Breast cancer begins when abnormal cancerous cells in the breast grow and multiply without stopping, creating a tumour; metastatic breast cancer (MBC), a.k.a. advanced breast cancer (ABC) or secondary cancer in general means that the cancer has spread from where it started in the breast to other parts of the body. Although there is no cure for MBC today, there are better treatments that can lead to a longer life and a better quality of life. Women with MBC often face different challenges than women with earlier stages of breast cancer, and EUROPA DONNA – The European Breast Cancer Coalition (ED) has made MBC a priority focus in our strategic plan for 2014-2018. To this end, EUROPA DONNA’s Breast Cancer Advocacy Leader Conference, held in Milan, Italy on 24 September 2016, highlighted MBC. ED was also an advocacy partner in the Advanced Breast Cancer Second International Consensus Conference 3 (ABC3) which was held in Lisbon, Portugal in November 2015. Olivia Pagani, MD, Director of the Breast Unit of Southern Switzerland, Institute of Oncology of Southern Switzerland and ED Board member, provided an overview on research and new treatments for women with MBC at the 2016 Advocacy Leader Conference in which she presented research results from ABC3 and recommendations concerning endocrine therapy and the addition of the CDK4/6 inhibitor, HER2-directed therapy and triple negative ABC.

A special session for advocates with MBC was held during ED’s 2016 Advocacy Leader Conference and was attended by 16 women with MBC from 15 countries: Albania, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Ireland, Italy, Luxembourg, Malta, the Netherlands, Norway, Russia, and Turkey. The following is an overview of this session. First, ABC3 patient advocacy committee member and ED Vice President Evi Papadopoulos discussed recent advocacy developments in MBC, including the Advocacy Session of the ABC 3rd international consensus conference for advanced breast cancer, the findings of the Global Status of Advanced/Metastatic Breast Cancer 2005 – 2015 Decade Report, an overview of the Here & Now campaign and MBC Alliance’s Dandelion Report. It is essential to ensure that all our countries are aware of current developments and initiatives to improve awareness and outcomes in MBC and the importance of the implementation of best practice in MBC across Europe.

Overviews are also given of presentations by ED Italy on its Blogging Project “Fight, Live, Keep Smiling”, ED Czech Republic’s support projects for women with MBC, and the development of an MBC section of the EUROPA DONNA - The European Breast Cancer Coalition website. Finally, the results of a discussion on how to move forward regarding MBC advocacy held at the Advocacy Leader Conference for 16 women with MBC and the results of a survey completed by these participants are outlined.

The following is an overview of recent important events and initiatives that aim to support people with metastatic disease, as seen from the patient’s perspective:

**3rd International Consensus Guidelines for Advanced Breast Cancer – ABC 3**

ABC (Advanced Breast Cancer) Conferences were initiated by ESO (European School of Oncology), supported by ESMO (European Society for Medical Oncology), under the auspices of The Breast Cancer Research Foundation, OECI (Organisation of European Cancer Institutes), and UIICC (Union for International Cancer Control), and are endorsed by many societies, including EUSOMA (European Society of Breast Cancer Specialists), FLAM (Federación Latinoamericana de Mastología) and SIS (Senologic International Society). The EUROPA DONNA coalition is deeply involved; a number of ED leaders attended ABC1 and the Coalition served on the newly developed Advocacy Committees for ABC2 and 3. Below is the key point Evi Papadopoulos highlighted from the conference, in terms of advocating for people with MBC.

From the consensus guidelines developed at ABC3: “Following a thorough assessment and confirmation of MBC, the potential treatment goals of care should be discussed. Patients should be told that MBC is incurable but treatable, and that some patients can live with MBC for extended periods of time (many years in some circumstances). This conversation should be conducted in accessible language, respecting patient privacy and cultural differences, and whenever possible, written information should be provided.” (Level of Evidence: expert opinion) (97%)  

For additional information: [http://www.abc-lisbon.org/](http://www.abc-lisbon.org/)

**Developments in MBC: An Overview Of Events and Support Initiatives**

**Speaker:** Evi Papadopoulos, Vice President, EUROPA DONNA

**Facts and Needs**

Patients with MBC are surviving longer today than in the past due to treatment improvements, but they still have many unmet needs. Advocacy priorities for MBC include issues such as drug availability, patient access to drugs and specialised care, psychosocial support, quality of life, and the need for information.

