

Highlights from EUROPA DONNA's 1st Metastatic Breast Cancer Advocacy Training Course



28-30 September 2018 Milan, Italy

EUROPA DONNA – The European Breast Cancer Coalition's 1st Metastatic Breast Cancer Advocacy Training Course provided training on current advocacy priorities and gave participants the chance to share strategies to advocate with and for other women with metastatic breast cancer (MBC). At the introductory session, the 37 MBC advocates from 26 of ED's 47 member countries gave a brief history of their personal fight against MBC and as advocates. Many of them had been living with MBC for 3 or 4 years, while some for much longer, and a number had been diagnosed de novo. Most were older, but many were young – diagnosed at 27 and with MBC at 33, for instance. They had metastasis to the liver, bone, lung, stomach, among other sites, and most reported that they were now "doing fine". Some were running blogs, writing books, and accompanying other women through the journey of MBC. All were advocates gaining strength and knowledge from each other and the course materials: sessions on treatment, access to treatment, work issues, breast cancer registries, advocacy tools and communications training. EUROPA DONNA has made MBC an advocacy priority and is involved in multiple initiatives in Europe, internationally and at a local level to address the unique needs of this group of women. By training women with MBC, more women who know the issues first-hand will be prepared to advocate on behalf of women with this disease. This report highlights some of the main messages from the course.



1st Metastatic Breast Cancer Advocacy Training Course participants.

The basics of MBC treatment and biosimilars

Olivia Pagani, Director of the Breast Unit of Southern Switzerland, and member of the ED Executive Board, said that while MBC cannot be cured it can be treated. The treatment depends on many factors such as patient age, tumour characteristics, metastatic spread and sites, and previous treatments. In HER2-positive disease, anti-HER2 therapy should be offered early. In those with oestrogen-receptor positive MBC, she said that endocrine therapy is the preferred choice as it has less toxicity than chemotherapy. Where chemotherapy is needed, the ABC guidelines call for it to be given one agent at a time because this approach is effective and has less toxicity than combination chemotherapy. Women with MBC may need to be on treatment for long periods of time, so tolerability is a key consideration. She emphasised the need for evidence-based medicine and individualised treatment.

In this new era of biosimilars, Dr Pagani outlined the topic for advocates using the case of trastuzumab. Biosimilars are designed to be "copies" of biologic drugs (ie, a drug derived from living cells). They aim to be essentially the same as their reference biologic or originator but have a degree of natural variability. For a biosimilar to receive regulatory approval it has to prove that it is equivalent to the originator. This means that the clinical trial process is shorter for the biosimilar than for the originator, which should make the biosimilars available more quickly and, most importantly, help to provide drugs that are about 30% less expensive than the originator. She added that like any drug, biosimilars need to undergo pharmacovigilance (ie, a process of long-term reporting of adverse events) to ensure safety.



Getting patient groups involved in HTA

Tamás Bereczky, the Communications Officer for the European Patients' Academy on Therapeutic Innovation (EUPATI), described the role of patients in health technology assessment (HTA). HTA is a multidisciplinary process involving a systematic evaluation of the benefits and risks of a health technology compared with the standard treatment in order to inform health care policy makers. He said that it is more than just an economic evaluation: the clinical effectiveness, safety and impact on quality of life come first. He encouraged ED advocates to find out which HTA bodies exist in their countries and to contact them. An HTA Patient Group Submission Template is available to help patients in the formal procedures for communicating with HTA committees. Patients are crucial members in this process as they can provide insight on, for example, the advantages and limitations, side effects and impact on quality of life of an existing or new treatment. In his advice to advocates he said that they need to be able to communicate effectively and follow procedures, show that they are informed, know the science and speak for the community, not as individuals. "Who else can critically appraise a treatment better than those who take it?" he asked.



Olivia Pagani speaking to MBC advocates.

