

Highlights from EUROPA DONNA's Metastatic Breast Cancer Advocacy Webinar



30-31 October 2020

EUROPA DONNA – The European Breast Cancer Coalition held a metastatic breast cancer (MBC) advocacy webinar on 30 and 31 October with 32 advocates from 18 of its member countries. A majority of the participants have MBC, recurrent breast cancer or triple-negative breast cancer and are active in advocacy on behalf of women with MBC in their countries. The virtual format allowed them to interact with the speakers during the sessions and with each other in break-out rooms for workshop activities – the format even made it possible for some women who were recovering from recent chemotherapy sessions to participate. The advocates were able to connect on a personal level, interact and support each other and offer suggestions based on their experience with successful advocacy strategies. During the second day they were trained on communications skills to aid in their advocacy work. This was the fourth event that EUROPA DONNA has held to address the unmet needs of women with MBC, which is a Coalition advocacy priority. This report highlights some of the main messages from the virtual course.



Insights on treatment and current research for MBC

Fatima Cardoso, Director of the Breast Unit in Champalimaud Clinical Centre in Lisbon, Portugal and President of the ABC Global Alliance, gave two comprehensive presentations on research and treatment for MBC. She said that it is crucial for MBC management to be provided by a multidisciplinary team different from the early breast cancer team. This and other main recommendations are all published in the ESO-ESMO ABC5 guidelines. They state that at diagnosis, a biopsy should be performed, and psychosocial care should also be offered. Biological markers, especially hormone receptor and HER2 status, should be assessed at least once in the metastatic setting. Knowing the treatment history in early breast cancer and advanced stages is important for choosing therapies to reduce treatment resistance. She said that patients should be told that MBC is currently incurable but treatable.

Treatments for MBC

Dr Cardoso described the treatment approaches for specific disease characteristics. For example, for **luminal-like** tumours (ie, endocrine receptor [ER]-positive, HER2-negative), endocrine therapy (ET) is preferred. To delay ET resistance, the standard of care is combining ET with a CDK4/6 inhibitor, which increases overall survival (OS)



and quality of life (QoL). In patients with **HER2-positive** MBC, there has been a change in paradigm: trastuzumab should be offered early (first-line) and continued beyond progression. Trastuzumab can be combined for a dual blockade with pertuzumab, or drugs targeting other pathways, such as lapatinib or tucatinib. Trastuzumab DM1 targets delivery of chemotherapy to the tumour cell. In **triple-negative** MBC, which has no identified targets for treatment, research is under way to dissect hidden subtypes that might offer a possible target. PARP inhibition is an example for patients with **BRCA mutations**. Checkpoint inhibitors are a type of immunotherapy that triggers the immune system to destroy tumour cells. The balance of efficacy and toxicity with this treatment needs to be considered. Finally, for chemotherapy, sequential monotherapy (ie, one therapy given at a time) is preferred over combinations, and the latter should be reserved for rapid progression. The goal of therapy for MBC is to treat for as long as possible with a good QoL, bearing in mind the toxicity profile, the convenience of oral treatments over intravenous, and patient preferences.



Dr Fatima Cardoso

Research on MBC

Dr Cardoso encouraged advocates to get involved in the **ABC Global Alliance**, with members in 81 countries; in many of these countries representation is provided via EUROPA DONNA which is a member of the Alliance. The Alliance's number 1 goal over 10 years is to double the median overall survival for ABC/MBC by 2025. As such, research aims to identify effective, tolerable treatments that can turn MBC into a chronic disease. She said that to do this, two main problems need to be addressed: **patient selection** for treatments and **overcoming treatment resistance**. For instance, identifying biomarkers that indicate which ET to use (eg, tamoxifen, an aromatase inhibitor [AI] or fulvestrant) would be an advancement. In research to date, ESR1 mutations seem to be associated with resistance to AIs. She said that high-quality pathology is essential. In MBC, multigene panels are not recommended, rather biomarker testing should focus on ER and HER-2 status, BRCA, PIK3CA mutations, and PD-L1 expression status. For treatment resistance, she said biopsy of metastases is crucial. As the tumour's natural history is to progress, treatment should be switched to a drug with a different mechanism of action. The best treatment sequences still need to be defined. She said that there is an enormous gap in registry data for MBC. She also called for reconsideration of trial endpoints in MBC (eg, progression-free survival plus an overall survival benefit), and the inclusion of patient-reported outcome measures. Additionally, advocates should fight to overcome inequalities in access to treatment (including pathology and radiotherapy), between and within countries. She added that because a treatment is new does not always mean that it is better.

