

The European Voice of Gynaecological Oncology



Report

ESGO Patient Seminar

Gynaecological cancers in Europe:
patient advocacy and collaboration
19 October 2013

Held during the 18th International Meeting of the
European Society of Gynaecological Oncology (ESGO)
19-22 October 2013, Liverpool, UK

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About ESGO and ENGAGe

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 members in over 40 countries in Europe.

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.

What is ENGAGe?

Established in 2012, the European Network of Gynaecological Cancer Advocacy Groups is a network of European patient advocacy groups established by ESGO and representing all gynaecological cancers particularly (ovary, endometrial, cervix, vulva and rare cancers).

Why is ENGAGe needed?

- There are wide variations in patient care across Europe.
- Patients are not adequately informed about gynaecological cancer and their management.
- Survivorship issues are not adequately addressed and psychosocial support in general is poor.

The ENGAGe objectives are to:

- Facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate networking and collaboration between them.
- Disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
- To increase patient representation in ESGO activities by education on current research and health policy.
- To advocate patient care policies, practices and access to appropriate care at both national and European levels.
 - To educate patient groups, health professionals, the public and health decision makers.

ENGAGe resources

Facts & Figures – Women's silent cancers: The state of gynaecological cancers in Europe

This is a revised and fully updated edition of a report first published in 2011 to mark ESGO's first Patient Seminar and is a tool for both patient groups and policy makers to create awareness and break the silence about women's cancers. Progress and policy change can often only be achieved with a united voice across specific diseases; that is why facing the challenges together is so important.

Advocacy Guide

An Advocacy guide was created by Isabel Mortara, Kenes Associations Worldwide for ESGO ENGAGe, which should help patient organisations develop and implement effective advocacy campaigns.

The guide explains in 10 simple steps how to create an advocacy strategy and action plan as well as how to evaluate your efforts to make sure you're heading in the right direction.

The Advocacy guide will be a useful tool both for those of you who are just starting to think about conducting advocacy activities as well as for those of you who have advocacy plans already in place.

'Working with the Media' toolkit

Working with the media is an integral part of accomplishing a patient organisation's mission helps establish your credibility in the community, attracts allies, and sways public opinion.

This toolkit provides useful tips, samples and how-tos to help non-profit volunteers and professionals work with the media to advocate on behalf of your organisation and mission. For those who are new to media work, this toolkit provides the basics for getting started. For those who are more experienced, each part of the resource guide can serve as a checklist for your ongoing efforts to keep the public informed through media.



Foreword

Dr Vesna Kesic (ESGO President)

Welcome to the second ESGO Patient Seminar, organised by ENGAGE, the European Network of Gynaecological Advocacy Groups. Established following the first ESGO Patient Seminar in 2011, ENGAGE aims to promote collaboration among organisations representing patients with gynaecological cancers.

Every year in Europe, 1.5 million women are diagnosed with cancer and 42%—almost half—of these women have a gynaecological or breast cancer. These cancers not only affect women's physical health, but also their psychological and social wellbeing, their body image, their sexuality and, for younger women, their future fertility. Gynaecological and breast cancers often develop silently, but can be detected early. This is why they deserve much attention from, not only doctors and the public, but also policy makers, who may help in the organisation of the services needed for optimal management of women diagnosed with gynaecological and breast cancers.



Dr Vesna Kesic, ESGO President

As outcomes continue to improve and cancer increasingly becomes a chronic disease, we are no longer concerned simply about a woman's survival, but must also take into account all aspects of her quality of life. This is why gynaecological cancer patient organisations and ENGAGE are so necessary.

Many thanks to every delegate who has come to Liverpool today, to work together and to incorporate the patient's voice into ESGO, the European voice of gynaecological cancer. I know that you will help ENGAGE and ESGO to ensure all women with gynaecological will be able to say: "Nothing about us, without us."

