

How to Find and Access Clinical Trials



People with brain tumors often consider enrolling in a clinical trial as a potential treatment option. However, knowing how to identify and evaluate the many different trials can feel overwhelming. Follow these steps to get started.

Step 1: Learn as much about your diagnosis and disease as you possibly can.

Know the name, grade, size of the tumor, tumor location(s), and the standard treatment(s) for your diagnosis.

Step 2: Gather details about your diagnosis and treatment history and keep them accessible.

Write down any treatment(s) you received for the tumor, including drug names, date of surgery, type of radiation treatment(s), dates and numbers of treatment(s), and the location and extent of any recurrence (if applicable). Ask your doctor's staff to help you gather information and request copies of your medical records (MRI scans, pathology reports, etc.). REMEMBER: Information in your medical record belongs to you, so be persistent.

Step 3: Practice summarizing your diagnosis and treatment.

You will need to present a brief summary of your diagnosis and treatment history when you inquire about specific trials. Learn to do this quickly with no extraneous information, just the facts!

Step 4: Notify your doctor that you are investigating your clinical trial options.

Physicians are a valuable resource for identifying and evaluating potential clinical trials. However, doctors, especially oncologists, are extremely busy and may not have time or staff available to explore clinical trials with you in detail. Tell your doctor that you are gathering information

and you welcome his or her advice. Be sure your doctor understands that you are only in the information-gathering stage, and that once you determine the trials for which you may be eligible you will want to discuss your potential choices.

Step 5: Find clinical trial listings by phone or on the internet.

The National Brain Tumor Society Clinical Trial Matching Service offers brain tumor patients and their families a way to find clinical trials that may be an option. Clinical trial navigators search for clinical trials that match the patient's specific diagnosis and treatment history. To use this free, confidential service, call 877 769 4812 or complete an online profile by visiting www.emergingmed.com/networks/nbts.

For additional help identifying trials, call the NBTS Patient Services Line or contact the NCI. Several searchable online databases of clinical trials may also be helpful (see resource list). Find step-by-step instructions for using the databases at the NBTS website, www.braintumor.org/patients-family-friends/treatment/clinical-trials.

For each clinical trial listing, review the following points: the trial objective (what scientists are trying to learn from conducting the study), locations where the trial will be conducted, and eligibility criteria for determining who can participate in the trial.

Step 6: Compare the trial eligibility criteria with your diagnosis and treatment history to narrow your selection.

Examples of eligibility criteria include tumor type, tumor grade, type(s) of prior treatment, age, and level of functioning. Select trials that seem to match. Also examine who is sponsoring the trial, what institutions are participating, and whether the center has a designated brain tumor program.

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Practical considerations may also help you narrow your selection. For instance, consider the distance you are willing to travel; many trials are offered at multiple locations, so check to see if there is a more convenient location.

Try to narrow the selection down to two or three trials before seeking your doctor's advice.

Step 7: Contact the clinical trial sites for more information.

Call the site phone number and ask to speak to the protocol nurse or research assistant. Ask these questions:

- Is the trial still recruiting patients? If the trial is closed, is another site recruiting? Or are there other trials at the location that I may be eligible to enter?
- Am I eligible for the trial? (Present the brief summary of your case.)
- What is the trial objective? What is the phase of the trial?
- Has the treatment been tested on people with brain tumors before?
- How many patients have been recruited thus far? How many are being recruited in total?
- What tests, treatments, hospital stay, and commitment of time does the study involve?
- What potential side effects may occur and how can day-to-day life be affected?
- What does the treatment cost and is any part provided for free? Is any other support offered to patients? (For example, trials conducted by the National Cancer Institute at the facility in Bethesda, MD are free-of-charge and include reimbursement for some travel expenses.)
- May I see the informed consent document? What risks and benefits does it outline?

Step 8: Use the information you have gathered to evaluate trials and make a decision.

Consult with your medical team, family, and trusted friends. Strategize ahead of time about what you will do if your doctor or loved ones disagree with your decision. Remember that there are a variety of views on clinical trials, but deciding to participate is your decision. Do not hesitate to ask questions or bring up any concerns that will help you in the decision-making process.

Resources

The following organizations can provide you with more information about clinical trials and treatments for brain tumors:

- **National Brain Tumor Society**
Clinical Trial Matching Service: 877 769 4812
www.emergingmed.com/networks/nbts
- **National Cancer Institute**
Cancer Information Service: 800 422 6237
www.cancer.gov/clinicaltrials
- **Neuro-oncology Branch**
National Cancer Institute / National Institute of Neurological Disorders and Stroke
New Patient Line: 866 251 9686
- **CureSearch** (pediatric): www.curesearch.org
- **Musella Foundation:** www.virtualtrials.org
- **National Institutes of Health:** www.clinicaltrials.gov

Adapted from a previous version by Patty Delaney.

The information in this publication is subject to change. The reader is advised that information obtained from a physician should be considered more up to date and accurate than the information in the publication and that this publication does not and cannot purport to address facts and circumstances particular to any patient. This is something that can only be done by the patient's physician. Sponsorship of this publication does not imply the National Brain Tumor Society's endorsement or recommendation of any particular form or forms of therapy, regimen, or behavior. The information in this publication is not meant to be legal advice or replace the advice of an attorney.

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About National Brain Tumor Society

Today there are over 600,000 people in the US living with the devastating diagnosis of a brain tumor and NBTS is fiercely committed to finding a cure for all of them. Learn more about our targeted adult and pediatric brain tumor research programs, and our latest advocacy efforts at www.brainumor.org.