Increasing Survival and Hope**



Submitted by [UnlockingBrain Tumors.org](http://UnlockingBrainTumors.org)

Brain Tumors:

Unlocking A Mystery, Increasing Survival and Hope

Mission

UnlockingBrainTumors.org is a registered 501(c)3 public charity dedicated to raising awareness about brain tumors, and raising funds to efficiently channel to research.

Vision

UnlockingBrainTumors.org will work to maximize its effectiveness and impact by keeping its operating costs very low, operating primarily through the efforts of volunteers, and aiming to send 95% of every donated dollar directly to research funding.

Our Board

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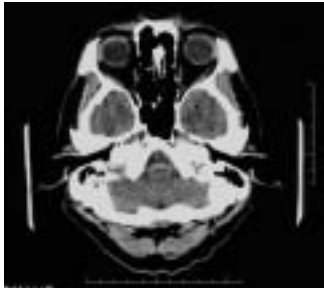
Volunteers will play a critical role for our organization. Whether you have a particular skill or specific way you'd like to help us, or simply want to learn more about ways to get involved in this very important cause, please call, write or visit us. You'll find that it's easy to help, and that your help will quickly be operationalized. Whether you have a preferred beneficiary, level of involvement, or simply want to help our team in whatever area possible, we'll make it easy for you to do just that.

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INTRODUCTION

Brain Tumors Overview



Every day, talented researchers, physicians and experts are working to unlock the mystery behind brain tumors. Brain tumors are one of the most feared but also one of a few cancers that does not resonate to the masses like breast or lung cancer. The result is a

lack of awareness for these tumors and a lack of funding initiatives to help find cures for the many different types of brain tumors, most of which are fatal. While great advancements in treatment have given so many cancer victims many extra years or even decades of living and return to well being, brain tumors remain one of the most costly and debilitating forms of cancer. Because of its location, the brain tumor can have serious impact on an individual's personality, memories and basic motor skills, robbing the patient of their very being; in this way, the impact on family and friends is also felt, as the brain tumor patient may be "lost" to them even earlier than feared.

Survival rates vary by the type of tumor. The most common adult primary brain tumor, Glioblastoma multiforme (or GBM) is the most serious type, the chances of living 5 years is less than 3%, with most patients living about a year. Often the remaining months or years may be characterized primarily by patient discomfort and palliative efforts at stabilization. The financial impact of a brain tumor on patient and family is staggering. A May 2007 report by the National Brain Tumor Foundation concluded that the financial impact for a brain tumor patient could be ruinous; the high cost of drugs, diagnostics and other treatment, coupled with greater difficulty in obtaining healthcare coverage and an inability to work and earn income present unique challenges to these patients and their families.¹

The devastating brain tumor picture is especially in need of support. Research funding, which has historically already less adequate than necessary, has been further curtailed, and the National Cancer Institute reports decreased research funding for the most common forms of cancer in the United States.² A slowing of research has impacted the ability to focus on long term results, and coupled with shrinking research budgets and rising operational costs, critical research advancements are under funded. And while many organizations and individuals are expending great energy

and dedication in these efforts, there is too often difficulty in getting existing dollars directly into the hands of researchers. The advancements we need - possibly just 4-6 years right away if the right research get fully funded, are simply out of reach right now due to research budget deficits. Few maladies manage to both simultaneously confound researchers in their mystery, yet hold such promise for the cure and management as prominently as brain tumors. While substantial progress is being made toward unlocking the mystery of brain tumors, advancements in isolating causes, and improved treatments, are desperately needed as survival outcomes have marginally changed in the last 40-50 years.

Pediatric Brain Tumors

The Pediatric Brain Tumor Association shares sobering information on the youngest sufferers. Among the more than 359,000 people in the U.S. living with a diagnosis of a primary brain and central nervous system tumor in the year 2000, more than 26,000 children in the U.S. were living with the diagnosis of a primary central nervous system tumor. Each year 3,200 new cases are diagnosed.³ Brain tumors are the leading cause of cancer death from childhood cancer, accounting for 24 percent of cancer-related deaths in 1997 among persons up to 19.⁴ Seventy-six percent of children diagnosed with a brain tumor are younger than 15. Brain tumors are also the second most common cancer in children.

There are more than 120 different types of brain tumors, making effective treatment very complicated. Pediatric brain tumors are different from those in adults and are often treated differently. The combined five-year survival rates for childhood brain tumors have increased slowly, from 54 percent to approximately 60 percent.⁵ However, for some pediatric brain tumors (e.g., brain stem gliomas, atypical teritoid/rhabdoid and glioblastoma multifome), long-term survival rates remain below 20 percent with most patients dying within 2 years of diagnosis. Because brain tumors are located at the control center for thought, emotion and movement, their effects on a child's physical and cognitive abilities can be devastating. Quality of life for survivors of pediatric brain tumors is influenced by the long-term side effects of treatments such as chemotherapy and radiation. Some brain tumor survivors require physical, cognitive and rehabilitation services to allow them to return to tasks of everyday life, an even then many are afflicted with either deficits from their tumor or from treatment.