Programme

Session 1: Setting the scene and ENGAGe

Chairs: John Green, Liverpool Gynaecological Cancer Group, UK, & Chair, ENGAGe & Louise Bayne, Chief Executive, Ovacom, UK

Status update on ENGAGe—how far have we come since ESGO17? (John Green, Liverpool Gynaecological Cancer Group, UK, & Chair, ENGAGe)

Challenges of (gynaecological) cancers in Europe in 2013 and beyond (Ate van der Zee, Professor of Gynaecological Oncology, Professor of Obstetrics and Gynaecology, Groningen, The Netherlands)

The patient voice: turning health policy into opportunity (Jan Geissler, Co-Founder, CML Advocates Network & Director, European Patients' Academy on Therapeutic Innovation, Germany)

Session 2: Hot topics in gynaecological cancer – news on research

Chair: Nick Reed, Consultant Clinical Oncologist, Beatson Oncology Centre, Glasgow

Securing a patient voice in clinical trials (EU initiative) (Dominika Trzaska, Scientific Officer, European Commission, DG Research & Innovation, Brussels, Belgium)

Current options and the ongoing future of clinical trials (Jalid Sehouli, Director, Department of Gynaecology, Charité, Campus Virchow Clinic & Medical Director, Head of European Competence, Center for Ovarian Cancer, Berlin, Germany)

Innovation target therapies and individualised medicine: what are the new trends and what about following guidelines vs. individualised treatment? (Nicoletta Colombo, ESGO president & University of Milan Bicocca, European Institute of Oncology, Italy)

Session 3: Best practice—marketplace

Chair: Jan Geissler, Co-Founder, CML Advocates Network & Director, European Patients' Academy on Therapeutic Innovation, Germany

Let's talk about international collaboration between our patient groups (Elisabeth Baugh Ross, CEO, Ovarian Cancer Canada & Marcia Donziger, Founder & Chief Mission Officer, Mylifeline.org, USA)

Developing standards of care (Louise Bayne, Chief Executive, Ovacom, UK)

How to organise events to raise awareness about gynaecological cancer and to fundraise for your patient organisation (Gilda Witte, Chief Executive, Ovarian Cancer Action, UK)

Taking a concept across national boundaries and cultures (Sarah Beard, Maggie's Centres, UK)

Session 4: Securing a gynaecological cancer patient voice

Chair: Isabel Mortara, ENGAGe Coordinator
Panel interviewer: Peter O'Donnell, Associate Editor, European Voice

1. Health policy and patient representation

The Swedish model (Gunilla Gunnarsson, Coordinator Cancer Strategy, Swedish Association of Local Authorities and Regions & Barbro Sjölander, Nätverket mot Gynekologisk Cancer (Sweden))

The UK model of working between the charitable sector and government (Annwen Jones, CEO, Target Ovarian Cancer (UK) & Rob Music, Director, Jo's Cervical Cancer Trust)

2. Getting the gynaecological cancer message right with the media (Peter O'Donnell, Associate Editor, European Voice)

3. Advocating for change (Isabel Mortara, ENGAGe Coordinator)

4. Acknowledgement of sponsors

Session 5: Closing remarks

Summary of sessions

Session 1

Setting the scene and ENGAGE



John Green

Dr John Green: Status update on ENGAGE—
how far have we come since ESG017?

ENGAGE was inspired by delegate feedback at the first ESGO patient seminar, held in Milan in October 2011. Following the formation of an ESGO Patient Committee, ENGAGE was launched in 2012. The network now includes over 100 gynaecological patient groups and cancer leagues in more than 25 European countries, and welcomes participation by any patient organisation that shares our objectives.

ENGAGE now has a dedicated section within the ESGO website¹ and is represented on Facebook and Twitter. Two issues of the newsletter have been published, and ENGAGE is able to offer capacity-building grants for gynaecological patient organisations. At this meeting, ENGAGE is launching two patient advocacy toolkits to support patient groups in raising public awareness, shaping the national agenda and promoting the interests of the women they represent.

We welcome all delegates to this Patient Seminar, and your thoughts and ideas on the future of ENGAGE.

Session 2

Hot topics in gynaecological cancers

Professor Ate van der Zee: Challenges of (gynaecological) cancers in Europe in 2013 and beyond

The essence of Europe is diversity not only in language and income, but also in the occurrence and outcomes of cancer. Many factors contribute, but variability in national policies on screening and HPV vaccination is one of the most important.

