



A breast cancer
awareness initiative at
the European
Parliament



**Nov 8, 2017: An Initiative on Breast Cancer Awareness:
A Report From The European Parliament**

Key messages

- **Call for co-ordination**
 - New Europe-wide standards of data management
 - More efficient pan-European screening network
 - Closer collaborations to tackle breast cancer earlier
- **Empowering women in the workplace**
 - Management training to ease return to work
 - Clinician support for working mothers
 - Government protection of female workers' rights
- **Technological revaluations**
 - Need to embrace mobile technology to empower patients at home
 - Transformation of quality of life measurements
- **Spreading opportunity**
 - Reassessment of in-country reimbursement policies

Co-hosted by:

- MEP Elena Gentile, Group of the Progressive Alliance of Socialists and Democrats in the European Parliament
- MEP Lieve Wierinck, Alliance of Liberals and Democrats for Europe

Esteemed speakers:

- Karen Benn, Europa Donna

- Susanne Schaffert, Novartis Oncology Region Europe
- Barbara Wilson, Working with Cancer
- Kathi Apostolidis, European Cancer Patient Coalition
- Arnaud Portalier, GE Healthcare Europe
- Carmela Totaro, Breast Cancer Care Centre, ASL Foggia-Manfredonia

It is not just the enormity of the disease but the socio-economic impact that breast cancer has on society – extended families, the workplace, the emotional as well as the physical suffering. This, said MEP Elena Gentile, of the Progressive Alliance of Socialists and Democrats, is the true context of breast cancer.

She believes women suffer because, 'Healthcare professionals, work colleagues and families need to understand a better life does not simply mean better screening and treatment but also requires better support networks, more understanding in the workplace, greater help at home.'

In particular, countries – led by the European Parliament - need to enable women's return to work if this is their choice, so they can contribute both to the economies of nations and the wellbeing of their families. 'We must be closer to women,' added Ms Gentile, 'listen to their stories and experiences to help them and their families.'



MEP Elena Gentile, Group of the Progressive Alliance of Socialists and Democrats in the European Parliament

CALL FOR CO-ORDINATION

According to Karen Benn, deputy CEO of, Europa Donna – The European Breast Cancer Coalition, that ambition is more likely to be achieved with greater co-ordination. 'As well as having the right and expanded access to treatment and information,' she said, 'it's important that we work together.' For instance, specialist Breast Cancer Units need to have multi-disciplinary teams – led by a key worker - that decide treatment plans together, specifically for those with metastatic conditions.

Equally, when it comes to accreditation of breast cancer services, quality assurance, guidelines and registries, there needs to be a Europe-wide standard for the collection, measurement and analysis of data. 'Different nations and organisations need to set similar targets and use similar methodologies,' she added. In addition, greater effort should be made to simplify and translate complex published medical guidelines so that more women are aware of the condition, what it means and how it will impact their lives.

Though advanced breast cancer is currently still incurable there are a series of changes that can be made to Europe-wide healthcare policies to aid prevention. One in eight women will have breast cancer in their lives but, says Fatima Cardoso, the European School of Oncology's Co-ordinator and Director of the Breast Unit, Champalimaud Clinical Center, there could be up to 30 per cent fewer deaths from the advanced form of the disease if everyone was treated with all the knowledge that is at hand.

She suggested a series of measures. 'First, we need better quality of life data to measure how patients cope with disease and treatments. Then we need to discuss management of the disease rather than simply debate the efficacy of drugs. Reimbursement policies in different countries need to change so financial considerations of hospital appointments, intravenous drugs and chemotherapy are relegated to patients' individual needs. Finally, we must fight the stigma of death and have honest conversations with patients about what advanced breast cancer will mean. It's not a happy ending but we shouldn't be frightened of saying so.'



Dr. Fatima Cardoso, European School of Oncology

Susanne Schaffert, European Head of Novartis Oncology, understands that patients, especially those with advanced breast cancer can feel neglected and forgotten - while these women around the world are continuing to live their lives with purpose, bringing value to their communities, their workplaces and amongst loved ones.

So it's vital that effective collaborations, bringing together politicians, industry, specialists and support groups, have patients' needs at the centre. If diagnosis and treatment can be given earlier, survival rates may improve, women can return to work, continue their lives and continue contributing to society.

EMPOWERING WOMEN IN THE WORKPLACE

The needs of working women need to be addressed too. Barbara Wilson, founder of advice group Working With Cancer, believes greater support is needed from government, employers and clinicians so that women affected by cancer can return to work more easily if this is their choice. Currently, clinicians have little interest in women's working lives, management lack basic guidance and information into how to counsel those with illness and governments lack strategic thinking.

'This is about women's identity, self-esteem, income, social structures, friendships and how we're perceived as people,' she said. 'If we lose confidence, our employers lose confidence in us. So everyone in society needs to help women not just through the period of treatment but its after-effects. Governments need to insist upon European-standard legal protection so people can't be discriminated against, clinicians need to show more interest in the world of work, and employers be flexible enough to attend to individual needs instead of having company-wide sickness and absentee policies, along with trained managers able to offer psychological support.'



Barbara Wilson, Working with Cancer

TECHNOLOGICAL REVOLUTIONS

Alongside training, there should be wider use of technology, believes Kathi Apostolidis, vice president of the European Cancer Patient Coalition, particularly in a mobile-first world. 'We need to be there with them,' she said. 'In their homes and communities, using hand-held devices such as new ultrasound technologies that enable even the most isolated to be tested.' Patients need to participate too, helping monitor symptoms and using remote technology so hospital appointments can, sometimes, be replaced or supplemented with data-enhanced mobile technology, or M-health devices. She added: 'M-health gives patients control, a feeling they are able to care for. Professionals and health systems need to learn to trust such technology and integrate it into their decision-making and healthcare plans.'

Private companies also have a role to play. Arnaud Portalier of GE Healthcare in Europe said companies like his are developing new technologies with the full patient experience in mind, from clinical screening through to diagnosis. 'New solutions, such as less painful mammogram examinations,' he said, 'give women a sense of control and a more positive experience. Faster screenings and diagnoses can also have a positive impact on care and cost effectiveness. Always, though, technology must focus on outcomes that matter to the patient.'

ALIGNMENT ON SCREENING

Governments also need to be clear on the importance of screening programmes – the more people who attend, the greater survival rates. Carmela Totaro works at the Breast Care Centre at ASL Foggia-Manfredonia (Italy) and believes pan-European governments must improve information programmes, make clear the benefits of screening and how disease can rapidly worsen to aid persuasion. She said: 'The EU needs to help build a more efficient screening network for those with breast cancer, with highly specialised professionals who are able to make effective early diagnoses. The more we can do that and create a form of personalised care, the higher the probability of survival. We need to provide everyone with the same opportunity, no matter their background, where they live or their age – screening before 50 could transform survival rates.'

CHANGING DECISIONS

In conclusion, MEP Lieve Wierinck from the Alliance of Liberals and Democrats for Europe, said that politicians need to design policies that give breast cancer and advanced breast cancer patients the opportunity to maximise their lives and their contributions to society. 'Women must have access to early diagnosis and treatment across the EU,' she said. 'We need to use technology, fight inconsistencies and disparities and ensure the needs of those with breast cancer are heard by Europe's decision-makers.'



From right to left:
Karen Benn, Europa Donna; Susanne Schaffert, Novartis Oncology Region Europe; MEP Elena Gentile, Group of the Progressive Alliance of Socialists and Democrats in the European Parliament ; MEP Lieve Wierinck, Alliance of Liberals and Democrats for Europe; Barbara Wilson, Working with Cancer