

Report

ESGO Patient Seminar

The patient perspective:
gynaecological cancer in Europe
11 September 2011



Held during the 17th International Meeting of the
European Society of Gynaecological Oncology (ESGO)
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About ESGO: The European Voice of Gynaecological Oncology!

The European Society of Gynaecological Oncology (ESGO) is the principal European society of gynaecological oncology contributing to the study, prevention and treatment of gynaecological cancer. Today, ESGO has over 1300 members in more than 40 countries worldwide.

ESGO's mission:

ESGO strives to improve the health and well-being of European women with gynaecological (genital and breast) cancer through prevention, excellence in care, high quality research and education.

Together with the International Gynecologic Cancer Society (IGCS), ESGO publishes the bi-monthly International Journal of Gynecological Cancer (IJGC) – a highly popular journal covering topics, including basic science, epidemiology, diagnostic techniques, surgery, radiotherapy, chemotherapy, pathology and experimental studies.

As a leading oncology society, ESGO holds a biennial meeting where 2400 experts meet to discuss the latest advances in gynaecological treatment and care. ESGO, together with the European Board & College of Obstetrics and Gynaecology (EBCOG), set up the European standards of training in gynaecological cancer and provides accreditation of European training centres in excellence in gynaecological oncology. ESGO also holds numerous workshops throughout the calendar year, provides clinical and research grants and fellowships, different online educational materials, webcasts and numerous networking possibilities to members. ESGO also provides certification of European training centres in excellence in gynaecological oncology and accredits individual accredited training of gynaecological oncologists.

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Industry partners who sponsored the seminar:





Foreword

Dr Nicoletta Colombo (ESGO President)

Gynaecological cancers, such as those of the ovaries, cervix and womb, are among the most common cancers to affect women. Yet they are often silent, since they do not attract the attention they deserve from the general public, policy makers and women themselves. Patient organisations across Europe are working to break this silence to improve the prevention, screening, treatment and care of gynaecological cancers. As the voice of European gynaecological oncology, ESGO shares these goals with patient organisations, and is excited to welcome 50 participants to this first ESGO Patient Seminar.

The presentations at this meeting pointed to the impressive outcomes that could be achieved through action by committed patient advocates. We all recognised the many challenges that must be overcome if we are to address the inequalities that exist between and within European countries. More ef-

forts are needed to prevent gynaecological cancers, through public education, screening programmes and vaccination. Every woman with a gynaecological cancer should receive treatment from a multidisciplinary specialist team of knowledgeable and expert healthcare professionals. The results of basic research must be more rapidly translated from the laboratory to the bedside, and we must ensure that patients are empowered to drive up standards of care in all European countries.

ESGO pledges to continue the dialogue begun at this meeting to collaborate with the patient community to ensure that women with gynaecological cancer throughout Europe have the best chance of survival and quality of life.



Nicoletta Colombo, ESGO President, calls on patient groups to work together with ESGO to improve the care of gynaecological cancers in Europe.

Programme

Session 1: Setting the scene: gynaecological cancer and inequalities

Chair: Ate van der Zee, ESGO Past-President, Netherlands

Inequalities in survival of gynaecological cancers in Europe today

John Butler, International Cancer Benchmarking Partnership, Gynaecological Oncology Fellow, St Bartholemew's and Royal Marsden Hospitals, UK

Session 2: Innovation in treating gynaecological cancers and improving outcomes

Chair: Flavia Bideri, ACTO Onlus, Italy

Innovative targeted therapies and individualised medicine

Frédéric Amant, Department of Obstetrics & Gynaecology, UZ Gasthuisberg/Katholieke Universiteit Leuven, Belgium

Current options and the ongoing future of clinical trials

Jalid Sehouli, Charité Universitätsmedizin Berlin, Germany

Multidisciplinary treatment in gynaecological cancer

Emma Elliott, Macmillan Lead Clinical Nurse Specialist in Gynaecological Oncology, University College London Hospitals, UK

