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Europa Donna – The European Breast Cancer Coalition Holds 16th Pan-European Conference in Croatia Intent on Breaking Down the Barriers in Breast Cancer Care

EU Commissioner for Health and Food Safety Stella Kyriakides is keynote speaker

More than 200 advocates from 32 countries spent an action-packed weekend at the Europa Donna Pan-European Conference in Zagreb, Croatia, in the company of other advocates, breast cancer experts and the European Commissioner for Health and Food Safety. Held 28-29 October, it was the Coalition’s first in-person Pan-European conference since the pandemic and was themed “Breaking Down the Barriers Starts With Us.” The programme provided the evidence base – from European policy and guidelines, to disparities in care, survivorship, and the latest science – to build advocacy campaigns to improve breast cancer care and erase the wide disparities between countries and regions, and between the subsets of patients with breast cancer, such as younger and older women, and those with metastatic disease.

Opening the conference, Stella Kyriakides, EU Commissioner for Health and Food Safety and a former ED President, spoke from her role as Commissioner and her decades of dedication to Europa Donna and breast cancer advocacy. “Let us keep on breaking the barriers together,” she said. She gave an update on Europe’s Beating Cancer Plan which is dedicating over 4 billion euros to cancer care with key initiatives in prevention, early detection, diagnosis and treatment, and quality of life. This includes the milestone reached in December 2022 with the update of the Council Recommendations on Cancer Screening, which for the first time sets the goal of offering breast, cervical and colorectal cancer screening to 90% of those eligible in the EU by 2025. Other key initiatives the Commissioner cited include the recent European guidelines on breast screening and diagnosis, as well as an EU joint action to establish a network of Comprehensive Cancer Centres to give patients easier access to high-quality diagnostics and innovative treatments. The Cancer Imaging Initiative is under way with a prototype platform now live and linking images and datasets on breast cancer and other cancer types. And to address the persisting inequalities in care between countries and regions, the Cancer Inequalities Registry is gathering data and will assist in guiding future policies and investment.

“In 21st century Europe, it is unacceptable for access to screening or to diagnosis and treatment to be dependent on where you are born or on other factors over which you have no control,” Commissioner Kyriakides said.

She nonetheless reminded advocates of the achievements of earlier detection and fewer deaths due to breast cancer in recent decades. This means that the needs of women during and beyond treatment require attention. One such need is access to financial services. She said there is a plan to draft the first EU code of conduct on fair access to financial services for people who have had cancer, a.k.a., “The Right to be Forgotten”. Europa Donna has been selected as a stakeholder in this initiative.

“Europa Donna has been and remains trailblazers in the work to raise awareness of the challenges and to promote solutions,” Commissioner Kyriakides said. “And for us, here, wearing pink is not just a colour, it is an attitude. It is about hope and determination. We have a huge opportunity in Europe and we cannot fail.”

Following this was a very powerful session dedicated to Europa Donna’s Cancer Currency Campaign (www.thecancercurrency.com) to draw attention to the unmet needs of women with metastatic breast cancer. The protagonists of the campaign personally presented the
Commissioner with their own banknotes tailormade for the campaign to tell their stories and to represent the value of their lives. Each presentation ended with a specific policy ask to European institutions: see me, count me, treat me, support me, act now! All was met with a long and moving standing ovation. Stay tuned for additional information to be provided on this campaign coverage.

Sessions and panel discussions with experts in all areas of breast cancer then followed, designed to provide the tools needed to “break down the barriers”. Marzia Zambon, Europa Donna CEO/Executive Director, told the advocates present, “Once the barriers are down, the logical thinking is to create pathways and build bridges. As advocates and people living with and after breast cancer, the most effective service we can provide is to create alliances – with policy makers, payers, other patient organisations, researchers, oncologists, pathologists, surgeons, nurses, industry, insurance companies and patients.”

Providing more evidence for the inequalities referred to by Commissioner Kyriakides, Bettina Borisch, from the MPH Institute of Global Health, University of Geneva, Switzerland, and Executive Director of the World Federation of Public Health Associations – and also a past Europa Donna president – said that the greatest cause of ill health is inequity, not only economic but also education, living conditions and other interrelated factors. Yet data from the European Cancer Inequalities Registry show wide disparities in breast cancer mortality that cannot be explained by GDP: rates are high in Luxembourg and Germany and low in Scandinavia and the Iberian peninsula. However, regional data show that individuals with higher income are more likely to survive a breast cancer diagnosis. To address this, advocacy can aim to undo the causes, prevent them, and then mitigate them using individual experience.