Improving the outlook for children with brain tumors requires research into the causes of and better treatments for brain tumors.



Steve Coffman – Project Sponsor

Steve Coffman is the executive sponsor and director of the project. He resides in Holland, Michigan. Steve is in a unique position to launch and support this effort, for many reasons. He was diagnosed with a head and neck cancer in 2003 which caused him to leave a 25 year career in the Human Resource Services arena, first as president of Reid Psychological Systems and later as General Manager of Pearson Reid London house which was formed by joining two industry competitors. During a routine follow up CT scan in 2005, a tumor in the brain was noted. Steve was diagnosed with a GBM brain tumor after surgery, and then treated with radiation and chemotherapy. Now two years and three craniotomies into the journey, Steve would like to share how he has used the Internet as well as other available data sources as a means to build confidence about his diagnosis and on how to be a

good consumer of medical information while not becoming overwhelmed by the sheer volume of information that is available. Steve's only goal here is to help those also diagnosed with a brain tumor and to speed up the timeline for finding a Cure, to help identify improved treatment methods and improve quality of life for individuals living with brain tumors.

During Steve's career he also participated in a number of service and business organizations in Chicago including the Worksite Wellness Council of Illinois as a board member, an active member of the Rotary Club of Chicago chairing various committee's including *The Gift of Life* program, Youth Services and the International Services Committee and was a founding member and past board chair of the Association of Test Publishers and industry trade association.

1. BRAIN TUMORS – THE FACTS AND THEORIES ABOUT CAUSES

Some of the challenge for researchers lies in the diversity of tumors and their pathogenic origins or movement.

Primary Brain Tumors

Tumors that begin in brain tissue are known as *primary tumors* of the brain. Primary brain tumors are named according to the type of cells or the part of the brain in which they begin. The most common primary brain tumors are gliomas and originate from glial cells. There are many types of gliomas⁶:

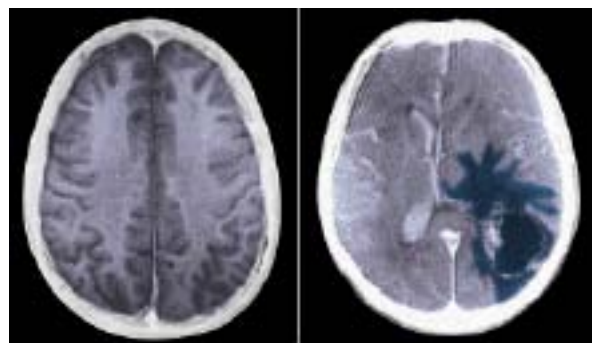
- **Astrocytoma**— The tumor arises from star-shaped glial cells called astrocytes. In adults, astrocytomas most often arise in the cerebrum. In children, they occur in the brain stem, the cerebrum, and the cerebellum. A grade III astrocytoma is also called an anaplastic astrocytoma. A grade IV astrocytoma is called a glioblastoma multiforme.
- **Brain stem glioma**— The tumor occurs in the lowest part of the brain. Brain stem gliomas most often are diagnosed in young children and middle-aged adults.
- **Ependymoma**—The tumor arises from cells that line the ventricles or the central canal of the spinal cord. They are most commonly found in children and young adults.
- **Oligodendroglioma**—This rare tumor arises from cells that make the fatty substance that covers and protects nerves. These tumors usually occur in the cerebrum. They are most common in middle-aged adults.

Some types of brain tumors do not begin in glial cells. The most common of these are:

- **Medulloblastoma**—This tumor usually arises in the cerebellum. It is the most common brain tumor in children. It is sometimes called a primitive neuroectodermal tumor.
- **Meningioma**—This tumor arises in the meninges. It usually grows slowly and is almost always a tumor of adults.
- **Schwannoma**—A tumor that arises from a Schwann cell. These cells line the nerve that controls balance and hearing. This nerve is in the inner ear. The tumor is also called an acoustic neuroma. It occurs most often in adults.

- **Craniopharyngioma**—The tumor grows at the base of the brain, near the pituitary gland. This type of tumor most often occurs in children.
- **Germ cell tumor of the brain**—The tumor arises from a germ cell. Most germ cell tumors that arise in the brain occur in people younger than 30. The most common type of germ cell tumor of the brain is a germinoma.
- **Pineal region tumor**—This rare brain tumor arises in or near the pineal gland. The pineal gland is located between the cerebrum and the cerebellum.⁷
- **Primary Central Nervous System Lymphoma**— A type of lymphoma restricted to the nervous system seen in adults > 50 in most cases.

