

BrainMetsBC.ORG: EVALUATION OF A NEW RESOURCE FOR BREAST CANCER PATIENTS WITH BRAIN METASTASES

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Introduction: As improved treatments control extracranial disease and extend survival, more women with metastatic breast cancer face a diagnosis of CNS metastases. An estimated 10% to 16% of all breast cancer patients whose disease has spread develop brain metastases; for those whose cancer is HER2-positive, a brain metastasis incidence of 25% to 48% has been reported. To address this growing crisis, a 5-year Center of Excellence (COE) comprised of scientists, translational researchers, and advocates was funded by the Department of Defense Breast Cancer Research Program.

Studies have shown that women with metastatic breast cancer need dedicated resources. In December 2007, patient advocates working with the COE launched a new consumer website, BRAINMETSBC.ORG, to offer information and support about brain and other CNS metastases to patients and caregivers. The present survey assesses how well BRAINMETSBC.ORG meets this need.

Methods: Visitors to BRAINMETSBC.ORG were invited to fill out an 18-question anonymous survey examining the helpfulness, clarity, and design of this website. Responses were elicited from patients and caregivers dealing with brain metastases, metastatic patients not yet facing this diagnosis, patient advocates, and health care providers.

Results: There were 84 survey responses within the first 2 weeks of website launch. Nearly half (47%) were patients dealing with brain metastases or their caregivers. Respondents were young with 52% aged 50–59, 19% aged 40–49, and 24% aged 30–39. Nearly half (46%) had been living with metastatic breast cancer for 3 to 5 years while an equal proportion (43%) had been dealing with brain metastases for less than 1 year.

Most patients and caregivers (89%) said they would have found the website helpful when first diagnosed with brain metastases; 86% found it helpful at the present time. Disease and treatment information was rated as most helpful, followed by patient experiences, ongoing research efforts, researcher interviews, and clinical trials listing. Almost all (90%) said they knew more about CNS metastases after visiting the website. Most patients and caregivers (64%) said they found it reassuring to know that some women can live with brain mets. Many felt less worried (52%) and more in control (41%) after reading the website, by contrast with 9% who felt this kind of information was better on a “need to know” basis.

The patient advocates and health care providers who rated the website said it would be very (78%) or somewhat (22%) helpful to them in working with patients and families. Almost all survey respondents found the medical information clearly presented (93%) and said the website was well organized (89%) and easy to navigate (91). The most common expressed need (43%) was for more treatment information.

Conclusions: Most patients and caregivers, advocates, and health care providers highly rated BRAINMETSBC.ORG. Those already diagnosed wished this resource had been there for them while those worried about getting brain metastases felt less fearful, armed with medically reviewed information, and stories from women who have been there. The in-depth information provided and the reassurances from patients living with the disease were cited as valuable as was learning that ongoing research is being actively pursued. Treatment updates and refinements will be crucial to the ongoing success of this website.