surveillance and, where appropriate, ovarian screening, but they may not be aware of the limitations of current screening methods. For high-risk women considering risk-reducing mastectomies, the trade off between risk reduction and personal issues such as body image and sexuality has to be carefully balanced, and pre-operative counselling and well-informed decision-making can help achieve favourable outcomes. For 100 women assessed in Manchester, cancer worries were highly significantly reduced and there were low levels of mental health problems and body image concerns in the first year after surgery. These findings appear to be stable over time, but one in six women, especially those experiencing short term or late complications, report negative changes in self image, or mood which require further assessment and, in some cases, psychological intervention. In summary, there are complex issues and risk management decisions facing women following risk communication, and continued access to information services and psychological care is essential.

473 INVITED

Hereditary breast and ovarian cancer: an advocate's viewpoint

F.E.G. Bach Kolling-Dandrieu. *Meersel-Dreef, Belgium*

Being in the chair of the Advocate support group for hereditary breast and ovarian cancer of the "BorstkankerVereniging Nederland" (BVN) I will discuss our work in general and, more specifically, I will dwell upon what we have accomplished so far and explain about the work that still remains to be done. At this moment the Advocate support group not only has established a phone help line but also a national network, which enables patients to exchange information on genetic testing and its consequences. Furthermore, the Advocate support group organizes seminars and represents the interests of patients at relevant meetings throughout *the country.*

It has been a little more than ten years since the discovery of the breast and ovarian cancer genes BRCA1 and BRCA2 and it is likely that in future years more genes will be discovered in relation to many other diseases. Our experience in the Netherlands is that BRCA1 and BRCA2 gene mutations are often used as an example to start a debate on a multitude of questions relating to ethical issues. It is clear that we will be forced to take new attitudes towards many topics such as the patenting of human genes and insurance discrimination of gene mutation carriers. Also, we will have to change our views on ethical codes and have to decide how we are going to handle the knowledge that certain diseases are related to a specific genetic predisposition.

It is often argued that BRCA1 and BRCA2 mutation carriers should join their efforts in all European countries, because the hereditary breast and ovarian cancer group is considered a relatively small part of all the breast and ovarian cancer patients. It is indeed our position that we can all benefit from sharing mutual experiences, so we encourage and support cross-border co-operation and the exchange of information as much as possible. However, I dare to challenge the assumption that we are merely a small group of patients, since in the particular case of the genetically predisposed patient, the threat of cancer hangs over the entire family and therefore, the group of mutation carriers is in fact much larger than just the affected patients.

It can be concluded that we hope to find support through the Advocacy Channels of Europa Donna to accomplish more awareness in Europe for specific problems concerning hereditary breast and ovarian cancer. Secondly, it is of the utmost importance that specialists in the medical profession support us in order to improve the well-being of patients and their families. Furthermore, we should promote communication and exchange of data at various European Institutions on all levels with the ultimate goal to achieve some standardization of policies relating to genetics throughout Europe.

In this Genetics symposium we ask ourselves: where are we?.

I would like to add this question: Genetic Advocates, where are YOU?