Healthy brain (left) compared to brain tumor (*shown in blue, right*). Photo from www.healthinplainenglish.com



According to the **American Brain Tumor Association's** book, *A Primer of Brain Tumors*, no risk factor accounting for the majority of brain tumors has been identified, even though many environmental genetic factors have been, and are, being studied. Brain tumor epidemiologists look for causes and risk factors that would explain why people develop brain tumors. Causes and risk factors can be environmental, such as being exposed to poisonous substances in the home or at work, eating or not eating certain foods, or whether we exercise/smoke cigarettes/drink alcohol. They can be genetic, such as being born with a mutation/susceptibility that one inherits from parents. These genetic mutations or susceptibilities may also accumulate over time, as one grows older.



Environmental Factors

Many studies have examined a wide spectrum of environmental factors as a cause for brain tumors. Of the long list of factors studied, only exposure to ionizing radiation has consistently been shown to put one at increased risk for developing a brain tumor. Some studies have shown a history of allergies as an adult, a mother eating fruits and vegetables during pregnancy, eating fruits and vegetables as a child, and having chicken pox as a child puts one at a decreased risk of development of brain tumors.

However, environmental exposures can be difficult to accurately measure leading to inconsistent results across studies. Therefore, inconsistent results have been found, in both adults and children, for a long list of environmental factors. These factors include: vinyl chloride exposure, working in synthetic rubber manufacturing or petroleum refining/production, history of head trauma, epilepsy, seizures or convulsions, cured food consumption (nitrites), viruses and common infections, cigarette smoking, alcohol consumption, cell phone use (in the United States and in Europe), residential power line exposure, exposure to air pollution, smoking when pregnant, second hand smoke exposure, agricultural worker exposures, industrial formaldehyde exposure and use of common drugs (for example, birth control pills, sleeping pills, headache medication, over the counter pain medication, antihistamines). More studies need to be performed before we can say whether or not these are true risk factors for developing a brain tumor and some large scale studies are underway.

Genetic Factors

Anything that refers to our genes can be called “genetic”. However, only 5-10% of all cancer is actually inherited from one generation to another in a family. Hence, there are very few families where multiple people in that family would have a brain tumor. There are a few rare, hereditary genetic syndromes that involve brain tumors. In those syndromes, a mutation in a specific gene is passed from grandparent, to parent, to child.

The vast majority of genetic risk factors are not inherited at birth but actually accumulate over time as we age. Genes are the operating instructions for the entire body. While most of our genes go about their jobs as expected, a small number may become inactive or begin functioning abnormally. The end result of an abnormal gene can be as simple as two different colored eyes or as complex as the onset of a disease. There are many different types of genes thought to be working incorrectly in brain tumors:

- Tumor suppressor genes make proteins that stop tumor growth in normal cells
- Oncogenes make proteins that cause cells to grow in an out-of-control manner
- Growth factors that play a role in making sure that cells grow normally
- Cyclin-dependent kinase inhibitors play a role in making sure that the cell goes through its growth cycle normally
- DNA repair genes make proteins that control accurate repair of damaged DNA
- Carcinogen metabolizing genes make proteins that break down toxic chemicals in the body that could cause damage to one’s DNA, like the chemicals in cigarette smoke and/or alcohol
- Immune response genes make proteins that control how one’s immune system responds to viruses and infections.

Studies of any specific gene are complicated by the fact that there are many potential genes in the human genome to consider. One must also consider that many of these genes interact with one another, and they may interact with environmental factors as well. Tumors can also have loss or gain of certain pieces of chromosomes.”

“Only 5-10% of all cancer is actually inherited from one generation to another in a family.”

2. BRAIN TUMOR AND DATA – INCIDENCES, FREQUENCIES

One of the great challenges in presenting data is the variety of sources that collect data, the methodologies they use and the manner in which data is reported. It can also be challenging to reconcile data presented in different formats; for example overall incidence rates based on census norms compared with survival rates based on identified patients. A significant effort is being made to present data in the most easily reviewed format. As we get closer to statistics that are more easily understood on incidence, survival and other criteria, we will update this paper accordingly.

Cancer of the Brain and Other Nervous System

It is estimated that 20,500 men and women (11,170 men and 9,330 women) will be diagnosed with and 12,740 men and women will die of cancer of the brain and other nervous system in 2007.

