

### **EUROPA DONNA**

Breast Cancer Advocacy Leader Conference

### Reducing Health Inequalities and Fostering Healthy Ways of Life

25 September 2010 – Milan, Italy



EUROPA DONNA - The European Breast Cancer Coalition's first Breast Cancer Advocacy Leader Conference provided the 62 national representatives and delegates from 36 countries who attended with extra advocacy tools through inspirational, scientific presentations by experts and motivational workshops for advocates to compare their strategies. The conference and this Proceedings Highlights document were co-funded by the European Union in the framework of the Public Health Programme.

"Our purpose is to eradicate the inequalities between countries and to see that women in all our member countries have access to state-of-the-art early detection and treatment services for breast cancer as well as access to care in specialist breast units. It is also of utmost importance that women across Europe be educated about breast health and breast cancer prevention," Ellen Verschuur, President of EUROPA DONNA, told the advocates present.

The conference was divided into two main sessions: overcoming the obstacles to implementing the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis and breast cancer prevention through promoting healthy ways of life, using EUROPA DONNA's Breast Health Day campaign as a model. Each session included presentations by renowned speakers, followed by interactive workshops where advocates described activities undertaken in their countries, the obstacles faced and suggested methods to overcome them.

In her opening presentation, Susan Knox, EUROPA DONNA Executive Director, told the advocates: "All our activities are based on scientifically sound and proven evidence and this is our strength. Using evidence, such as that found in the EU guidelines, is key to establishing a leadership role and therefore to effective advocacy."







Sweden Switzerland Turkey Ukraine United Kingdom Uzbekistan

**Participating** 

countries

Albania

Belarus







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#### EUROPA DONNA Breast Cancer Advocacy Leader Conference

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Dr. Galina Maistruk (Ukraine)
Dr. Larry von Karsa (IARC)
Dr. Marco Rosselli del Turco (EUSOMA)

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### Session 1

Overcoming Obstacles in Advocating for Implementation of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis



Effective leadership: why using evidence in advocating for implementation of the EU Guidelines is so important in reducing inequalities regarding breast health

Susan Knox

Susan Knox, EUROPA DONNA Executive Director, opened the conference by calling on the EUROPA DONNA national representatives and delegates present at the conference, as leaders in their countries, to bring other advocates and professional partners on board to implement the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis.

"Evidence-based guidelines are important in reducing inequalities and our leadership can make the difference," she told the advocates.

EUROPA DONNA's strength as an organisation comes from its use of scientifically proven evidence approved by distinguished sources such as IARC, EUSOMA, EORTC, EUREF and ECN and the Coalition's partnerships with these same organisations. She added that this evidence has also been endorsed and disseminated by the European Commission in the form of the EU guidelines, thus arming advocates with the same facts and figures for use across Europe.

# EU documents aiming to reduce inequalities in breast cancer services among countries: key tools for advocates

- European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis, 4th edition
- The European Parliament Resolutions on Breast Cancer, 2003 and 2006
- European Commission Recommendations on Cancer Screening
- The European Parliament Written Declaration on the Fight Against Breast Cancer in the EU, March 2010
- For the future: An EU protocol for accreditation of specialist breast units

#### **EUROPA DONNA documents**

- A Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis
- EUROPA DONNA Guide to Breast Health

For more see www.europadonna.org

Ms Knox emphasised the importance of choosing credible professional, political and funding partners and ensuring that they represent the same fact-based interests. She also recognised the many issues and obstacles advocates face in their countries, such as differences in health systems, vast regional variations, lack of standards and breast service requirements, and a closed medical establishment.

EUROPA DONNA serves as the link between professionals, politicians and the lay public, a key example being its "Short Guide to the EU Guidelines", translated into 11 languages to date and used to approach non-scientific groups, such as national politicians and even EU representatives.

EUROPA DONNA has a growing international presence. Ms Knox added, "It is hard to argue with patients or advocates who are knowledgeable, whose facts

are backed up by the international scientific organisations. As you take the leadership role in disseminating the guidelines information across your countries, it will be difficult for European countries not to provide these services."



