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.

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 Welcome

09.10 - 10.10 Session 1: Setting the scene: trends & hot topics in research
Speaker: John Butler (International Cancer Benchmarking Partnership, Gynaecological Oncology Consultant, St Bartholomew’s and Royal Mandern Hospitals, UK)

10.10 - 10.25 Tea Break

10.25 - 11.40 Session 2: Prevention & screening
Speaker: Helga Salvesen (Centre for Cancer Biomarkers CCBIO, Bergen University, Norway)

11.40 - 12.10 Lunch

12.10 - 13.30 Session 3: Innovation & treatment
Speaker: Usha Menon (UCL Elizabeth Garrett Anderson Institute of Women’s Health, UK)

13.30 - 13.40 Short Break

13.40 - 15.15 Session 4: Best practice marketplace (parallel sessions)

15.15 - 15.30 Coffee Break

15.30 - 16.10 Session 5: Securing a gynaecological cancer patient voice using social media
Speaker: Vesna Kasic (Department of Obstetrics and Gynaecology Clinical Center of Serbia, Serbia)

16.10 - 17.00 Session 6: Cancer in the workplace: Do employment discrimination laws protect employees with cancers
Speaker: Ward Rommel (Kom op tegen Kanker, Belgium)

17.00 - 17.30 Session 7: Advocacy in Action: panel: Influencing health policy
Speaker: Annwen Jones (Target Ovarian Cancer, UK)

17.40 - 17.45 Session 8: Meeting close

17.45 - 17.50 Welcome

John Green, Seminar Chair
Isabel Mortara, ENGAGE Coordinator

SESSION 1: setting the scene: trends & hot topics in research
Chair: Elisabeth Avall Lundqvist, Dept of Oncology and Department 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 Mandern 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 – UKCTOCS 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 Kasic (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 Centre (LUMC), The Netherlands)

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

Speaker: Jaid Sehoulh (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.

3. Setting up & building the capacity of a gynaecological cancer advocacy group
Speakers: Barbro Sjölander (Nätverket mot gyniekologisk cancer, Sweden), Paz Ferrero (ASACO, Spain)

2. Communications & campaigns on a shoestring budget
Speakers: Slavica Pericak (Anti-Cancer Society Sombor, Serbia), Myrto Maria Skotida (Association of Cancer Patients of Athens ‘K.E.F.’)

3. Gynaecological cancers campaigns with cross border initiatives
Speaker: Elisabeth Baugh (Ovarian Cancer Canada)

4. Patient involvement in research – clinical trials
Speaker: Anwen Jones (Target Ovarian Cancer, UK)

Discussion with audience (16.00-16.10)

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 cancers? (16.10-17.00)
Chair: Isabel Mortara, ENGAGE Coordinator

A patient experience
Speaker: Isabelle Lobrocyq (ePuce, The Netherlands)

The European landscape
Speaker: Ward Rommel (Kom op tegen Kanker, Belgium)

Discussion with audience (16.17-16.50)

SESSION 7: ‘Advocacy in Action’ Panel: Influencing health policy
Chair: Jan Geissler, Patvocates, Germany

1. Using data in health policy: How we use research findings to advocate for change.
Speaker: Louise Bayne (Ovacome, UK)

Speaker: Barbro Sjölander (Nätverket mot gyniekologisk cancer, Sweden)

3. The Angelina Jolie effect in the context of the health policy landscape.
Speaker: Louise Horner (Target Ovarian Cancer, UK)

Discussion with audience (17.00-17.30)

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.

ENGAGe is the European Network of Gynaecological Cancer Advocacy Groups in Europe. It 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
Email: esgo.engage@gmail.com
Web: www.esgo.org/ENGAGe/Pages/Home.aspx

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