

GUIDELINES FOR VOLUNTARY ORGANIZATIONS WORKING IN MULTIDISCIPLINARY BREAST CENTRES



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EUROPA DONNA'S AIM is to advocate for high quality Breast Centres where European women can be treated according to the standards set by the European Society of Breast Cancer Specialist - Eusoma. **ONE OF EUROPA DONNA ITALIA'S LEADING AIMS** is to set up high-standard voluntary organizations to support women in every Breast Centre.

METHOD: Following the example of 75 Voluntary Organizations and the exchange of opinions with specialists working in Breast care centres, Europa Donna ITALIA has asked ITALCERT, a Certification Body and the Scheme Owner of Breast Centres Certification®, to draw up clearer Guidelines so that the Voluntary Organizations might all operate in a more transparent and homogenous way with all interested parties - the women and their families, the professionals in the Breast Centres, and the local and political bodies involved in the healthcare service.

Voluntary Organizations in Italy interact with women and with the scientific community so that every woman, no matter where she lives, can be treated in the same way; which means having access to the same screening programmes and to the same breast cancer therapies. For this to happen, each Voluntary Organization must partake in a network of organizations, as exemplified by Europa Donna Italia, with the overriding aim of improving the healthcare system at a national level. This is the way to establish an approved Advocacy, credible enough to gain the necessary support not only from governing bodies but also from scientific ones. Thanks to this coalition of advocates, patients will have the opportunity to receive improved healthcare services and to make themselves heard.

120

Number of Voluntary Organizations involved

50

Number of professional caregivers working in Breast Centres and involved in Voluntary Organizations training courses

240

Number of Breast Centres in Italy in respect of the Italian laws

100

Number of hours needed for the training of high quality Voluntary Organization members

58

The minimum requisites set by Europa Donna Italia guidelines: the "must haves" 58, of which 40 mandatory

THE MOST IMPORTANT ASPECTS REGARDING THE GUIDELINES FOR VOLUNTARY ORGANIZATIONS WORKING IN A BREAST CENTRE

THE STRUCTURE OF THE ORGANIZATION

A Voluntary Organization must have:

- An unequivocal mission to help women gain access to Breast Centres. A clear message and transparent purpose and state of its finances.
- An examination of the activities carried out to gauge the trend of performance (eg. no° of voluntary workers involved in the VO, the number of women welcomed every year, the funds raised for initiatives supporting women/patients, the number of training and informative activities organized for patients and the number of participants, no° of projects/events ideated and/or held for women).
- A clear map of all the interested parties to whom the political and social healthcare bodies can and/or must turn and a genuine evaluation of the voluntary workers' tasks and skills in the organization.
- A comfortable and private space where to meet women and/or patients.

WHAT THE VOLUNTARY ORGANIZATION SHOULD DO FOR WOMEN:

COMMUNICATE / PROMOTE / COORDINATE

- COMMUNICATION AND INFORMATION FOR WOMEN**
The Voluntary Organization should give support to women and patients in need of:
 - assistance and healthcare treatments;
 - information regarding: studies on prevention, clinical studies and women's participation in innovative treatments and diagnostics, information in the Breast Centre.
 The Voluntary Organization should make available adequate supporting material: brochures, leaflets, videos, access to controlled websites etc. counseling with healthcare givers and/or Breast Centres to improve the quality of the services offered. The Voluntary Organization should also contribute to acknowledging customer satisfaction regarding the assistance and services offered.
- PROMOTING SUPPORTIVE ACTIVITIES**
The Voluntary Organization should promote courses devoted to womens'/patients' mental and physical well-being: for example, yoga, swimming, drama, painting, nutrition, controlled gym activities
The Voluntary Organization should help women/patients:
 - to communicate with the specialists in the Breast Centre;
 - to promote transportation to and from the Breast Centre for the length of their therapy at a reasonable price (by means of a direct service offered by the healthcare centre or indirectly in agreement with a taxi or other company service);
 - to seek support from professionals, such as psychologists and sex therapists, for themselves and/or their relatives (partners, children, patients, etc.);
 - to find mental and physical relief during and after the illness by promoting a healthy lifestyle and treatments to counter possible side effects of the surgery and therapies, such as lymphatic edema and chronic pain, as well as provide rehabilitation in case of axillary web syndrome;
 - to obtain information and advice regarding, for example, wigs and make-up due to hair loss, and post-mastectomy bras;
 - to seek cultural mediation if Italy is a foreign country for them.
- COORDINATING THE INTERACTION WITHIN THE BREAST CENTRE**
The Voluntary Organization within a Breast Centre should make sure the interaction between caregivers and administrators is coordinated and that all women can have access to the healthcare system.
Two important objectives, among the many, for any Voluntary Organization are:
 - choosing one or more spots within the Breast Centre where the Voluntary Organization can be set up and to which women can go;
 - choosing a representative who can coordinate the relations between the Voluntary Organization and the specialists (e.g. breast nurses, psychotherapists) in the interests of both parties involved in the Breast Centre.