**Metastatic Breast Cancer 2005-2015 Decade Report:** This report was developed by Pfizer, working collaboratively with the European School of Oncology (ESO) and within the scope of ABC3. It outlines the baseline from which emerging recommendations can be developed, to advance care and outcomes for patients with MBC over the next 10 years. Below is Evi’s summary of important points for MBC advocates from the 2015 report:
GLOBAL MBC FACTS AND FIGURES

- MBC is the most advanced stage of breast cancer, where the cancer has spread from the breast to other parts of the body
- 1.7 million new cases of breast cancer were diagnosed in 2012 worldwide (IARC, Breast Cancer, 2015; Lu, 2009)
- 5-10% of patients are diagnosed at the metastatic stage of the disease (Cardoso, 2012) with as many as 50-80% in developing countries (Unger-Saldana, 2014)
- While data are lacking, some studies have found that approximately 20-30% of early breast cancer patients may recur with MBC (O’Shaughnessy, 2005; EBCTCG, 2015)
- Median survival for MBC is 2-3 years (NCI SEER, 2015; Weide, 2014; Lobbezoo, 2013)
- It is estimated that 561,334 breast cancer deaths occurred worldwide in 2015, primarily from MBC. By 2030, the number of deaths is estimated to reach 805,116, representing a 43% increase in absolute number of breast cancer deaths. (World Health Organization, 2013)

Key Findings:

1. Patient and caregiver understanding of MBC are often limited at the moment of diagnosis. The degree to which understanding of MBC increases is varied, generally being more restricted for those with lower education levels
2. Patients focus on maintaining a sense of self and hope. Focus is on MBC rather than perceptions of others
3. Patients feel very well-supported by family and close friends. Close networks of family and close friends tend to strengthen upon MBC diagnosis
4. Burden on caregivers can be high, with little opportunity to express their own feelings. Minority mentions of patients not being aware of diagnosis, increasing burden on caregiver

Report Conclusion:

While there have been efforts to advance the management of MBC, considerable room for improvement in patient care remains. Patient care and support needs evolve along the care continuum and include: information and communication needs, decision-making, quality of life and daily living, supportive care, and end-of-life care. Improvements in all of these areas can allow patients to lead more fulfilling lives.

For additional information:

MBC Alliance Dandelion Report / Metastatic Breast Cancer Communications Toolkit: The Dandelion Report is a project that aims to aid health professionals in guiding their MBC patients in making health decisions through the use of a set of visual tools. These visual tools are used to communicate in a time effective way, they are designed to appeal to a wide demographic of metastatic breast cancer patients of various literacy levels and they increase patient engagement despite the emotional distress that most MBC patients experience at the time of diagnosis.

For additional information:

Here & Now Campaign: Here & Now is a pan-European MBC awareness initiative launched in 2013 by Novartis Oncology. Through a series of activities, Here & Now aims to raise awareness of MBC and the realities of living with the disease, in order to improve the level of care and support available.

For additional information: http://wearehereandnow.com/

European Policy Initiatives on Breast Cancer/MBC

Although many EU initiatives on health are at a horizontal level (i.e. focused on health in general rather than specific diseases), cancers with high incidence rates – including breast cancer – have received targeted action in recent years. Until now, early stage breast cancer has been the primary focus of EU policy initiatives. Moving forward and capitalising on the success of these initiatives, much can and should be done at a policy level to raise awareness of MBC, address these patients’ unmet needs, and facilitate their access to support, care, and treatment options. Key EU policy milestones on EBC and MBC to date are:

- Written Declaration on the Fight Against Breast Cancer in the European Union (2015): On July 22, 2015, the European Parliament adopted the written declaration “On the Fight Against Breast Cancer in the EU” (0017/2015), which calls for the implementation of measures across Europe to fight this disease, the leading cause of death in European women aged 35 to 59. A majority of Members of European Parliament (MEPs) signed the declaration, which was co-authored by 10 MEPs and backed by EUROPA DONNA. Among other measures, the declaration 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)

- The Written Declaration of 2010 called on the European Commission to implement an accreditation protocol to ensure that breast units across the EU are meeting the standards described in the EU Guidelines by 2016. The European Commission has set up the ECIBC (European Commission Initiative on Breast Cancer) to carry this out. This project will define a quality assurance programme that can be implemented by countries covering the entire breast cancer pathway from screening and diagnosis to treatment, rehabilitation, follow-up and palliative care. Services and support needed for MBC patients will be included in this project and implementation should begin in 2019

- A recent European Parliament motion for a resolution on the EU Strategic Framework on Health and Safety at Work 2014-2020, which was backed by the European Patients’ Forum and called on Member States to put more focus on integration of people with chronic and long term conditions at the workplace, and urged the European Commission to promote integration and rehabilitation measures for people with disabilities and to support Member States’ efforts by raising awareness and sharing good practices on accommodations and adjustments in the workplace. While not legally binding, the text paves the way for more recognition of this issue at EU level.

Unmet Needs of Women with MBC

Evi concluded her presentation by outlining her assessment of the most pressing unmet needs of women with MBC. They include the need for:

- Greater public awareness and visibility within the breast cancer community
- Better treatments that may help extend life and delay progression of the disease
- Information and support for people with the disease and living with MBC on a daily basis
- Greater investment in MBC research & development and more effective treatments
**Blogging Project “Fight, Live, Keep Smiling” - ED Italy - How it works; how it helps**

Speakers: Tiziana Moriconi, Galileo Editorial Services, Salute Seno and Barbara Bragato, ED Italy

Tiziana Moriconi and Barbara Bragato spoke about their successful blog project, “Fight, live, keep smiling,” the first Italian blog about metastatic breast cancer whose target audience is the general public in addition to women with MBC.

**Background**

Metastatic breast cancer patients are often younger women, and many of them have a job, a family and children. Despite this, little is said about their stories and needs in the media; advanced cancer is still a taboo subject in Italy. In order to address this situation, five women from the EUROPA DONNA Italy MBC Working Group created a blog on the website of D la Repubblica, one of the most popular women’s magazines in the country.

The editorial plan called for five women with MBC from different regions of the country willing to tell their stories of living and disease through the medium of the blog, one of whom is Barbara Bragato. There was to be one blog coordinator (journalist Tiziana Moriconi) and 16 scheduled posts, to be published one day a week.

The initial posts started in January 2014 and dealt with topics including: the discovery of having MBC; choices that needed to be made—what to do; where; psychological issues and tiredness; “ongoing life”; MBC patients’ rights and bureaucracy; motherhood and the children impacted; sex; family and supporters; life on the Internet; the metastasis; the economic crisis and the healthcare system in Italy; the doctor-patient relationship; communication issues; the lack of information about therapies; clinical trials; and MBC advocacy.

The project was so successful that D la Repubblica chose to carry it forward after the first 16 posts were published. At the present time, this blog is one of the largest online self-help communities dedicated to the needs of advanced/metastatic breast cancer patients in Italy. The goal is to tell stories of life with MBC, and to get in touch with many of the 30,000 MBC patients who live in Italy today.

**Data**

Since the blog was created in January 2014, it collected approximately 1,000 comments as of September 2016, and the blog has had 16,000 page views per month (source: Wevtrek).

A reader’s comment to the bloggers, 13 May 2014: “The most beautiful and the most important thing you have emphasized is this: we die because of cancer, but we can also live with it. Cancer is not a death sentence as it is always seen, but it is a different way of living.

If today I see this terrible disease as curable, it is thanks to your concrete example: a positive life is possible. You were able to go beyond the pain, the fear, and starting from this point, I have improved my way of handling the disease. You are, indeed, the warriors that we should be and could be.

