



## Viewpoints and debate

## The European advocacy perspective on mammography screening

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## ABSTRACT

Controversy and publicity about the value of mammography screening programs continue in Europe and across the globe. As Europe's breast cancer advocacy organisation, Europa Donna –The European Breast Cancer Coalition advocates for mammography screening as one of the essential services to which all women should have access, stipulating, however, that mammography screening programs must be set up and carried out in accordance with *the European Guidelines for quality assurance in breast cancer screening and diagnosis*. Europa Donna's involvement and history in following programs and progress in this area is extensive and dates back to 2001. The communication process for women eligible for screening is complicated and needs to be addressed appropriately in every country. However, the position of our organisation remains unchanged: Mammography screening carried out according to EU Guidelines is the best form of early detection available today and the scientific evidence shows that it improves mortality rates from the disease.

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As Europe's breast cancer advocacy organisation Europa Donna represents groups in 45 European countries including all 27 EU countries. Mammography screening is one of the essential services for which we are advocating, but with the clear condition that mammography screening programs must be carried out in accordance with the "European guidelines for quality assurance in breast cancer screening and diagnosis"<sup>1</sup>; the key words here are "quality assurance." The history of our involvement and study of mammography screening programs started in 2001 and is on-going; it has included evaluating reports by a myriad of experts in Europe and the United States, as well as trial results and evidence agreed by members of the European Breast Cancer Screening Network, the International Agency for Cancer Research(IARC)and the World Health Organisation(WHO). This brought our organisation to support population based mammography screening starting in 2002 and our position is so far unchanged 8 years later because 1) there is insufficient evidence on which to base a change, and 2) we now have additional evidence from more programs that have over 10 years experience to substantiate that these programs provide a significant benefit to women in improving mortality rates from this disease.

There are valid concerns about the anxiety related to screening results such as "false positive" or possible cases of over treatment. Communication materials sent to women about mammography screening do not always clearly explain both the benefits and the

risks; however, the fact remains *mammography screening is the best form of early detection of breast cancer available today and it does improve mortality*. This is the message that bears repeating while at the same time continuing to review and study the scientific evidence as it emerges. It therefore remains one of the key priorities for which our organisation continues to advocate across Europe today.

## Background

Europa Donna was invited to participate in the European Breast Cancer Network (EBCN) starting in 2001 and this enabled us to stay aware of and be updated on all the progress/developments in the mammography screening projects taking place in Europe on a continuous basis. It enabled us to understand the complexity of the subject and to appreciate the communication issues both for women and the public that accompany it and may always accompany it. At EBCN meetings with the participation of EUREF (European Reference Organisation for quality assured breast screening and diagnostic services), experts across Europe from all the fields, epidemiology, radiology, pathology, public health etc. involved in screening programs reviewed the findings, the trials, and the pilot programs that had been launched under the Europe Against Cancer programme. Europa Donna attended these annual meetings where studies, programs and data were presented and reviewed; this was essential in having us understand not only how important these programs are, but also how important it is for them to be carried out in accordance with high quality standards to be effective. There was complete openness, transparency and accessibility to experts

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and data, and to all the analysis and work that took place in the development of the “EU guidelines for quality assurance in breast cancer screening and diagnosis.”

It is this process that led to acceptance and recommendation by all the public bodies of the European Union that all women should have the right to receive population based mammography screening in programs set up and conducted according to these EU Guidelines. In 2003 the European Code on Cancer<sup>2</sup> was amended to include screening; the European Council Recommendation on Screening<sup>3</sup> was passed in 2003 and the European Parliament Resolutions of 2003<sup>4</sup> and 2006<sup>5</sup> urge that mammography screening programs should be implemented in all countries according to these guidelines. Most recently the European Parliament Declaration on the fight against breast cancer in the EU passed in March 2010,<sup>6</sup> re-confirms that programs set up according to the EU Guidelines should be implemented across the EU.

Based on all the evidence, Europa Donna determined that mammography screening should be one of its main priorities. We have made it a topic of all our educational, information and lobbying programs from 2001 to the present including our Pan European conferences, our annual advocacy trainings courses, our publications, and our lobbying at both national parliaments and at the European parliament. Progress continues and most EU countries now offer mammography screening or are piloting programs.<sup>7</sup>

Europa Donna continues to both advocate for programs set up according to EU Guidelines and to review new data and information as it is published. Nick Perry, Chair of the European Reference Organisation for quality assured breast screening and diagnostic services and editor of the EU Guidelines addressed our members in 2007<sup>8</sup>; he emphasized the importance of implementing programs in accordance with the EU Guidelines and stressed the need for specific quality assurance in all stages of the screening process from invitation to treatment. A program must meet established standards to ensure its value and this requires attention to many aspects; systematic training of personnel involved, follow up of screened women and on-going evaluation of screening results.

