

# PATIENT SEMINAR

Nice, France - 24 October, 2015, 09:00-17.45 during the ESGO Congress  
Calliope Room - Nice Acropolis Congress Centre.

Advances in cancer care mean that, even when a cure is not possible, many cancers can be controlled for long periods of time. As the number of cancer survivors continues to grow, many more people are living with an illness that is increasingly classified as a chronic disease. Women living with a gynaecological cancer not only have unique medical and psychological needs. They also frequently meet discrimination in the workplace or from financial services, and in some countries face stigma due to misconceptions about cancer.

Patient organisations offer crucial support to women living with a gynaecological cancer by providing the united voice that changes public attitudes and produces policy change. This patient voice has become progressively more influential with the help of strong patient advocates. Increasingly patients are now seen as partners, sitting at the same table as scientists, researchers, clinicians, and health policy makers.

Online and social media have also played their part in magnifying the patient voice. We have recently seen the effect of a celebrity awareness campaign in the so-called Angelina Jolie effect, which led to a worldwide increase in the number of women requesting genetic testing to help determine their risk for hereditary breast cancer and ovarian cancer.

Advocacy continues to be a key driver in changing the public health landscape. Again the patient voice plays an increasingly important role in providing key insights about disease, treatment and quality of life for researchers and policy makers when priorities need to be set.

More women with gynaecological cancers are now participating in clinical trials. However, there is still a huge need for patients to be involved right at the start of trial design to ensure that outcomes are relevant to patients and will produce the information that women and their healthcare teams need to choose the best treatment plan.

These are only a few of the topics to be discussed during our 3rd Patient Seminar. The seminar is just one of the ways in which ENGAGe is supporting gynaecological cancer patient groups by providing a platform for dialogue and action on key issues concerning gynaecological cancers in Europe.

Activities like this seminar would not be possible without the generous support and interest of our sponsors, and we extend our heartfelt thanks to them for giving us the opportunity to organise the 3rd Patient Seminar in Nice, France. We are also grateful to the speakers for sharing their unique knowledge and experience, and to all the participants who made the journey to Nice to learn, share information and best practice, take the opportunity to meet old and make new friends - and above all magnify the patient voice.

**This is why facing the challenges together is so important!**



**John Green**  
Liverpool Gynaecological  
Cancer Group, UK  
Co-Chair  
3rd Patient Seminar



**Isabel Mortara**  
ENGAGe Coordinator  
Co-Chair  
3rd Patient Seminar

## Magnifying the patient voice.

**Seminar Co-chairs:** John Green and Isabel Mortara

**Format:** Eight sessions with presentations and discussions

09.00 - 09.10	<b>Welcome</b>
09.10 - 10.10	<b>Session 1:</b> Setting the scene: trends & hot topics in research
10.10 - 10.25	<b>Tea Break</b>
10.25 - 11.40	<b>Session 2:</b> Prevention & screening
11.40 - 12.10	<b>Lunch</b>
12.10 - 13.30	<b>Session 3:</b> Innovation & treatment
13.30 - 13.40	<b>Short Break</b>
13.40 - 15.15	<b>Session 4:</b> Best practice marketplace (parallel sessions)
15.15 - 15.30	<b>Coffee Break</b>
15.30 - 16.10	<b>Session 5:</b> Securing a gynaecological cancer patient voice using social media
16.10 - 17.00	<b>Session 6:</b> Cancer in the workplace: Do employment discrimination laws protect employees with
17.00 - 17.30	<b>Session 7:</b> 'Advocacy in Action' panel: Influencing health policy
17.40 - 17.45	<b>Session 8:</b> Meeting close

### WELCOME

**John Green**, Seminar Chair  
**Isabel Mortara**, ENGAGe Coordinator

### SESSION 1: setting the scene: trends & hot topics in research

**Chair:** Elisabeth Åvall Lundqvist, Dept of Oncology and Dept of Clinical and Experimental Medicine, Linköping University & Dept of Oncology-Pathology, Karolinska Institute, Sweden

#### 1. Trends in gynaecological cancer in Europe

(09.10 - 09.25)

**Speaker:** John Butler (International Cancer Benchmarking Partnership, Gynaecological Oncology Consultant St Bartholomew's and Royal Marsden Hospitals, UK)

#### 2. Hot topics in research (09.25 - 09.40)

**Speaker:** Helga Salvesen (Centre for Cancer Biomarkers CCBIO, Bergen University, Norway)

#### 3. Ovarian cancer – UKTOCS study: the outcomes

(09.40 - 09.55)

**Speaker:** Usha Menon (UCL Elizabeth Garrett Anderson Institute of Women's Health, UK)

Discussion with audience (09.55-10.10)

### SESSION 2: Prevention & screening

**Chair:** Denis Querleu (Institut Claudius Regaud, France)

#### 1. Physical activity & cancer risk

(10.25-10.40)

**Speaker:** Helena Rundqvist (Karolinska Institute, Sweden)

#### 2. Cervical cancer - today and tomorrow

(10.40-10.55)

