

2019 Patient Advocacy Seminar Report



ESGO ENGAGe Patient Seminar in Gynaecological Cancers

November 1–3, 2019

Held during the European Society of Gynaecological Oncology Congress in Athens, Greece



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PROGRAMME

DAY 1: Friday, November 1st

Chairs: Murat Gultekin (TR), Esra Urkmez (USA)

10:00-13:00	EEG Meeting		MC2
14:00	<i>Beginning of the PAS</i>		
14:00 - 14:10	PAS Welcome word	<i>Denis Querleu (FR), Elzbieta van der Banasik (NL), Esra Urkmez (USA), Murat Gultekin (TR)</i>	MC2
14:10 - 15:00	ESGO guidelines adapted for patients	<i>Eka Sanikadze (GE), Maria Papageorgiou (GR), Nicoletta Cerana (IT), Kim Hulscher/Linda Snoep (NL)</i>	MC2
10'	Introduction	<i>Eka Sanikadze (GE)</i>	
10'	Endometrial cancer	<i>Maria Papageorgiou (GR)</i>	
10'	Ovarian cancer	<i>Nicoletta Cerana (IT)</i>	
10'	Cervical cancer	<i>Ic6 T6th (HU)</i>	
10'	Vulvar cancer	<i>Kim Hulscher/Linda Snoep</i>	
15:00 - 15:30	Coffee break + posters viewing		
15:30 - 16:15	Best poster presentations and discussion	<i>Karina Dahl Stefenssen (DK)</i>	Poster area
7'+5'	The Venus Project by BRACHA - Living with a high risk of hereditary cancer	<i>Lisa Cohen (Israel)</i>	
7'+5'	Ricerca In-Acto: a multicentre, perspective survey about knowledge, attitudes and experience on randomized controlled trials	<i>Nicoletta Cerana (IT), Elisabetta Ricotti (IT)</i>	
7'+5'	Deciding together	<i>Kim Hulscher/Linda Snoep (NL)</i>	
9'	Wrap up	<i>Karina Dahl Stefenssen (DK)</i>	
16:15 - 16:45	Improving Care Pilot programs	<i>Chair: Esra Urkmez - short opening, results</i>	MC2
4'	Introduction - Survey 2017	<i>Esra Urkmez (USA) - 3 slides</i>	
10'+3'	Results of first ENGAGE pilot projects	<i>Veronika Cibulov6 (CZ)</i>	
10'+3'	Results of first ENGAGE pilot projects	<i>Kamil Zalewski (PL)</i>	
16:45 - 17:30	Psycho-oncology in GO	<i>Karina Dahl Stefenssen (DK)</i>	MC2
17:30 - 18:30	Round table discussion		MC2
10'+5'	Table 1: Ovarian cancer campaign	<i>Elisabetta Ricotti (IT)</i>	
10'+5'	Table 2: Campaign - lobbying	<i>Charo Hierro (ES)</i>	
10'+5'	Table 3: Campaign -HPV vaccination and GO Day	<i>Ic6 T6th (HU), Esra Urkmez (USA)</i>	
10'+5'	Table 4: WHO cervical cancer elimination campaign	<i>Elena Fidarova (WHO)</i>	
18:30	<i>End of the meeting</i>		
19:30-21:00	<i>Together dinner for ENGAGE members</i>		<i>Balcony Restaurant</i>

PROGRAMME

DAY 2: Saturday, November 2nd

Chairs: Karina Dahl Steffensen, Maria Papageorgiou

7:30-8:30	ESGO run	<i>optional</i>	
8:30-9:20	<i>Move back to the Megaron Congress Center</i>		
9:20-9:30	Opening Day 2	<i>Karina Dahl Steffensen (DK), Maria Papageorgiou (GR)</i>	
9:30 - 10:15	Metastatic cervical and endometrial carcinoma	<i>Zoltan Novak (HU)</i>	MC2
10:15 - 10:30	Coffee break		
10:30 - 11:15	Clinical Trials (cooperation with ENGOT)	<i>Antonio González (ES), Birthe Lemley (DK)</i>	MC2
11:15-11:45	Quality of life - nutrition, fatigue and lifestyle	<i>Christos Papavagelis (GR), Ioanna Tsiaousi (GR)</i>	MC2
10' + 5'	Nutrition	<i>Christos Papavagelis (GR)</i>	
10' + 5'	Sexual health care after Gynecologic cancer	<i>Ioanna Tsiaousi (GR)</i>	
11:45 - 12:30	<i>Lunch + move to the square</i>		
12:30 - 14:30	Live happening at the square - filming		Syntagma Square
14:30 - 15:00	Move back to the Megaron Congress centre		
15:00 - 16:20	Round table discussion		MC2
10' + 10'	Table 1: Ovarian cancer	<i>Jonathan Lederman (UK), Esra Urkmez (USA) as facilitator</i>	
10' + 10'	Table 2: Cervical cancer	<i>David Cibula (CZ), Simona Ene (RO) as facilitator</i>	
10' + 10'	Table 3: Endometrial cancer	<i>Mansoor Mirza (DK), Birthe Lemley (DK) as facilitator</i>	
10' + 10'	Table 4: Quality of life	<i>Jalid Sehouli (DE), Icó Tóth (HU) as facilitator</i>	
16:20 - 16:30	<i>Coffee break</i>		
16:30 - 17:15	Immunotherapy in GYN Oncology	<i>Christian Marth (AT)</i>	MC2
17:15 - 18:00	ESGO ESMO Ovarian cancer guidelines		MC2
10'	Quality	<i>Murat Gultekin (TR)</i>	
10'	Advanced stage	<i>Denis Querleu (FR)</i>	
10'	Recurrent	<i>Nicoletta Colombo (IT)</i>	
15'	Discussion		
18:00	<i>End of the meeting</i>		

