



# Perspectives on Advocacy for Women with Metastatic Breast Cancer:

## An Interim Report from the EUROPA DONNA Advocacy Leader Conference

22 September 2012 – Milan, Italy

### Advocating for improved care for women with metastatic breast cancer

Breast cancer is the most common type of cancer in European women and has the highest mortality of any cancer; however women with metastatic breast cancer (MBC) are fortunately living longer. Yet in many countries, all their needs and rights to high quality care are not being fulfilled. EUROPA DONNA – The European Breast Cancer Coalition – has brought the concerns of women with MBC to the forefront at every conference in which it has been involved in recent years and has made it an advocacy priority. Through the implementation of the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* – another of the Coalition's main priorities – the needs of these women can be met more effectively. The current guidelines call for women with MBC to receive care from a multidisciplinary team in a specialist breast unit holding regular advanced/metastatic breast cancer clinics. More requirements, as stated in the guidelines, are highlighted in the box below.

### The EUROPA DONNA metastatic breast cancer survey and other initiatives

With the objective of identifying the needs of women with MBC and the level of services available to them in member countries, EUROPA DONNA conducted an informal survey of its member fora. The results of the survey and other studies have clearly indicated that women with MBC are underserved in terms of being cared for in specialist breast units, by multidisciplinary teams including breast care nurses, having treatment guidelines, registry statistics, and are also underserved by support groups. To gather more information on these areas and identify solutions, workshops on the topic were held at the EUROPA DONNA Advocacy Leader Conference on 22 September 2012 and are provided herein. The Coalition has also led sessions on the topic at the European Breast Cancer Conference (EBCC) and is now a member of the Advanced Breast Cancer International Consensus Conference – ABC2 – Advocacy Committee.

### European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis, 4th edition

#### 9.7.6 Advanced and Recurrent Breast Cancer

- ▶ An advanced breast cancer clinic must be held once every 2 weeks at specialist breast units
- ▶ A breast oncologist and/or medical oncologist is to attend the clinic and a surgeon must be available if required
- ▶ All patients with advanced breast cancer or recurrence must be managed in this clinic according to protocols established by the multidisciplinary team
- ▶ Patients receiving radiotherapy or chemotherapy elsewhere should be referred back to the team at the advanced breast cancer clinic for follow-up and decision making
- ▶ Palliative care/pain control service must be easily accessible

#### 9.4.9 Breast units must provide care for all stages of breast disease, from screening to care for advanced disease

#### 9.5.2.5 Breast oncologists must hold advanced disease clinics with other members of the breast team at the breast unit

#### 9.5.2.8 Patient support staff, such as breast care nurses and psychologists specialised in breast cancer, should be available on demand at the advanced breast cancer clinic and should be present to support women when they are given the diagnosis that they have metastatic disease

#### 9.7.3 Multidisciplinary teams should discuss cases in follow-up that have undergone diagnostic testing for possible symptoms of advanced disease

#### 9.8.4 A specialist palliative care service must be available for referral of patients with advanced breast cancer. There must be a close working relationship between team members at the breast unit, especially breast nurses, and the palliative care service and home assistance network to ensure continuity of care



#### Participating countries

Austria  
Belarus  
Belgium  
Bulgaria  
Croatia  
Cyprus  
Czech Republic  
Estonia  
Finland  
France  
Georgia  
Greece  
Ireland  
Italy  
Kyrgyzstan  
Latvia  
Luxembourg  
Macedonia  
Malta  
Netherlands  
Poland  
Portugal  
Slovenia  
Spain  
Sweden  
Switzerland  
Tajikistan  
Turkey  
Ukraine  
United Kingdom

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- ▶ Findings from the EUROPA DONNA informal survey on metastatic breast cancer
- ▶ Conclusions from the Advocacy Leader Conference workshops on local and national support and advocacy for women with MBC

## EUROPA DONNA informal survey on metastatic breast cancer: key findings

### Responding countries

Albania, Belgium, Croatia, Cyprus, Denmark, Estonia, Finland, France, Georgia, Iceland, Ireland, Israel, Italy, Kyrgyzstan, Luxembourg, Malta, Netherlands, Norway, Slovenia, Spain, Sweden, Turkey, Ukraine, United Kingdom

A EUROPA DONNA informal survey of its member countries has indicated that further work is required to ensure that women with MBC receive the services that are stipulated in the EU guidelines. Of the 24 respondents, 16 countries claimed that women with MBC could return to the **specialist breast unit** where they were initially treated. Only one-third reported that women with MBC are given enough **support**, including psychological support, when they receive their MBC diagnosis.

The informal, unvalidated, 26-question survey was sent to EUROPA DONNA's 46 member countries with the aim of determining their knowledge of data, care, treatment and advocacy for MBC and identify potential areas to address in the future. Twenty-four ED member countries responded, with 75% answering the survey based on consultation with at least one woman with MBC. The most used and preferred term was "metastatic breast cancer" followed by "advanced breast cancer."