Also speaking on this topic from a policy perspective, Tit Albrecht, from the Centre for Health Care, National Institute of Public Health in Ljubljana, Slovenia, said that one of the ways to overcome inequalities nationally and internationally is to promote and improve health literacy, ie, where people can easily understand medical explanations, process information, and adapt their lives as needed for their condition. He said it is also key to involve patients when developing national cancer plans, and to intensify networking and patient presence in all areas of cancer research.

The next topic on the agenda was the latest on the European Breast Cancer Guidelines and Quality Assurance Scheme, developed by the European Commission Initiative on Breast Cancer (ECIBC). Robert Mansel, Emeritus Professor of Surgery from Cardiff University School of Medicine in the UK and Chair of the Quality Assurance Scheme (QAS) Development Group described the pilot testing of the identified breast centre requirements and certification process in 20 breast centres. The programme involves centres meeting specific quality indicators for services that are audited by a QAS team. The pilot showed that the QAS and audit were both useful and relevant for improving services. Validation of the QAS by European Accreditation is expected in 2024. ED’s Marzia Zambon is a member of the QAS Development Group.

Prof Borisch, who is also a member of the ECIBC Guideline Development Group, then gave an update on the ECIBC European breast cancer guidelines which are now being implemented or considered in 10 countries inside and outside the EU. She described the stringent development process for these evidence-based, expert-led guidelines that are constantly updated and revised on the dedicated guidelines platform. Their implementation – and overcoming the
barriers to this – is the next step. ED’s Executive Director Emeritus Susan Knox is a member of this committee.

The latest in imaging was the next topic on the agenda. Mireille Broeders, Professor of Personalised Cancer Screening at Radboud University, The Netherlands, said that artificial intelligence (AI) will find its way into breast cancer care, and a possible application would be for the double-reading of mammograms, or for a third opinion. It can also help identify specific risks for a risk-based screening approach where, for example, the screening ages or intervals are adapted, or specific imaging modalities are applied, to fit the specific risk factor (eg, dense breasts). The main challenge in this approach is addressing women with low risk who do not want to be excluded from screening, and also in providing access to such a strategy. She said that training and communication will be key.

On the topic of risk factors such as dense breasts, Alexandra Athanasiou, Head of Breast Imaging Department at Mitera Hospital, Greece, reminded advocates that the European breast cancer guidelines are designed for women at average risk of breast cancer. Among the highest degree of breast density – which is about 10% of women – there is an almost 4 times greater risk of interval cancer (ie, between screening rounds) compared with the lowest density. Nonetheless, she said that she agrees with the European guidelines for screening, which do not recommend magnetic resonance imaging (MRI) for dense breasts as there is a need for further research and randomised controlled trials. However, the European Society of Breast Imaging guidelines for extremely dense breasts suggest supplemental screening with MRI based on level 1 evidence. Dr Athanasiou concluded that we need more data and research, equal access and well-trained radiologists.

Next on the agenda was the needs of younger women (ie, pre-menopausal) vs those of post-menopausal and older women with presentation of specific cases for discussion. Representing post-menopausal women, ED’s Susan Knox described her personal experience with being diagnosed both pre- and post-menopause. When later in life, the diagnosis comes when a woman is more independent and fertility is no longer an issue, for example. She said advocacy is needed for individual treatment plans, adequate follow-up, and access to and more research regarding complementary therapies in alleviating side effects of long-term therapy. Laura Biganzoli, Director of the Breast Centre at the Oncology Department of the Hospital of Prato, Italy, then presented a case of a 76-year-old woman in order to draw attention to the plights of older women diagnosed with breast cancer as data are lacking in this group and age may determine their access to therapy. Tanja Spanic, President of Europa Donna and diagnosed at the young age of 26, gave the young woman’s perspective, and the fact that women under 40 are rarely included in clinical trials. An exception is the POSITIVE study that provided evidence for stopping endocrine therapy to enable pregnancy in younger women. Tanja said it is important to advocate for personalised treatment and preferences and access to fertility preservation. Fedro A. Peccatori, Medical Oncologist, European Institute of Oncology in Italy, also presented and discussed the case of a young woman with breast cancer. He noted that the effect on some of the newer therapies on fertility is not yet known.

Survivorship was next on the agenda. Davide Soldato, a Medical Oncologist from Gustave Roussy in France, outlined the latest approaches to address side effects of therapy, including low-dose antidepressants for vasomotor symptoms (eg, hot flushes), moisturizers and lubricants for vulvo-vaginal symptoms, physical activity for fatigue, plus approaches to cognitive impairment (ie, chemo brain), depression and anxiety. He said that collaboration
with patient advocates is fundamental to understand and integrate patient perspectives on the side effects that affect their quality of life.