Patient participation and research: how patient groups contribute to clinical research

Flavia Bideri, ACTO Onlus, Italy

Session 3: Best practice in patient-driven initiatives

Chair: Jan Geissler, CEO Patvocates and Co-Founder CML Advocates Network

Ovacom – leading initiatives in ovarian cancer

Louise Bayne, Ovacom, UK

PATH – patient-driven breast cancer tumour bank

Doris Schmitt, PATH, Germany

From health literacy to advocacy

Paola Mosconi, Istituto di Ricerche Farmacologiche Mario Negri, Italy

Workshop

Chair: Louise Byrne, CEO Ovacom, UK

Collaboration across gynaecological cancer patient groups

Session 4: The way forward and closing remarks

Chair: Nicoletta Colombo, ESGO President, Italy

Summary of sessions

Session 1

Setting the scene: gynaecological cancer and inequalities

Professor Ate van der Zee (ESGO Past-President): *Introduction*

Cancer survivors have an increasingly important role in advising medical societies, governments, charities, health services and industry. ESGO shares the goal of patient groups to help women living with gynaecological cancers to obtain accurate, reliable and timely information about their disease, to understand treatment options and to have access to the best possible care. Through the ESGO Patient Seminar, ESGO aims to provide a platform for patient organisations to share and exchange information, and identify where there is a need to join forces at national or European level.

ESGO is committed to providing a platform for dialogue, sharing and exchange with patient organisations throughout Europe. Progress and policy change can often only be achieved by a united voice across specific diseases: this is why facing the challenges together is so important. ESGO aims to learn from and work with its patient partners to break the silence about gynaecological cancers: to improve their prevention, screening, treatment and care to ensure that women throughout Europe have the best chance of survival and quality of life.



John Butler of the International Cancer Benchmarking Partnership discusses variations between countries that lead to inequalities in outcomes for women with gynaecological cancer today.

Dr John Butler (UK): *Inequalities in survival of gynaecological cancers in Europe today*

Each year in Europe, about 190,000 women are diagnosed with and about 90,000 women die from a gynaecological cancer. These statistics are approximate as they are based on data from many countries that do not provide comprehensive national cancer registration. This makes international comparisons difficult, but in 2007 EURO CARE 4¹ demonstrated continuing inequalities in cancer survival in Europe.

Since this study examined outcomes for patients diagnosed in 1995-99, the relevance of these findings was questioned. In January 2011 the International Cancer Benchmarking Partnership (ICBP)² provided more up-to-date and comparable data. This unique partnership between countries with comprehensive cancer registration and similar healthcare systems reported consistently lower five-year survival in the UK and Denmark compared to Australia, Canada, Sweden and Norway from 1995 to 2007.³

In ovarian cancer, for example, although survival has generally improved, women in the UK and Denmark continue to have the lowest one-year survival – consistent with later-stage diagnosis and/or lower treatment rates in these countries. Older women fared especially badly in the UK, but survival in the elderly is lower in all regions, suggesting that they, too, are diagnosed late and/or undertreated.

The ICBP is now investigating possible explanations for these inequalities, with studies into: public awareness and beliefs about cancer; beliefs, behaviour and systems in general practice; causes of diagnosis and treatment delays; and variation in treatment and comorbidities. In future, it may be possible for ICBP to include other registries and for its methodology to be transferred to other parts of world. However, to ensure accurate international comparison, more countries need to initiate or develop cancer registries that include high-quality stage, treatment and survival data on all patients.

Session 2

Innovation in treating gynaecological cancers and improving outcomes

Professor Frédéric Amant (Belgium): *Innovative targeted therapies and individualised medicine*

Cancer is the result of uncontrolled growth of cells, involving dysregulation in signalling pathways and gene mutation. Since conventional cytotoxic drugs act by interfering in rapid cell growth, they are ineffective in slow-growing cancers. Tumours become resistant, and conventional drugs also interrupt rapidly growing cells in the skin, bone marrow and gastrointestinal tract, causing serious side-effects.

