

Venezuelan Breast Cancer Research and Education Foundation

Reframing advanced breast cancer:
from expectations to facts



Capacity building Advocacy

Reframing advanced breast cancer: from expectations to facts

Themes: **Information and support**

Context

In Venezuela, breast cancer patients often feel powerless in a country where almost half of the women already have advanced at first diagnosis. With the current economic and political crisis, patients need to take an even more active approach to receive the necessary support and access services. Reducing the gap in patient information by disseminating locally relevant materials will empower metastatic breast cancer (MBC) patients to make informed decisions.

The

[Venezuelan Breast Cancer Research and Education Foundation \(Fundación Venezolana de Educación e Investigación contra el Cáncer de Mama-FUVEICAM\)](http://fuveicam.org/) [\(http://fuveicam.org/\)](http://fuveicam.org/)

is a growing non-profit organisation that places its efforts on improving the breast cancer outcomes of the population through designing interventions that are systematic and scientifically supported, taking into consideration the

diversity of the health system and existing resources. With this new project, the Foundation will enable patients, caregivers and healthcare workers to access relevant information on MBC through a website.

Project description

FUVEICAM was awarded a SPARC award in October 2019 to launch an informational website with relevant materials on MBC, adapted to the local context. The aim of the project is to design and develop online educational resources, that will brief doctors and patients on advanced breast cancer, influence public policies and improve the continuum of care by supporting patients and their caregivers.



“The patients and their caregivers need to know that they are welcome to co-create their care with control over their treatment and funding choices. The crucial thing is shared decision-making and goal-concordant care planning done with and by the patients.”

Maria Eugenia Aponte-Rueda

President of FUVEICAM [.\(http://fuveicam.org\)](http://fuveicam.org)

The website materials will not only be used by MBC patients and their caregivers but also target health professionals. **Sharing knowledge to decrease the information asymmetry between clinicians and patients is at the heart of**

the project. The main outcomes expected from this project are access to reliable health information about advanced breast cancer adapted to the local language (in Spanish); support to patients, families, and caregivers in their treatment decisions; influencing public policies; improving the continuity of care; and strengthening the breast cancer workforce capacity.

Impact

It is expected that by producing and disseminating adequate resources on treatment options, possible side effects and other relevant considerations for patients will contribute to help MBC patients be more knowledgeable and confident in their choices. It is also hoped that the project will see improved performance of breast cancer health care professionals as materials on the latest news about the disease will be shared with them. Finally, it is believed that the website will support efforts to influence public policies through the collection of up to date evidence-based information and data.



(Information from the project description and context is compiled from the grant application)

More about the project

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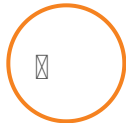
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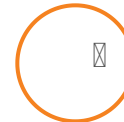
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