Session IV:
Therapy Development: Challenges & Opportunities

Joohee Sul, MD, Co-Chair, US Food and Drug Administration
Patrick Wen, MD, Co-Chair, Dana Farber Cancer Institute
Overview of the American Brain Tumor Association’s Metastatic Brain Tumor Initiative

Ralph DeVitto
President and CEO

Nicole Willmarth, PhD
Chief Mission Officer
• ABTA is conducting three surveys designed to explore the following topic areas, and that contain questions tailored specifically to patients, caregivers, and oncologists:

  • Understand the awareness in terms of their risk for brain metastases
  • Understand their journey in terms of diagnosis and treatment
Collaborators and Advisors

Manmeet Ahluwalia, MD, FACP
Burkhardt Brain Tumor NeuroOncology Center, Cleveland Clinic, OH
Priscilla Brastianos, MD
Massachusetts General Hospital and Harvard Medical School, Boston, MA
Dan Brat, MD, PhD
Northwestern University Feinberg School of Medicine, Chicago, IL
Minesh Mehta, MD, FASTRO
Miami Cancer Institute, Baptist Health South Florida, Miami, FL
Jill Barnholtz-Sloan, PhD
Case Western Reserve University School of Medicine, Cleveland, OH
Robin Page (patient representative)
• ABTA is supporting n=600 interviews online among our key audiences, as well as additional interviews among ABTA's partner advocacy organization constituents.

• This approach will give us enough responses to draw meaningful conclusions across overall populations (patients, caregivers, and oncologists) and directional findings for large sub-groups within those overall populations.
Patient and Caregiver Surveys

Methodology

- Online quantitative survey among:
  - \( n = 237 \) Cancer Patients
    - representative mix of patients with brain metastases
  - \( n = 211 \) Caregivers
    - of cancer patients who have brain metastases

Conducted across the United States from 08/13 – 09/16/2018

Sample provided by PSB panel and advocacy partner sources
A diagnosis of brain metastases was a surprise to nine in ten patients.

Top concerns upon learning of the diagnosis was the impact on their quality of life and the likelihood of treatment success.

Fewer than half sought a second opinion.
Some patients reported being denied participation in clinical trials, and the experience for them was emotionally taxing.

- 24% were denied participation in a clinical trial related to their primary form of cancer because of their brain metastases.

- 19% were denied participation in a clinical trial related to brain metastases because of previous treatments of their primary form of cancer.

- It was so disheartening to be close to a possible treatment, only to be rejected.

- It was a very brutal and emotionally taxing experience.

- I was interested in pursuing a particular clinical trial but it excluded people with brain metastases.
• Most caregivers had a personal relationship with their patient - a plurality of whom were their parent.

• Caregivers expressed many of the same reactions to learning of the diagnosis as patients. Shock and depression were cited by caregivers as initial reactions.

• Over six in ten said they were familiar with brain metastases before becoming caregivers.

• Caregivers were most concerned about the effect on the QOL of the person under their care and the likely success of treatments.

• Nearly nine in ten caregivers (88%) said there was an emotional impact on them as a result of caring for a brain metastasis patient.
Next Steps: Oncologist Survey

• We are currently developing a survey for oncologists who treat brain metastasis patients

• The questions are being developed in a way that mirrors the patient and caregiver survey to identify where there is agreement or disagreement in knowledge or perception

• Once all the survey results have been compiled and analyzed we hope to present the data at the SNO meeting in November