### Context and diagnosis

Regarding **MBC incidence**, 60% of the respondents reported that data are available, and in 45% of these, the information comes from the National Cancer Registry. Nearly 50% said that women are given information about MBC during their primary breast cancer treatment or during follow-up, in the majority. Half said MBC is detected by **screening** and nearly all said it was detected by **symptoms** or during follow-up. Of these, one country reported that the diagnosis could be delivered by telephone, while in the rest it was delivered in person. Only one-third of the respondents said that women with MBC felt that they were given enough information at the time of their diagnosis of MBC.

### Treatment and care

**Guidelines for MBC** were reported to exist in 40% of the responding countries, while others used international or the American Society of Clinical Oncology guidelines. Wide disparity was seen between countries with regard to support and information provided to women at diagnosis and during treatment.

Support at time of diagnosis	Yes	No
Women with MBC receive adequate support (including psychological support)	8 countries	12 countries
Women with MBC receive enough information at the time of diagnosis	8 countries	10 countries
Treatment starts in a timely manner	18 countries	6 countries (not always or don't know)
Women receive a written treatment plan	7 countries	—
Women are cared for by the same health professionals when they attend clinics	15 countries	—
Women diagnosed with MBC feel that they have received enough information about signs and symptoms which could indicate further disease progression	7 countries (+1 partial information)	5 countries (9 don't know)

### Support and advocacy

With regard to **support for family members** of those diagnosed, 14 countries said that the families receive support. Nearly all respondents, 22 of 24 countries, said that patient organisations support women with MBC. Just over 50% of countries said **local patient organisations** help with support and information on absence from work and home help, while 8 said this was not the case. In 80%, women with MBC actively participate in local breast cancer support or advocacy group activities; 45% claimed local breast cancer groups adequately meet the needs of women with MBC for information and support, although several added that this was difficult to judge.

Twenty countries agreed that there is a **need to advocate for special rights** for women with MBC with regard to information, treatment and counselling. All countries felt such needs and rights should be included in **national guidelines** on breast cancer treatment, and 21 countries said this should be included, in addition to treatment, in the next edition of the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*.

*There is a need to advocate for special rights for women with MBC with regard to information, treatment and counselling.*

## Workshops on local and national support and advocacy for women with metastatic breast cancer

### EUROPA DONNA Breast Cancer Advocacy Leader Conference

Milan, Italy  
22 September 2012

Results of workshops held at the Coalition's Breast Cancer Advocacy Leader Conference and involving National Representatives and delegates from 31 countries indicated that the response to the needs of women with metastatic breast cancer **varies greatly** among member countries. While some countries have launched activities to further identify the needs of women and to even provide information to women on the topic of MBC, some are still facing more fundamental issues such as lack of screening, breast services or public health care.

Some informal ideas and comments from the workshop groups included the following:

- ▶ Specialist breast units must care for women with MBC
- ▶ Women should always receive a written treatment plan both at first diagnosis and when they receive a MBC diagnosis. They should also receive a final report so they know where they stand when treatment is finished
- ▶ Women with MBC need to receive psychological support
- ▶ Well-trained specialist breast nurses should be available to provide support
- ▶ Advocates should provide support for patients' psychological health and to help bolster their will to survive
- ▶ Advocacy groups should ensure that professionals are aware of issues affecting women with MBC
- ▶ Education should be improved for doctors in communicating with patients regarding possible recurrence and risk of MBC
- ▶ Enrolment in clinical trials should be increased
- ▶ Medicines need to be available to all free of charge and government support needs to improve to provide treatment for all women
- ▶ Public awareness of MBC can be increased through advocacy