The American Cancer Society sites detailed SEER data and reports that 1 of 2 men and 1 of 3 women will develop cancer in their lifetime.⁸ Owing to a combination of causes including genetic and environmental, more than 120 types of brain tumors⁹ and associated cancers have led to enormous challenges in both research efforts and in developing appropriate and successful treatment regimens. Additionally deadly is metastasis to the brain, the most feared complication of systemic cancer and the most common intracranial tumor in adults. Incidence is rising with improved survival of cancer patients, and brain metastases are an increasingly important cause of morbidity and mortality in cancer patients. Thus, brain metastases present a therapeutic challenge for the treating physician and an emotionally and physically debilitating event for the patient. In the US: Approximately 170,000 cancer patients develop brain metastases annually. Intracranial metastases are seen in approximately 24% (11-35% in different series) of patients that die from cancer.¹⁰

Incidence & Mortality – Surveillance Epidemiology and End Results (SEER) Incidence

From 2000-2004, the median age at diagnosis for cancer of the brain and other nervous system was 55 years of age. Approximately 13.6% were diagnosed under age 20; 9.4% between 20 and 34; 10.6% between 35 and 44; 15.1% between 45 and 54; 16.6% between 55 and 64; 16.5% between 65 and 74; 14.3% between 75 and 84; and 3.9% 85+ years of age. The age-adjusted incidence rate was 6.4 per 100,000 men and women per year. These rates are based on cases diagnosed in 2000-2004 from 17 SEER geographic areas.

Incidence Rates by Race		
Race/Ethnicity	Male	Female
All Races	7.7 per 100,000 men	5.4 per 100,000 women
White	8.3 per 100,000 men	5.9 per 100,000 women
Black	4.9 per 100,000 men	3.5 per 100,000 women
Asian/Pacific Islander	3.9 per 100,000 men	3.0 per 100,000 women
American Indian/Alaska Native	3.5 per 100,000 men	2.2 per 100,000 women
Hispanic	6.0 per 100,000 men	4.7 per 100,000 women

“1 of 2 men and 1 of 3 women will develop cancer in their lifetime”.

U.S. Mortality

From 2000-2004, the median age at death for cancer of the brain and other nervous system was 64 years of age⁴. Approximately 4.3% died under age 20; 4.0% between 20 and 34; 8.0% between 35 and 44; 15.4% between 45 and 54; 20.1% between 55 and 64; 22.8% between 65 and 74; 19.6% between 75 and 84; and 5.8% 85+ years of age. The age-adjusted death rate was 4.4 per 100,000 men and women per year. These rates are based on patients who died in 2000-2004 in the US.

Death Rates by Race		
Race/Ethnicity	Male	Female
All Races	5.4 per 100,000 men	3.6 per 100,000 women
White	5.8 per 100,000 men	3.9 per 100,000 women
Black	3.2 per 100,000 men	2.2 per 100,000 women
Asian/Pacific Islander	2.5 per 100,000 men	1.5 per 100,000 women
American Indian/Alaska Native	2.6 per 100,000 men	1.8 per 100,000 women
Hispanic	3.4 per 100,000 men	2.4 per 100,000 women

Survival

Survival rates can be calculated by different methods for different purposes. The survival rates presented here are based on the relative survival rate, which measures the survival of the cancer patients in comparison to the general population to estimate the effect of cancer. The overall 5-year relative survival rate for 1996-2003 from 17 SEER geographic areas for this group of cancer patients was 33.9%. Five-year relative survival rates by race and sex were: 31.8% for white men; 35.0% for white women; 31.6% for black men; 39.5% for black women.

Lifetime Risk

Based on rates from 2002-2004, 0.60% of men and women born today will be diagnosed with cancer of the brain and other nervous system at some time during their lifetime. This number can also be expressed as 1 in 167 men and women will be diagnosed with cancer of the brain and other nervous system during their lifetime. These statistics are called the lifetime risk of developing cancer. Sometimes it is more useful to look at the probability of developing cancer of the brain and other nervous system between two age groups. For example, 0.26% of men will develop cancer of the brain and other nervous system between their 50th and 70th birthdays compared to 0.18% for women.¹¹

References

All statistics in this section are based on SEER incidence and NCHS mortality statistics.¹² Please consult SEER for further detail.



3. RESEARCH – UPDATES ON OUR PROGRESS, AND OUR CLOSENESS TO CURES

Today's landscape of treatment and research has provided exciting advances. Several new drugs and therapies are proving effective in treatment in clinical trials, and greater ability to focus efforts on brain cancer has shown ability to increase effectiveness while limiting side effects and discomfort for some patients.