PROGRAMME

DAY 3: Sunday, November 3rd

Chairs: Esra Urkmez (USA), Birthe Lemley (DK)

8:00 - 10:00	ENGAGe General Assembly		MC2
10´	Report of Chair		
10´	Ideas for Patient Seminar 2020 and ENGAGe products/Feedback from members		
10´	Change of Bylaws		
90´	Elections		
10:00 - 10:15	<i>Coffee break</i>		
10:15 - 10:50	HYPE or HIPEC in ovarian cancer?	<i>Giovanni Scambia (IT) / Andreas du Bois (DE)</i>	MC2
10´	Giovanni Scambia (IT) is PRO		
10´	Andreas du Bois (DE) is CON		
15´	Discussion		
10:50 - 11:00	<i>Move to the Congress hall Banquet</i>		
11:00 - 11:20	Lymphedema from patient's perspective	<i>Maria Papageorgiou (GR) is presenting in the framework of the ESGO Congress</i>	Banquet
11:20 - 11:30	<i>Move to the MC2</i>		
11:30 - 11:35	Closing remark	<i>Esra Urkmez (USA), Murat Gultekin (TR)</i>	
11:35 - 12:00	<i>Lunch</i>		
12:00 - 12:30	meeting of the „new“ and „old“ EEG		

About ESGO

The European Society of Gynaecological Oncology (ESGO) is the leading European organisation in the field, with more than 2,500 professionals involved in the treatment, care, and research of gynaecological cancers.

ESGO's mission

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

Activities

- Publications: The International Journal of Gynecological Cancer (co-owner), the Textbook of Gynaecological Oncology, the Cancer in Pregnancy textbook, the LiFE Report (reviews of the most relevant published articles).
- Primary event in the field: ESGO Congress (one held every two years).
- Professional niche events: State-of-the-art conferences, Masterclasses, workshops.
- ESGO eAcademy, a unique comprehensive knowledge portal for postgraduate education.
- Six established networks, including ENGAGe, and three task forces
- Development of clinical guidelines for ovarian, vulvar, endometrial and cervical cancers.



About 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 and representing all gynaecological cancers (ovarian, endometrial, cervical, vulvar, and rare cancers).

Objectives

- Facilitate the development of national gynaecological cancer patient groups in Europe and facilitate networking and collaborative operation between them.
- Disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
- Increase patient representation and ESGO activities through education on current research and health policy.
- Advocate patient care policies, practices, and access to appropriate care at both national and European levels.
- Educate patient groups, health professionals, the public, and help decision-makers.

SUMMARY OF SESSIONS

Welcome remarks

ESGO President Denis Querleu (FR), ESGO Council member Elzbieta van der Steen-Banasik (NL)
ENGAGe co-chairs Esra Urkmez (USA) and Murat Gultekin (TR)



“We absolutely want to be a society for all the patients and all the women in Europe.”

Denis Querleu

Key messages

- The ENGAGe patient advocacy network is an important part of the European Society of Gynaecological Oncology’s mission to improve gynaecological cancer care for women in Europe.
- In the last decade, a lot of improvement has been made in the understanding and treatment of gynaecological cancer. For the years to come, it is important that clinicians and patients join forces to continue. In addition, ENGAGe has been able to form many relationships—and even friendships—between networks which will guarantee the success of ENGAGe projects going forward.
- Although the leadership of ESGO and ENGAGe is changing with the recent Council and Executive Group elections, the ongoing projects will continue, and cooperation will be even stronger than before.
- Thanks to patient participation in clinical trials over the past decade, the gynaecological oncology field has made huge progress. The medical professionals attending the ESGO Congress November 2–5 have a large debt to the patience and knowledge of the patients.
- Maria Papageorgiou, Greek representative, was recognised for her work for the network and particularly for the local programme of this Patient Seminar.
- The next ENGAGe Patient Seminar will be held in June 2020.

ESGO Guidelines adapted for patients

Eka Sanikazde (GE), Maria Papageorgiou (GR), Nicoletta Cerana (IT), Kim Hulscher and Linda Snoep (NL),
Ic  T th (HU)



“Thank you for the work you have done teaching the doctors.”

Eka Sanikadze

Key messages

- The ENGAGe initiative to adapt the ESGO guidelines is an important project because it simplifies the professional guidelines used by medical care teams for patients who want and need to learn about their treatment. These “lay summaries” are made possible with grants and with the hard work of many volunteers.
 - Patients, families, doctors, and hospital managers all benefit from the lay summaries.
 - The aim is to provide basic information about treatment and risks to patients, but they are not beginner level documents. For an introduction to individual gynaecological cancers, see ENGAGe’s factsheets.
 - The full professional guidelines are developed by ESGO (sometimes with the cooperation of other organisations), based on a clearly defined scientific procedure that took the bulk of scientific research, current practices, and expert knowledge into consideration.
- Patients can use the adapted guidelines to understand the responsibilities and limitations a doctor has when directing treatment. Doctors may also have to follow national guidelines, which, though they will not conflict with the ESGO guidelines, may present further information for both the patient and the doctor to consider.
- Patients can compare their real-life experiences to the protocol outlined in the guidelines.
 - Because each patient’s treatment has individual challenges and concerns, it should be understood that procedures will vary from individual to individual.
- Four ENGAGe lay summaries were presented and discussed at the Patient Advocacy Seminar by the volunteers who helped produce the documents:

Endometrial Cancer (presented by Maria Papageorgiou, GR)

- The full text of these guidelines was the result of a cooperation between ESGO and ESMO that aims to improve patient outcomes. Of particular importance to patients are the sections presenting the level of evidence and the grade of each recommendation for individual procedures.
- The guidelines cover many topics, for example, if procedures are evidence-based, what is the patient risk, and what level of surgery is necessary in certain situations.
- The lay summaries will help endometrial cancer patients ask questions of their doctor to understand the manner in which their doctor is approaching their disease treatment and if their doctor is following best practice recommendations.