On the topic of **physical activity**, Anne May, Lead Researcher of the **PREFERABLE project**, The Netherlands, provided evidence supporting the beneficial effects of physical activity quality of life and secondary prevention in breast cancer. As studies in metastatic disease are lacking, the **PREFERABLE project (Project on Exercise for Fatigue Eradication in Advanced Breast cancer to improve quality of life)** in which Europa Donna is partner, has performed a randomised controlled trial of the effects of structured and individualised exercise on fatigue and quality of life in patients with metastatic breast cancer (MBC). The results are to be presented at a major conference in 2023, but Dr May revealed that participants were able to adhere to the 9-month exercise programme and many continued exercising afterward. The **PREFERABLE Perspective** study, with the help of Europa Donna, gathered information on attitudes and knowledge about exercise and MBC, and found that women generally had a positive attitude towards physical activity. Implementation of such programmes is the next step. “I will give you my evidence, but we need the voice of the patients to get this exercise programme implemented and have it reimbursed,” Dr May said.

Given the need for patient advocates to be involved in research and the growing demand for their involvement in clinical trials, Ximena Montano, Principal Investigator and Lecturer at King’s College and Westminster University in London, UK, and an ED Board Member, outlined the **clinical trial process** and how advocates should contribute to breast cancer trials from their outset. For phase 3 trials – the last phase before approval of an intervention – she suggested advocates provide input into the design of the trial protocol for the trial, the informed consent documents, and potentially be included on the Independent Data Monitoring Committee. She concluded with the long list of studies and research networks, from BIG to Horizon 2020 projects, in which Europa Donna is participating or has an advisory role.

In a final session on the science of various therapeutic approaches, Natalija Dedić Plavetić, a medical oncologist at University Hospital Centre Zagreb, Croatia, described the active area of **research into therapies** for early breast cancer and metastatic disease. In a comprehensive talk, she covered the various approaches to treatment escalation according to the many breast cancer subtypes, and also de-escalation, where patients can be spared aggressive treatment (eg, chemotherapy) when little or no benefit will be gained.

Fiorita Poulakaki, a breast surgeon and Head of Breast Surgery Department, Euroclinic Athens, and Vice-President of Europa Donna, presented data showing that there is also a trend towards de-escalating surgery. There are ongoing studies on surgery vs surveillance for DCIS (ductal carcinoma in situ, usually a low-risk tumour), plus paradigm-changing studies where lymph nodes in the axilla are no longer removed in favour of sentinel lymph node biopsy in most cases. At the same time, there has been an increase in bilateral mastectomy rates. The **13th European Breast Cancer Conference (EBCC-13)** manifesto, in which Europa Donna participated, includes a list of discussion points for patients considering having a contralateral mastectomy, including that such a procedure will not reduce the risk of the known cancer returning.

Zrinka Rendić-Miočević, an oncology and radiotherapy specialist at Clinical Hospital Centre SM in Zagreb, outlined the lasted in **radiotherapy**, including changes in dosing that has reduced the duration of radiotherapy from 5 or 6 weeks to 3 weeks and a possible 1 week in the future.
She also described the intraoperative radiotherapy (IORT) approach in use in her hospital where radiation of the tumour bed is delivered in a single fraction immediately following surgical removal of the tumour, particularly for patients with a high risk of recurrence. She called for an increased number of radiotherapy machines and updating of equipment.

**Iva Kirac**, a surgical oncology specialist, at the University Hospital of Tumors in Zagreb, described the approach they use to test for hereditary gene mutations in breast cancer in a person with breast cancer, a relevant family history and whose therapy may depend on the results. Next generation sequencing for 113 genes is performed. Croatian guidelines cover criteria and processes for genetic testing, and reimbursement of the genetic panels is now possible.

The last day of the conference focused on specific projects carried out by three Europa Donna Fora. **ED Cyprus** launched a "Right to be Forgotten" campaign and is close to seeing an amendment passed in parliament to eliminate financial discrimination against cancer survivors. **ED Luxembourg** implemented a project to provide support to families of women undergoing breast cancer treatment. **ED Serbia** created a “Pink Recipes” app providing shopping advice and healthy recipes that may reduce cancer risk.

A highlight of this in-person conference was a special gala dinner to commemorate **Susan Knox**’s retirement and her more than two decades of dedication to Europa Donna during which she grew the organisation to its current reach and reputability. Susan retired from the CEO position in 2020 but continues in a policy advisor capacity.

A full report on this conference will be produced for easy access to key advocacy items and messages.

The Europa Donna Pan-European conference is held every 2 years and brings together patient advocates and breast cancer experts from the Coalition’s 47 member countries.

**About EUROPA DONNA**

EUROPA DONNA – The European Breast Cancer Coalition – is an independent, non-profit organisation whose members are affiliated groups from countries throughout Europe. EUROPA DONNA works to raise public 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. Member countries currently number 47.

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