



**BRAINS
FOR THE CURE**

Patient Resource Guide

A guide created to help you navigate through your journey.
brainsforthecure.org

brought to you by

**Head for the Cure
Foundation™**





BRAINS FOR THE CURE

Brains for the Cure was created as a tool for those going through a journey with brain cancer. Whether a patient, caregiver, friend, spouse, or supporter, you can find resources and personal stories to help them through their journey. Brains for the Cure (BFTC) is a program within the Head for the Cure Foundation (HFTC).

The Navigator A brain cancer diagnosis can set one's life on a path that feels convoluted and fraught with emotional twists and turns. In 2017, Head for the Cure launched this navigator, to further bring awareness to brain cancer and provide resources to guide someone through their journey.

The Resources BFTC is an online patient and caregiver navigator and is updated as new resources and research is found. Online you will find information for each stage of someone's journey; newly diagnosed, in treatment, having a recurrence, and life after treatment. We are continuously adding resources regarding financial help, support groups, clinical trials, and much more.

The Stories As the medical field and brain cancer research evolves, so does BFTC. To cultivate this, we have created a new video platform to address the questions so many patients and caregivers wonder about. From learning about clinical trials, to changing your diet, to talking with your friends and family, we try to cover a broad spectrum of topics.

The Inspiration Chris Anthony was diagnosed with a glioblastoma multiforme (GBM) brain tumor in October 2000 at age 34. After his passing, Chris' family took on the fight in his honor and created the Head for the Cure Foundation (HFTC). After 14 years of serving the brain tumor community, Head for the Cure recognized the need for another resource for patients and families out of the clinic. From that, the idea for Brains for the Cure was formed, and in April of 2017, the initial website was launched. Improvements and additions have been continuously made since then and will continue to be made as research and resources grows and evolves.

Find more information at brainsforthecure.org.

Building Your Medical Team



Neuro-oncologist - A doctor who has studied neurology, the brain, and oncology. Your neuro-oncologist will coordinate with the other members of your team in regards to your treatment and care.



Neurosurgeon - A neurosurgeon is a doctor experienced in performing surgery on the central nervous system and brain. Not all neurosurgeons have experience working with brain tumors and brain tumor patients. It is important to determine the amount of experience your neurosurgeon has with brain tumors.



Pathologist - A pathologist will examine tissue from the tumor under a microscope and determines what type and grade of tumor it is.



Physical Therapist - Physical therapists can help brain tumor patients through symptoms and side-effects of treatment such as lack of balance or weakness.



Radiation Oncologist - A radiation oncologist will provide the radiation treatment to the tumor.



Neuro-radiologist - These doctors examine the images taken of the tumor, including from MRI scans and CT scans.



Family and Friends - A good support system can be one of the most important parts of your team.



Speech Therapist - Symptoms and treatments can affect patients as they speak and eat. Speech therapists can assist in regaining or relearning these skills.



Nurses - A medical professional responsible for performing exams and tests to help your other doctors. Most nurses you interact with will have specific training for working with neuro-oncology patients.



Social Worker - A social worker can offer support and resources. These could cover financial concerns, home health care options, support groups, and many other resources of guidance and support.



Mental Health - Many patients find help by speaking with a mental health professional. Patients, as well as their family and friends, could benefit from these discussions.



Occupational Therapist - An occupational therapist can assist patients in relearning daily activities, such as brushing their teeth or fixing meals.

Find more information and resources at brainsforthecure.org.

Who is my....?

*Add phone numbers, addresses, emails, notes,
etc. about your medical team*

Neuro-oncologist: _____

Neurosurgeon: _____

Pathologist: _____

Physical Therapist: _____

Radiation-oncologist: _____

Neuro-radiologist: _____

Family and Friends: _____

Speech Therapist: _____

Nurses: _____

Social Worker: _____

Mental Health: _____

Occupational Therapist: _____

QUESTIONS TO ASK YOUR DOCTOR

How many years have you been practicing? _____

What is your specialty? _____

Did you have a fellowship or complete specialized training in neuro-oncology? _____

Are you board certified? _____

Do you have any additional certifications? _____

How many brain tumor patients have you treated? _____

How many patients have you treated with my specific brain tumor diagnosis? _____

Find more information and resources at brainsforthecure.org.

QUESTIONS TO ASK ABOUT TREATMENT OPTIONS

If I want a second opinion, who do you recommend I see? _____

What are the treatment options available? _____

What is the standard treatment versus clinical trials? _____

How long do I have to make decisions about my course of treatment? When would I need to start this treatment? _____

How long will I be on this treatment? _____

Will insurance cover this treatment? _____

How will the treatment be administered [oral or IV]? _____

Are there alternative treatment options? _____

Find more information and resources at brainsforthecure.org.

QUESTIONS TO ASK ABOUT TREATMENT CONT...

How do you determine if the treatment is effective? _____

How often do you recommend I get MRIs? _____

What are common treatment side effects and how should I manage them? _____

Are there long-term effects of the treatment I should be aware of? _____

Can I work and/or resume normal activities while in treatment? _____

Find more information and resources at brainsforthecure.org.



QUESTIONS TO ASK YOUR NEURO-SURGEON

Why is surgery needed? _____

Are there other treatment options available based on my current medical condition?