### Activities and materials on MBC available in EUROPA DONNA member countries

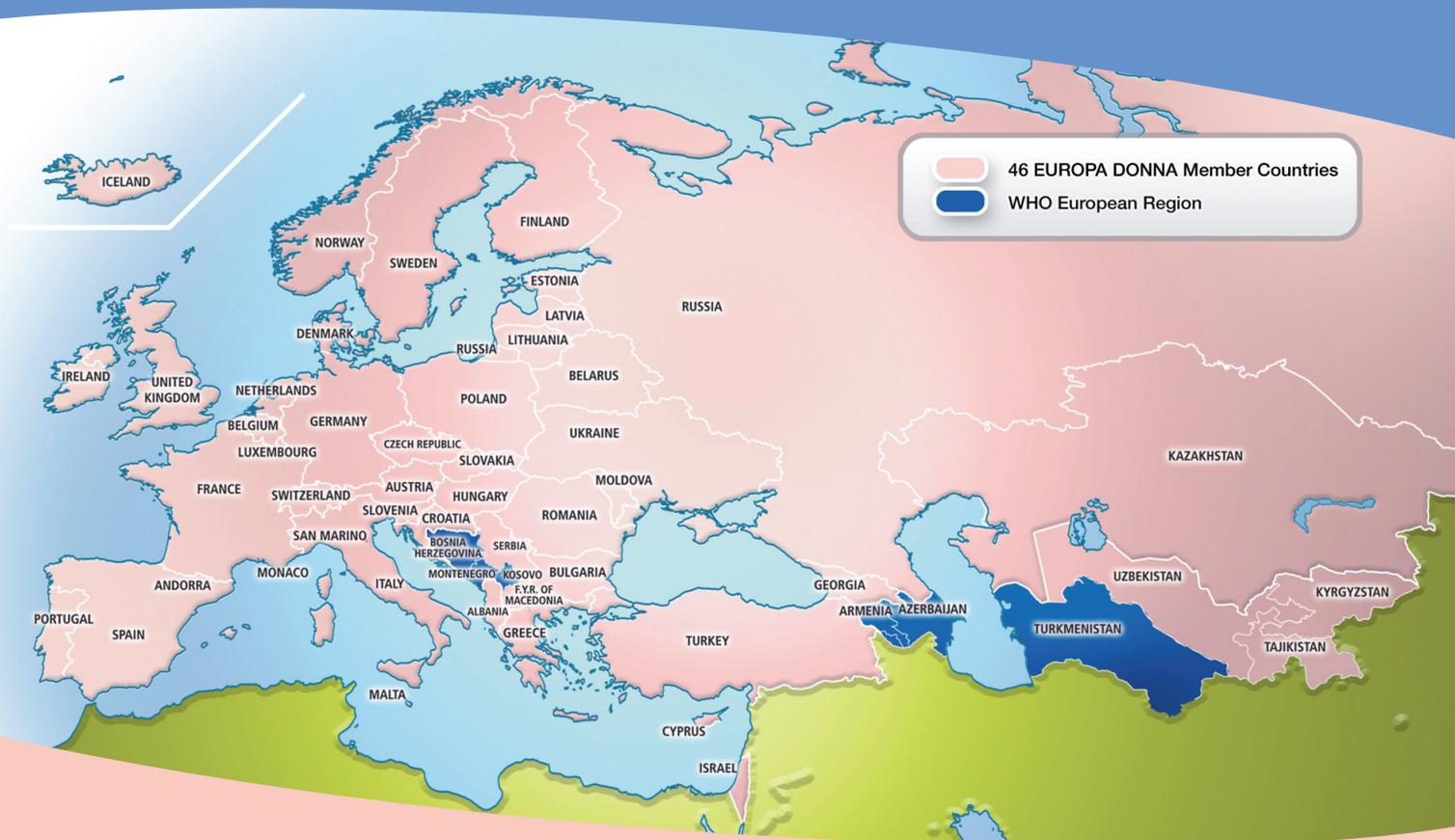
- ▶ Creation of a booklet on MBC containing information written by prominent doctors and psychologists. It is available in French on [www.europadonna.org](http://www.europadonna.org) and has also been professionally translated into Portuguese and English. Further translation is permitted if reviewed by patients and doctors and acknowledgement is given to the original authors (*ED France*)
- ▶ Translation of the UK booklet *Living with Advanced Disease* into Greek (*ED Cyprus*)
- ▶ A research study into the needs of women with MBC. Funding was secured and a research institute was appointed to contact doctors to identify the 100 women taking part in the study. Survey questions cover such areas as quality of life and needs (*ED Italy*)
- ▶ Monthly support group meetings with patients, a psychologist and volunteers (*ED Finland*)
- ▶ An annual support group for women with MBC involving a psychologist and an oncologist. Sweden has a five-point plan for MBC: 1) flexible working conditions; 2) psychosocial care; 3) support system; 4) written care plan; and 5) information about patient groups (*ED Sweden*)
- ▶ A special conference addressing women with MBC, their quality of life, work life and home life, as well as a short film on MBC available on [www.borstkanker.nl/europa\\_donna](http://www.borstkanker.nl/europa_donna) (*ED Netherlands*)

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## Workshop conclusions: areas for future advocacy

- ▶ Advocacy efforts to have the EU guidelines implemented must continue such that women with MBC are guaranteed care within specialist breast units
- ▶ MBC should be included in greater detail in the next edition of the EU guidelines
- ▶ Advocacy must be undertaken to improve awareness of the needs of women with this disease and reinforce their right to high-quality breast care
- ▶ Efforts must be taken to ensure that women with MBC have access to the latest and best treatments
- ▶ Advocates and women with MBC should have input into conferences dedicated to the needs of women with this disease



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[www.breasthealthday.org](http://www.breasthealthday.org)

[www.facebook.com/EuropaDonna](https://www.facebook.com/EuropaDonna)

<http://twitter.com/BreastHealthDay>

[www.youtube.com/BreastHealthDay](http://www.youtube.com/BreastHealthDay)



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