I told friends and relatives about you, and I hope they are reading this blog because your journey is full of hope, but it is also real. A reality that may be scary, but it is not dark. I believe that as you have helped me, you can help many other women.”

**Related MBC Projects Run by ED Italy**

- Have a coffee with the bloggers: itinerant meetings about MBC
- Faces of the Bloggers, a photographic exhibition by Elena Datrino
- MBC Community Italy
- Poster Presentation: a semantic analysis of all the comments collated from the blog, presented at the ABC3 Consensus Conference in 2015

**ED Czech Republic Support Projects for Women with MBC:**

**Speaker: Marta Kostrová, ED Czech Republic**

**Background of the MBC Support Projects**

ED Czech Republic began to actively support women with MBC after attending the Here & Now: Invisible Women Novartis MBC campaign event held in Brussels in 2013, which unveiled the impact of advanced breast cancer on women, families, society and the economy across Europe, and after receiving feedback from a workshop with 40 local participating organisations at the ED Czech Republic-Alliance of Women with Breast Cancer Annual Conference.

**MBC Issues and Focus for Advocacy**

The main issues faced by women with MBC in the Czech Republic are the need to better understand the disease, the need for high quality medical and psychical care, the need for information and a better quality of life, and the need for greater societal awareness of the disease.

ED Czech Republic’s main focus for MBC is on: providing information (scientifically verified information about the illness, treatment options, getting a second opinion, participating in clinical trials, research on MBC, and social welfare programmes); support/help available for people with MBC (psychical and material help to increase quality of life); and making MBC patients and their problems visible to the larger public.

**MBC Initiatives**

ED Czech Republic provides information on MBC directly to women through a leaflet offering help and support for women with MBC and through its website: http://nevidi.telnnezeny.cz/cs/. The forum has also translated into Czech language the Metastatic Breast Cancer Annex to the Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis, published by EUROPA DONNA – The European Breast Cancer Coalition. This annex outlines best practice for MBC as defined in the EU Guidelines and this is therefore the document can be used to advocate for improved services throughout Europe. ED Czech Republic actively seeks to learn the latest scientifically proven information at the international level through ESMO congresses, EBCCs, ED Advocacy Leader Conferences and Pan-European conferences in order to spread it widely to its own stakeholders.

Primary activities carried out include: educational seminars for MBC communicators, each specialized in certain aspects of the illness (medical care, social care, psychological care, nutrition); afternoon meetings with a psychologist include patients and their close friends or relatives; weekend meetings for MBC patients and their friends with lectures, discussions, and individual consultations with oncology professionals, leisure time activities, and networking; participation of women with MBC in international conferences organized by ED.
Professional help is provided on ED Czech Republic’s website and Facebook, and the translation of brochures concerning issues of MBC including the ED MBC Annex to the Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis.

Help is provided by local communications who run a 24-hour helpdesk operated by the MBC Project psychologist. The Alliance also includes women with MBC in lobbying the Ministry of Health, for example in its advocacy for specialized onco-psychologists. Furthermore, the Alliance is cooperating with another NGO, Amelie, o.s., to organise a self-help scheme with ten psychological education workshops for MBC patients in different Czech towns.

**Planned Activities**

Activities planned for the future include a meeting of patients from other areas, a seminar to educate MBC communicators on various aspects of the disease, a weekend meeting of MBC patients in Moravia, My Story: What Helped Me articles by MBC patients to be published on the website, and a new programme in which families of MBC patients can contact the MBC Project psychologist through a help line.

## New MBC Section of EUROPA DONNA Website

**Speaker:** Paige Robinson, Development Officer, EUROPA DONNA – The European Breast Cancer Coalition

EUROPA DONNA – The European Breast Cancer Coalition is in the process of creating and designing a new and substantial section on the ED website www.europadonna.org dedicated to MBC. The goals of this section are to deliver targeted advocacy messages, to provide advocacy tools related to MBC, and to increase societal knowledge about MBC.

