National Brain Tumor Society conducted an online survey to determine the level of knowledge, experience, and perceptions of brain tumor patients and caregivers with respect to education and participation in clinical trials. The results of our survey underscore the need for better resources and decision support that will enable all patients to be more fully informed about their diagnosis, treatments options, and the importance of their participation in appropriately matched clinical trials.

**WHO TOOK THE SURVEY?**

- **1463 TOTAL PATIENTS & CAREGIVERS**
  - 46% PATIENTS
  - 54% CAREGIVER

**BRAIN TUMOR PATIENTS IN SURVEY**

- 46% MALE
- 54% FEMALE

**WHICH TYPE OF BRAIN TUMOR DO PATIENTS REPORT HAVING?**

- OLIGODENDROGLIOMA 10%
- ASTROCYTOMA 17%
- MENINGIOMA 18%
- OTHER 18%
- CHOROID PLEXUS 1%
- Ependymoma 1%
- MEDULLOBlastoma 1%

**DID THE MEDICAL PROVIDER DISCUSS CLINICAL TRIALS?**

- Only 42% of patients were informed about clinical trials by their medical team
- 36% of patients NEVER discussed clinical trials with their provider

**WHO PARTICIPATED IN BRAIN TUMOR CLINICAL TRIALS?**

- 21% of all patients surveyed participated in a clinical trial for a brain tumor
  - 39% of GBM Patients
  - 18% of ASTROCYTOMA Patients
  - 12% of OLIGODENDROGLIOMA Patients
  - 2% of MENINGIOMA patients

**WHEN WERE CLINICAL TRIALS DISCUSSED?**

- Only around 24% of patients were informed about clinical trials at the time of diagnosis

**WHY DO PATIENTS PARTICIPATE OR NOT PARTICIPATE IN CLINICAL TRIALS?**

**TOP REASONS PATIENTS DO PARTICIPATE**

- The patient felt that it would not only help them but also help future brain tumor patients
- The patient felt their chances of survival seemed better with the proposed experimental treatment
- The patient felt the potential benefits outweighed the risks of the clinical trial

**TOP REASONS PATIENTS DO NOT PARTICIPATE**

- The patient’s doctor did not recommend participating in the clinical trial
- The patient did not qualify for the clinical trial
- The patient and caregiver did not know where to find a clinical trial

**CALL TO ACTION**

- It is important for brain tumor patients and caregivers to be made aware of all treatment options, including clinical trials, early in their journey so that they have the opportunity to find a treatment that may be effective for them, and for future patients.
- The results of our survey have highlighted clear gaps in terms of patient awareness and participation in clinical trials and underline the need for NBTS to launch a program that will enable all patients to be fully informed about their diagnosis, treatments options, and the importance of their participation in appropriately matched clinical trials.