Returning to work

ED Deputy CEO Karen Benn gave an overview of the rights of breast cancer patients returning to work, as she said that a return to work can provide stimulation and promote quality of life, in addition to the financial considerations. She said that the EU Employment Equality Framework Directive of 2000 specifies that employers cannot discriminate against employees on the grounds of disability. Despite this legislation, there are vast differences between countries and, in some cases, employers still discriminate against cancer patients. She added that an EU draft report on "reintegration into work after illness" is being prepared by MEPs and should become a resolution. With regard to MBC, she added that there is a lack of data even on how many people it affects; however, a pilot project on MBC and work has been proposed by MEP Deirdre Clune (Ireland). "Attitudes need to change and we need to advocate for a more positive approach towards women returning to work at any point after their breast cancer diagnosis," Ms Benn said.

ED Board member and lawyer Elizabeth Bergsten Nordström then shared experience on work and insurance issues facing women in Sweden. She said that results of a survey by her organisation showed that almost all the women wanted to go back to work after treatment, but that many can experience a decline a few months later. They feel pressure to show that their ability to work remains unchanged. Many women choose to look for other job opportunities because they want to be less dependent on a full-time job. She added that as the legislation is open to interpretation, many women would not be able to face or win a legal dispute against their employer. Regarding insurance, she said that in Sweden, insurance companies cannot deny coverage to breast cancer patients, but that the high premiums they charge survivors (eg, for travel insurance) can make taking out such insurance prohibitive. ED Vice President Mona Knotek-Roggenbauer presented the results of a survey of breast cancer survivors in Austria. New legislation in her country means that as of 1 July 2017, it is possible to gradually return to work after extended sick leave, with a maximum reduction in working hours of 50% and a minimum of 25% for 6 months at the most. The model is voluntary for both employers and employees. At the conference, ED also launched a survey of its members with regard to work-related issues (see last page).

What advocates need to know about breast cancer registries

Ciarán Nicholl, Head of the Health in Society Unit in the Health, Consumers and Reference Materials Directorate, European Commission-Joint Research Centre, gave an overview of cancer information in Europe and its vast potential for learning about breast cancer and for fostering cancer prevention and control strategies. He said that while the cost of cancer registration is very low, the potential the data can unleash is very high. The JRC's European Cancer Information System (<https://ecis.jrc.ec.europa.eu>) contains more than 33 million records of information on individual cancer cases and covers about half of the European population. These data originate from hospital-based registries and both specialised and general population-based breast cancer registries. He emphasised that high quality, harmonised data is a must and JRC initiatives to achieve this include: (1) the provision of Quality Checks Software to all registries free of charge, and (2) training events for cancer registries. He said in the near future the data will be geographically positioned and then they will overlay the data with, for example, environmental, socio-economic and other indicators. The ensuing cancer incidence and/or mortality spikes should yield new insights into cancer causality. Finally he encouraged advocates to also get involved in data collection policy meetings and to "spread the word" about the need for high quality cancer registries.



Ciarán Nicholl, JRC, and Mona Knotek-Roggenbauer, ED Vice President

Exchanging advocacy tools and experiences

At the training course, ED's Karen Benn and Paige Robinson, ED Training and Development Officer, described the EUROPA DONNA advocacy tools available to advocates, such as the website dedicated to MBC, and the advocacy tool kit. Participants heard an inspiring presentation on living with MBC by ED's President Evi Papadopolous who herself has been living with MBC for many years. It covered the different challenges, needs and priorities of women with MBC. Sabine Spitz of ED Austria, who is also living with MBC, described the activities of her Forum which are growing to include more MBC-related initiatives, from information and awareness campaigns to supportive care campaigns. ED's Executive Director Susan Knox described the ABC Alliance, a multi-stakeholder platform for all those interested in collaborating in common projects relating to MBC. It runs webinars, has videos and is active on social media and in the European Parliament with, for example, an event on work issues for women with MBC.



MBC advocates



ED Deputy CEO Karen Benn

Advocates shared advocacy strategies from their countries, such as establishing 13 October as MBC day, an MBC postage stamp, online petitions, crowd-funding for projects and meetings with high-level politicians. The course ended with a full day's communication skills training and workshops so that advocates could learn to use their personal stories and other tools to advocate for increased attention to MBC. Some of the advocates participated in videos about their personal experiences for the MBC section of the ED website. A snapshot of these is provided below.