### Take home messages for advocates

- You are the leaders in your countries
- You need to form partnerships with credible professional organisations
- Use scientifically proven evidence such as the EU guidelines
- Use the communication technology available today to access and share reliable information
- Use the tools provided by Head Office
- You are not alone

Reducing Health Inequalities and Fostering Healthy Ways of Life

Overcoming Obstacles in Advocating for Implementation of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis



Current evidence about the efficacy of mammography screening programmes set up according to the EU Guidelines: overcoming obstacles to the implementation of screening programmes

Peter B. Dean

Peter B. Dean, Professor of Diagnostic Radiology at the University of Turku and Director of Breast Imaging at Turku University Hospital in Finland, stated that the most important aspect of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis is their emphasis upon quality assurance. He also cited a number of poorly designed studies that have posed an obstacle to the implementation of screening programmes. He termed them a "Tragedy of Errors" and provided a recent example of a study published in the New England Journal of Medicine stating the effects of screening based on just two years of follow-up.

"This is not science, it is journalism," he said. Later he added, "Studies with verified data on individual patients carefully performed over many years are far more reliable than any registry data publication or meta-analysis of work by other investigators."

He stated that to perform an accurate evaluation of the effects of screening, studies must compare women who actually underwent mammography with those who did not. All early screening studies have consistently underestimated the effect of mammography by evaluating women invited for screening rather those actually attending. A later study by the Swedish Organised Service Screening Evaluation Group showed how this underestimation affects screening results. In a study where

## Some essential stipulations of screening programmes

- Training in screening should be mandatory for all radiographers and radiologists
- Attendance at multidisciplinary conferences should be obligatory for all involved
- All patients should have the benefit of both preoperative and postoperative multidisciplinary meetings
- Double reading with consensus can be built into the computerised screening reporting system so that it is obligatory
- All screening radiologists should also perform the evaluation studies on women recalled from screening for suspicious findings
- Screening and evaluation of recalled women should be performed by the same individuals so that they will learn from their mistakes and continue to improve their performance
- Results of individual radiologists should be monitored
- Previous films of all cancer cases must be reviewed to determine if the lesion should have been detected earlier
- Quality assurance and monitoring of performance of screening programmes must be mandatory

three out of four invited women attended screening, there was a 27% mortality reduction; however, when this was calculated based on women actually having a mammogram the mortality reduction was 43%. In this study, less than 500 women needed to be regularly screened to save one life.

Prof. Dean added that analysis of registry data, without knowledge of individual patient data always reduces the measured effect of screening. Another Swedish study from 2009 compared registry data with individual data and found that registry data had an error rate of 18%.

Quality assurance and monitoring of performance, as stipulated in the EU guidelines, is an integral part of every screening programme and, he stated, will not be done comprehensively unless it is mandatory and is paid for.

He stated that of all the preoperative evaluation methods, including inspection, palpation, ultrasound, magnetic resonance imaging (MRI) and percutaneous biopsy (core needle), mammography is the only method with a proven effect upon breast cancer mortality. Nonetheless, he recommends a preoperative MRI since at least 40% of breast cancers have more than one focus and MRI can detect many cancers not seen on mammography. He added that MRI is less expensive than reoperations and chemotherapy.

With regard to any harmful effects of the mammogram itself he stated that a Swedish study showed that women who did not have screening mammograms died of breast cancer at a significantly higher rate than those who did have screening mammograms.

Prof. Dean said that early diagnosis and treatment improve the outcome of all cancers and that breast cancer is no exception. He suggested finding out who is paying for the attacks on screening, and what they want to use to replace it.