In contrast, targeted therapies, such as pazopanib in ovarian cancer, interfere with specific signalling pathways. As a result, there is less damage to normal cells and a lower rate of side effects. Treatment is now being refined still further by individualised targeted therapy, in which genetic testing identifies biomarkers of a patient's response to a drug. Examples include cetuximab in wild-type (non-mutated) KRAS gene colorectal cancer, and vemurafenib in BRAF V600E mutation-positive advanced melanoma.

The development of individualised targeted therapy has implications for clinical trials. As cancer therapy becomes individualised to patients with a particular genetic profile, it is becoming less practical to perform traditional large, randomised controlled (phase 3) studies. In future, therefore, novel

¹ Lancet Oncology 2011;8: 773-83. See also www.eurocare.it/Home/tabid/36/Default.aspx (last accessed 16 September 2011)

² <http://info.cancerresearchuk.org/spotcancerearly/ICBP/> (last accessed 16 September 2011)

³ Lancet 2011;377:127-38

drugs are likely to be investigated in smaller, phase 2 studies, followed by biomarker testing in each patient.

It is the 'beginning of the beginning' for targeted therapies. The future of personalised cancer medicine will depend on a strong alliance between researchers to find target mutations and industry to develop new drugs. Patients, too, can make an important contribution by donating their tissue and blood samples. Ultimately, however, European governments must recognise the value of these new treatments.

Professor Jalid Sehouli (Germany): *Current options and the ongoing future of clinical trials*

Evidence-based clinical guidelines are important but, because they are revised every three to five years, they do not take into account the latest developments. Optimising cancer treatment and outcomes is therefore possible only through clinical trials. These are major undertakings, but women of all ages will participate if they trust their doctor, and know that there is always time for a second opinion on their treatment

Involvement in clinical trials involves detailed analysis of efficacy and side effects, as well as access to modern and innovative treatments. Participation in these studies by cancer centres is therefore a marker of quality; for example, patients at centres in the German AGO-OVAR network are three times more likely to receive recommended cancer treatments than those at non-study centres. Indeed, outcomes at study centres are better even if women are not included in a clinical trial.

However, even in the best centres, conventional therapy is unlikely to further improve cancer survival.⁴ Instead, future clinical trials in gynaecological cancer will focus on individualised therapies using the tumour's genetic profile to predict individual response to treatment. But there is also an urgent need to educate patients about clinical trials and for these studies to focus on continuing unmet needs in gynaecological cancer: rare types of tumour, treatment of older women and improvement in patients' quality of life. Transparent publication of information is also essential to empower and provide real choice for patients.

Emma Elliott (UK): *Multidisciplinary treatment in gynaecological cancer*

Treatment of gynaecological cancer is now multidisciplinary, involving surgery, radiotherapy and medical therapies. For more than a decade in the UK, national policy and guidance have placed the nurse at the centre of this model of collaborative, multidisciplinary cancer care.

By acting as the patient's 'key worker',⁵ nurses play a critical role in ensuring that the multidisciplinary team adheres to national guidance by providing truly holistic care for patients.⁶ Clinical nurse specialists are now the key point of contact for gynaecological cancer patients: providing psycho-social support and education, co-ordinating the multidisciplinary team, and acting as advocates for women and their families.

More European countries should recognise the value of placing nurses at the centre of multidisciplinary cancer care. This wider role for nurses also benefits patients by improving nurses' skills, enabling nurse-led clinics and other initiatives.

Flavia Bideri (Italy): *Patient participation and research*

ACTO Onlus⁷ provides an online source of information and exchange for ovarian cancer patients, together with patient meetings and events to raise awareness. In a recent survey of patient participation in the clinical research agenda, ACTO Onlus found that:

- Patients and physicians agree on priorities for research
- Few physicians, but most patients, believe that patient groups have the skills to participate in a working group with doctors and researchers
- Few patients, but most physicians, believe that research results are shared with patient organisations.