For more on MBC treatment guidelines [See](https://mbc.europadonna.org/guidelines-on-mbc) <https://mbc.europadonna.org/guidelines-on-mbc>

Effects of physical exercise on cancer treatment-related side effects and PREFERABLE exercise trial for MBC

With a focus on survivorship, **Prof Anne May** of the Julius Center, University Medical Center Utrecht in The Netherlands described the benefits of physical exercise and the ongoing PREFERABLE trial in MBC. In early breast cancer, aerobic and/or resistance exercise during treatment has been shown to decrease cancer- and treatment-related fatigue, anxiety and depression and increase quality of life. **Exercise guidelines** for cancer survivors recommend 30 minutes of moderate intensity aerobic exercise three times per week and two 30-minute resistance exercise sessions. Based on this, it was then asked whether exercise could have a beneficial effect in women on treatment for MBC. Feasibility studies of the safety and efficacy of an **aerobic exercise** training programme for women with MBC were performed and found that it was safe and effective. Now, the PREFERABLE EFFECT randomised controlled trial is evaluating the role of a structured and individualised 9-month exercise intervention in women with MBC on quality of life, fatigue, and other disease- and treatment-related effects. In all, 350 participants are being randomly allocated to an exercise intervention (supervised and home-based) or no intervention (exercise advice). Recruitment began in January 2020 with a better than expected response, but some delays have been experienced due to COVID-19 restrictions. Participants who had already started before COVID-19 continued exercising at home using a hometrainer and dumbbells in combination with a smart phone application, and recruitment has been re-started around lockdowns. Prof May said that it is hoped that results will be available in about 2 years' time. EUROPA DONNA is a partner in PREFERABLE, which is an international collaborative project funded by the European Union within the Horizon 2020 programme.



Prof Anne May

[See](https://www.h2020preferable.eu) <https://www.h2020preferable.eu>

MBC ForteMente project for psycho-oncological support

Rosanna D'Antona, President of EUROPA DONNA Italy, described the ForteMente advocacy programme undertaken in Italy with the aim of providing psycho-oncological support to patients in all **specialist breast units (SBUs)** in the country. This involved conducting a national survey of women with MBC and their caregivers, as well as performing in-depth interviews of women with MBC. The survey showed that 98% of women with MBC and their caregivers believe that women should receive psychological support provided by qualified health care professionals, yet only 25% who seek such support find a psycho-oncologist in their health centre. Of the health care centres surveyed, 45% did not contemplate providing psycho-oncological support for MBC. In terms of the impact of MBC on women's lives, 29% had to leave their job and 50% had to reduce their workload. The illness caused 86% to change their life priorities, 69% to lose faith and certainty, and 51% to feel lost pleasure in living. Ms D'Antona said that while the findings may not be a surprise, they provide the data necessary to **advocate for psycho-oncological services**. At a public event in March 2019, ED Italy presented these findings to the Ministry of Health and gained the support and approval of the regional health authorities, more than half of which agreed to implement the services requested. A new phase of the project is now assessing psychological support provided through a **virtual platform**, with results expected by early 2021. This involved first surveying hospitals in 3 main regions to identify the number of health care professionals providing psychological support. The data being collected have confirmed the findings of the previous survey. Once the virtual services pilot programme is completed, they plan to present the data to the health authorities. Ms D'Antona outlined the steps undertaken to advocate for services: identifying a need, finding scientific or institutional partners, surveying the public to gather data, obtaining government approval, and receiving media support.