### Background

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 has made MBC a priority focus in our strategic plan for 2014-2018. To this end, 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-Europe Conference programmes, as well as workshops for women with MBC at our Advocacy Leader Conferences of 2014 and 2016.

EUROPA DONNA has also served on the Breast Cancer Patient Advocacy Committee of the Advanced Breast Cancer Conferences 2, 3 and 4. We have produced several publications highlighting the needs and concerns of women with MBC and are actively engaged in advocating for the rights of women with MBC at European institutions: the European Parliament, Council of Europe and European Commission.

As indicated earlier in this document, ED is working with Members of the European Parliament to improve breast cancer services and to raise awareness of the needs of women with MBC. On July 22, 2015, the European Parliament adopted the written declaration “On the Fight Against Breast Cancer in the EU” (0017/2015). A majority of Members of European Parliament (MEPs) signed the declaration, which was co-authored by 10 MEPs and backed by ED. Among other measures, the declaration calls for Members 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.

In 2013 EUROPA DONNA published the Metastatic Breast Cancer Annex to the Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Diagnosis. This annex outlines best practice for MBC as defined in the EU Guidelines and this is therefore the document we use to advocate for improved services throughout Europe. It has now been translated into Portuguese, Czech and German languages and is currently being translated into Italian.

### MBC Section of the ED Website

Since this workshop, the MBC section of the EUROPA DONNA website has been published and can be viewed at http://mbc.europadonna.org/. It highlights the following:

1) An introductory MBC page including background information on the policy basis for EUROPA DONNA’s work on MBC, with information on and links to the ECIBC project and to the European Parliament’s Declaration on the Fight Against Breast Cancer in the European Union

2) The following categories that can be clicked on and explored in-depth:
   - About MBC: facts and statistics for breast cancer advocates regarding MBC, including points that are not well understood
   - Challenges: issues MBC patients often face with their health care providers, psychosocial support and other important matters including family, work and social stigma
   - Addressing the Issues: strategies to address issues with MBC
   - Resource Library: providing resources specific to MBC including information on clinical trials, guidelines, reports and publications, current MBC activities run by ED fora, MBC advocacy organisations and organisations with strong MBC programmes, a glossary of commonly used MBC terms
   - Advocacy Toolkit: ED provides a toolkit which has been designed as a guide to help advocates develop a dialogue with legislators, to get important policy changes made, and to carry out their ongoing campaigns to raise public awareness about Metastatic Breast Cancer.
   - Advocates Speak Out: brief video and written interviews covering advocacy issues that need to be addressed

ED has posted a link to Third International Concensus Guidelines for Advanced Breast Cancer (ABC3) on our website at http://mbc.europadonna.org/guidelines-on-mbc
Developing Consensus on Next Steps: Discussion with all Participants on How to Move Forward
Facilitators: Evi Papadopoulos and Paige Robinson

The major issues continue to be around lack of support and feelings of “invisibility” in terms of the breast cancer world, though clearly improvements have been made over the last few years, and some of the ED groups are particularly supportive. Some ED organisations now offer special “sub-groups” for MBC women, along the lines of the young women’s groups, and some women have access to specialized MBC groups through other breast cancer organisations in their countries. Online social networks are extremely important for some women with MBC and can help with their feelings of isolation. There was debate as to whether it is more beneficial to host closed groups that are only for women with metastatic disease or if it is better to keep open groups available to all.

Issues discussed that were deemed to be of particular importance to be addressed through advocacy and as appropriate on the ED MBC section of the website are:

1. **Data collection** – data on MBC is lacking; numbers are unknown; if you don’t know the size of the problem you can’t provide adequate services. Barriers to starting data collection in European countries include lack of money for data managers to institute and maintain data collection systems as well as privacy issues. ED should advocate for improved data collection and the resources and cooperation necessary for this; we should ensure this is included in future health policy demands