Ovarian Cancer (presented by Nicoletta Cerana, IT)

- The lay summaries are now presented in a more intuitive manner for patients to understand than the professional guidelines, with particular care given to the length and included graphics as well as summarising the original text with all of the information a patient might find helpful. Bullet points were used to make the information clear.

Cervical Cancer (presented by Icó Tóth, HU)

- In addition to the above, the lay summaries help patients learn the vocabulary they need to navigate their treatment and understand what and why doctors are asking them to do.
 - Of particular interest to patients for cervical cancer is the description in the lay summaries of the possibilities for fertility-sparing surgery and other techniques.

Vulvar Cancer with Kim Hulscher and Linda Snoep (NL)

- The lay summaries will help spread information about the symptoms of vulvar cancer, which is rare, to the public and even to general practitioners. Because of the rarity of the disease, primary care physicians don't always recognise the symptoms and instead treat it as a yeast infection. It will also help educate people about the lichen sclerosis and HPV connection to vulvar cancer risk.
 - Of particular interest to patients in the summary is the discussion of aftercare, sexual health (not only for women under 70), and physical rehabilitation following surgery to allow patients in recovery to enjoy physical activity and avoid discomfort with normal activities such as bike riding or wearing sanitary napkins.

Resources

ENGAGE fact sheets: <https://engage.esgo.org/resources/cancer-fact-sheets/>

ESGO full guidelines: <https://guidelines.esgo.org>

Best poster presentations and discussion

Karina Dahl Stefenssen (DK)



"Clinical studies are vital in ovarian cancer because we need new treatments for these mortal cancers."

Nicoletta Cerana

- The Venus Project by BRACHA – living with a high risk of hereditary cancer.

Lisa Cohen (IL)

- Ricerca In-Acto: a multicentre, prospective survey about knowledge, attitudes, and experience on randomized controlled trials.

Nicoletta Cerana (IT), Elisabetta Ricotti (IT)

- Deciding together.

Kim Hulscher/Linda Snoep (NL)

Key messages

- The ENGAGe network and its member organisations have many excellent projects that would be interesting and helpful to clinicians. In order to help spread awareness of the network's member activities and give visibility to the members themselves, a poster project has been underway for the past two years.
 - o At a previous Patient Advocacy Seminar, attendees learned how to search on PubMed.
 - o In spring 2019, a webinar was held on how to make an academic poster in the correct format for medical conferences and other events.
 - o For this Patient Advocacy Seminar and the concurrently running ESGO Congress, member organisations were invited to submit. Eight abstracts were submitted, and all were accepted. The three best were invited to present them in person; one author was unable to attend.

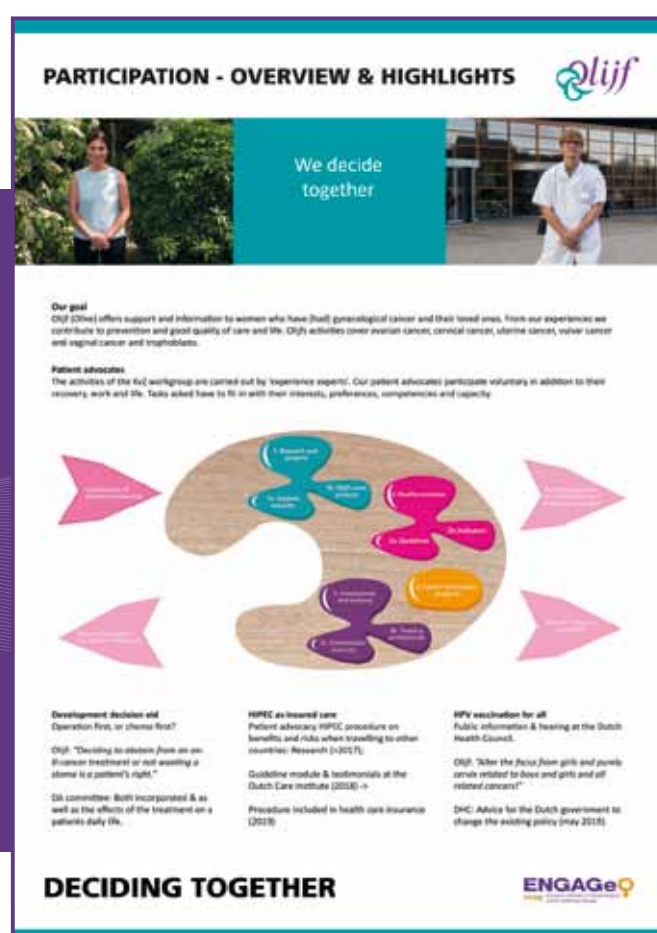
Ricerca In-Acto: a multicentre, prospective survey about knowledge, attitudes, and experience on randomized controlled trials.