The 2006 4th edition of the EU Guidelines, published by the European Commission, represented a document developed and agreed upon by experts across Europe and included for the first time the guidelines for specialist breast units. This was a key priority for ED and we participated in the working group that developed this chapter. As countries were beginning to move toward implementing screening programs, it quickly became evident that there had to be high quality centers where women could be treated once a tumor was detected. Europa Donna began advocating for both mammography screening and specialist breast units where women would be treated by a multi disciplinary team and receive a range of services as described in the EU Guidelines. High quality screening must be accompanied by high quality breast services once a diagnosis is made.

### Current situation

Europa Donna continues to review its position on mammography screening periodically and revisits the subject at each of its Pan European conferences. In October 2009 Dr Laszlo Tabar reviewed trial data and results of nation-wide service screening in Sweden<sup>9</sup>; he re-iterated that the evidence was unequivocal: early detection through mammography screening followed by appropriate treatment results in a significant reduction in mortality from the disease.

Experts from all fields of oncology, both in Europe and the U.S., are in agreement with the basic principal and continue to support quality screening for women ages from 50–69. These experts as well as others from IARC, EUREF, and EUSOMA have reviewed the Meta analysis and the Cochrane review of Gotzsche PC and Nielsen

M; however, their opinions remain basically unchanged. The 2002 IARC statement regarding this confirmed 35% mortality improvement.<sup>10</sup> Chris de Wolf in the EJC (2009) reports on 7 programs' results at 10 years stating that they have approximately the same improvement in mortality as the trial data indicate (25–30%).<sup>11</sup> The 2008 World Health Organisation, “World Cancer Report<sup>12</sup>” states definitively “The large randomised trials performed from 1976 to 1990 have shown that an invitation to breast cancer screening based on mammography can reduce mortality from breast cancer averaging 25% in women aged 50–69”.

There are still important communication issues to resolve. The confusion created by the media has been extremely destructive in terms of the public's understanding of mammography screening. Recent news coverage concerning screening recommendations in the U.S. is a good example of how conflicting messages can and do confuse the public and women generally. When the Preventive Services Taskforce modified its guidelines, newspaper headlines gave the impression that mammography screening was no longer of any value; the reality was that the Taskforce had changed its recommendation concerning the age group to be screened and the time interval between screenings.

For the women screened the communication process is extremely important and must be geared to the culture, education, background, language of the women being screened. This is often difficult to do and remains a key challenge for advocacy and screening service organisations in each country. Each person working in a screening unit also needs to be trained in proper communication concerning the program. Concern about misdiagnosis, over treatment, psychological disturbances, and even pain related to mammography screening should be addressed not by questioning the viability of mammography screening programs per se, but rather by improving them through proper implementation of the EU Guidelines.

Europa Donna is committed to disseminating correct, evidence based information on this subject, and so has developed **The Short Guide to the European Guidelines for quality assurance in breast cancer screening and diagnosis**.<sup>13</sup> It is our most important tool today for use in lobbying and educational activities both at the EU level and national level as it describes all of the basic services which women should have a right to receive. It has been translated into 11 European languages and 3 more are currently being prepared. This guide describes, in lay language, the importance of adherence to the EU Guidelines for effectiveness. The success of a screening program depends greatly on the quality of the equipment, the skill of persons operating the equipment, and the skill of those interpreting results etc. It also points out that the purpose of the program, including both its benefits and risks, must be communicated honestly and effectively. High quality must be assured in all aspects of conducting a program.

Europa Donna continues to follow new developments in this field and participates actively in meetings in Europe on this topic, especially those of the European Cancer Network (ECN) at the International Agency for Research on Cancer whose review and evaluations will ultimately result in a 5th edition of the European Guidelines. While the EU Guidelines today do not recommend that women between ages 40–49 will benefit from screening, more studies are needed to determine the efficacy of screening for this age group and/or if other diagnostic tests should be recommended for this age group. Further attention also needs to be directed toward raising the age limit for screening to include women over 70 as has already occurred in several European countries.

### Conclusion

At this time Europa Donna's position remains unchanged: mammography screening is the best means of early detection of

breast cancer available today, which, when followed by proper treatment provides the best chance of long term survival. To ensure effectiveness mammography screening programs must be carried out in accordance with the “European Guidelines for quality assurance in breast cancer screening and diagnosis” and communicated properly to the public.

### Conflict of interest statement

None declared.

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