**Speaker:** Vesna Kesic (Department of Obstetrics and Gynaecology Clinical Center of Serbia, Serbia)

#### 3. Management of women with a genetic predisposition (10.55-11.10)

**Speaker:** Jan C. Oosterwijk (Department of Genetics, University Medical Center Groningen, The Netherlands)

#### 4. Utility of a screening program of high risk groups.

(11.10-11.25)

**Speaker:** Ranjit Manchanda (Bartshealth NHS Trust, Royal London Hospital, UK)

Discussion with audience (11.25-11.40)

### SESSION 3: Innovation & treatment

**Chair:** Nicoletta Colombo, European Institute of Oncology, Italy

#### 1. Surgery: when, why and how?

(12.10-12.25)

**Speaker:** Jalid Sehoul (Charité – Universitätsmedizin Berlin Campus Virchow Medical Centre, Department of Gynaecology, Germany)

#### 2. New advances in radiation oncology for gynaecologic cancer.

(12.25-12.40)

**Speaker:** Remi Nout (Radiation Oncologist, Leiden University Medical Centre (LUMC), The Netherlands)

#### 3. FP7 EpiFemCare: novel ways to detect women's cancers early and to personalise treatment - a European initiative

(12.40-12.55)

**Speaker:** Martin Widschwendter (Professor in Women's Cancer, Head of the Department of Women's Cancer at University College London (UCL), UK)

#### 4. Improving the treatment of rare gynaecological cancers (12.55 -13.10)

**Speaker:** Isabelle Ray Coquard (Centre Léon Bérard, Centre de Lutte Contre le Cancer (CLCC), France)

Discussion with audience (13.10-13.30)

### SESSION 4: Best practice marketplace (parallel sessions)

**Chair:** Jan Geissler, Patvocates, Germany

**1. Best practice from patient groups:** 4x10 minute "elevator pitch" presentations of leading initiatives by gynaecological cancer patient groups, plus 10 minutes Q&A after each presentation.

**2. At the end:** Discussion with audience (15 minutes): How can we learn more from each other and share best practice, replicating success stories.

#### 1. Setting up & building the capacity of a gynaecological cancer advocacy group

**Speakers:** Barbro Sjölander (Nätverket mot gynekologisk cancer, Sweden), Paz Ferrero (ASACO, Spain)

#### 2. Communications & campaigns on a shoestring budget

**Speakers:** Slavica Periskic (Anti-Cancer Society Sombor, Serbia), Myrto Maria Skotida (Association of Cancer Patients of Athens "K.E.F.I")

#### 3. Gynaecological cancer campaigns with cross border initiatives

**Speaker:** Elisabeth Baugh (Ovarian Cancer Canada)

#### 4. Patient involvement in research – clinical trials

**Speaker:** Annwen Jones (Target Ovarian Cancer, UK)

### SESSION 5: Social media: securing a gynaecological cancer patient voice using social media (At the end: Get back together as a group for summary & feedback)

**Chair:** Jan Geissler, Patvocates, Germany

#### Plenary lecture - running a campaign and social media - experience from cervical cancer.

(#SmearforSmear) (15.30-15.40)

**Speaker:** Rob Music (Jo's Trust, UK)

#### 1. Break out groups - beginners and advanced social media session (15.40-16.00)

**Beginners group – facilitator:** Louise Horner (Target Ovarian Cancer, UK)

**Advanced group – facilitator:** Jan Geissler (Patvocates, Germany)

Get back together as a group for summary & feedback (16.00-16.10)

### SESSION 6: Cancer in the workplace: do employment discrimination laws protect employees with cancer? (16.10-17.00)

**Chair:** Isabel Mortara, ENGAGe Coordinator

#### A patient experience

**Speaker:** Isabelle Lebrocqy (oPuce, The Netherlands)

#### The European landscape

**Speaker:** Ward Rommel (Kom op tegen Kanker, Belgium)

Discussion with audience (16.50-17.00)

### SESSION 7: 'Advocacy in Action' Panel: influencing health policy (17.00-17.30)

**Chair:** Jan Geissler, Patvocates, Germany

#### 1. Using data in health policy: How we use research findings to advocate for change.

**Speaker:** Louise Bayne (Ovacom, UK)

#### 2. Zerovision for Cervical Cancer.

**Speaker:** Barbro Sjölander (Nätverket mot gynekologisk cancer, Sweden)

#### 3. The Angelina Jolie effect in the context of the health policy landscape.

**Speaker:** Annwen Jones (Target Ovarian Cancer, UK)

Discussion with audience (17.30-17.40)

### SESSION 8: Meeting close

**Chair:** John Green, ENGAGe Chair

# 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 in Europe is a network of European patient advocacy groups established by ESGO 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.

## **Contact us:**

ENGAGe Secretariat

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*We would like to take this opportunity to thank our lead sponsors for their generous support of the ESGO Patient Seminar.*



**The European Voice of Gynaecological Oncology**