

White Paper: Advancing Brain Tumor Care Through Collaboration

Summary of the 4th Annual Brain Tumor Organization Leadership Fly-In Hosted by the Sontag Foundation | July 8-9, 2025 | Ponte Vedra Beach, FL

Overview

On July 8 and 9, 2025, the Sontag Foundation hosted the 4th Annual Brain Tumor Organization Leadership Fly-In, convening nearly 40 leaders from 17 organizations across the United States and Canada. This annual convening brings together stakeholders across research, advocacy, philanthropy, and patient navigation to drive collaborative strategies that ensure brain tumor patients have access to optimal, personalized care.

Building on the 2024 Fly-In, which focused on the importance of molecular profiling in informing brain tumor treatment, the 2025 event advanced this dialogue by exploring both the research and patient-centered challenges that continue to hinder progress.

Key Highlights

Standardizing Molecular Profiling in the Community

Dr. Christine Lu Emerson (Maine Health), representing the Society for Neuro-Oncology's (SNO) Community Neuro-Oncology Committee, provided an update on national efforts to implement molecular profiling standards across community settings. These efforts aim to ensure that every patient, regardless of geography, has access to comprehensive diagnostic information.

SNO Update

Shelley Pressley, provided an update on current initiatives, including the Organization's investment in the future of neuro-oncology, including providing a platform to disseminate high-quality neuro-oncology education; supporting members as they advance in their careers; and efforts to continue to recruit the best and brightest to the field. She also provided updates on SNO's family of journals, including the new Neuro-Oncology Pediatric journal, information about the SNO Annual Meeting and World Federation of Neuro-Oncology Societies (WFNOS), and preparations for SNO's 30th anniversary celebrations.

Public Policy & Advocacy

Gary Heimberg, National Brain Tumor Society (NBTS) presented the NBTS' public policy and advocacy update. He gave an overview of the NBTS 2025 priorities, including monitoring of Executive Branch activities; Head to the Hill; Day of Action; status of the Brain Act; federal appropriations for Brain Tumor Research; and advocacy opportunities ahead.

Collaborative Funding Efforts

Participants received updates from the Brain Tumor Funders' Collaborative on the Liquid Biopsy Request for Proposals (RFP) and the Congressionally Directed Medical Research Program

(CDMRP) for Glioblastoma. New opportunities to fund highly scored but unfunded research proposals were discussed, representing a critical moment to maximize collaborative impact.

Evaluating the Impact of Philanthropic Research Funding

A panel chaired by Nicole Wilmarth, PhD (American Brain Tumor Association), Sue Ruypers (Brain Tumour Foundation of Canada), and Cristi Frazier, PhD (Circle of Service Foundation) featured Jennifer Mortensen, PhD (American Heart Association), and Janice Lin, PhD (The Mark Foundation). Panelists shared how their organizations evaluate research impact, followed by breakout discussions on strategies to align brain tumor funders around shared definitions and metrics of impact.

Breakout Session 1: Research Roundtable – Key Themes:

- Defining "high-impact" research: from paradigm-shifting discoveries to protocol development and quality-of-life improvements.
- Evaluating outcomes: from survival metrics to collaborative influence and follow-on funding.
- Unanswered questions: how to track long-term grantee impact, capture quality-of-life data, and encourage better science communication.

Scott Davis, PhD (Sontag Innovation Fund) also shared insights on where philanthropic funding can close gaps in the research pipeline to accelerate therapeutic development.

Addressing Barriers to Clinical Trials and Second Opinions

Expanding on 2024 discussions, this year's patient-centered panel focused on the persistent barriers patients face in accessing second opinions and enrolling in clinical trials—particularly at the time of diagnosis.

Chaired by Kim Wallgren (CERN/NBTS), Laura Hynes (Brain Tumor Network), Daniel Lipka (Making Headway), and Kelli Duprey (Our Brain Bank), the session used real-world data and patient stories to illustrate how delays, misinformation, and institutional roadblocks prevent timely access to optimal care.

Breakout Session 2: Key Barriers and Strategies Identified:

I. Provider Education and Systemic Solutions

- Launch collective awareness campaigns to ensure every patient knows about clinical trials on Day 1
- Integrate education into triage, informed consent, and new patient intake
- Promote provider training via CMEs, Grand Rounds, and institutional protocols
- Engage professional societies (SNO, ASCO) to shift language, incentives, and referral norms

- Address logistical barriers to second opinions (e.g., record sharing, imaging access)

II. Challenges in Rural and Underserved Settings

- Delayed diagnosis and lack of neuro-oncology expertise
- Difficulty accessing molecular testing and clinical trials
- Distrust of the medical system and stigmas around trials

III. Awareness and Education Opportunities

- Target clinical oncologists, radiologists, ER physicians, and allied health professionals
- Collaborate with wholesalers, public libraries, and nonprofit websites
- Use social media (Reddit, LinkedIn) and influencers
- Develop unbranded educational tools usable by all orgs

IV. Financial Support Solutions

- Provide direct patient aid: travel, housing, food, molecular testing
- Develop a universal application where patients can apply for assistance with filters to access nonprofit support in those areas
- Collaborate with insurance companies and partners to streamline aid

Conclusion: A Call to Action

Participants of the 4th Annual Fly-In agreed: the time for coordinated action is now. Ensuring every patient receives optimal care—regardless of diagnosis location—requires:

- Uniform, patient-friendly educational tools at the point of diagnosis
- Shared frameworks for evaluating research impact
- Better mechanisms to connect patients to clinical trials, second opinions, and support resources

As organizations move forward, the collective goal is clear: to bridge the gaps in access, inform patient-centered decision-making, and ensure that every brain tumor patient is given the best possible opportunity for care.

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