Nicoletta Cerana (IT), Elisabetta Ricotti (IT)

- Clinical studies in Italy are finding it difficult to enrol sufficient numbers of patients, even though new treatments for ovarian cancer are sorely needed. In order to understand why women don't participate, Cerana and Ricotti's group is exploring five topics related to participation, including obstacles and trust levels, and the level of satisfaction among women who do participate. The ongoing survey is being delivered by a series of two questionnaires to eligible patients at participating centres. There will be 38 centres participating.
- The results will help show the attitudes of Italian women to clinical trial participation as well as shed light on the existing culture of compliance and the communication between doctors and patients.

Resources

<https://clinicaltrials.gov>



Deciding together.

Kim Hulscher/Linda Snoep (NL)

- The poster from Dutch advocacy group Stichting Olijf highlighted the importance of gynaecological cancer patients and doctors working together. Their myriad projects include: research projects about the time from contacting HPV to developing cancer; patient awareness; the consequences of different treatments within the guidelines; involvement in commissions and trials, where they provide the patients' point of view; information projects such as a brochure of 23 questions to ask the doctor and warning signs to be taken seriously. Upcoming projects include a project about HIPEC connecting new patients with patients who have undergone the procedure and another about granulosa cell tumours.

Improving Care pilot programmes

Chair: Esra Urkmez (USA). Presenters: Veronika Cibulová (CZ), Kamil Zalewski (PL)



Key messages

- The results of the first ENGAGe Improving Care pilot projects have been collected. This project stemmed from the results of a 2017 ENGAGe survey on patient care that demonstrated wide disparities across Europe for some factors, including prevention, access to clinical trials, access to written information, access to psychological and social services.
 - With grant money and volunteers, two pilot projects that set out to address these disparities were launched: at the Department of Gynaecological Oncology General Faculty Hospital, Prague, Czech Republic, and Holy Cross Cancer Centre, Kielce Poland.

Department of Gynaecological Oncology General Faculty Hospital, Prague, Czech Republic, presented by Veronika Cibulová

- The Czech pilot programme aimed to address a lack of access to information and counselling about sexual health—which Czech patients had zero access to—as well as improve access to those for nutrition, palliative care, and psychological support.
- A tailor-made questionnaire helped pinpoint the current situation for Czech patients, and then the programme created printed brochures and in-person and video workshops (so that unwell patients could watch the workshops at home) and other services to fill in gaps in information.
 - Printed brochures on palliative care, nutrition, sexual health were placed in hospitals for patients and handed out at networking events to ignite the interest of other hospitals and cancer centres to continue the initiative.
 - A sexologist was engaged to offer services free of charge to gynaecological cancer patients and lead workshops.

- A palliative care team carried out educational workshops.
- A nutritional consultant was engaged.
- A psychologist will now meet every patient who is recommended for surgery so that, if the patient later wishes to seek counselling, it will be easier for them to begin.
- Other brochures were prepared: A BRCA mutation leaflet, a practical physiotherapy brochure, a leaflet for one particular centre that lists the physician's names with their photos.
- Another leaflet is being prepared, covering questions patients might have for their doctors after receiving a diagnosis.

Holy Cross Cancer Centre, Kielce Poland, presented by Kamil Zalewski

- The Polish pilot programme aimed to help patients get information about clinical trials, improve access to psychological and nutritional services and social support. There was no patient group in Kielce at all.
- Once the goal was identified, the project volunteers began to work on it systematically.
 - To improve access to clinical trial information and other areas, materials sourced from ENGAGe and other ENGAGe member groups were translated into Polish and distributed. Informational videos were also made and screened in patient areas so that they could learn more while waiting at the hospital.
 - A cooperation between the centre's psychology and oncology departments was founded, and videos were also recorded with the psychologists. A psychologist came to the cancer patients in hospital for introductions.
 - A part-time nutritionist was hired to help the patients in the gynaecological oncology department, and leaflets about nutrition during certain types of treatment were prepared.
 - A workshop focusing on sexual issues was held by a gynaecologist.
 - A contract was signed with the patient organisation Blue Butterfly (Niebieski Motyl), and now monthly workshops will be held. A multi-day retreat was also held for 12 patients outside the hospital where they worked on a strategic plan for the group.
 - Future plans will finalise more publications and extrapolate the gained experience to other groups in Poland. The centre is also working on preparing a Wellness Room, and on more retreats for patients, among other projects.

Resources

<https://www.pacientska-organizacja.cz/edukacni-materialy/>

<http://niebieskimotyl.pl/projekt-poprawic-opieke-w-swietokrzyskim-centrum-onkologii/>

Psycho-oncology in GO

Karina Dahl Stefenssen (DK)



“Asking about quality of life is the new black in oncology.”

Karina Dahl Stefenssen

Key messages

- A cancer diagnosis doesn't only affect patients medically. It turns the patient's whole life upside down, including large psychological and social factors. Thus, treatment of cancer is not just treatment of the body but of all the other aspects.
 - The World Health Organisation defines “healthy” as a complete state of physical, social, and mental well-being. It's not just the absence of an illness.
- Quality of life is a measure to evaluate general well-being. Screening tools that ask questions about quality of life factors can be used as secondary endpoints for a clinical trial and can also be used by an individual doctor to measure a patient's current well-being.
- Patient reported outcomes (sometimes abbreviated to PROs) are another tool. Patients answer one basic set of standardised questions for cancer patients plus questionnaires for their cancer subtypes. Doctors use these periodically submitted patient questionnaires either passively or actively.
 - Passive use doesn't benefit the patient reporting but aggregates the data from one set of patients and uses it to improve outcomes for the next set of patients. Patients may not continue to fill these out as consistently as they do for actively used questionnaires.
 - Active use means a clinician can use patient questionnaires as a screening tool, and the data can be used to affect their current situation. For example, a doctor could compare a patient's toxicity screening, the doctor's own evaluation, and the patient's own self-reported evaluation to measure pain, discomfort, and other symptom severity.
- Distress is a marker of poor quality of life (considered the sixth vital sign) that is often exhibited in cancer patients, with one-third suffering from extensive symptoms. It is brought by changes to the patient's body, fertility, identity. A screening tool exists for distress and is highly accepted among experts, but it isn't yet used on a large number of patients.
 - More than 50 percent of ovarian cancer patients exhibit depression, which may be causing them to experience higher amounts of pain than patients who are not depressed.