Drugs like the combination of CTP-11 and Avastin are providing promising outcomes, and new research in dual agent treatments is furthering their effectiveness for some patients over longer periods. Extensive focus on clinical trials and patient histories is a priority, and our lead beneficiary, the Musella Foundation, has been a leading force for visibility on these trials as we track effectiveness.

Dr. Jeffrey Cozzens, Director of *Surgical Neuro-Oncology, Evanston Northwestern Healthcare*, Evanston, Illinois and Associate Professor of Neurosurgery, *Northwestern University Feinberg School of Medicine*, provided the following information in a discussion of treatment methods which appeared at www.abta.org.

Treatment

Advances have been made in new and improved methods in surgery, radiation and chemotherapy and in various combinations of these treatments. It has been known for some time that primary malignant brain tumors are difficult tumors to treat, and neither surgery alone, radiation alone, nor chemotherapy alone can treat these tumors successfully. On the other hand, it is also well established that various combinations of these modalities can have a significantly favorable impact on these tumors.

For many years, standard chemotherapy for brain tumors involved the injection of alkylating agents, such as BCNU, which worked by scrambling the DNA in cells ready to divide. This prevented cellular division and eventually led to cell death. Unfortunately these drugs were not very specific, affecting normal dividing cells as well as tumor cells, and causing significant side effects. Some of these drugs were also unable to pass through the blood-brain barrier which serves as a filter between the blood and the brain. A newer generation oral drug, temozolomide (Temodar, passes through the blood-brain barrier and has already been shown to be a major advance in the treatment of brain tumors.

It has always been felt that the ideal anti-brain tumor drug or agent would be a substance that selectively seeks out and destroys tumor cells, leaving normal cells alone. Antibodies are natural immune system molecules that perform such a function when they seek out and destroy invading bacteria, but until recently, scientists were unable to engineer these molecules to effectively and selectively recognize and destroy only brain tumor cells. In recent years, great strides were made toward accomplishing this “selectivity” feat and research now focuses on the best way to deliver these molecules. Current studies inoculate or “vaccinate” patients with their own tumors, building up the patient's immune system and stimulating it to make antibodies against the tumor cells.

New therapies have also been developed which combine surgery and a drug delivery system that bypasses the blood brain barrier obstacle. Other study designs combine an anti-tumor antibody with a radioactive agent that attaches itself to the tumor cells, and then kills them with radioactivity. In some trials, these agents are delivered using CED, where the drug is pumped into a tumor very slowly over several days. In other trials, the agents are injected into the hole left behind after the tumor has been removed.

Advances in radiation delivery have also made it possible to more effectively and safely treat brain tumors. New ways of focusing radiation beams allow the delivery of more radiation to the tumor and less radiation to the surrounding normal brain. Computerized robotic radiation delivery systems make these advances possible. These highly focused radiation systems are called stereotactic radiosurgery (SRS) since the ultimate effect is similar to a surgical resection. The most recent advances in radiosurgery combine the abilities of several pieces of radiation equipment into one unit although overall evaluation of the benefit of this approach is ongoing.

Recently, it was proposed that malignant brain tumors arise primarily from brain tumor stem cells. It is thought a certain population of cells in a brain tumor act very much like normal stem cells seen elsewhere in the body—except these stem cells are out of control and are programmed to produce brain tumor cells. These cells, characterized by a marker called CD133, are being intensively investigated in the hope future drugs can be designed to stop these stem cells from producing tumor cells.



Finally, the most important advance is the recognition that the successful treatment of brain tumors requires a dedicated team of researchers, neurosurgeons, neurologists, radiation oncologists, neuroradiologists, neuropathologists, medical oncologists, nurses, social workers, neuropsychologists, and rehabilitative medicine specialists all working together with the patient and his or her family. It is through this team effort that the best results, and highest quality of life, are achieved.¹³

T-cell-Based Approaches

The human immune system is a remarkably intelligent and sophisticated system, which distinguishes "self" versus "non-self" components in the body. It fights against "non-self" targets and works to eliminate them while sparing your own body parts. The idea behind cancer-immunotherapy is to engineer/improve the ability of the immune system to recognize and attack cancer cells. Even though cancers originate from one's own body, cancers express unique proteins that are not usually made by other normal cells at high levels (i.e. tumor antigens). Discovery and characterization of tumor antigens may allow us to effectively and selectively target cancer cells by enhancing the ability of the immune system to attack and destroy cancer cells.