# Take home messages on screening statistics

Studies based on registry data underestimate the effects of screening

- Studies using individual patient data are more reliable
- Beware of studies published due to their controversial value rather than their scientific value. General medical journals often do this, and tend to have little expertise in screening
- There is a 43% reduction in breast cancer mortality among screening participants and for every 500 women undergoing regular screening, one early death from breast cancer can be avoided (Cancer Epidemiol Biomarkers Prev 2006; 15(1): 45–51)

### Session1

Overcoming Obstacles in Advocating for Implementation of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis



What the EU Guidelines say about Specialist Breast Units: overcoming obstacles in the implementation of Specialist Breast Units

Marco Rosselli del Turco and Astrid Scharpantgen

Dr. Marco Rosselli del Turco, President of the European Society of Breast Cancer Specialists (EUSOMA), emphasised the important role that specialist breast units play in solving the wide disparities in breast cancer services between countries and even between regions or within regions. He added that breast cancer care provided through specialist breast units is associated with 15-20% increased survival.

"Breast cancer care, whether we are talking about detection, treatment, follow-up, or all aspects of care, is highly inhomogeneous. You should try to bring all the countries in Europe to a higher level, though it is not an easy task," he said, adding that while the best services cannot be available everywhere, optimal standards must be achieved.

He stated that EUROPA DONNA has already made great progress through advocating for the European Parliament Resolution on Breast Cancer, which calls on member states to ensure nation-wide provision of multidisciplinary breast units by 2016

Various region-based studies in the UK and in Italy indicate that the treatment women receive can vary between districts and between hospitals. A study performed in the Florence area showed that women's survival from breast cancer differed according to the women's socioeconomic level, regardless of age. These survival differences later disappeared with the introduction of a screening programme. "Screening guarantees that all women, whether rich or poor, have the same assessment for diagnosis as well as the same treatment," he said.

### Some specialist breast unit requirements

- Single integrated unit working in multidisciplinary fashion (over 95% of cases have to be discussed at a multidisciplinary meeting)
- >150 new breast cancer cases treated yearly
- Care by breast specialists in all the required disciplines (from genetics and prevention, through treatment and patient support)
- Dedicated staff in all disciplines (from screening and genetic counselling to treatment and patient support)
- Data collection and medical auditing

Further studies in Scotland have shown that specialist treatment improves survival, a benefit which is apparent for all age groups, for small and large tumours, whether node positive or negative.

EUSOMA's requirements for specialist breast units are included in the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* and the organisation has recently published an article on its workshop to determine quality indicators for breast cancer care. EUSOMA applies such indicators in its database of certified breast units, thus providing a system for benchmarking between units.

Dr. Rosselli del Turco added that the process for EUSOMA breast unit certification has been decentralised to an external body called the European Cancer Care Certification, based on an EU recommendation that the body that establishes the guidelines must be different from the body providing certification.

Dr. Rosselli del Turco said that there can be cultural, training and career obstacles to implementing breast units. "The main obstacle to a wider implementation of breast units in Europe is the resistance of some specialists to be fully dedicated to breast cancer care and to work with a real multidisciplinary approach. EUROPA DONNA has a primary role in supporting the development of specialist breast units," he noted.

He concluded that promotion of breast unit implementation can be done through national and regional resolutions and through a breast unit certification procedure.

# Take home messages on specialist breast units

 There are wide inter-country and regional differences in breast cancer care and therefore differences in survival

- Countries should at least be able to offer optimal standards of breast care
- Breast cancer care offered in a specialist breast unit can increase survival by 18-20%
- The European Parliament Resolution on Breast Cancer calls on member states to ensure nation-wide provision of interdisciplinary breast units by 2016
- As a developer of breast unit guidelines, EUSOMA has decentralised its breast unit certification programme

## Reducing Inequalities Across Euro









Three parallel workshops enabled advocates to exchange experiences, ideas and best practices by hearing first from the workshop facilitator about the well-established screening programme and how it was achieved in her country, i.e., Luxembourg (Astrid Scharpantgen, Executive Board Member), Sweden (Elizabeth Nordström, Executive Board Member) and the Netherlands (Ellen Verschuur, EUROPA DONNA President). Representatives from the various EUROPA DONNA member countries then informally presented the situation in their countries, the obstacles faced and discussed how these could be overcome.

# 1. How did those countries that have high quality breast cancer services and have implemented the EU Guidelines achieve this?