Metastatic cervical and endometrial carcinoma

Zoltan Novak (HU)



"You have extremely important work. From a doctor's perspective, we need the patient feedback. It's a great collaboration."

Zoltan Novak

Key messages

- Primary metastatic cervical cancer is quite complicated to treat. A recurrent cancer, it can exhibit lymphatic recurrence or distant recurrence and has an overall survival rate of 16%.
- Recurrent cervical cancer, with local recurrence in the pelvis, is potentially curable, with exenteration post-radiotherapy the only curative option. In cases of distant recurrence, hematogenous is the worst. Diagnosis depends on the symptoms and can involve a physical exam, ultrasound, CT, MR, PET CT. A biopsy is quite important.
 - Treatment for local recurrence starts with radiation therapy or a combination of radiation therapy and surgery. If surgery is not possible, then chemotherapy is also a treatment.
 - The surgery for local recurrence is a radical hysterectomy, exenteration.
 - When exenteration is used, there is a five-year overall survival rate of 20–50%, with a complication rate of 70–80% and mortality rate of 1–2%.
- Chemotherapy is the recommended treatment for metastatic cervical cancer, notably taxol+platina+bevacizumab. Immunotherapy is another option, and there are clinical trials ongoing. However, it is crucial to consider quality of life for these patients.
 - Side effects of taxol+platina+bevacizumab include neutropenia, neuropathy, hair loss, fistula.
- After first-line chemotherapy, treatment options progress to the question of a second line of chemotherapy, single-agent versus non, checkpoint inhibitor, clinical trials and, then, palliative care.
- With recurrent endometrial cancer, the most frequent isolated local recurrence is in the vagina. It is considered curable. Of its treatment options, exenteration is the most established, with a 20–50% five-year overall survival rate.
- When a patient is diagnosed with metastatic endometrial cancer, complete surgical cytoreduction is recommended as well as aggressive multivisceral surgery and adjuvant chemotherapy.
- For the medical treatment of metastatic endometrial cancer, taxol-carboplatin for six times per week for three weeks is recommended, though patients should be advised about the side effects of this drug combination. Hormone therapy is also possible, as well as immunotherapy: checkpoint inhibitor. With single-agent chemotherapy, the overall response rate is 9–20%. These patients will benefit from end-of-life discussions.

Clinical trials (cooperation with ENGOT)

Antonio González Martín (ES), Birthe Lemley (DK)



“ENGOT’s partnership with ENGAGE can lead to even more patient-focused clinical trials.”

Antonio González Martín

Key messages

- The European Network for Gynaecological Oncological Trial groups (ENGOT) is a research network of the European Society of Gynaecological Oncology (ESGO) and was founded in Berlin in October 2007.
- ENGOT is a network of national and regional cooperative groups, ENGOT coordinates and promotes clinical trials within Europe on patients with gynaecological cancer. ENGOT consists of 21 groups from 25 ESGO countries. ENGOT is a platform that guarantees that the European spirit and culture is incorporated into the medical progress in gynaecological oncology, and that all European patients and countries can participate in an active way in clinical research and progress.
- ENGAGE and ENGOT have been working together for more than a year to increase patient involvement in trial design, among other benefits. ENGAGE aims to make it possible for clinical trials to have patient perspectives on the design and all other aspects of a study.
 - Patients give input on trial design: identification of unmet needs, convenience of administration, visits to the clinic, procedures, trial documentation (Informed Consent Forms), patient reported outcome (PRO), and quality of life questionnaires. They also help in disseminating information and getting patients access to clinical trials.
 - This coordination is particularly relevant for academic clinical trials, translational research, research on rare diseases, and for clinical trials sponsored by the industry to perform multinational studies in Europe.
- ENGOT’s achievements include 84 trials so far. ENGOT’s trials are conducted according to database models, differentiated by where the database is stored.
- Patient involvement is one of the many strengths of the ENGOT clinical trial design.
 - **Other strengths are that the clinical design** focuses on unmet medical needs, includes academic participation and “validation” of clinical trials design (a plus for credibility), includes clinically-oriented translational research designs (Translational Research Group), has the opportunity of helping in the development of the pipeline from the beginning (from Phase I/II Group to phase III design).

Resources

<https://www.ncbi.nlm.nih.gov/pubmed/26067859>

<https://www.cancerprogressreport.org/Pages/cpr17-contents.aspx>

QUALITY OF LIFE – nutrition, fatigue and lifestyle

Nutrition

Christos Papavagelis (GR)



"Don't take vitamins just because someone said you should take them."