How many brain tumor patients with my tumor type do you treat each year? _____

What other specialists will be a part of my healthcare team [i.e. neuro-oncologist, radiation oncologist, nurse navigator, pharmacist, social worker, physical therapist]?

What are the benefits of the surgery? _____

How long will the surgery last? _____

Find more information and resources at brainsforthecure.org.

QUESTIONS TO ASK YOUR NEURO-SURGEON CONT...

What are the risks and possible complications of having the operation? _____

What happens if I do not have the operation? _____

Should I get a second opinion? _____

What is your experience in doing this operation? _____

Find more information and resources at brainsforthecure.org.



QUESTIONS TO ASK ABOUT CLINICAL TRIALS

What is the purpose of the trial? _____

In what phase is the clinical trial? _____

Why would this treatment be better than treatment being used now? _____

How long do I have to decide whether I want to participate? _____

How does the treatment work to treat my brain tumor? _____

What are the criteria used to determine if I am eligible for the trial? _____

How is the treatment evaluated and how often do I need to have MRIs? _____

How long is the treatment given? _____

QUESTIONS TO ASK ABOUT CLINICAL TRIALS CONT...

How will I be informed of the results? _____

How is the treatment given? (pills, IV, surgery or procedure required) _____

How often do I have to be seen in the clinic or hospital? _____

What are the known side effects and how are they managed? _____

Are there other risks by participating in the trial? _____

How could the trial affect my daily life? _____

What are the costs to me for participating in this trial? _____

Find more information and resources at brainsforthecure.org.



QUESTIONS TO ASK ABOUT SUPPORT

Where do you recommend I get more information about my diagnosis? _____

What support services are available to me and my family/caregiver? _____

Do you recommend I return to work and other normal activities at this time? _____

Do you anticipate that I will be able to return to work in the future? _____

How do I talk to my family and friends about my diagnosis? _____

What can I expect during recovery? _____

What are my needs for equipment or supervision at home? _____

How do I talk to my employer about my diagnosis? _____

Brains for the Cure brought to you by the

HEAD FOR THE CURE FOUNDATION

The Head for the Cure Foundation is committed to raising awareness, funds, and hope for the fight against brain cancer. Head for the Cure is a registered 501(c)3 organization.



The Inspiration Chris Anthony was diagnosed with a glioblastoma multiforme (GBM) brain tumor in October 2000 at age 34. A husband, father, son and brother, he fought the disease with dignity, grace and courage. An avid runner with an unmatched competitive spirit, Chris had the idea to start a run to raise money and awareness for brain cancer. After his passing, Chris' family, led by brother Matt, took on the fight in his honor.

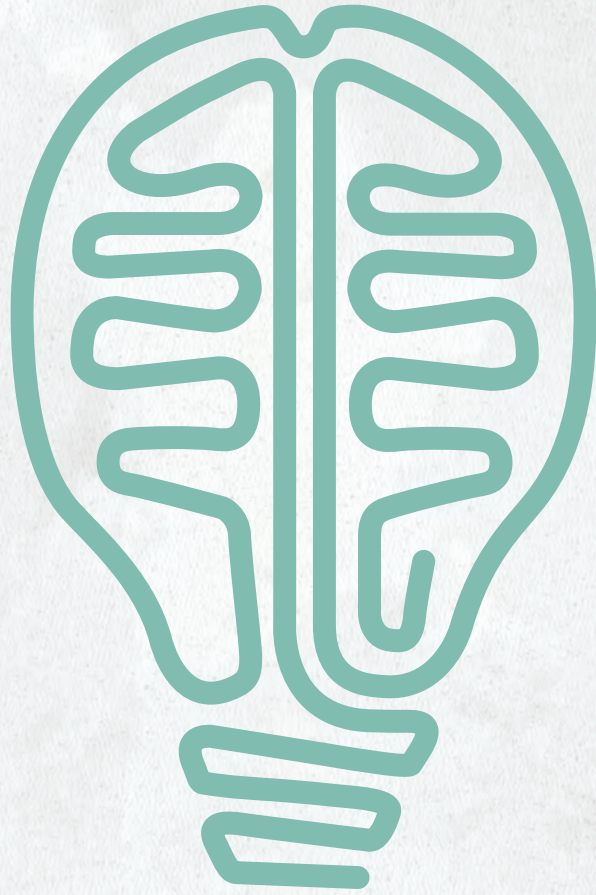
The Beginning The first Head for the Cure 5K event was held in the Kansas City Metro area in October 2003 and raised approximately \$18,000. By 2006, this 5K event had raised approximately \$150,000 and the Head for the Cure Foundation was formally established.

The Beneficiaries At each 5K, Head for the Cure partners with a local brain tumor clinic or advocacy organization to support their research and programs. The primary beneficiary of the Head for the Cure foundation is the Brain Tumor Trials Collaborative (BTTTC). Housed within the National Institutes of Health (NIH), the BTTTC is comprised of more than 30 of the top brain tumor centers across the country who work together on brain tumor clinical trials.

The Movement In 2018, nearly \$2.3 million was generated by 5K Run/Walk events and other fundraisers in over 20 markets, and across the country. To date, Head for the Cure has raised more than \$12 million to support brain cancer research and programs. 5K Run/Walk events continue to drive Head for the Cure fundraising. Approximately 17,500 runners, walkers and supporters participated in events in 2018. Growth continues in 2019 with over 26 events planned.

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