Since endometrial cancer is associated with obesity, prevention depends on public health programmes to encourage women to adopt healthier lifestyles. Western Europe has rising rates of both obesity and endometrial cancer, but most tumours are detected at an early stage because women know that postmenopausal bleeding should prompt them to consult a doctor. This contrasts with Eastern Europe, where awareness is lower and death rates are higher.

The benefits of ovarian cancer screening remain an open question that should be resolved when large UK studies report in 2015. In the meantime, removal of ovaries and fallopian tubes is available to prevent hereditary ovarian cancer in women with BRCA1/2 mutations in Western Europe, but not in Eastern Europe. In many European countries, patients are still treated by general gynaecologists even though outcomes depend on the surgeon's specialist skills.

While some countries offer HPV vaccination to girls, others, including those with the highest cervical cancer rates, have yet to introduce effective programmes. Although HPV vaccination should reduce the future incidence of cervical cancer, screening will still be necessary and its effectiveness can be increased through population screening and HPV testing.

European population ageing means a continuing rise in the incidence of cancer, and we must ensure that a career in gynaecological oncology is attractive for young doctors. European collaboration will be essential to test novel targeted therapies for the distinct types of ovarian, endometrial, cervical and other gynaecological cancers. These future developments will be costly, and gynaecologists will need the help of ENGAGE to balance needs of individual patients with those of society.

Jan Geissler: The patient voice:
turning health policy into opportunity

Patient groups are very active within their own countries, but collaboration across national borders is also essential to make the patient voice heard at the European level. Although health policy is the responsibility of Member States, European law affects the activities of patient groups at a national level. For example, European legislation preventing direct promotion of prescription drugs was designed to protect individual patients, but it has also reduced patient groups' access to essential information. Similarly, the European Clinical Trials Directive (ECTD) aims to protect patients, but it has hindered cancer research by imposing a greater administrative burden and higher costs that reduce the feasibility of non-commercial trials. The patient voice is now included in discussions about revision of the ECTD, underlining the importance of collaborating with groups such as the European Patients' Forum (EPF)², the European Cancer Patient Coalition (ECPC)³, EURORDIS⁴, the European Commission (EC)⁵ and the European Council⁶.



Ate van der Zee



Jan Geissler

1 <http://esgo.org/ENGAGE/Pages/Home.aspx>

2 www.eu-patient.eu

3 www.ecpc.org

4 www.eurordis.org

5 <http://ec.europa.eu>

6 www.european-council.europa.eu

Collaboration is particularly important in rare cancers, where prevention and screening are not currently practicable, late or incorrect diagnosis is frequent, access to medical expertise is often difficult and there is a lack of appropriate therapies and research. People with some rare cancers also face stigma, and may not have access to a patient organisation or information about their cancer.

By working together across borders we can turn European health policy into opportunities. We must collaborate to join European action programmes and research projects, influence European policies that affect us at a national level, ensure we have a voice in competent authorities and agencies, and educate ourselves to be partners in professional research groups. In short, no policy, regulation or research about us, without us.



Dominika Trzaska

Dominika Trzaska : Securing a patient voice in clinical trials (EU initiative)

The Directorate General (DG) for Research and Innovation⁷ is a funding arm of the EC. The FP7 Health Programme,⁸ now approaching the end of its planned term, is the largest

multinational fund. It addresses key health challenges that are too important or too large for any one country alone, and works with key players within and outside Europe.

Although national investment is substantial, research and innovation in cancer is also a priority for the EU. The EU Research Framework Programme adds value to national efforts by addressing complex issues across borders in a multidisciplinary co-ordinated manner, often in areas that are beyond of the scope national research funding. The aim at all times is to keep patients' needs at the centre of research, and FP7 invested £1.4 billion in basic, translational and clinical research through about 10,000 cross-border networks of cancer researchers in approximately 3000 institutions within Europe. We are also involved in international programmes such as the International Cancer Genomics Consortium and the International Rare Disease Research Consortium.