2. **Communication with doctors** – often doctors do not communicate well with patients, especially when they are giving an initial diagnosis of MBC. Terminology and the way things are said are very important. When speaking with patients, doctors have to move away from terminology of science and use words that are more understandable to patients and their families. Open, honest and compassionate communication is important; doctors should tell patients that MBC is incurable but treatable and immediately give patients an arsenal of weapons to fight the disease. Doctors should give patients the prospect and possibilities to go on

3. **Invisibility and isolation** – In breast cancer support and advocacy groups there is a danger of invisibility (when others do not want to understand the gravity of MBC and refuse to see it) and/or isolation of women with MBC (when they are sequestered to a different group); although having separate MBC meetings and groups can be very positive and helpful, all breast cancer organisations must also maintain a united front with everyone standing together as equals. Likewise, there should not be separate breast units for women with MBC and other countries can also participate.

ABC Global Alliance

In closing the session, Evi announced that an ABC Global Alliance is currently being formed and a Call to Action will be made. EUROPA DONNA – The European Breast Cancer is among the founding participants. The ABC Global Alliance, established by the European School of Oncology (ESO), is a multi-stakeholder platform for those interested in collaborating in common projects relating to advanced breast cancer (ABC) around the world.

MBC Survey 2016

EUROPA DONNA designed a 16-question survey for women with MBC attending the Advocacy Leader Conference in September; it is important to note that the data reported reflects the knowledge and personal experience of the individual ED members with MBC only.

The survey was divided into:

- Information and support for people with MBC – what kinds of information and support are available and from what organisations?
- Advocacy for people with MBC – what are the most important things that need to be advocated for in different countries? What kinds of information can ED provide to help MBC advocates? How do people pay for treatment?
- Public awareness of MBC – What, if anything, does the public need to understand better about MBC? Does breast cancer advocacy focus too much on early breast cancer? Should ED declare October 13th as MBC Awareness Day?

**RESULTS**

A total of 16 women from 15 countries responded to the survey. Countries were Albania, Croatia, Cyprus (2), Czech Republic, Estonia, Finland, France, Ireland, Italy, Luxembourg, Malta, The Netherlands, Norway, Russia and Turkey.

**Information and Support for People with MBC (Questions 1 – 4)**

Question 1: Do patient organisations in your country provide women with information on MBC? To this, 10 responded yes, 3 responded no, and 2 said they did not know. Some of those who responded yes added that while information is provided, it is “very little”, “a few [patient organisations] do [provide information], with very few words,” and, “yes, but could do more”. One country commented, “yes, but MBC is not very well recognised”.

The sub-questions of question 1 were for those who responded yes to the above: which organisations provide services and which type of information do they provide? People responded citing their national ED organisations, medical centres, and other cancer support organisations:
ED Cyprus, the Oncology Centre; ED Ireland, Marie Keating Foundation, Irish Cancer Society; Breast Cancer Organisation and the Norwegian Cancer Society; Alliance of Women with Breast Cancer; Club Women”UN7”VINnovci; Breast Cancer Organisation; ED Malta and Oncology Hospital and Nurse Support; ED Finland; ED France.

Type of information provided includes: emotional support (8 countries); follow up (5 countries); practical guidance (5 countries); occupational and financial guidance (2 countries); end of life care (1 country). Three people cited other information, including advocacy and a forum to meet other MBC patients “Connect MBC Network”, education materials and meeting, and an MBC brochure and discussions during Café Donna.

Question 2: Do women with MBC find support and information regarding absence from work in your country? 5 people responded yes, 10 responded no and 1 said she didn’t know. Those who responded in the positive were then asked to explain where: they cited unions, government agencies, and support groups. Two people noted that in their countries that this support exists but people with MBC must search for it themselves, the information is not readily available.

Question 3: Do women with MBC find support and information regarding receiving home help in your country? 5 said yes, 6 said no and 4 didn’t know. Those who responded positively were asked to name where they could find this support. Responses varied. One said, “There is little available help available at breast clinics and bigger hospitals”. Another noted, “Often there is more financial help, I think. Families with children can get help during the time the mom gets chemotherapy. But no one offers you that; you have to ask for help.” Others said help could be found in the local community and in community meetings as well as on the website Invisible Woman.