Christos Papavagelis

Key messages

- Quality of life has a specific definition and at its heart is an overall sense of well-being. When clinicians measure a patient's quality of life, it can be defined by many factors, for example: ability to use the telephone, do the laundry and get dressed, go shopping or run errands, use transport, make meals, manage their own medication, household chores, and the ability to manage their finances.
 - Medical care teams must respect the time, space, pain, emotional status and mobility of a patient.
 - Cancer patients may often have nutritional issues that affect their quality of life.
- Any nutritional issues, in particular, dehydration, alcoholism, and/or Vitamin B12 deficiency can relate to functional impairments. With age, people's nutritional needs change; some of these can affect quality of life as well.
- Various tools have been used to help medical care teams assess patients' nutritional needs and issues as part of an overall assay into the patients' quality of life.
 - Current best practice is to administer a 24-question self-evaluation designed specifically for cancer patients.
- Patients at risk of nutritional issues should seek nutrition counselling by a health care professional, or better yet, a nutritional support team. Such a team is multidisciplinary and supports hospital or cancer centre staff.
 - Proper counselling rather than casual advice is needed as more casual or lay advice on this topic often leads to the patient taking needless supplements or other inappropriate or needless measures.

- o Though vitamin and other supplements are popularly suggested to cancer patients, the clinical recommendation is to only have vitamins and trace elements in the normal recommended daily allowances, unless testing has indicated a true deficiency. Vitamins are often equal to “fake hope” for patients hoping to find an easy remedy. Cannabinoids for appetite stimulation and androgens for muscle mass have also been shown to have low efficacy. Instead, clinicians should show empathy for the patients and only recommend evidence-based treatments.
- Enhanced Recovery After Surgery (ERAS) recommended procedures include screening patients for malnutrition and giving them additional nutritional support if necessary.

Resources

<https://www.espen.org/files/ESPEN-Guidelines/PIIS0261561417302285.pdf>

<https://www.ncbi.nlm.nih.gov/pubmed/25524803>

Sexual health care after gynaecological cancer

Ioanna Tsiaousi (GR)



“Maintaining sexual intimacy is one of the essential elements in the journey of recovery.”

Ioanna Tsiaousi

Key messages

- The World Health Organisation defines sexuality as one of the major components contributing to a sense of a fulfilled life. This is also supported by research.
- More conservative surgery for gynaecological and breast cancers (including nerve-sparing surgery and fertility-preservation surgery), increased instances of primary diagnosis in early stages of cancer, advanced chemotherapy, and new techniques in radiotherapy have all led to better prognoses for patients and more survivors after cancer. The growing population of survivors has created the motivation for post-treatment sexual medicine.
 - o There are about 12 million people are living with cancer, and 55% are female.
 - o 35–50% of cancer survivors may experience sexual dysfunction as a consequence of the treatment.

- People engage in sexual activity for a variety of reasons, including fertility, but also for emotional attachment, pleasure or recreation, expression of their gender identity, and more.
- Cancer patients may experience a variety of sexual disorders, including sexual hypoactive desire disorder (about 40–68% of women), sexual arousal/interest disorder (80%), orgasm disorder (75% of patients), and painful intercourse (dyspareunia; about 22–62%).
- Disturbances in a person's endocrine, circulatory, and nervous system—all potentially affected by cancer—can cause or contribute to sexual disorders.
 - The endocrine system can be damaged by chemotherapy, radiotherapy or hormonal therapy; this affects desire.
 - Circulation can be damaged by surgery or radiotherapy; this affects excitement and arousal.
 - Nerves and neurotransmitters can be damaged by surgery, chemotherapy, and antidepressants; this affects orgasm.
- Rehabilitation approaches for sexual health include hormonal medication, nonhormonal medication, nonpharmacological addition, a psychological/psychosexual approach, and lifestyle adaptations.
 - Hormonal pharmacological treatments include topical oestrogens (oestradiol, estriol, promestriene, conjugated oestrogens) which should be prescribed soon after surgery. Local estriol has 1/80 of oestradiol potency, and it is the safest oestrogen (as it has a prominent action on oestrogens receptors beta, which have antiproliferative and reparative actions). Key points in using local oestrogen are proper timing and lifelong treatment. This treatment should not be used with patients of hormone-dependent cancers like adenocarcinoma of the cervix or cancer of the breast.
 - A decrease of testosterone creates sexual symptoms (loss of desire/interest and drive, of systemic and genital arousal, reduced lubrication, and cavernosal congestion and impaired orgasm) and systemic symptoms (depression, low vital energy, fatigue) unless testosterone is replaced. Testosterone can be used topically as cream of testosterone propionate (2%) or testosterone of vegetal origin.
 - DHEA can be taken topically as a cream to enhance vaginal lubrication or orally 10 or 25 mg daily. DHEA helps give more energy, more positive feelings, increased muscle tone, and strength. In addition, DHEA has an overall positive impact on mood and sexuality.
 - For non-hormonal treatments, SERMS—OSPEMIFAININE has a good safety profile. Hyaluronic acid for improved lubrication and the condition of the vagina. It is almost comparable to the local efficacy of estriol.
 - In addition, moisturisers, lubricants, and vaginal dilators can be used. Moisturisers hydrate the vaginal mucosa, lubricants can be used in the sexual context and should also be used when training with vaginal dilators. Vaginal dilators are recommended to help vaginal elasticity, especially after pelvic radiotherapy for women younger than 70, to reduce the impact on vaginal elasticity. Dilation should start four weeks after treatment, to be done two to three times per week for one to three minutes and to be continued for nine–12 months.
- Although medical interventions work for some, we should not forget that erections and orgasms are just ingredients in sex, not the whole recipe. We need to address issues like affection, communication, patience, and creativity.