Rosanna D'Antona

Living and working with cancer

Isabelle Lebrocqy, Founder of oPuce in The Netherlands, described how she started this organisation after losing her job following her cancer treatment. After gathering missing data herself through an online survey, she found that almost one-quarter of the more than 1000 respondents had lost their job during or shortly after cancer. Many were in their 40s or 50s and the majority were women, and many had breast cancer. Access to **affordable insurance** was another issue. She took the cause to the Dutch parliament, where a motion was unanimously signed, and endorsement was received from the Ministry of Employment and Social Welfare. Working groups were set up to address employment issues and access to insurance for cancer patients and survivors. The Right to be Forgotten, a "clean-slate policy" for specific types of insurance for cancer survivors was passed in the Netherlands in January 2020. In 2016, she established the social enterprise oPuce to create opportunities for cancer survivors in some large multinational companies offering flexible timetables or training in news skills, for example. The organisation held **networking meetings** for the companies featuring talks about cancer and work, and social legislation. In 2017, this resulted in 12 corporate employers signing a covenant that they would do their utmost to keep people in their jobs and help people return to work. To understand why one in four people with cancer lose their job, the organisation performed a survey and found that the income loss was the highest for younger people, and there was greater job loss with more aggressive treatment. Ms Lebrocqy said that gathering good data was key to helping policymakers find solutions. With the group of companies, the organisation also created a "**talent connector**" app to bring together cancer patients and employers (www.talentconnector.nl) and is working on creating tools for job retention. This platform helps speed up the job finding and reinsertion process. As many people living with chronic cancer or MBC had lost their jobs and had difficulty finding a new one, freelance opportunities were included for people looking for temporary projects or contracts. The employers who signed the covenant said that they look at talent not the disease. Ms Lebrocqy said that she started the initiative in The Netherlands, but that it could be rolled out across other countries.



Isabelle Lebrocqy

Joining together in virtual workshops

MBC advocates were able to participate in three separate groups to discuss their experience and advocacy strategies related to survivorship, psychosocial support, and return to work/insurance issues facilitated by those who presented on each topic. This allowed for more intimate groups where the participants could 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 communications skills training, designed specifically for this event.

EUROPA DONNA survey on the current state of breast cancer services in Europe: MBC Findings

To assess the breast care services available across Europe, EUROPA DONNA conducted a survey from June through August 2020 and received one response per country from breast cancer advocacy leaders representing ED national groups in 34 countries (24 of which are in the European Union). The findings indicated that 35% of European women living with MBC do not have access to specialist breast units. There is a lack of special health care units or departments for people with MBC, a lack of programmes and services providing counselling, employment and return-to-work advice, addressing financial concerns, insurance coverage and family issues. Most glaring is the lack of registries that record MBC cases. On the positive side, in many countries women with MBC can be treated in the same health facilities where they were originally treated, there is generally good communication with health care professionals in terms of treatment decision-making and good therapy available. The table below shows the specific responses.

Questionnaire on Current State of Breast Services

Question	Answer			
	Yes	No	Don't know	Total
With regards to MBC care in your country:				
1) Do women who have been diagnosed with MBC have access to services within a Specialist Breast Cancer Unit?	61.8% 21	35.3% 12	2.9% 1	34
2) Can women with MBC return to the health facilities where they were initially treated for on-going care, and follow-up including palliative care?	79.4% 27	17.7% 6	2.9% 1	34
3) Are there special health care units/departments to care for MBC?	8.8% 3	82.3% 28	8.8% 3	34
4) Is communication of each step of or change in therapy effectively explained, underlining positive and negative aspects of each option, so that women with MBC can make an informed decision?	67.7% 23	23.5% 8	8.8% 3	34
5) Are all drugs/therapies which have been proven to be effective available to women with MBC at no charge/paid by the Public Health system?	67.7% 23	29.4% 10	2.9% 1	34
6) Are there structures, programmes, facilities and services aimed at providing counselling, sustaining and advising women with MBC regarding employment, return to work, financial concerns, insurance coverage, family concerns, psychological issues, etc.?	52.9% 18	47.1% 16	0.0% 0	34
7) Are they publicly funded?	40.6% 13	50.0% 16	9.4% 3	32
8) Is there a Registry that records MBC cases?	25.0% 8	65.6% 21	9.4% 3	32

Responding countries: Albania, Armenia, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Ireland, Israel, Italy, Latvia, Luxembourg, Malta, Monaco, the Netherlands, North Macedonia, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, and Ukraine. Answers are percent and number of respondents.



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