There are two major effector systems in the human immune system: humoral (antibody) and cellular effector mechanisms. With regard to cellular effector mechanisms, among a variety of immune cell types, researchers have mostly focused on T-lymphocyte (T-cell) based approaches because T-cells recognize and destroy target cells in an antigen-specific manner. Even though blood brain barrier serves as a natural barrier for human brain, it is well-known that activated T-cells can cross the blood brain barrier and selectively destroy the targets in the brain. Most brain tumor vaccine approaches attempt to activate T-cells that specifically recognize brain tumor cells. To stimulate such T-cells, dendritic cells are often used as vaccines. Before injection to patients, in the laboratory, these dendritic cells are loaded with tumor antigens so that they can activate T-cells that recognize tumor antigens.

Other treatment regimens including focus on nutritional strategies and the use of dietary supplements are also ongoing and being evaluated for effectiveness.

"Extensive focus on clinical trials and patient histories is a priority."

4. FUNDING – GAPS THAT THREATEN RESEARCH AND PROGRESS

Despite the efforts of an active and dedicated community, brain tumor research has historically suffered from under funding and the current state of research funding in this arena remains dire.

The NCI's total budget for Fiscal Year 2005 was \$4.83 billion. The NCI will invest an estimated \$4.79 billion during Fiscal Year 2006. The budget is expected to decrease to \$4.75 billion in Fiscal Year 2007.¹⁴

In addition to diminishing funding, brain tumor research has also suffered from difficulty in turning donated monies around to operational efforts and researchers. Much of the funding has traditionally been channeled to universities who often maintain costly infrastructure, or even have an inability to conduct some research because of project overloads. Additionally, there are a great many researchers outside of the traditional university setting who are "at the ready" for research but who struggle to access research dollars. These researchers, outside the usual channels, have a harder time contributing and receiving the funds they need to do their work. Delays in funding mean delays in answers, expiration of grants and increased costs. Furthermore, the commitment to conduct necessary research has at times given way, understandably, to costs associated with diagnosis and treatment during the survival period. This has meant greater support for brain tumor victims but has necessarily impacted available research resources toward long-term solutions. Many established researchers are now turning to private foundations to access more funding, in turn making it difficult for junior investigators to access funds for initial data.



"There are a great many researchers outside of the traditional university setting who are "at the ready" for research but who struggle to access research dollars."

5. THIS PROJECT – OUR GOALS

A primary assumption of our program is “ask” and people will seek to help. Every dollar counts and any help will be greatly appreciated. This project has an ambitious, yet simple goal: Rapid fundraising dedicated to research for brain tumors. There is strong evidence to suggest that some solutions, with proper funding, may only be 4-6 years away. All funds raised through this project will be allocated in streamlined fashion, using existing channels and foundations with the goal of distributing money quickly and fairly, to those who can operationalize it quickly, and who limit their overhead to make more money available for research and treatment. Good research takes a long time, and sizeable amounts of money need to be raised. **OUR PROJECT GOAL IS AN AMBITIOUS \$53 MILLION.**

Money we raise will go directly toward novel brain tumor research, exciting novel treatment targets and improved treatment choices. Together, we will help reignite existing research teams at top medical institutions that are underfunded or have faced funding shutoff, thus stalling their research. Some of the nation’s most talented researchers and physicians are making strong progress in solving the brain tumor mystery, but have literally lost the funding needed to continue their work. We also will help new investigators access the resources so they can add to existing research or bring new ideas into the action.

The value of research and finding a cure is even more important because of challenges in the healthcare landscape. As many commentators have noted, access to promising cancer treatments and therapies may be restricted by federal agencies or funding, further slowing the ability to explore trials based on new treatments and therapies.¹⁵

It should be noted that significant fundraising and matching efforts for brain tumor research, treatment and support are raised every day, by large organizations, small groups and dedicated employees, friends and families. These inspiring efforts demonstrate to us that there are many who are like-minded and committed to solving this tragic mystery.

Because research is a painstaking process, the sooner that it can get underway, by as many researchers as possible, the more likely we are to find cures. And along the way, these researchers will continue to learn and discover things about our bodies and cancer that has impact well beyond the brain tumor community. In short, support of this project will offer support to many more victims and their families, as we gain greater understanding of cancers and how to conquer them.

Beneficiaries

In addition to our overall purpose of drawing attention to this terrible disease and increasing education and awareness, this project has identified several important and worthy beneficiaries who will play important roles. The below organizations and projects have proven exemplary in their dedication to brain tumor research and treatment efforts, bringing unrivaled commitment and expertise to the cause, as well as demonstrating to be extremely effective in the key goal of putting research dollars into the hands of those on the front line of this battle

The *Musella Foundation For Brain Tumor Research & Information* is our lead beneficiary. The Musella Foundation is a non-profit organization dedicated to improving the quality of life and survival times for brain tumor patients by using computer technology to index brain tumor clinical trials, streamline the flow of information, organize the brain tumor community and raise money for brain tumor research. It operates virtualtrials.com, and has worked tirelessly and successfully to bring attention to clinical trials, patient outcomes, research, letter writing campaigns for expanded treatment options, and a great many other contributions to the community. In our experience, the Musella Foundation has demonstrated an untiring commitment to the brain tumor cause, and it operates with a streamlined, influential and productive model that is known throughout the brain tumor community. (www.virtualtrials.com) -