There is undoubtedly greater scope for patient involvement in research, and under the FP7 several projects were funded that address these issues. The involvement of patient organisations in clinical research projects is also encouraged, and to this end the Innovative Medicines Initiative has funded the European Patients Academy on Therapeutic Innovation (EU-

PATI).⁹ The aim is to provide scientifically reliable, objective and comprehensive information on medicines research and development, so that patient organisations can be effective advocates and advisors in research.

For the future, the EC is responding to the economic crisis by investing in future jobs and growth through Horizon 2020.¹⁰ This single programme for all EU research and innovation has a proposed budget of €70 billion—a 46% increase compared to FP7—and will focus on societal challenges and provide wider access to funding than ever before. Patients must be at the centre of Horizon 2020, and we welcome enquiries from organisations that wish to be involved.

Jalid Sehoul: Current options and the ongoing future of clinical trials

When considering clinical trials, it is essential to understand that cancer is not a single disease. There are, for example, at least 12 different types of ovarian cancer that we must understand if we are to avoid either under- or over-treatment. We must also discriminate between pathological subtypes with different tumour expression, pathology and response to treatment.

Future clinical trials must more carefully define their inclusion criteria to ensure a more tailored or personalised approach to treatment. An important barrier lies in the lack of evidence about the approximately 25% of ovarian cancer patients aged over 65-70 years. A consortium has been established to understand how age-related fragility influences outcomes, and this very early research needs patients' support.

Doctors' and patients' views on treatment are often very different. EXPRESSION III¹¹ was the first trial to ask patients with primary or recurrent ovarian about their expectations of maintenance therapy. Performed with the help of the ENGA-Ge Committee, the study involved over 1700 patients from eight European countries, and its outcomes will influence the future design of clinical trials. The next step is EXPRESSION IV-Qvar,¹² a European-wide questionnaire about patients' expectations of maintenance treatment.

In conclusion, there are many clinical trials of new treatments for gynaecological cancer. In clinical practice, however, it is essential that choice of treatment takes into account each woman's needs and preferences.



Jalid Sehoul

7 <http://ec.europa.eu/research>

8 <http://cordis.europa.eu/fp7/health/>

9 www.patientsacademy.eu

10 <http://ec.europa.eu/research/horizon2020>

11 Oskay-Ozcelik G, et al. Presented at the 49th Annual Meeting of the American Society of Clinical Oncology, Chicago, USA, 30 May-3 June 2013

12 www.expression4.net



Nicoletta Colombo

Nicoletta Colombo: Innovation target therapies and individualised medicine: what are the new trends and what about following guidelines vs individualised treatment?

It is depressing that the incidence of and mortality from ovarian cancer have not fallen over the last 15-20 years. Clinical trials have tested several new cytotoxic agents, usually with disappointing or controversial results.¹³⁻¹⁷

Trabectedin is the only new cytotoxic drug to become available in Europe, and paclitaxel and carboplatin remain the standard, non-specific systemic therapies.

We are now in the era of precision medicine that targets a pathway in the endothelial cell or the ovarian cancer cell itself, or a receptor on its surface. Tumours need a blood supply to grow, and the endothelial 'angiogenic switch', which promotes the growth of new blood vessels to the tumour, is an important target for novel drugs. Bevacizumab blocks a major contributor to angiogenesis, vascular endothelial growth factor (VEGF), and when combined with chemotherapy improves progression-free survival in both primary and recurrent ovarian cancer.¹⁸⁻²¹ Since angiogenesis is a complex process, multiple pathways may be targeted with oral drugs such as nintedanib, cediranib, pazopanib and trebananib, but doctors face the challenge of discovering when and how to use these novel therapies.

One method of targeting the cell nucleus is with drugs that inhibit PARP, an enzyme involved in repairing damaged DNA. In clinical trials, the PARP inhibitor olaparib significantly reduced the risk of disease progression or death from recurrent platinum-sensitive serous ovarian cancer in patients with a BRCA mutation.²²⁻²³ Studies are now under way to investigate maintenance olaparib in primary ovarian cancer.