Question 4: Do women with MBC find support and information regarding receiving financial assistance in your country? 5 responded affirmatively, 10 negatively and 1 didn’t know. Those who responded yes were asked to explain where people find this support and information. Answers included government agencies, hospitals and through support groups. In one country oncology doctors recommend charity foundations who support metastatic cancers.

Support Offered by Local Breast Cancer Support and Advocacy Groups (Questions 5 – 7)

Question 5: Do women with MBC participate actively in your local breast cancer support or advocacy group activities/meetings, etc.? Although 7 responded yes, their comments were mixed: “Yes but not everyone definitely”, “Yes and no”, and “I am the only one as far as I know”. Another wrote, “There are a few MBC women at the Cafes Donna who actively participate in the group discussions”. 6 responded no and 2 didn’t know.

Question 6: Do you feel that your local breast cancer support or advocacy group adequately meets the needs of women with MBC for information and support? Significantly, only 4 responded yes, 9 said no, and 1 didn’t know.

Question 7: In your opinion, what could your local breast cancer support or advocacy group do better (if anything) to support women with MBC? Answers were as follows:

- Awareness, psychological support, information
- Have at least one advocate specialised in MBC and be able to answer questions or address needs that might occur
- Give some support and advice on how to cope with new circumstances, how to manage with fear about the future. How to address financial challenges. How to play important part to become healthier (reduce stress level, improve your diet, exercise, etc.)
- Facebook to link patients has just begun and that is very good. We need the support centres to promote this. A yearly meet-up of MBC patients on October 13th would help bring people together and not feel so alone
- Let patients know that we exist and that they are not alone
- Organise more meetings for MBC patients and with family members
- Involve the whole family/partner; MBC blogs in my country to meet other MBC patients
- Support groups online or in-person; provide a website on MBC (facts, FAQs)
- Promote it more on a country level as I myself who search and try my very best to collect information was not very aware of the disease. Promote: “Fight, live, keep smiling”
- Cover the lack of information with website or leaflet
- Try to advocate to assess an actual key fact figure: how many MBC women are we in each country? MBC women shouldn’t remain a percentage. It’s the preliminary effort to become visible

Advocacy for People with MBC (Questions 8 – 10)

Question 8: What are the most important things that need to be advocated for in your country regarding MBC? Answers appear below starting from highest ranked:

1. Access to the best, most effective treatments financed by the public health system
2. Need for better understanding of the disease from the lay public
3. Support for partners/carers of women with MBC
4. Better communication and engagement between patients and doctors
5. Service counselling and information availability through treatment centres
7. National Cancer Registry that includes MBC
8. Financial support for those undergoing treatment
9. Employment support for those undergoing treatment
10. Information about self-help, support groups with fellow MBC patients

Question 9: What information can we provide on EUROPA DONNA’s website that would be helpful to your MBC advocacy work? Answers appear below starting from most often cited:

- Cited 13 times: Publications on MBC; Dictionary of commonly used MBC terms
• MBC does not mean that you are dying; there are
• That people can live with this disease with a good quality
• The most common misconception is that everyone
• Not curable, but treatable
• That it is incurable but you can live for a long time!
• That it is an incurable, chronic illness. That 20-30% of
• How people who don’t have MBC should react to the
• To support and accept women with MBC
• Many people don’t want to know as if it is never going to
• Clinical trials; that MBC is a disease with which people
• What it is, what to expect if you or a loved one has MBC
• That we are living, we have hope and have a future
• Diagnoses of which people live and not only die
• Many people don’t want to know as if it is never going to
• But access to information beforehand prepares one better for a diagnosis
• To support and accept women with MBC
• That an MBC patient can live for years with the new
drugs and treatments
• How people who don’t have MBC should react to the
news and support MBC patients
• That it is an incurable, chronic illness. That 20-30% of
people diagnosed with EBC early will go on to get MBC
by no fault of their own
• That it is incurable but you can live for a long time!
• Not curable, but treatable
• What it means: physically and emotionally and how it
invades your life
• The most common misconception is that everyone
survives breast cancer and even from MBC
• That people can live with this disease with a good quality
of life and also for a long time
• MBC does not mean that you are dying; there are
thousands of people living (many) years with MBC;
progress is achieved on survivorship and quality of life

