



1st Europa Donna Metastatic Breast Cancer Advocacy Conference

9 - 11 June 2017

Metastatic Breast Cancer (MBC), also called advanced breast cancer (ABC) and secondary breast cancer, means that the cancer has spread from where it started in the breast to other parts of the body. It is also referred to as stage IV breast cancer. Women with MBC face different challenges compared to women with earlier stages of breast cancer and today many of their needs are unmet and not well understood. For this reason Europa Donna – The European Breast Cancer Coalition (ED) has made MBC a priority for its future advocacy activities.

ED has been introducing MBC elements into all of our education, information and policy projects, ensuring that MBC advocacy topics are included in EBCC (European Breast Cancer Conference) programmes, Europa Donna Pan-European Conference programmes, as well as workshops for women with MBC at our Advocacy Leader Conferences. We also added a section of our website dedicated exclusively to advocacy for and with women living with MBC, <https://mbc.europadonna.org/>. In 2017 we launched the 1st Europa Donna Metastatic Breast Cancer Advocacy Conference on 9-11 June.

Conference Summary

Europa Donna's 1st Metastatic Breast Cancer Advocacy Conference brought together 68 metastatic breast cancer advocates from 34 countries, including women from among the Coalition's 47 member countries as well as advocates from Australia, Canada, Japan, Kuwait, Mexico and Uganda in Milan on 9-11 June. Building upon Europa Donna's ongoing MBC initiatives, the conference addressed the need to bring advocates together from around Europe and the world to advance the five key areas where advocacy for MBC is needed today: awareness, information, access to best treatment, support, and registries and data collection. Conference participants were selected based on their advocacy experience in their countries.

The 1st ED MBC Advocacy Conference began on Friday evening with ED President Roswitha Britz and Executive Director Susan Knox welcoming the participants and giving an overview of the conference. After that, in a ninety-minute session each participant introduced herself and spoke, often in a very personal way, of her experience as an MBC advocate and/or patient.

On Saturday morning, participants first heard about the latest in MBC treatments and research from Fatima Cardoso, Director, Breast Unit of the Champalimaud Clinical Center, Lisbon, Portugal and Chair of the Advanced Breast Cancer Fourth International Consensus Conference (ABC4). Next, a panel comprised

of Karen Benn, ED Deputy CEO / Head of Public Affairs; Cathy Ammendolea, CEO of Canadian Breast Cancer Network (CBCN); Catherine Priestley, Clinical Nurse Specialist of Breast Cancer Care in the UK; Rosanna D'Antona, President of ED Italy; and Nicole Zernik, President of ED France addressed successful MBC advocacy strategies and best practices in Europe, Canada, UK, Italy and France.

Initiatives discussed included MBC patients' needs as revealed in a new MBC blog page in Italy and a monthly face-to-face meeting of MBC patients organized by ED France. In addition, the barriers and opportunities policy makers face in MBC data collection in the UK were addressed.

In her presentation on *Successful MBC Strategies*, ED Deputy CEO Karen Benn underscored the importance of raising awareness of the needs of women with MBC among policymakers. She pointed out the support received from the European Parliament (EP) in July 2015, when the EP adopted the Written Declaration "On the Fight Against Breast Cancer in the EU" (0017/2015). The Written Declaration calls for the implementation of measures across Europe to fight this disease, which is the leading cause of death in European women aged 35 to 59. The declaration also calls for Member States to ensure that people with MBC have access to, and are treated in, a Specialist Breast Unit (SBU) and that

their ongoing needs for care and psychosocial services are coordinated and supported by the SBU, as per the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis (4th edition). This is a critically important point for which Europa Donna will continue to advocate strongly in the coming years.

On Saturday afternoon, advocacy skills training workshops, designed specifically for this event, provided participants with the tools necessary to communicate their messages effectively to the media and policy makers in their countries, using their personal stories. Several advocates were filmed recounting their MBC stories, and some of these videos can be found at <https://mbc.europadonna.org/advocates-speak-out>.

Sunday morning dealt with moving forward with MBC advocacy. Paige Robinson, ED's Development Officer, gave an overview of the Europa Donna MBC Web subsite <https://mbc.europadonna.org/>; Karen Benn reviewed ED's MBC advocacy toolkit <https://mbc.europadonna.org/introduction-advocacy-toolkit>;

and a panel consisting of Evi Papadopoulos, ED Vice President; Fatima Cardoso; Olivia Pagani, ED Board member and Director, Breast Unit Southern Switzerland, Institute of Oncology of Southern Switzerland (IOSI); and Susan Knox discussed news from ABC4, the ABC Global Alliance and the need for national MBC plans.

The conference closed with a special advocacy showcase where campaign videos, brochures and other materials developed and produced by organisations participating in the conference and specifically related to MBC, were spotlighted. Videos presented included ED Norway's "To Mummy", La Asociación de Mujeres Aragonesas de Cáncer Genital y de Mama's "Contigo" (Spain), Breast Cancer Care's series of four videos "Secondary, Not Second Rate" (UK), Canadian Breast Cancer Network's "Living Legacy: Our Lives with Metastatic Breast Cancer" and "Susan's Living Legacy", a video from Fadia Survive & Thrive Association (Europe, Middle East and Kuwait), Alianza Mexicana's "Joven e Fuerte" and a video of ED Austria's Rebecca Llewellyn demonstrating the power of singing in breast cancer patients.

MBC Survey 2017 Results: Identifying Unmet Needs

Europa Donna designed an eight-question survey for women attending the 1st ED Metastatic Breast Cancer Advocacy Conference; it is important to note that the data reported reflects the knowledge and personal experience of the individuals only.

