#MetsCNS2019
#CNSMetsWorkshop2019

Session IV:

Therapy Development: Challenges & Opportunities

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Overview of the American Brain Tumor Association's Metastatic Brain Tumor Initiative

Ralph DeVitto

President and CEO

Nicole Willmarth, PhD

Chief Mission Officer

ABTA Metastatic Brain Tumor Initiative Objectives

- 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

LUNGEVITY
Find it. Treat it. Live.

MRF MELANOMA RESEARCH FOUNDATION

Kidney Cancer Association

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Methodology & Audiences

- 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

n=200 Cancer Patients

n=200 Caregivers

n=200 Oncologists

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

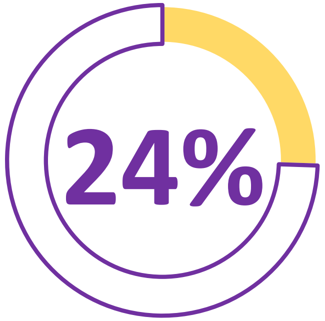
Sample provided by PSB panel and advocacy partner sources

Summary: Patients Survey

- 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.

Clinical Trial Exclusion

- Some patients reported being denied participation in clinical trials, and the experience for them was emotionally taxing.



Were denied participation in a clinical trial related to their **primary form** of cancer because of their brain metastases

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.*

Summary: Caregiver Survey

- **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