

# Highlights from EUROPA DONNA's Metastatic Breast Cancer Advocacy Webinar 2021



18-19 June 2021

EUROPA DONNA – The European Breast Cancer Coalition held a webinar on metastatic breast cancer (MBC) advocacy for women to gain skills and tools for MBC advocacy and to make personal contact with other women who advocate for awareness and improvements for this disease. Forty participants from 20 of the Coalition's 47 member countries connected on this virtual course on 18 and 19 June, which covered topics including research focusing on MBC and the latest treatments available, as well as psychosocial support and the importance of busting the taboos. A majority of the participating advocates were aware of these issues first-hand because they have MBC, recurrent breast cancer and/or triple-negative breast cancer and are active in advocacy on behalf of women with the disease in their countries. Many were young when first diagnosed with breast cancer, had metastatic disease for under 5 years, and had been on multiple lines of treatment. This was the second virtual conference since the Coalition began holding yearly MBC conferences and training in 2017 to address the unmet needs of women with MBC, which is an advocacy priority for the Coalition. This report highlights some of the main messages from the virtual course. Videos of the webinar presentations are available for viewing on the EUROPA DONNA website. [See !\[\]\(666e09182d4cd268646ea700ea60dcdf\_img.jpg\) https://mbc.europadonna.org/webinar-videos](https://mbc.europadonna.org/webinar-videos)



## Update on treatment and research for MBC

**Olivia Pagani**, Breast Cancer Programme coordinator for the European School of Oncology, brought the participants up to date on current treatment and research on treatment for MBC. She began with some encouraging data showing 5-year relative **survival rates after a diagnosis of MBC** of about 33% in 2011, compared with 15% about 30 years earlier. The best results are for **luminal A** cancers (ie, endocrine receptor-positive [ER+], HER2-negative). She said that while MBC is not curable it is treatable and that the goal of treatment is disease control or regression, prolongation of life, and improving symptoms and quality of life (QoL). Throughout, she cited the ESO-ESMO ABC5 guidelines, a key resource on MBC management. [See !\[\]\(529949c2c3dadbaa4e538e8c643454bc\_img.jpg\) https://www.europadonna.org/wp-content/uploads/ABC-5-Consensus-Guidelines-for-ABC.pdf](https://www.europadonna.org/wp-content/uploads/ABC-5-Consensus-Guidelines-for-ABC.pdf)



Olivia Pagani

### What's new in treatment?

Dr Pagani described the recommended treatment approaches for the various MBC subtypes. She added that age – whether old or young – should not be the sole criterion for treatment choice. In addition to tumour status, treatment choice will be governed by a woman's **previous treatments**, extent and sites of the disease, and **access to therapies**. In **ER+ MBC**, endocrine therapy is the preferred first-line approach because it has fewer side effects than chemotherapy and is as effective. The exceptions are cases of **endocrine resistance** or a need for a fast response. Some recent encouraging long-term data show **overall survival (OS) benefits** with CDK4/6 inhibitors combined with fulvestrant in ER+ disease. In patients with PIK3CA mutations, a PIK3 inhibitor showed disease improvement but not a benefit for OS, suggesting a need to follow patients for a longer period of time. In patients needing chemotherapy, sequential single-agent treatment is preferred to **reduce side effects**. For HER2+ MBC, anti-HER2 therapy should be **offered early** to all patients, although the ideal duration is not known. Dr Pagani pointed to the importance of availability of this treatment and the relevance of **biosimilars** as a replacement option. For triple negative MBC (**TNMBC**) without BRCA mutations, chemotherapy recommendations should follow those for ER+ cancers. Carboplatin may be added to the treatment armamentarium in certain cases. There has been some promise with **immune-based therapy** in women whose tumours express PD1/PDL1. In cases of **BRCA** mutations, PARP inhibition showed a significant increase in progression-free survival (PFS) and QoL, but no improvement in OS to date. Dr Pagani added that all women should be tested for PI3K, if ER+, and BRCA mutations at MBC diagnosis because there are targeted inhibitors that are **effective and well tolerated**. Testing of the metastatic tumour is important because tumour characteristics (eg, ER, HER2 status) can change from primary disease. Broad **genetic testing**, while popular, is expensive and not clinically helpful at this time.

### What's new in research?

Regarding research, Dr Pagani presented some key data on the quickly evolving area of treatment trials. In **ER+ MBC**, a new CDK4/6 inhibitor, dalpiciclib, has shown a 55% increase in PFS over the placebo comparator. Oral selective oestrogen receptor degraders (SERDs) are also in early-stage development. In **HER2+** disease early results with a tyrosine kinase inhibitor (pyrotinib) are encouraging. There are also favourable OS data for **omission of chemotherapy**. In TNMBC, results with a taxoid for taxane-resistant MBC have been disappointing.

Dr Pagani added that the **collaborative research into the COVID-19 vaccine** and the wealth of public funding for that endeavour show what could be done with the right combination of private and public funding for treatment research. The pandemic has also highlighted new approaches that **could speed up trials and make participation easier for patients**, such as use of telemedicine and mobile apps for patient-reported outcomes including adverse effects reporting. She also recommended advocating for **funding of long-term extensions of clinical trials**.