Resources

<https://www.psychiatry.org/psychiatrists/practice/dsm>

Immunotherapy in GYN oncology

Christian Marth (AT)



"Immunotherapy has some side effects, usually some kinds of inflammation. It's important to understand there are different side effects and that the patient should communicate symptoms to the doctor."

Christian Marth

Key messages

- In the past ten years, immunotherapy has become more effective for the treatment of cancers. It has made headlines for remarkable results in other disciplines, for example, metastatic melanoma.
 - The duration of the response for immunotherapy is very long compared to chemotherapy.
 - Immunotherapy uses the body's immune system to attack cancer cells.
 - The immune system is a network of cells, tissues, and organs that work together to defend the body against attacks by "foreign" invaders. These are primarily microbes (germs)—tiny, infection-causing organisms such as bacteria, viruses, parasites, and fungi.
- The organs of the immune system are positioned throughout the body.
 - Immune cells and foreign particles enter the lymph nodes via incoming lymphatic vessels or the lymph nodes' tiny blood vessels.
 - Antigens carry marker molecules that identify them to antibodies as foreign.
 - B cells mature into plasma cells that produce antibodies.
 - Antibodies targeted to cancer cells can deliver toxins, drugs, or radioactive substances directly to the cancer cell.
 - Some T cells are helper cells; others are killer cells. A killer cell makes contact with a target cell, then strikes.
 - T cells are mobilised when they detect a cell that has digested an antigen. The T cell secretes lymphokines, some of which spurs the growth of more T-cells.

- A cancer cell can rouse several types of immune defences. The immunity cycle for ovarian cancer is: the cancer cell is released, cancer antigen presentation, T cells and APC are activated, T-cells are trafficked to tumours, T-cells infiltrate the tumour, T-cells recognise the tumour, cancer cells are killed.
 - Positive and negative regulators of the immune system can serve as potential targets for immunotherapy.
- In some cancers, for example, endometrial cancer, some tumours have DNA repair errors, „e.g., Lynch Syndrome) and these are the best candidates for immunotherapy because the mutated cells are easily identifiable by the antibodies.
- Endometrial cancer is the most common gynaecologic malignancy, with increasing incidence and mortality, and the use of immunotherapy to treat MSI-high (mutation) established cases is established.
- There are a number of advances in immunotherapy being investigated now.
 - Angiogenesis inhibitor plus immunotherapy is promising, and denosumab, a fully human monoclonal antibody, is being investigated for potential use in a broad range of patients.
 - In a tumour cell vaccine procedure, cancer cells from a patient are removed, irradiated, genetically modified, and then re-introduced into the patient, where they spark an enhanced immune response. Trials are ongoing for this procedure and seem quite promising for future use.
 - Intracellular bacteria, such as listeria, are able to generate strong cell-mediated immune responses and can be used as an antigen delivery system.
 - Immunotherapy for cervical cancer sometimes targets the E7 protein because it is expressed in most cervical cancers and is necessary for maintenance of the malignant state.
- Pseudo-progression is possible during immunotherapy treatment. In these cases the tumour may increase from the baseline or new lesions may develop before a noticeable response.
- Immunotherapy works well for some cancers but not for others, because cancers have different types. Cancers which have a lot of mutations are easily recognised as foreign intruders, but other types may not be so easy for the immune system to recognise as something to attack.
 - Immunotherapy is not a good choice for ovarian cancer at the moment.

Resources

<https://ijgc.bmj.com/content/29/1/201>

<https://www.ncbi.nlm.nih.gov/pubmed/22193102>

<https://www.ncbi.nlm.nih.gov/pubmed/22576456>

<https://www.ncbi.nlm.nih.gov/pubmed/22437870>

<https://www.ncbi.nlm.nih.gov/pubmed/18612161>

<https://www.ncbi.nlm.nih.gov/pubmed/23460533>

<https://www.ncbi.nlm.nih.gov/pubmed/24403232>

ESGO-ESMO OVARIAN CANCER GUIDELINES

Introduction to the Guidelines

- Implementation of a quality management program has been associated with longer survival in patients with advanced ovarian cancer. Six months ago the ESGO-ESMO Ovarian Cancer Consensus Guidelines were published. To prepare the guidelines, co-chairs Denis Querleu (FR), representing ESGO, and Nicoletta Colombo (IT), representing ESMO, brought together 42 international experts in ovarian cancer.
 - This was the first European consensus conference.
 - Quality of surgical care modifies the survival of patients with ovarian cancer. Reduced residual tumour cells following surgery for ovarian cancer is closely correlated with overall survival.
 - Working in groups, the experts took into consideration all of the national ovarian cancer guidelines for Europe as well as published research, common practice, and the experts' opinions. The following three presentations from Querleu, Colombo, and Murat Gultekin (TR) describe highlights of the guidelines interesting for cancer patients.

Resources

<https://guidelines.esgo.org/ovarian-cancer/guidelines/recommendations/>

<https://academic.oup.com/annonc/article/30/5/672/5482247>

Advanced stage ovarian cancer

Denis Querleu (FR)

"We are now at a place where overall survival for advanced stage ovarian cancer after surgery is more than six years. Can you imagine!"

Denis Querleu

Key messages

- Advanced-stage ovarian cancer cases have longer survival periods than ever before, particularly when surgery eliminates all resectable disease. This is possible with high-quality surgery performed by experienced surgeons in an adequate facility. The ESGO-ESMO Guidelines help define with precise criteria the conditions needed for best practice surgery for advanced (FIGO stage III–IV) invasive epithelial ovarian cancer.
 - For example, in stage IVA, the pleural cavity must be surgically assessed by thoracoscopy or intraoperatively. Many stage IV sites are resectable. Some may require another approach during the same procedure or at a later stage.