EUROPA DONNA MBC resources

<https://mbc.europadonna.org>

<https://mbc.europadonna.org/campaign-materials>



Claudia Altmann-Pospischek — Austria

"I try to tell people what it means to live with metastatic breast cancer. I want to be the voice and the face of an illness that is not known in the public."



Feride Dorothy Güneri — Turkey

"I want to be a well-informed patient. I want to be aware of the good news and the bad news...I also want to remain optimistic and hopeful."



Kate Henwood — United Kingdom

"Metastatic breast cancer, although it is treatable but not curable, doesn't have to be a death sentence. It's not the end. It's the beginning of a different way of life."



Paola Cornero — Italy

"With this disease you really empower your life with special meaning. You give special meaning to many other things that you did not even realize before that they were so important."

Watch these and other videos at: <https://mbc.europadonna.org/advocates-speak-out>

Findings from the EUROPA DONNA questionnaire: Return to work issues for people living with MBC

In a EUROPA DONNA survey on returning to work issues and MBC, a majority of respondents (62%) reported that women with MBC are able to return to work on a part-time or limited basis while they are recovering, yet a majority (64%) also responded that there is stigma or lack of awareness on the part of employers that make a return to work difficult for people living with MBC. These are some of the findings from the ED questionnaire distributed at its 1st MBC Training Course, and to which 66 advocates responded, including 28 MBC advocates and 38 ED National Leaders (comprising 23 women with MBC, 25 with early breast cancer, and 18 without breast cancer). A total of 35 countries from Albania to Uzbekistan were represented (see full list below). Respondents were also encouraged to provide more information to explain their answer choice.

In many countries, the rights of patients with MBC to return to work are protected by discrimination legislation which protects them on the grounds of disability legislation and/or other laws against discrimination. A number of the respondents also commented that laws do not protect people with MBC per se but cancer patients or patients in general. Many (67%) reported that MBC patients receive information on disability or social insurance benefits, primarily from government agencies, support groups, hospitals and treatment centres. Some stated that the process starts from primary care and so good coordination with oncology centres is needed. Regarding return to work, many commented that the specific conditions for a return to work — and also any pressure not to return — often depend on the employer and may differ in each case. Many of those surveyed reported a lack of awareness and information about MBC among employers. Regarding breast cancer support and advocacy groups, many stated that their organisations were starting up activities for women with MBC. They called for more education and improved information on MBC for patients and for employers.

Results of the ED Questionnaire: Return to work issues for people living with MBC. Number of respondents 66.

Question	Answer			
	Yes	No	Don't know	No answer
1) Does the disability legislation in your country include people who have MBC to protect them from discrimination?	23	16	27	0
2) Are there <i>other</i> laws in your country that protect people from discrimination in the work place so that they can return to work after/during treatment for MBC?	18	25	21	2
3) Do people with MBC find support and information regarding receiving disability or social insurance in your country?	44	12	8	2
4) Do people with MBC find support and information regarding absence from and return to work in your country?	33	13	17	3
5) Are people in your country able to return to work on a part-time or limited basis while they are recovering/receiving treatment from MBC?	41	4	11	10
6) Are there pressures that take place at work that discourage people from continuing after being diagnosed/treated for MBC?	25	17	17	7
7) Is there still stigma/lack of awareness on the part of employers that make it difficult for people living with MBC to return to work?	42	9	12	3
8) Do you feel that your local breast cancer support or advocacy group adequately meets the needs of people with MBC for information and support?	40	21	4	1

Responding countries: Albania, Armenia, Austria, Belarus, Belgium, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Netherlands, Norway, Poland, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Ukraine, United Kingdom and Uzbekistan.



Piazza Amendola, 3
20149 Milan, Italy
Tel: +39 02 3659 2280
Fax: +39 02 3659 2284
Email: info@europadonna.org
www.europadonna.org
<https://mbc.europadonna.org>

EUROPA DONNA gratefully acknowledges



for their support