

ESGO Patient Seminar at ESGO18

Place, Date and Time: Liverpool, UK, Saturday, 19 October, 2013 during the ESGO Congress

Title of Seminar: “Gynaecological Cancers in Europe: Patient Advocacy and Collaboration”

Seminar: Co-Chair: John Green & Louise Bayne

Format: Three plenary sessions with one break-out marketplace session

Time	Session title
09.00-10.10	Session 1: Setting the scene & ENGAGe
10.10-10.25	Coffee break
10.25-12.00	Session 2: Hot topics in gynaecological cancers – news from research
12.00-12.30	Lunch break
12.30-14.00	Session 3: Best Practice Marketplace (parallel sessions)
14.00-14.15	Coffee break
14.15-15.50	Session 4: Securing a gynaecological cancer patient voice
15.50-16.00	Session 5: Close of meeting

Detailed programme

Title of Seminar: Gynaecological Cancers in Europe: Patient Advocacy and Collaboration

Word of welcome: Co-Chairs: John Green & Louise Bayne

Session 1: (1 hour 10 minutes):

Setting the Scene: Gynaecological cancer in Europe, and ENGAGE

Chair: Vesna Kesic, *Institute of Obstetrics and Gynaecology Clinical Center of Serbia* & Louise Bayne, *CEO, Ovacome UK*

Take-home message: Understanding today's challenges in gynaecological cancers from the very common to the rarer forms. Understanding what ENGAGE has achieved in the past 12 months in order to bring together patient groups across gynaecological indications. Learning from best practice examples how the patient voice can turn health policy into advocacy opportunities

Presentations:

1. Challenges of (gynaecological) cancers in Europe in 2013 and beyond. **Speaker: Ate van der Zee, Professor of Obstetrics and Gynaecology, Groningen, The Netherlands**
2. Status update on ENGAGE – how far have we come since ESGO17? **Speaker: John Green, University of Liverpool, UK & Chair ENGAGE Network**
3. The patient voice: turning health policy into opportunity **Speaker: Jan Geissler, Director, European Patients' Academy on Therapeutic Innovation & Co-Founder, CML Advocates Network, Germany**
4. Discussion with audience

Session 2 (1 hour 30 minutes): Hot topics in gynaecological cancers - news on research

Chair: Nick Reed, *Consultant Clinical Oncologist, Beatson Oncology Centre, London, UK* & Flavia Bideri, *Acto Onlus, Milan, Italy*

Take-home message: There is innovation in all disciplines of gynaecological cancers: vaccination/prevention, surgery, oncology, nursing. Individualised treatment, clinical trials. Multi-professionality and multi-disciplinarity would increase outcomes. Pro's and con's, what are the limitations.

Presentations:

1. Innovation target therapies and individualized medicine: What are the new trends and what about following guidelines vs. individualized treatment? **Speaker: Nicoletta Colombo, Director, Gynaecological Oncology Department, European Institute of Oncology, Milan, Italy**
2. Current options and the ongoing future of clinical trials. **Speaker: Jalid Sehouli, Director, Department of Gynecology, Charité, Campus Virchow Clinic & Medical Director, Head of European Competence Center for Ovarian Cancer, Berlin, Germany**
3. Securing a patient voice in clinical trials (EU initiative) **Speaker: Dominika Trzaska, Scientific Officer, European Commission, DG Research & Innovation, Brussels, Belgium**
4. Acute and late effects of treatment vs quality of life - taking an integrated approach. **Speaker: Mari Lloyd-Williams, Professor of Community Health, University of Liverpool, UK**
5. Discussion with audience

Session 3 (1 hour 30 minutes):

Best Practice - Marketplace

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

Take-home message: Patient groups across gynaecological diseases already have inspiring success stories of their patient campaign work to share – outstanding projects in a number of gynaecological cancers that have largely impacted patient care in their disease area.

Format: The Marketplace is a highly interactive session with very short presentations and concise, focused discussions. The aim of the session is provide participants with the opportunity to discuss topics with experts in an informal small group setting.

The marketplace consists of 4 "flipchart islands" each covering a different topic. Participants have pre-registered for 3 out of the 4 topics. During each session there will be approximately 10 participants at each island. The speaker will stay at his/her island for the entire Best Practice Marketplace Session whilst the participants will move from one island to the next. Over a one and a half hour period the speaker will repeat the presentation 3 times, 25 minutes each.



Experts should give a maximum 5 minutes presentation to introduce the topic and then facilitate questions/discussion/sharing best practice for 20 minutes. The focus of discussion will depend on the needs/interest of the participants. After 25 minutes a bell will ring and participants will have 5 minutes to move to the next island.

This session is about dialogue and sharing. Speakers are not allowed to show any slides. Each island will have a flipchart on which they can list key points they want to make. They can prepare these bullet points beforehand or write the list up on the flipchart before the Marketplace session starts. Alternatively, they can bring a poster.

Agreed Marketplace topics:

1. Let's talk about International collaboration between our patient groups (**Elisabeth Ross, CEO Ovarian Cancer Canada & Marcia Donziger, Founder & Chief Mission Officer, Mylifeline.org, USA**)
2. Developing Standards of Care: The Patient perspective (**Louise Bayne, Chief Executive, Ovacom, UK**)
3. How to organize events to raise awareness about gynaecological cancer and to fundraise for your patient organisation (**Gilda Witte, Chief Executive, Ovarian Cancer Action, UK**)
4. Taking a concept across national boundaries and cultures (**Sarah Beard, Maggie's Centres UK**)

Session 4 (1 hour 30 minutes):

Securing a gynaecological cancer patient voice

Chair: Isabel Mortara

Panel interviewer: Peter O'Donnell, Associate Editor, European Voice

Take-home message: Sharing the Swedish model where patients are included in high level decision making policy forums & the UK model of working between the charitable sector & government and How do we get the gynaecological cancer message right with the media as well as addressing gynaecological cancer advocacy issues.

1. Health Policy and patient representation

- I. The Swedish model (2 speakers – 1 representing government and the other the patient perspective). **Speakers:** *Gunilla Gunnarsson, Coordinator Cancer Strategy, Swedish Association of Local Authorities and Regions & Barbro Sjölander, Nätverket mot Gynekologisk Cancer (Sweden)*
- II. The UK model of working between the charitable sector and government (2 speakers – the charitable sector perspective). **Speakers:** *& Rob Music, Director, Jo's Cervical Cancer Trust & Annwen Jones, CEO, Target Ovarian Cancer (UK)*
- III. Discussion

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

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

- I. ENGAGe resources
- II. Advocacy Topics & discussion

Session 5: Meeting close (10 minutes)

1. ESGO's commitment to the gynaecological cancer patient community **Speaker:** *Vesna Kesic, ESGO President-elect*