



Brain Tumor
Network

2022 ANNUAL REPORT

GUIDING PATIENTS.
EMPOWERING CARE.



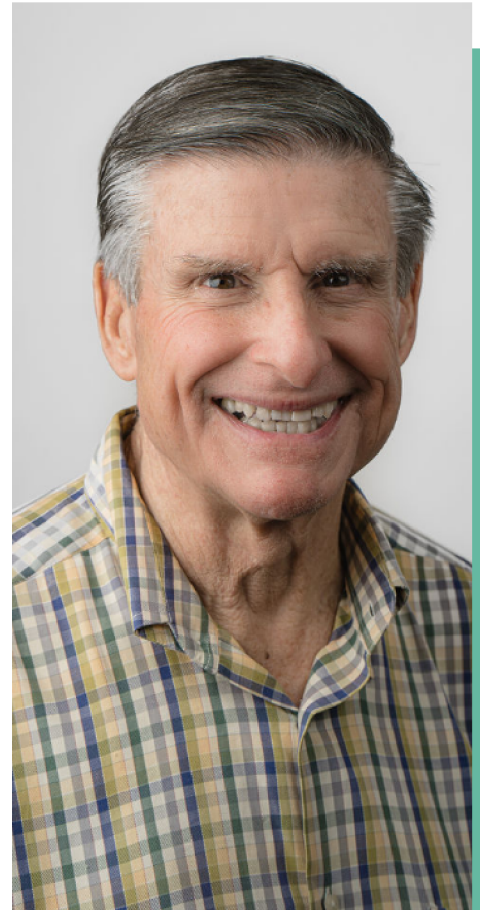
A WORD FROM OUR FOUNDER & PRESIDENT

Brain Tumor Network's mission is very personal to me. When my wife Susan was diagnosed with brain cancer in 1994, I found it very difficult to learn about the disease and find treatments that might benefit her. The internet was in its infancy. Online information was scarce. It was difficult to know if we were charting the best path for Susan's treatment.

The situation has changed significantly over the last 25 years. The main difference is the maturation and growth of the internet. Today, a vast amount of information is available. Now, the problem is sorting through that deluge of input while trying to understand a physician's advice. **A better way of navigating the medical system for brain tumor patients had been begging to be found.**

The answer came in 2014, when we established the Brain Tumor Network. It is a solution we desperately sought in 1994 but couldn't find. And it's been a godsend to over 2,000 patients who have benefited from its services in its eight years of operation.

There's not much more personal to me than using the struggles Susan and I experienced to help others.



Rick Sontag
President and Founder



IN LOVING MEMORY OF SUSAN T. SONTAG
APRIL 10, 1943 - SEPTEMBER 10, 2022

OUR BOARD OF DIRECTORS



Rick Sontag
President and Founder,
Brain Tumor Network



Hilary Keeley
Executive Director,
Sontag Foundation



David Foster
Senior Director,
Healthwise



Kent C. New, MD, PhD
Retired Neurosurgeon



Dan Ryan
Partner,
Spring Bay Companies



Kay Verble
Former Executive Director,
Sontag Foundation



Jill Wyant
Chief Executive Officer,
Madison IAQ

Our **mission** is to provide free, individualized navigation to help patients and loved ones manage a primary brain tumor diagnosis, overcome treatment obstacles, and facilitate access to quality health care.

TOP NAVIGATION SERVICES



Disease and Treatment Options Education

- Comprehension of diagnosis and interventions available
- Biomarker research



Personalized Clinical Trial Search and Enrollment Assistance

- Utilization of internal proprietary clinical trial matching system
- Education on trial requirements and design
- Facilitation of trial screening
- Eliminate barriers to trial enrollment



Second Opinions and Treatment Center Identification

- Local and national brain tumors center of excellence
- Facilitation of gathering medical records and imaging
- Consultations based on tumor pathology



Social Work Support Services

- Emotional support
- Connection to financial assistance
- Health insurance and disability information
- Support group connection
- Advance care planning
- Community resource identification



In April, Brain Tumor Network expanded navigation services to include **pediatric** patient families challenged by a primary brain tumor, made possible by a generous grant from the **Dianne T. and Charles E. Rice Family Foundation**.

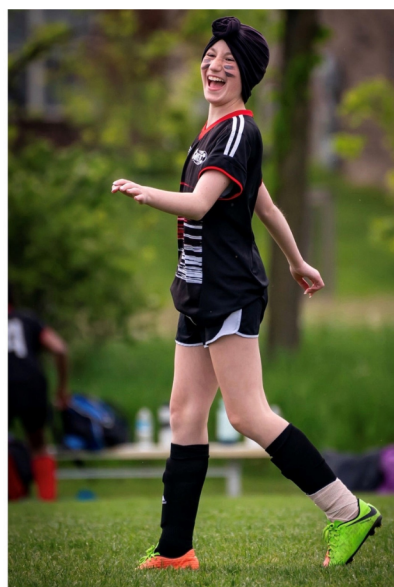
HARPER'S STORY

MEDULLOBLASTOMA



Meet Harper: A 13-year-old who loves soccer, making Tik Tok videos, and being with her family. After experiencing sporadic vomiting and multiple visits to the doctor, Harper was diagnosed with group 4 medulloblastoma in July 2020. Harper underwent aggressive treatment comprised of surgery, proton therapy, and a Children's Oncology Group protocol.