These findings have formed the basis for future action. Since December 2010, ACTOS Onlus has been collaborating with two research institutes and one hospital to translate basic research from the laboratory bench to clinical practice and the patient's bedside. Ultimately, the aim is to establish an international network of patient organisations and researchers.



Speakers discuss issues raised by delegates concerning innovations in treating gynaecological and improving outcomes. From left to right: Flavia Bideri, ACTO Onlus, Italy; Jalid Sehouli, Charité Universitätsmedizin Berlin, Germany; Emma Elliott, Macmillan Lead Clinical Nurse Specialist in Gynaecological Oncology, University College London Hospitals, UK; Frédéric Amant, UZ Gasthuisberg/Katholieke Universiteit Leuven, Belgium.

4 J Clin Oncol 2009;27:1429-25

5 Improving supportive and palliative care for adults with cancer: the manual (2004). <http://guidance.nice.org.uk/CSGSP/Guidance/pdf/English> (last accessed 16 September 2011)

6 Manual for cancer services (2008). www.dh.gov.uk/en/Healthcare/Cancer/Treatment/DH_101998 (last accessed 16 September 2011)

7 www.actoonlus.it

Session 3

Best practice in patient-driven initiatives

Louise Bayne (UK): Ovacome – leading initiatives in ovarian cancer

Since 1997, Ovacome⁸ has been a UK-wide support and advocacy charity for everyone affected by ovarian cancer, including patients, families, friends, carers and health professionals. The organisation has 4500 members, a helpline and website, and publishes newsletters and factsheets.

It continues to be challenging to steer a course between activism and collaboration; for example, when working with industry, or with professionals to improve the quality of patient services. But the aim is always to maintain credibility, guided by the members' committee and the multidisciplinary professional advisory board.

Ovacome's initiatives include:

- A consensus statement on signs and symptoms of ovarian cancer⁹ (subsequently adopted nationally)
- The BEAT campaign and symptom tracker¹⁰, designed to raise awareness of symptoms among health professionals and women themselves
- My Ovacome, an online forum for women to share their experiences of ovarian cancer
- Co-operative engagement with national politicians.

Based on Ovacome's experience, the three key ways to help a patient organisation to develop are:

- Identify a critical issue or problem, and provide a solution
- Provide a service for members
- Work in partnership with clinicians and other health professionals.

Doris Schmitt (Germany): PATH – patient-driven breast cancer tumour bank

PATH (Patients' Tumour Bank of Hope)¹¹ was founded in 2002 by a group of German breast cancer patients, and operates tumour tissue banks of samples from more than 5000 patients in seven German breast cancer centres.

Each tissue bank contains fresh frozen (at -152°C) tumour, tissue and blood samples, donated at the time of initial surgery. Storage is free of charge to the patient, who has lifelong access to her tissue, providing her with future opportunities for

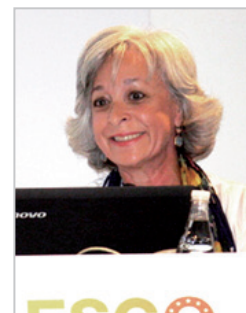
testing new diagnostic and treatment options. The first aliquot of each specimen is stored exclusively for the patient, who donates the remainder to PATH to give to research groups after evaluation of applications by trustees and the scientific board.

Based on PATH's experience:

- Most women agree to donate tissue if they trust their doctor, and are given written information, with online and telephone support
- Voluntary patient groups can make a huge difference and are drivers of change, but they require resources at national and European level to ensure long-term sustainability
- Tissue banks are expensive, so begin with a small project
- Professional advocacy requires funding, so develop relationships with industry and encourage donations from patients
- Develop good contacts with the relevant experts before starting the organisation
- Be aware that national privacy and data protection laws may limit your activities.

Paola Mosconi (Italy): From health literacy to advocacy

Launched in 2005, the Laboratory for Medical Research and Consumer Involvement¹², established at Mario Negri Institute, Milan, aims to foster an alliance between consumer/patient organisations and scientists to promote better health and shared decision-making. The Laboratory runs an annual training course for representatives of patient and consumer associations on decision-making about clinical research and health care. There is also a consumer website¹³, which includes a toolkit to evaluate the quality of health information, patient associations and websites.