It is possible to use a carrier to take a drug inside the cell, and vintafolide is example of this 'Trojan horse' approach when used with etarfolatide. This imaging agent identifies tumours that over-express the folate receptor and are likely to be sensitive to vintafolide. A large randomised study is now in progress to confirm findings of the PRECEDENT study, in which vintafolide plus liposomal doxorubicin improved progression-free survival in platinum-resistant ovarian cancer.²⁴

Targeting a specific pathway inside the cell is challenging because ovarian cancer is not one, but several diseases with dif-

ferent natural histories, clinical behaviour and molecular mechanisms. Overall, however, the future looks very bright, and the ultimate aim is personalised medicine that profiles each patient's tumour to deliver precision genomics-based therapy. The task facing doctors will be to understand and interpret the evidence to provide optimal treatment for each patient.

Session 3

Best practice – marketplace

Elisabeth Baugh Ross & Marcia Donziger: Let's talk about international collaboration between our patient groups

MyLifeline.org²⁵ is a non-profit organisation that helps cancer patients to create a free, customised website to simplify communication with friends and family. Ovarian Cancer Canada²⁶ is the only national organisation for any of the gynaecological cancers, and aims to support women, raise awareness and fund research.

World Ovarian Cancer Day, which first took place on 8 May 2013, is a very successful example of international collaboration. It created a strong, global voice for women with ovarian cancer, involving 28 organisations in 18 countries and a website²⁷ that was viewed in 148 countries. Key to success was that the Day's brand or logo reflected the values of all those involved: integrity, strength, and feelings of support, warmth and love. International collaboration is challenging, but based on this experience, best practices are compatibility in shared values and aims, ensuring the right timing to obtain funding, and appreciation of the value of the bigger international picture rather than the territory or 'turf' of a single patient organisation.



Elisabeth Baugh Ross & Marcia Donziger



Louise Bayne

Louise Bayne: Developing standards of care

Developing standards of gynaecological cancer care involves advocacy with the clinical community, health authorities and politicians. A good advocate is open, honest, respectful

13 Banerjee S, et al. *Ann Oncol* 2013;24:679-87

14 Pignata S, et al. *J Clin Oncol* 2011;29:3628-35

15 Wagner U, et al. *Br J Cancer* 2012;107:588-91

16 Armstrong DK, et al. *N Engl J Med* 2006;354:34-43

17 Katsumata N, et al. *Lancet Oncol* 2013;14:102-6

18 Burger RA, et al. *N Engl J Med* 2011;365:2473-83

19 Perron TJ, et al. *N Engl J Med* 2011;365:2484-96

20 Aghajanian C, et al. *J Clin Oncol* 2012;30:2039-45

21 Pujade-Lauraine E, et al. Presented at the 48th Annual Meeting of the American Society of Clinical Oncology, Chicago, USA, 1-5 June 2012

22 Ledermann JA, et al. Presented at the 49th Annual Meeting of the American Society of Clinical Oncology, Chicago, USA, 30 May-3 June 2013

23 Oza AM, et al. Presented at the European Cancer Conference, Amsterdam, 27 September-1 October 2013

24 Naumann RW, et al. *J Clin Oncol* 2013; epub ahead of print 14 October

and helpful, and is prepared to collaborate. She also forgets her own agenda; while personal experience of gynaecological cancer is valid, a campaign must benefit all women.

The first step is to identify the issue and understand the problem. Do your research to prove that your views are correct and be prepared to share your evidence. Then identify key influences—i.e. those that can make the change that you want—and understand the barriers. Aim to achieve consensus with other interested parties that will make it hard to resist the change you are seeking. In the UK, for example, Ovacome was able to achieve a consensus that was the basis of the successful BEAT campaign²⁸ to encourage women and health professionals to recognise the symptoms of ovarian cancer.

In conclusion, if you are dissatisfied with standards of care, stop complaining and get campaigning!



Gilda Witte

Gilda Witte: How to organise events to raise awareness about gynaecological cancer and to fundraise for your patient organisation

Raising awareness to raise funds is one of the core activities of any patient advocacy group. It can be challenging especially for smaller charities, but it is possible to overcome barriers to organise your own event or take part in an established awareness day or event. Simplicity is key to encourage involvement. Make your event fun and accessible so that it is enjoyable and engaging, and people remember your messages. Do not go it alone; get help, ideas and materials from charities and other organisations. Use social media to garner support and keep an eye on your costs to get the best value.