Results

A total of 44 women from 27 countries responded to the survey, 24 of whom are advocates with MBC and 20 are high level MBC advocates who do not have MBC. Countries represented were Albania, Austria, Canada, Cyprus, Czech Republic, Estonia, Finland, France, Georgia, Israel, Ireland, Italy, Japan, Kuwait, Macedonia, Malta, Mexico, Netherlands, Norway, Romania, Russia, Slovenia, Spain, Sweden, Switzerland, Turkey and the UK.

Question 1: *How do most women with MBC in your country pay for their treatment?* To this, 31 responded the public health system (PHS) pays for treatment and 13 responded that it was paid for by: either PHS or private insurance (2); either PHS or women pay with own money (2); PHS or women pay or private insurance (2); PHS but some patients mix all of the aforementioned (1); PHS paid from Bank of Cyprus Oncology Center (1); PHS pays for most of treatment but it's not a rule (1); PHS covers half of treatment

costs (1); PHS but sometimes a combination of public, private and women pay for newer treatment (1); PHS and through private health insurance, which is mandatory and covers all (1); it depends—sometimes PHS but drugs are frequently missing (1) .

Question 2: *Do women with MBC find support and information regarding receiving financial assistance in your country?* 24 people responded yes, 15 responded no, 2 said they didn't know and one added in, "partly".

The sub-question of question 2 was for those who responded yes to the above: *explain where*. Responses included: government agencies, support groups, treatment centers, cancer associations, social security, in hospitals.

Question 3: *Do women with MBC find support and information regarding absence from work in your country?* To this, 24 people responded yes, 10 responded no, and 8 said they didn't know.

The sub-question of question 3 was for those who responded yes to the above: *explain where*. Responses included: their employers, social security, Web government, pension insurance/cancer aid, support groups, government agencies, cancer organisations, hospital social workers.

Question 4: *Do women with MBC find support and information regarding receiving home help in your country?* 20 people responded yes to this, 16 responded no and 5 said they didn't know.

The sub-question of question 4 was for those who responded yes to the above: *explain where*.

Responses included: support groups, the healthcare system, cancer associations and other charity associations, government agencies' social services, hospitals, pension insurance, and palliative care. Several noted that although services exist, people need to be made aware of them and that patients must ask for and claim such services. Some noted that services are available for some but not all.

Question 5: *Do patient organisations in your country provide women with information on MBC?*

To this, 37 responded yes, 5 responded no and 1 said she didn't know.

The first sub-question of question 5 was for those who responded yes to the above: *which organisations?* Responses included: Europa Donna (21 responses), oncology centre, hospitals, PA, CY, CAF, Bellio Young Cancer, cancer organisations, BUN breast cancer organisation, government organisations, Noi Ci Siamo, 1 out of 9, Ezes Mt, Zion, Tadiad Asociadiaoas, CBCN, Sja Rider, MILC, Salvatti, AMLC, Breast Cancer Care, MacMillan Cancer Support, Cancer Research UK, FECMA, GrupAgoto, AMCC Gemma, Alba, Patient Oncology Organisation, hospice, local PO, LPR, through medical conferences and teaching hospitals, Irish Cancer Society, Keating Foundation.

The second sub-question of question 5 was again for those who responded yes: *Please indicate which types of information:* thirty indicated emotional support, 23 practical guidance, 21 follow-up, 14 end-of-life care, 10 occupational and financial guidance. Other types of information added by respondents included: education support, clinical trials, drug navigation, survivorship issues, making difficult decisions, information provided on MBC sites, disease awareness, and publications, lectures and seminars.

Question 6: *Do women with MBC participate actively in your local breast cancer support or advocacy group activities/meetings etc.?* To this, 25 people responded yes, 13 responded no and 4 said they didn't know.

Several people who responded "no" added comments such as: "they don't want it being public", "for some a recurrence is a taboo" and "not yet; very sensitive issue". Others who responded "yes" added comments including: "very little though", "we do it but it can be better; we have to work on it", "some do but not as many as there could be", and "they are starting to."

Question 7: *Do you feel that your local breast cancer support or advocacy group adequately meets the needs of women with MBC for information and support?* 19 people responded yes, 20 responded no and 2 said they didn't know.

Several people who responded "no" added comments including: "it lacks resources and information", "still a lot of work to be done", "not enough", "we need to develop specific groups", and "these activities are good but more women throughout the country need support." Others who responded "yes" added comments such as: "work in progress", "but much more needs to be done", and "however, there need to be more opportunities for women with MBC to come together."

Question 8: *What are the most important things that need to be advocated for in your country regarding MBC?* Issues are listed as deemed most to least important:

- 1st Access to the best, most effective treatments financed by the public health system
- 2nd Better communication and engagement between patients and doctors
- 3rd National Cancer Registry that includes MBC
- 4th (tied) National guidelines for the treatment of MBC
- 4th (tied) Support for partners/carers of women with MBC
- 4th (tied) Service counselling and information availability through treatment centres
- 4th (tied) Financial support for those undergoing treatment
- 5th Employment support for those undergoing treatment
- 6th Need for better understanding of the disease from the lay public

For more information on MBC and Europa Donna:

<https://mbc.europadonna.org/>
and www.europadonna.org

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EUROPA DONNA - The European Breast Cancer Coalition,
is an independent, non-profit organisation whose members are affiliated
groups from countries throughout Europe.

The Coalition works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and care and increased funding for research. EUROPA DONNA represents the interests of European women regarding breast cancer to local and national authorities as well as to institutions of the European Union.



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