Paola Mosconi, Istituto di Ricerche Farmacologiche Mario Negri, Italy describes the skills needed to progress from health literacy to patient advocacy.

Based on this experience, successful progression from health literacy to advocacy depends on:

- Access to scientific evidence, clinical research protocols and quality assessment tools
- Organisation of and participation in empowerment programmes
- Participation in ethics committees, commissions and working groups
- Lobbying to support research and independent fund raising
- Following the principles of evidence-based advocacy
- Continuing independence to ensure acceptance as knowledgeable and experienced partners by professionals.



Doris Schmitt, PATH, Germany, discusses patient-driven tissue banks

⁸ www.ovacome.org.uk

⁹ Ovarian Cancer UK: consensus statement. www.ovacome.org.uk/media/10858/consensus_statement.pdf (last accessed 16 September 2011)

¹⁰ www.ovacome.org.uk/help-beat-ovarian-cancer-with-ovacome.aspx (last accessed 16 September 2011)

¹¹ www.stiftungpath.org

¹² www.marionegri.it/mn/en/sezioni/dipartimenti/labInfo170/attRicerca.html

¹³ www.partecipasalute.it/cms_2/node/44

Workshop

Collaboration across gynaecological cancer patient groups

Panel: Chair: Louise Bayne, UK; Paolo Casali, Italy; Jan Geissler, Germany; John Green, UK; Karen Orloff Kaplan, USA; Birthe Lemley, Denmark; Kristina Milosavljevic, Serbia

Patient advocate perspective

As patient advocates, it is essential to engage at a European level. While healthcare is organised nationally, Europe is responsible for important policies on patient information, pharmacovigilance and clinical trials. Europe and cancer are characterised by inequality, and advocacy is needed on all levels: patient support, health policy and research. Only patients can legitimately represent patients, but policy makers will only listen if patients speak with a united voice.

A gynaecological cancer patient group perspective

KIU (Kraeft I Underlivet)¹⁴ is a model of collaboration with the Danish Cancer Society to support women with gynaecological cancers and address inequalities in diagnosis and treatment. The main challenge is the comparatively poor survival in Danish women with ovarian cancer. But KIU is raising awareness among public and politicians by working with the media and by organising seminars for researchers, doctors and politicians.

Rare cancer perspective

Rare cancers are more common than is often realised, affecting about 4 million people and accounting for 20% of all cancers in Europe. Rare Cancers Europe (formerly European Action Against Rare Cancers)¹⁵ is a multidisciplinary initiative of patients, professionals and industry that co-ordinates joint action on less common cancers. Rare Cancers Europe was instrumental in formulating a consensus statement on improving care for rare cancers in Europe. But lack of professional expertise remains a challenge, and collaboration and networking are especially important in rare cancers. A new approach to clinical trials is also essential to improve the quality of evidence in rare cancers.

ESGO perspective

The new biology and techniques of personalised cancer medicine can only be integrated into clinical practice through education, not only of professionals and policy makers, but also of patients and patient groups. Informed patient organisations are also critical to challenging continuing variations in the quality of care in Europe by promoting standardisation in



Collaborating to ensure a successful seminar, organising committee members: Isabel Mortara, Executive Director, Kenes Associations Worldwide; Ate van der Zee, Immediate Past-President, ESGO; Louise Bayne, CEO, Ovacom UK; and Jan Geissler, CEO Patvocates and Co-Founder CML Advocates Network.

diagnostics and treatment. As the multidisciplinary professional organisation for the study, prevention and treatment of gynaecological cancers in Europe, ESGO is the natural organisation to engage with multiple partners to achieve a 'win-win' relationship with patient organisations.