Everything will take longer and involve more time than you envisage, but it will be worthwhile. Women V Cancer began with a charity bicycle ride in Kenya in 2011, followed by events in India in 2012 and Cuba in 2013. The first UK event will be held on 31 May 2014, when over 1600 women will cycle a 100 km circular route from Windsor to London.²⁹ To date, Women V Cancer has raised over £3 million (£3.5 million) for the three charities involved, Breast Cancer Care, Jo's Cervical Cancer Trust and Ovarian Cancer Action.

Sarah Beard: Taking a concept across national boundaries and cultures



Sarah Beard

Maggie Keswick Jencks was a landscape architect, who was diagnosed with breast cancer in 1988 at the age of 47 and died eight years later when her cancer returned. During that time, she felt that the environment in which she was treated did not inspire her to be well or to digest bad news, and that she needed a welcoming point of contact and information that would empower her to be actively involved in her care and support her family and friends.

This experience was the inspiration for Maggie's Centres,³⁰ small houses built within the grounds of hospitals and designed by internationally renowned architects. Operated by psychologists and nurses, the Centres aim to provide the best evidence-based care, support and information for each person's evolving needs. The environment is non-clinical and comfortable, there is no appointments system, and family, friends and children are welcome. There are now 17 Maggie's Centres: 15 in the UK, one in Hong Kong and a virtual Maggie's Centre delivering support online. Other Centres are planned in the UK, and Maggie's is working with teams in Spain, the Netherlands and Norway.

Session 4

Securing a gynaecological cancer patient voice

Gunilla Gunnarsson & Barbro Sjölander: The Swedish model

Responsibility for the healthcare of the 9.5 million people of Sweden lies with 21 county councils, which co-operate for more advanced care in six regions. Cancer survival is high in Sweden, but waiting times vary between regions, access to treatment is unequal due to geography and socioeconomic differences, and there has been an absence of patient focus and involvement in care.

Published in 2009, the Swedish national cancer strategy³¹ stipulated that all improvement work must involve patients. Patient organisations are also invited to share their views on

25 www.mylifeline.org

26 www.ovariancanada.org

27 <http://ovariancancerday.org>

28 www.ovacome.org.uk/beat-ovarian-cancer-with-ovacome.aspx

29 www.actionforcharity.co.uk/eventdetailsnew2.php?urlsearch/Women-V-Cancer-Ride-the-Night

30 www.maggiescentres.org/home.html

31 www.epaac.eu/national-cancer-plans

32 www.targetovariancancer.org.uk

issues such as partnership in research, and are involved in guideline development. Most important, every regional cancer centre has an advisory board of patient representatives, and patients are included on some management boards.

Working from the patient perspective represents a cultural revolution in Sweden and it can still be difficult to gain influence, especially for voluntary organisations with limited resources. It is important to set a clear vision and goals, and work on both the level of women themselves to, for example, encourage them to attend screening, and at the level of regional cancer centres to raise issues such as waiting times. However, perhaps the greatest challenge in Sweden is to reach the 90% of patients who do not belong to patient organisations.



Rob Music

Rob Music & Annwen Jones:
The UK model of working between the charitable sector and government

In the UK, patient organisations have moved from an adversarial relationship with policy makers to a more collaborative approach in which they seek to provide solutions for Government problems. Since patients must be at the heart of this advocacy work, charities must raise the issues that are important to patients, and be

in contact with patients who are prepared to speak to policy makers and in the media.