- Actively using the "Short Guide to the EU Guidelines" as a working tool
- Making use of the EUROPA DONNA Coalition
- Using clear messages
- Encouraging women to ask the right questions
- Networking with breast cancer organisations, clinicians, politicians, researchers, decision makers and the media
- Deciding on the message and goals
- Concentrating on specific objectives and having achievable goals
- Knowing the facts and having scientific-based evidence as support
- Finding target groups and individuals to contact and building relationships with people identified in each group
- Establishing the stakeholders and getting a champion on board (e.g., celebrity, politician, expert)

### 2. What are the main obstacles to getting the EU Guidelines implemented?

- Lack of well-trained professionals
- Women not taking advantage of existing services
- Tackling problems of high risk groups
- Financial constraints
- Need for equal access to services within a country
- · Varied cultural traditions between countries
- · Politicians having their own agenda
- Politicians constantly changing
- Knowing where to start once the problem areas are identified
- Knowing how to turn around bad press
- Doctors having their own agendas
- Overcoming stigmas and raising awareness

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# in Breast Cancer Services pean Countries

The main factors identified in most workshops as being necessary to establish screening programmes included: 1) having clear, achievable goals; 2) using the scientific evidence and the human and factual resources provided by our European Coalition; 3) making the right contacts. The main obstacles to implementing screening were lack of financing, lack of political will and consistency, and lack of co-operation from medical professionals. The main methods to overcome these obstacles included: networking with politicians, professionals and the media, and monitoring existing programmes to ensure quality. Answers to the three main workshop questions are provided below.







#### 3. How can these obstacles be overcome?

- Setting priorities
- Conducting surveys
- Starting from zero can be an advantage (i.e., countries now implementing screening can use the guidelines and experience of other countries to establish high quality programmes)
- Providing access to services free of charge
- Using each other for information exchange
- Using the media to focus on your goals/issues
- Convincing local politicians to lobby for implementation
- Getting the local medical profession behind you
- Visiting local schools to teach girls about lifestyle factors
- Volunteering to be a "professional" patient at medical schools
- Capitalising on any attention given to breast cancerrelated issues to further your goals
- Ensuring that mobile units are always operating within quality guidelines
- Monitoring quality closely at a local level, also by ED volunteers
- Having specialised ED volunteers (within each ED national or local group smaller groups can specialise in their area of interest instead of trying to become "experts" at everything)
- Collaborating between countries with and without programmes or equipment (countries switching to digital could donate mammography machinery to the countries in need)



Breast Cancer Prevention: Promoting Healthy Ways of Life through Breast Health Day and Information Dissemination

Reducing Health Inequalities and Fostering Healthy Ways of Life



### **Review of Breast Health Day** 2008 and 2009; overview of 2010 campaign

Susan Knox, Executive Director of EUROPA DONNA, gave an overview of the Coalition's Breast Health Day campaign launched in 2008 in recognition of definitive IARC data showing the role of lifestyle and early detection through populationbased mammography screening programmes in reducing the risk of breast cancer. In Europe alone there are some 430,000 new cases of breast cancer, 25-33% of which may be avoided through changes in lifestyle, especially physical exercise and

"We are trying to reach a new audience of people who may not be the usual EUROPA DONNA members. We want to reach women and girls in a non-threatening way and get them to change their lifestyles early to protect their breasts and improve their breast health," she said.

maintaining a normal body weight.

With the purpose of targeting younger women, the campaign has gone digital by expanding from the original www. breasthealthday.org website into popular social networking websites such as Facebook, Twitter and YouTube, thereby reaching a younger audience. The focus in 2010 is on all healthy aspects: eating a healthy diet, maintaining a normal body weight and increasing physical exercise. This year the campaign is extended to NGOs worldwide, and will include a pamphlet, T-shirt and media training.

In addition to country and local activities, EUROPA DONNA will be holding a healthy reception and exhibition at the European Parliament on 12 October to share this information and to talk to MEPs about breast health.

"The campaign does need to multiply exponentially, so we need the leadership in each of your groups to be doing the same thing. That way it will really multiply to thousands of women and girls in each of your countries and across the globe," she told the advocates.