"After months of radiation and nine cycles of chemotherapy, I had clear scans and was ready to get back to my normal life. I went back to in-person school, started playing on not one but two different soccer teams, life felt normal."



In April of 2022, Harper's family received devastating news. A routine MRI revealed the cancer had come back and this time, in seven new areas of Harper's brain. With the help of Brain Tumor Network, Harper's medical records and imaging scans were sent to multiple institutions for second opinions, and a personalized clinical trial search was performed. Brain Tumor Network also provided education and research to help Harper and her family best understand potential treatment options.

After Harper's parents discussed the options with the care team, the family decided to pursue a clinical trial 600 miles from home. Brain Tumor Network helped expedite the trial screening and enrollment process for the family. Resources for family support and travel were provided, as well.



Harper is currently the first medulloblastoma patient enrolled in the phase 2 trial. Even through the long days of travel and uncomfortable procedures, Harper stays positive, exudes bravery, and focuses on her schoolwork.

Harper's motto, "**The comeback is always stronger than the setback.**"

BY THE NUMBERS: 2022



737
FAMILIES
SERVED

NATIONALLY

205
INDIVIDUALIZED
CLINICAL TRIAL
SEARCHES
PRESENTED

PERSONALIZED
CONNECTIONS TO
519
SECOND OPINIONS

PATIENTS EDUCATED
ON DISEASE & TREATMENT OPTIONS **414**

PATIENTS SERVED
IN ALL



333

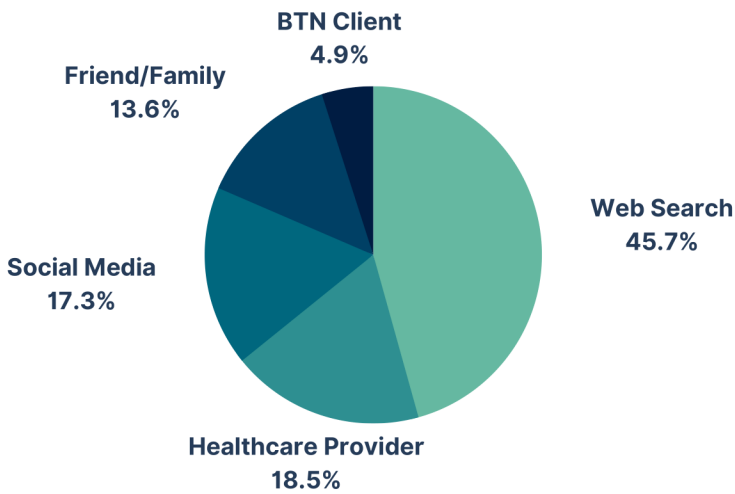
PATIENTS &
CAREGIVERS PROVIDED
SOCIAL SERVICES



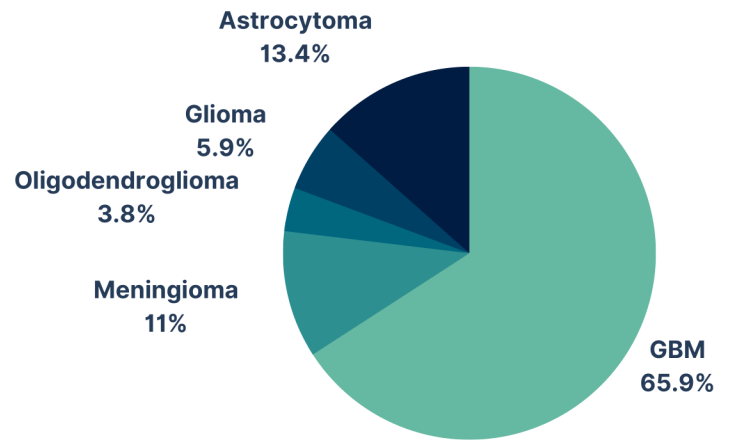
PEDIATRIC
PATIENT
FAMILIES
SERVED

43

REFERRAL SOURCE



TUMOR TYPES SERVED



*Numbers presented are not all-inclusive.

EXPENSE ALLOCATION



Brain Tumor Network received the highest level of recognition by Candid, the GuideStar Platinum Seal of Transparency. As this designation demonstrates, BTN is committed to transparent communication and responsible stewardship of donor investment.



In September, we resumed in-person meetings of the **Brain Tumor Support Group of Northeast Florida**. Monthly support group meetings are hosted by BTN's Social Work Department. All Northeast Florida and Southeast Georgia area families and loved ones impacted by a brain tumor diagnosis are encouraged to join.

“ They have been so very supportive and really filled in the blanks with things that our medical care team did not cover. We feel so lucky to have them!

“ I was immediately put at ease and received information that had not been shared with our family. The navigator was friendly, professional, caring, and knowledgeable.”

“ I needed someone to listen... the staff has been wonderful.”

“ The support has helped with the acceptance and healing through all of this.”

“ The information provided on clinical trials helped narrow our focus and make decisions when faced with overwhelming information.”



Brain Tumor Network

Guiding Patients. Empowering Care.