

## **Spanish Association for Metastatic Breast Cancer**

We are a non-profit organization devoted to support and empower patients with metastatic breast cancer, raising awareness about this stage of the disease and getting funds for specific research.

The association was created in 2018 by Chiara Giorgetti, a young woman diagnosed with metastatic breast cancer, who became aware of the different concerns and needs amongst women with this diagnosis and those with early breast cancer. She had started a first group of patients a year earlier, as an online community to share their experiences and support each other. With work, love and courage, this first group of women set the way of what would become our organization: an association made up of patients, working for patients.

During these five years, the association has continued increasing activities and attracting more awareness and support, thanks to the contribution of many donors and the dedication of many volunteer members.

We are the first and only association that addresses metastatic breast cancer in Spain.

## Our challenge

Metastatic breast cancer, or stage IV breast cancer, is cancer that has spread beyond the breasts and lymph nodes to other parts of the body, most commonly, to the bones, lungs, liver, or brain. Metastatic breast cancer is treatable but not curable. Approximately 30% of women with breast cancer could develop metastasis during their lifetime and between 5 and 6% of new cases present metastasis at diagnosis. The average survival rate for these women is less than 5 years.

In Spain, 34.750 women will be diagnosed with breast cancer in 2023. Besides, breast cancer is the main cause of death in our country in women aged 35-50 years. In 2021, the annual number of deaths from breast cancer in Spain (mostly women but also a small percentage of men) amounted to 6,614 cases. The only hope for these patients is research and development of new treatments, but less than 10% of research investment is allocated specifically to the metastatic stage of breast cancer.

#### Our mission

The aims of our association are summarized in three main activities:

 Support networks: We create a strong community of people, not only patients, but also relatives and anyone concerned about metastatic breast cancer. We connect people because nobody understands you better than who is experiences the same fears and desire to live. We want to empower this community with the knowledge, the awareness and the resources about the disease to allow them to manage better their own well-being.

- Active awareness: We raise and develop social awareness about metastatic breast cancer to ensure that public knows the reality of this disease and the differences between metastatic and early stage patients needs. We want to spread this social awareness at every possible level, to get involved healthcare providers, scientific community, public authorities, industry and society.
- 3. Specific research: We promote research by attracting financial resources and supporting the initiatives of oncologists and researchers in this field. We want to allocate funds to those innovative projects focused on the metastatic stage of the disease that can really change the prognosis for the patients. And we also want these research results, new treatments, to be equally available to all patients.

### Our commitment to research

Metastatic breast cancer patients depend upon the research and development of new treatments that increase survival rates and improve their quality of life. So, one of the main goals of our association is to acquire more funds to finance specific research projects for this stage of the disease. In memory of our founder, the association created in 2019 The Chiara Giorgetti Awards, whose economic endowment comes from the contributions of the members, activities carried out by the association and donations from different individuals and collaborating companies. These direct contributions to research are the raison d'être of the association, which is committed to devoting most of its incomes to promoting specific research in metastatic breast cancer.

Last year we have celebrated the IV edition of The Chiara Georgetti Awards, with a total endowment of €210,000, that have been allocated to three innovative projects from different research centers in Spain.

With this initiative we join the efforts from other patient associations, research groups, pharmaceuticals and healthcare providers, to obtain more funds for research that allow patients to have more treatments options, more efficient therapies and a better quality of life.

# Our messages and campaigns

**More research for more life** (hashtag #MásInvestigaciónParaMáVida in Spanish) is the motto of our main awareness campaign from the beginning of the association. This hashtag summarizes and reflects our mission and our commitment to research, as the only way for patients with metastatic breast cancer to achieve a longer life. We reinforce these messages with our calls for equitable access to innovative treatments (hashtag #AprobacióndeFármacosYA in Spanish) so that our national health system can provide these new medicines to all patients.

**No Winners No Losers** (hashtag #NiVencedorasNiVencidas in Spanish) is a campaign focused on the relevance of the language used in conversation about cancer and how patients can feel when war metaphors are used to describe their experience. Some patients may feel encouraged thinking they are "warriors" "fighting" against the disease, but many of them feel upset, guilty and responsible for the progression of the disease. This campaign calls for changing this military language to avoid this negative pressure on patients.

**The missing M** (hashtag **#laMquefalta** in Spanish) is another awarenes campaign, in which the M stands for the metastatic stage of breast cancer. The campaign encourages people to remove the letters M in social media posts to show how difficult it is to understand them when some letters are missing, just like breast cancer is not understood if you don't talk about metastasis.

# Letter from our president Pilar Fernández Pascual

"What one day was just a dream of a group of patients with advanced cancer is today a strong association with a future: the Metastatic Breast Cancer Association.

On this difficult journey, many times our strength failed us and at other times we lacked means but our enthusiasm and our desire to live were much stronger than any obstacle that may have arisen.

When our enthusiasm began to wane, generous hands, strong arms, big hearts and solidarity always appeared willing to help us continue weaving hope for the thousands of people who need it.

Thank you all for your unconditional support, your limitless solidarity, your words of encouragement at the right moment, but above all, thank you for believing in our project: #MoreResearchForMoreLife."