### Digital features of the 2010 Breast Health Day campaign

- Pages on Facebook, Twitter and YouTube
- · Widget on www.breasthealthday.org where women can set breast health goals and track their progress
- Video game based on selecting healthy choices to progress through the game
- Video messages on YouTube

Susan Knox and Ellen Verschuur





### Take home messages on Breast Health Day

- Breast Health Day is an opportunity for EUROPA DONNA fora to use one voice to reach women and girls across Europe
- Social networks can be used to spread the Breast Health Day message
- Some 25-33% of breast cancers may be avoided through changes in lifestyle

### Session 2

Breast Cancer Prevention: Promoting Healthy Ways of Life through Breast Health Day and Information Dissemination



# **Epidemiology and facts about lifestyle** and breast cancer prevention

#### Carlo La Vecchia

Dr. Carlo La Vecchia, Head of Epidemiology at Mario Negri Institute in Milan, Italy and temporary advisor at IARC/WHO, stated that some cases of breast cancer can be avoided through physical activity, avoiding obesity, limiting alcohol intake and avoiding long-term use of hormone replacement therapy (HRT).

"Excess body weight, physical inactivity and alcohol consumption account for approximately 33% of breast cancer cases," he stated. A study by Mezzetti et al. indicated that about 10% of breast cancers could be avoided by decreasing alcohol consumption, while 11% were influenced by body mass index. In another study by Boffetta et al., 10% of breast cancers could be attributed to physical inactivity, more than 9% to alcohol consumption, almost 5% to obesity and overweight, almost 11% to use of HRT or oral contraceptives and more than 5% to reproductive factors.

Dr. La Vecchia added that while breast cancer incidence is increasing, mortality is decreasing due to a variety of factors, including primary prevention, chemoprevention, screening, treatment and a combination of these factors. However, in several western countries, the trend for major risk factors is not positive: there is an increasing age at first pregnancy, fewer births per woman, less frequent breastfeeding, increasing age at menopause, increasing alcohol consumption and increasing prevalence of obesity and overweight.

He said that there is sufficient evidence to show that avoiding weight gain reduces the risk of breast cancer in post-menopausal women. Overweight or obese women who lose weight may reduce their risk of post-menopausal breast cancer, but the data are not definitive.

With regard to physical activity, the evidence shows that regular exercise reduces the risk of breast cancer and seems to be independent of weight control. A study by Dr. La Vecchia's group and another by Leitzmann et al. found that moderate physical activity may reduce the risk of breast cancer by as much as 30%.

### Reproductive factors influencing breast cancer risk

- The older a woman has her first menstrual cycle the lower her risk of breast cancer
- The younger a woman enters menopause the lower her risk
- Early age at first (and subsequent) full-term pregnancies is protective
- High number of births is also protective
- Childbearing above age 30-35 years may increase the risk
- Very long-term breastfeeding decreases the risk

Data on nutritional factors, while less conclusive than the influence of overweight and obesity, indicate that eating vegetables may have a protective effect, whereas the intake of dietary fat has been questioned. A study by Bosetti et al. examined flavonoids, which give fruits and vegetables their bright colours, and found that increased intake reduced the risk of breast cancer. Olive oil has also been shown to have a beneficial effect.

Dr. La Vecchia said that there is now sufficient evidence that alcohol increases breast cancer risk, since it increases endogenous oestrogen levels, and that ethanol is carcinogenic to humans. He added that consuming four drinks per day is associated with a 1.4- to 1.5-fold increase in breast cancer risk and that even one drink per day is associated with an excess risk of 7-10%.

Another factor highly associated with breast cancer risk is the use of combined (oestrogen and progestagen) HRT, as revealed in the Women's Health Initiative study. No difference in risk was evident during the first 4 years after starting treatment, but an excess risk of breast cancer was evident thereafter. Overall, at 7 years of follow-up, there was a 1.24 relative risk of breast cancer associated with combined HRT use. This risk declines in the short term once HRT use has been stopped. Dr. La Vecchia added that using oral contraceptives is relatively safe in women under age 35 and that the risk becomes similar to that of never users a few years after cessation of use.