## Psychosocial support: Dealing with an MBC diagnosis

Covering psychosocial support for women with MBC, **Luzia Travado**, a clinician and researcher in psycho-oncology at the Champalimaud Clinical Center in Portugal, described the psychological challenges of an MBC diagnosis, including distress, uncertainty, coping, and depression. A variety of psychological interventions have a **scientifically proven**



Luzia Travado

**benefit** in reducing emotional distress, depression and anxiety, and in **improving quality of life**; these include psychoeducational interventions, individual psychotherapy, cognitive behavioural therapy (CBT), and group interventions. Supportive-expressive group therapy has also been shown to **increase survival** in women with MBC. Research also demonstrates the negative physiological effects of emotional distress on brain metabolism and inflammation, indicating that by addressing psychosocial needs there may be **benefits on overall outcome**. She established that not only is there a **clear need for psycho-oncological support**, there is evidence for its benefit and recommended “hammering this home” at the policy level, as psychosocial care is not yet offered on a regular basis to cancer patients. Plus there is already policy to support this: The **European Commission Initiative on Breast Cancer’s quality assurance scheme** requires specialist breast units to have a psycho-oncologist as part of the core team. The *European Guide for Quality National Cancer Control Programmes* contains a chapter dedicated to psychosocial oncology care that informs about how to integrate it into routine cancer treatment and care.

### Case study: Best practice for MBC social support programmes

Providing a case example of an MBC social support programme that is running successfully in the Netherlands, **Mirjam Velting**, of EUROPA DONNA Netherlands, described the **monthly discussion groups** set up for women with MBC to connect and learn from each other. This helps to fill important gaps in support so that women can **address their unique needs** with others in a similar situation, while taking the focus off of treatment. Via the organisation called “Borstkanker Vereniging” (The Breast Cancer Patient Organisation), the discussion groups are led by volunteer, **trained cancer coaches** in accessible walk-in centres, with three groups currently set up in three areas of the country. In normal times, they meet 10 times per year and cover such topics as loneliness; communicating with health care professionals, family and others; work issues; diet and exercise; and palliative care. The group is currently funded through member fees and donations, is **staffed by volunteers**, and has meeting spaces that are rent-free. They reach members through health-care provider referral, social media, and word of mouth. Due to the COVID-19 situation, the meetings will be partly online (6 meetings) and face-to-face, with the aim to have more groups in the future.



Mirjam Velting

### Removing the taboo from MBC

MBC advocates **Claudia Altmann-Pospishek** from Austria, and **Natalia Tomasa Irriguible** from Spain described their own awareness-awakening activities associated with MBC that could inspire other similar initiatives. Claudia describes her quest through Claudia’s Cancer Challenge, her **blog and social media outlet**, as a woman with MBC and a resonating voice. She said that MBC is life-changing, but as it can be invisible to others, it is not well understood by the public. She outlined three key approaches to taboo-breaking through **building awareness, spreading information and creating a community**. She recommends building awareness by talking about MBC, advocating for new therapies, establishing official networks, and bringing women with MBC together because many voices are louder than one. It is important to have a message to share and be clear about improvements that can be made in the near future.

Also with first-hand experience with MBC, Natalia described the association “CMM cáncer de mama metastásico” **MBC advocacy group in Spain** that originated from a Facebook group. It aims to raise MBC visibility, promote research and to empower patients. She showed an **awareness video** created to challenge the taboos and break the silence around MBC. The group holds other awareness-raising activities through the media, and raises funds for research through social merchandising and events, and helps women find the **best clinical trials** for therapy.



Claudia Altmann-Pospishek



Natalia Tomasa Irriguible

## Joining together in virtual workshops

The MBC advocates had a chance to participate in two separate workshop groups to discuss their experience and advocacy strategies related to survivorship and psychosocial support. This is always a fundamental element of these meetings as they allow for more intimate groups where the participants can share experiences, both personal and advocacy-related, ask questions, and hear about effective strategies in other countries. The second day of the course consisted of advocacy skills training workshops, designed specifically for this event.

### EUROPA DONNA MBC advocates speak out

EUROPA DONNA's MBC website features video interviews where women with MBC share their personal experience with the disease and their advocacy initiatives. [See !\[\]\(dfbd6b3763a6d1d9afaa974f64e2e4b5\_img.jpg\) https://mbc.europadonna.org/advocates-speak-out](https://mbc.europadonna.org/advocates-speak-out)



**Elisabeth Tomassen** – Norway

*"I challenge myself every day to live. You might say that metastatic breast cancer awoke my inner warrior. I want everybody to know that they are not alone."*



**Natalia Tomasa** – Spain

*"Be ready for the worst but hope for the best.... We need to empower patients because we can do so many things. We need to be involved in decision-making and urge for more research to be done on MBC."*



**Rossella Tramontano** – Italy

*"I have never stopped believing that I will be safe one day and that I will be alive when researchers find a cure."*



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EUROPA DONNA gratefully acknowledges



for their support