A cancer patient group perspective

Increasing numbers of women live with a stoma (a surgical opening in the abdomen) following treatment for gynaecological cancer. Association ILCO Serbia¹⁶ is the national organisation for ostomy patients, and is an example of the achievements of patient organisations and the challenges faced in Serbia. The organisation has developed good relations with the Ministry of Health as well as with pharmaceutical companies, and works at national and European level to raise awareness and improve patients' economic and social well being. We are the only patient organisation in Serbia that has received accreditation for continuing education for all healthcare professionals and that has the right to issue a certificate-for-work licence. But the main challenges continue to be patients' lack of awareness, the practical barriers they face in their daily lives, and their fear of stigma, which makes them reluctant to take an active part in the organisation.

North American perspective

Ovarian Cancer National Alliance (ONCA)¹⁷ is the advocacy organisation at both state and national level for its 59 Partner Members and all other ovarian cancer groups in the USA. The Alliance is involved in educating trainee doctors, nurses and physician assistants; it provides information for patients and families, including an online community for women; it acts as a bridge for scientific communication between researchers and the public through its Teal Journal; and is represented on federal research panels. Through its State Resource Guide 'report card', ONCA has also raised awareness of deficiencies in standards¹⁸ of care in all US states. The organisation is encouraging partnership and accountability in research and, despite the current economic climate, has successfully prevented cuts in federal research funding.

¹⁴ www.cancer.dk/kiu

¹⁵ www.rarecancers.eu

¹⁶ www.ilco.org.rs

¹⁷ www.ovariancancer.org

¹⁸ www.ovariancancer.org/take-action/state/

Session 4

The way forward – discussions and recommendations from participants

Participants at the meeting concluded that, although they represent patients with different gynaecological cancers, they face many of the same challenges. They agreed that ESGO is well placed to provide support and a platform to enable gynaecological cancer patient organisations to develop and work in partnership.

Potential joint activities discussed during the meeting were:

- Founding an 'umbrella network' to bring together and share information among gynaecological cancer patient organisations and professionals from all countries in Europe
- Organising an annual meeting for patient groups to provide practical education and training on organisational development and advocacy, together with information on the latest scientific research
- Supporting patients in establishing patient advocacy groups for gynaecological cancers in countries where such organisations do not exist
- Holding a roundtable meeting with other advocacy organisations to discuss common actions at a European level
- Proclaiming one day each year in which all patient organisations in all countries commit to raising awareness of gynaecological cancers among women themselves, the general public, professionals and policy makers
- Creating a gynaecological cancer 'report card' based on agreed criteria to identify deficiencies in care and the actions to take in each country in Europe
- Setting up a gynaecological cancer Facebook group to act as a resource for patient organisations to communicate their ideas, questions and inspiration
- Posting clear links to other gynaecological patient groups on each patient organisation's website
- Collaborating more closely with rare cancer networks
- Fostering better comparative data collection across European countries.
- Educating patients about clinical trials.

Closing remarks

Dr Nicoletta Colombo (ESGO President)

As patients and professionals, we share the dream that in future no woman in Europe should die from a gynaecological cancer. But we have much to do to meet the challenges ahead.

The incidence of and mortality from gynaecological cancers are increasing in Europe, and all women—especially older women—are at risk. We must take steps to improve prevention, promote early diagnosis and ensure access to centres of expertise and innovative clinical trials and treatment for all women with gynaecological cancer. But we can start immediately to improve patient outcomes simply by providing women with information about and raising awareness of gynaecological cancers.

ESGO is ready to take up the challenge to work with patient organisations to:

- Increase public awareness
- Improve professional education and promote a multidisciplinary approach
- Educate policymakers and decision makers
- Overcome taboos and reduce stigma
- Promote good practice in cancer care
- Highlight the role of patient organisations
- Build on synergies across geographical divides
- Increase opportunities for patient involvement in research.

ESGO shares common goals with patient organisations, and wishes to start a dialogue to identify priorities and goals for future action in collaboration with the patient community. This meeting is only the start of this partnership, and ESGO is committed to providing a continuing platform for patient organisations to meet and work together.

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