Public Awareness of MBC (Questions 11-16)
Question 11: Is there a need for better understanding of MBC by the public? Significantly, all 16 people responded affirmatively.
The sub-question following 11 was: If yes, what does the public need to understand better about MBC? Answers were as follows:
• What it is, what to expect if you or a loved one has MBC
• That we are living, we have hope and have a future
• Clinical trials; that MBC is a disease with which people
live and not only die
• Many people don’t want to know as if it is never going to
happen to them. But access to information beforehand prepares one better for a diagnosis
• To support and accept women with MBC
• That an MBC patient can live for years with the new
drugs and treatments
• How people who don’t have MBC should react to the
news and support MBC patients
• That it is an incurable, chronic illness. That 20-30% of
people diagnosed with EBC early will go on to get MBC
by no fault of their own
• That it is incurable but you can live for a long time!
• Not curable, but treatable
• What it means: physically and emotionally and how it
invades your life
• The most common misconception is that everyone
survives breast cancer and even from MBC
• That people can live with this disease with a good quality
of life and also for a long time
• MBC does not mean that you are dying; there are
thousands of people living (many) years with MBC;
progress is achieved on survivorship and quality of life

Question 12: Do you feel that breast cancer advocacy focuses too much on early breast cancer and survivorship and not enough on MBC? To this, 11 people responded yes, 2 said no and 3 don’t know. Several people followed up on their answers with comments. After responding yes, some said: “MBC is the abandoned part of (breast) cancer; positive and hope-related information is not very available, nor emphasised”; “Not all breast cancer is curable!”; and “Let’s do more to expand the breast cancer conversation to include MBC.” One person who responded no added: “I think it’s good that they focus so much on EBC since we have a large number of patients dealing with this. But I also think it’s about time to start to focus on the small number of MBC people who have no one taking care of them. They can’t get any information or advice about their questions and worries.”

Question 13: Do you think an MBC Advocacy Summit meeting involving ED and non-ED countries would be beneficial at this time? To this, 13 people responded yes and 3 said they didn’t know. Two who responded yes added that it would be a positive step to share experiences and information.

Question 14: Some patient organisations in European countries have chosen to declare October 13th as MBC Awareness Day. Do you think EUROPA DONNA should do so? Eleven responded yes, 3 no and 2 don’t know. Doubts included: “Not necessarily as awareness should be 365 days a year”; “As we have 15th of October as BHD we would confuse the public”; and “I don’t think efforts should be put behind communication that is only communication.”

Question 15: Have you already participated in EUROPA DONNA’s Advocacy Training Course? This course is designed to train new breast cancer advocates and covers various areas of importance including diagnosis and treatment of breast cancer, to learning effective communication and public speaking skills, lobbying techniques and media training. Presentations are delivered by leading European experts. Five respondents answered yes and 11 no.

Question 16: Are there other messages that should be conveyed about MBC to people in your country? Responses included the following:
• Plenty, since this is my first involvement I cannot say
that I’m an expert but I would be happy to learn and
get more knowledge to share with people who have my
condition as I do not feel sick
• Patients with MBC need some extra support: financial
and emotional. We need to look at it as a chronic illness
and with that comes the need for other help. I propose
that communities come together to help patients by
doing odd jobs around the house
• Try to advocate to assess an actual key fact figure, like
how many MBC women are we in each country? MBC
shouldn’t remain a percentage. It’s not virtual.
This would be the preliminary effort to become visible
• Do not push patients away. Address them as people with
MBC but not as bodies with cancer!! (This goes for the
doctors too)
• I think that MBC patients are indeed an invisible group
that needs more attention. If the pain is not physical,
there always remains the emotional pain

1st EUROPA DONNA MBC Advocacy Conference 9 - 11 June 2017
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.