Target Ovarian Cancer³² aims to promote early diagnosis, find new treatments and provide support to women. In 2009, the charity commissioned the Pathfinder Study, which identified significant problems around late diagnosis, delayed diagnosis and poor awareness among general practitioners and women about early symptoms of ovarian cancer. Supported by evidence on poor ovarian cancer outcomes from the UK National Cancer Intelligence Network³³ and combined with effective patient advocacy led by the charity (including the formation of the All Party Parliamentary Group on Ovarian Cancer), the study eventually led to policy changes. Ovarian cancer has been included in the Be Clear on Cancer symptoms awareness campaign in England and a new Government awareness campaign in Northern Ireland.³⁴



Annwen Jones

Jo's Cervical Cancer Trust³⁵ is the only UK charity dedicated to women affected by cervical cancer and cervical abnormalities. In the UK, take-up of screening is falling, especially among women aged 25-29 and 60-64. There is also very poor understanding of cervical cancer, with women more likely consult a doctor after three weeks with a severe cold than if they have cervical cancer symptoms. The charity runs targeted campaigns in each UK country to engage policy holders in order to improve outcomes. In Wales, for example, the charity organised a major awareness campaign in the capital city of Cardiff that led to a 100% increase in local women using the charity's website. In addition, a meeting was organised at the Welsh Assembly involving supporters from the medical community and cervical cancer patients that encouraged Assembly Members to raise the issue of cervical cancer screening and HPV testing. This work helped highlight the importance of ensuring that Wales uses the latest screening technologies, and the charity is pleased to learn that the country will shortly be joining the rest of the UK in incorporating HPV testing into the national screening programme.

Peter O'Donnell: *Getting the gynaecological cancer message right with the media*

There are many opportunities to work with the media to get your message across, but you need to choose the right media to approach, decide on clear objectives and provide credible information and evidence.



Peter O'Donnell

Make sure that your message appeals to the media, whether they are national, regional or local, newspapers, women's magazines, television or radio. Some editors need serious, evidence-based information to support in-depth articles, while others respond to a 'human interest' story about a woman with a gynaecological cancer. Remember also that blogs, websites and social media can be used to raise awareness of gynaecological cancer within the traditional media. No editor wants to miss out on a story, so bear in mind the positive impact of collaboration and co-ordination to get across your message to both national and European media and reinforce its impact on governments and the European Union.

³³ www.ncin.org.uk

³⁴ <http://campaigns.dh.gov.uk/category/beclareoncancer/>

³⁵ www.jostrust.org.uk



Isabel Mortara

Isabel Mortara: Advocating for change

Advocacy describes the skills to mobilise resources, media and public opinion to support an issue and create a shift in policy. Patient advocacy is about making the pa-

tient voice heard, and is especially important now that health policy makers have competing priorities and need convincing arguments to make the best decisions about screening, prevention and treatments that take into consideration the patient perspective.

To support gynaecological patient advocacy, ENGAGe has produced a range of resources. *Women's silent cancers* has been updated with the latest facts and figures about gynaecological cancer in Europe. There is also a 'working with the media' toolkit, and a step-by-step *Guide to patient advocacy*, specifically designed for gynaecological cancer patient organisations. The guide must be tailored to the national situation, and ENGAGe would be delighted to pilot test the toolkit with a member group.

ENGAGe also offers small financial grants to support collaboration by gynaecological cancer patient groups. Two grants have now been allocated: to Ovacare Ireland to develop an online information resource for patients, families and the public; and to anticancer societies in Serbia and Croatia to launch gynaecological cancer awareness campaigns through their websites and media outreach.

The future agenda for ENGAGe includes an increase of public awareness, patient involvement in research, and symptom management, treatment and care—all priorities identified by members. This meeting has also urged ENGAGe to build capacity to stimulate the creation of at least one gynaecological patient advocacy group in each European country groups, and we will ask every member of the ESGO Council to ensure that they have a patient group in their own country. Also at members' request, ENGAGe and ESGO will help patient organisations to create a platform to enable you to meet and exchange information at ESGO conferences and between conferences.

Session 5

Closing remarks

Vesna Kesic, ESGO President

In Europe, we come from different countries, speak different languages, and have different histories and customs. But our dedication is the same—to help women who have gynaecological cancer. This second ESGO Patient Seminar demonstrates the commitment, energy and enthusiasm that gynaecological cancer patient organisations bring to their mission. Let us collaborate to increase our power so that, when we meet at the next ESGO Patient Seminar, we will share further achievements in our own countries and throughout Europe.



Vesna Kesic

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Industry partners who sponsored the seminar:



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