Selective oestrogen-receptor modulators such as tamoxifen and raloxifene have been shown to reduce recurrence of breast cancer and to prevent contralateral breast cancer.

In conclusion he said, "When putting together obesity, overweight and HRT you arrive at the possibility of avoiding between one-quarter and one-third of all breast cancers. So

the scope for prevention of breast cancer through lifestyle changes is substantial."

## Take home messages on main modifiable lifestyle factors

- Women should be advised to undertake some brisk physical activity every day and to avoid obesity and overweight. If overweight, they should lose weight
- Long-term use of hormone replacement therapy is a significant contributor to breast cancer risk
- Women should reduce their intake of alcohol: all other factors being taken into account, consumption of each daily additional glass of alcohol increases the risk of breast cancer by 7%

### Reducing Inequalities Across European Coun









The three parallel workshops dedicated to Breast Health Day (BHD), like the earlier screening workshops, were divided into three steps: describing how countries with successful activities achieved them, identifying obstacles faced and suggesting ideas for how to overcome them. Many countries have incorporated special BHD events – focused on prevention and targeting younger women – into their October activities. Each workshop began with a presentation by an ED national representative or delegate from a country that carried out extensive BHD activities in 2009, i.e., Deirdre O'Connell (Ireland), Sara Brom (Israel) and Stella Kyriakides (Cyprus).

### 1. How did countries with extensive Breast Health Day activities manage to achieve them?

- · Making use of the media
- Adapting and translating materials provided by Head Office (e.g., BHD Mini Diary, poster, digital materials)
- Using BHD to raise awareness rather than for fundraising
- · Lighting important landmarks in pink
- Holding a learning day for women still undergoing treatment
- · Having a special day for young women
- · Using the mobile mammography units
- Targeting people at a school level with a lecture series
- Holding a variety of awareness activities: an art exhibition, Chi Kung demonstrations, a fashion show with clothes donated by top designers, archery events, challenging the prostate cancer association to a health competition, distributing special articles or jewellery such as necklaces

### 2. What are the main obstacles to having a successful Breast Health Day at a national level?

- Difficulty in getting health messages to patients
- Financing and fundraising
- Getting politicians and doctors on board
- Getting volunteers
- Translating "Breast Health Day" and the slogans
- Inconsistency of BHD material design with Forum materials
- Competing with many breast cancer organisations for attention
- Getting media attention
- Being pressured from other organisations to take on other disease areas or women's cancers ("Pink Envy")
- Protecting the trademark or logo of pink ribbon or getting around trademarks registered by others

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# in Information Provision tries: Breast Health Day

During the workshops it was noted that Breast Health Day serves a number of advocacy functions beyond the usual Pink October activities. It allows all ED fora to be part of the same advocacy initiative on the same day; it gives them another method of reaching supporters and the public in general; and it brings new people, new groups and new sponsors into the fold. The BHD focus on healthy lifestyles gives women a sense of control and also attracts more media attention. It was further noted that younger ED fora have achieved a great deal with Breast Health Day and can serve as an example. A summary of the results of the three-step workshop process is provided below.







#### 3. How can these obstacles be overcome?

- Networking with journalists and creating enduring relationships
- Targeting individual journalists and appealing to their interests/style (e.g., statistics or human interest)
- Using different media to help different messages reach different audiences
- Fundraising activities
- Uniting all breast cancer organisations in the country to participate in one common activity
- Engaging a celebrity or political personality to give a human touch to the campaign
- Using other groups and networks such as business groups, unions, associations of professionals and hobby or sports groups, etc.
- Keeping the emphasis on October and breast cancer month
- Watching other organisations for ideas for public relations mechanisms
- · Using the ideas and materials of other ED fora
- Holding specific activities such as a quiz on simple breast cancer facts, a competition for journalists and involving women's sports teams in the awareness campaign







#### **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 46.

EUROPA DONNA – The European Breast Cancer Coalition

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