International Brain Tumour Alliance (IBTA) an alliance of the support, advocacy and information groups for brain tumour patients and carers in different countries and also includes researchers, scientists, clinicians and allied health professionals who work in the area of brain tumours. (www.theibta.org)

American Brain Tumor Association (ABTA), a not-for-profit, independent organization serving individuals globally and award funds to researchers throughout the United States and Canada. Founded in 1973 out of a desperate need, the American Brain Tumor Association exists to eliminate brain tumors through research and to meet the needs of brain tumor patients and their families. (<http://www.abta.org/index.cfm>)



6. TURNKEY CORPORATE AND ORGANIZATIONAL GIVING

We believe that the generosity of the world's corporations and foundations is great evidence of the commitment to solve the brain tumor mystery and many other diseases and conditions. Our goal is to harness the power of these organizations and to leverage their immense commitments to solve problems with all available resources:

- Their customers and patrons, through e-commerce donations and other promotions
- Their employees, through charitable giving and matching programs, volunteerism and fundraising
- Their foundational/charitable efforts, through structured giving programs, and
- Their commitment toward green living through dedication to environmentalism, conservationism and healthy living.

If you'd like information on the various programs we've structured around each of these giving models, please contact us.

There are other simple ways to support our efforts, simply by the way you search for information on the internet, or the shopping you already do.

- Igive.com
- Goodsearch.com
- Amazon.com
- Virtualtrials.com
- Online retailers such as Nordstrom's and Land's End
- Visit our web site at (www.unlockingbraintumors.org) for other charitable programs we'll link to who support our cause

"The advancements we need - possibly just 4-6 years right away if the right research get fully funded, are simply out of reach right now due to research budget deficits."

Beneficiaries continued

The Pediatric Brain Tumor Foundation is a nonprofit organization dedicated to supporting the search for the cause and cure of childhood brain tumors. PBTF is the world's largest non-governmental source of funding for childhood brain tumor research, dedicated to not only eradicating this disease, and to providing support to families. (www.pbtfus.org)

Recognizing the importance of local and alumnus giving, and in our effort be unbiased in our efforts, we will also send funding to a variety of ***University Hospitals, Medical Research Facilities and Comprehensive Cancer Centers*** including

- Memorial Sloan-Kettering Cancer Center
- Duke University Comprehensive Cancer Center
- Jonsson Comprehensive Cancer Center (UCLA)
- Robert H. Lurie Comprehensive Cancer Center of Northwestern University
- M. D. Anderson Cancer Center at the University of Texas
- University of Pittsburgh Cancer Institute

The Tug McGraw Foundation - www.tugmcgraw.com

Other credible groups that may be beneficiaries

7. FOR MORE INFORMATION – EXPERT PANEL, RESOURCES, KNOWLEDGE, REFERRALS

This white paper is simply a beginning point to learn more about the brain tumor mystery, its causes, treatment options and manageability. We have also assembled a panel of experts working on our behalf who give as generously of their time as they do of their skills and expertise. You are invited to reach out to these experts with questions, ideas, and discussion about how we can work together. We'll make experts available at donors' requests, based on the specific ways you'd like to support us.

Our Expert Panel, Links and Resources You May Find Helpful

There are also a great many resources ranging from scientific and research focus, treatment and trial updates, support services for patients and loved ones, and a very large community to become part of.

There are also a number of extraordinary individuals making a difference in this area each day. Please see our web site (www.unlockingbraintumors.org) for more information on the impressive cross section of subject matter experts and concerned parties that are helping to further our cause and who are available to interface with you. We also welcome your support if you are interested to be a resource for this cause or would like to volunteer.

- The Musella Foundation – www.musselafoundation.org and virtualtrials.com
- The International Brain Tumour Alliance - www.theibta.org

- The American Brain Tumor Association – www.abta.org
- The Brain Tumor Society - www.tbts.org
- National Brain Tumor Foundation – www.braintumor.org
- Pediatric Brain Tumor Foundation - <http://www.pbtfus.org/>
- National Institutes of Health's Clinical Trials - www.clinicaltrials.gov
- www.brainlife.org
- Jonsson Comprehensive Cancer Center (UCLA) - www.cancer.mednet.ucla.edu/
- Memorial Sloan-Kettering Cancer Center - www.mskcc.org/mskcc/html/44.cfm
- Duke University Comprehensive Cancer Center - <http://cancer.duke.edu/>
- Robert H. Lurie Comprehensive Cancer Center of Northwestern University - www.cancer.northwestern.edu/home/index.cfm
- M. D. Anderson Cancer Center at the University of Texas - www.mdanderson.org/
- University of Pittsburgh Cancer Institute - www.upci.upmc.edu/
- The Tug McGraw Foundation - www.tugmcgraw.com
- Books – Williams, Didier, others
- ***Surviving Terminal Cancer: Clinical Trials, Drug Cocktails, and Other Treatments Your Oncologist Won't Tell You About***, by Dr. Ben Williams.

