The Metastatic Breast Cancer Project: A national direct-to-patient initiative to accelerate genomics research

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Abstract
Background: Metastatic breast cancer (MBC) is a breast cancer that has not responded to prior therapies. In 2019, 250,000 women and men in the U.S. were living with metastatic breast cancer. 80% of people in the U.S. have metastatic breast cancer each year, accounting for 70% of all breast cancer deaths. Though most breast cancer treatments and clinical trials have targeted localized tumors, patients with MBC are often not included in trials. In our experience, most breast cancer patients who have MBC are not available for research. Existing breast cancer tissue banks have been initiated to include MBC tissue samples, largely beyond the cost and capacity of cancer centers for a community setting. The Metastatic Breast Cancer Project is a direct-to-patient initiative that will address this challenge by providing patients with the opportunity to contribute tumor, saliva, and medical records to a centralized initiative.

Methods: We identified large numbers of MBC patients willing to share tumors, saliva, & medical records.

Participation in the Metastatic Breast Cancer Project to Date

- Over 500 women and men with metastatic breast cancer have consented to share medical and demographic data, tumor, saliva, and sequencing on their tumor & saliva samples

Summary and Conclusions

- A direct-to-patient approach using social media & patientadvocacy partnerships enabled rapid identification of large numbers of MBC patients willing to share tumors, saliva, & medical records.
- This includes many with rare phenotypes, a group that has been challenging to identify with traditional approaches.
- Genomic analysis of tumors and saliva from patients with extraordinary responses, patients with de novo MBC, and young patients is underway.
- At the cut off date DNA sequencing from blood biopsies to study resistance, tumor evolution, and heterogeneity is planned.
- All identified clinically annotated genomic data will be shared widely with the research community as it is generated.

This study may serve as model for patient-driven research in other cancer types.

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The Patient Voice

"Our family could be the key to unlocking a cure for MBC" - Ingrido Tomlin: cancer patient (MBContact)

"If you’re looking for an advocate who does not think twice about helping people, who is always enthusiastic about research, you’ve found one!" - Jo Waltman: MBC patient

"Being on the MBC project has been empowering to both my health and my advocacy for myself and other women" - Kristine: MBC patient

www.mbcproject.org