8. SUPPORT OUR CAUSE – HOW TO HELP

For more in-depth discussions or to get involved in this very important cause, please call, write or visit us. You'll find that it's easy to help, and that your help will quickly be put to good use. Whether you have a preferred beneficiary, level of involvement, or simply want to help our team in whatever area possible, we'll make it easy for you to do just that. To contact us or make a donation:

www.unlockingbraintumors.org

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958 South Shore Drive - Holland, MI 49423
(616) 335-9050 (office) and (312) 375-8346 (cell)

"Together, we will help reignite existing research teams at top medical institutions that are underfunded or have faced funding shutoff, thus stalling their research."



Our Lead Beneficiary: *The Musella Foundation for Brain Tumor Research & Information*

The Musella Foundation For Brain Tumor Research & Information is our lead beneficiary. The Musella Foundation is a non-profit organization dedicated to improving the quality of life and survival times for brain tumor patients by using computer technology to index brain tumor clinical trials, streamline the flow of information, organize the brain tumor community and raise money for brain tumor research. It operates virtualtrials.com, and has worked tirelessly and successfully to bring attention to clinical trials, patient outcomes, research, letter writing campaigns for expanded treatment options, and a great many other contributions to the community. In our experience, the Musella Foundation has demonstrated an untiring commitment to the brain tumor cause, and it operates with a streamlined, influential and productive model that is known throughout the brain tumor community. *The Musella Foundation for Brain Tumor Research & Information, Inc.* strives to improve the lives of families dealing with brain cancer, by:

- Funding innovative and creative research, with a special emphasis on research that complements, rather than duplicates, the research funded by the federal government.
- Providing the most comprehensive and up to date information about brain tumor treatments to families dealing with brain tumors, including the largest video library of topics relating to brain tumors.
- Referrals to brain tumor centers and help finding clinical trials - including obtaining free scan reviews from some major brain tumor centers.
- Running online support groups
- Advocacy issues such as fighting Medicare decisions that deny treatments to our members
- The brain tumor virtual trial - the first patient registry of brain tumor patients, the treatments they choose to do and the outcome.
- Easy access for asking questions of their world renown medical advisory board

Musella Foundation for Brain Tumor Research
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888.295.4740/516.295.4740
Fax 516.295.2870
musella@virtualtrials.com



- ¹ Nobody Can Afford a Brain Tumor... The Financial Impact of Brain Tumors on Patients and Families: A Summary of Findings. Patterson, Harriet. National Brain Tumor Foundation. http://braintumor.org/newsroom/NBTF_no%20one%20report_correctedFINALa.pdf
- ² <http://www.cancer.gov/cancertopics/factsheet/nci/research-funding>
- ³ Central Brain Tumor Registry of the United States (CBTRUS) report, Primary Brain Tumors in the United States, 2004-2005.
- ⁴ Report of the Brain Tumor Progress Review Group; published in 2000 by the National Cancer Institute and the National Institute for Neurological Diseases and Stroke.
- ⁵ "Oncology," medical journal of the National Cancer Institute, March 1998.
- ⁶ <http://www.cancer.gov/cancertopics/wyntk/brain/page6>
- ⁷ <http://www.cancer.gov/cancertopics/wyntk/brain/page6>
- ⁸ http://www.cancer.org/docroot/CRI/content/CRI_2_6x_Lifetime_Probability_of_Developing_or_Dying_From_Cancer.asp?sitearea=
- ⁹ Pediatric Brain Tumor Association - <http://www.pbtfus.org/medcomm/research/Pediatric-brain-tumor-facts-updated.html>
- ¹⁰ <http://www.emedicine.com/radio/topic101.htm>
- ¹¹ <http://seer.cancer.gov/statfacts/html/brain.html>
- ¹² Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlander N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.
- ¹³ <http://www.abta.org/index.cfm?contentid=40&itemtype=2>
- ¹⁴ <http://www.cancer.gov/cancertopics/factsheet/nci/research-funding>
- ¹⁵ http://www.businessweek.com/technology/content/jul2007/tc20070724_550192.htm