- When preparing the guidelines, the experts voted on how strongly they agreed with certain procedures for the cancers, but physicians are not locked into only one option.
 - For example, complete surgery is strongly recommended for advanced ovarian cancer. However, not all patients are suitable for surgery, and some tumours are unresectable, while other patients are not well enough to operate. Decisions have to be made case-by-case for the patient.
- The guidelines were used to produce an algorithm for epithelial ovarian cancer surgery that helps show doctors and patients in a very clear way what steps are taken in treatment.
- There are also recommendations for the report following the operation, which makes it clear and simple for the medical team and the patient.

Recurrent ovarian cancer

Nicoletta Colombo (IT)

"It's not proven that to have a very intensive follow-up is worth it. And, in fact, it may even worsen the quality of life. Someone who knows that they have relapsed earlier, it may make them feel worse. But have to give patients the option to know an early diagnosis is very important."

Nicoletta Colombo

Key messages

- The Guidelines set out to answer the following questions: What is a reasonable monitoring and follow-up strategy following treatment of recurrent ovarian cancer? What is the place of surgery for recurrent disease? How should molecularly targeted therapy be integrated into the management of recurrent ovarian cancer? What defines platinum resistance and how does that influence subsequent treatment? How long should maintenance therapy be continued in recurrent disease?
 - Follow-up should be offered, and the value should be discussed individually with patients, as there is uncertainty about the benefit of early diagnosis and treatment of recurrent disease.
 - The algorithm prepared from the guidelines now helps the physician to find the right procedure for recurrent patients; for example, deciding if the patient is a candidate for surgery and if platinum is still an option or not.
- Related to recurrent disease, the AGO DESKTOP III study showed better progression-free survival after surgery with complete resection than with surgery that left residual tumours or no surgery. The overall survival data is not yet published.
- The AURELIA trial showed significant increased progression-free survival with bevacizumab in platinum-resistant recurrent ovarian cancer.

- Several pivotal studies discuss PARP-inhibitors in patients with recurrent ovarian cancer after response to platinum. This is an important benefit in the BRCA population, but also for other patients.
 - Results from SOLO 2 and Study 19 provide further evidence for olaparib in platinum-sensitive high grade serous relapsed ovarian cancer. The FDA approved olaparib tablets as maintenance.
 - EMA and Japan approved olaparib tablets as maintenance for high-grade serous, platinum-sensitive patients, regardless of BRCA status.
 - Investigator-assessed progression-free survival in the ARIEL3 study earned FDA and EMA approval of rucaparib maintenance, regardless of BRCA/HRD status.

Resources

https://ascopubs.org/doi/abs/10.1200/JCO.2017.35.15_suppl.5501

<https://www.ncbi.nlm.nih.gov/pubmed/24637997>

<https://www.ncbi.nlm.nih.gov/pubmed/28916367>

Quality

Murat Gultekin (TR)

“These are the questions you should always remember and push the centres to do better and better surgery.”

Murat Gultekin

Key messages

- In addition to providing Quality Indicators and Consensus Guidelines for individual clinicians to follow, ESGO uses the Quality Indicators when certifying institutions that demonstrate excellence in ovarian cancer surgery.
- Minimal residual disease equals better survival. This has been shown in several studies, and so this was one of the principal reasons ESGO began looking at the quality indicators for surgery. Therefore, Quality Indicator 1 in the guidelines is the rate of complete surgical resection. To get a top score, centres with 65% or higher patients with advanced epithelial ovarian cancer should undergo complete surgical resection.
 - Quality Indicator 1.2 was the rate of primary debulking surgery, with a target of 50%.
- Quality Indicator 2 is the number of cytoreductive surgeries performed per centre and per surgeon each year.
 - For example, for the best score, $\geq 95\%$ of surgeries should be performed by surgeons operating at least 10 patients a year.

- Quality Indicator 3 is surgery performed by a gynaecologic oncologist.
 - Ovarian cancer patients will be operated by a certified gynaecologic oncologist or, in countries where certification is not organised, by a trained surgeon dedicated to the management of gynaecologic cancer. This ensures the surgeon has the skills to successfully complete complex abdominal and that the pelvic surgery procedures necessary to achieve complete cytoreduction must be available.
- Quality Indicator 4: Centre participating in clinical trials.
- Quality Indicator 5: Treatment planned at a multidisciplinary meeting.
 - Before any surgery, a decision-making process should take place within a structured multidisciplinary team, including a gynaecologic oncologist, radiologist with a special interest in gynaecologic oncology, pathologist (if a biopsy is available) with a special interest in gynaecologic cancer, medical oncologist or gynaecologic oncologist certified to deliver chemotherapy.
- Quality Indicator 6: Required preoperative workup. Includes imaging screening for unresectable parenchymal metastases and metastases from other primaries.
- Quality Indicator 7: Pre-, intra-, and postoperative management.
 - ESGO sets out the best practice for management, which includes implementation of an ERAS programme.
- Quality Indicator 8: Minimum required elements in operative reports and Quality Indicator 9: Minimum required elements in pathology reports.
 - Each centre may have its own report template. For a top score from ESGO, the centre's reports should have at least 90% of the required elements. The required elements for the pathology reports are listed in the International Collaboration on Cancer Reporting Histopathology Guide.
- Quality Indicator 10: Structured reporting of postoperative complications. Surgeons should record all complications.
- Centres may request certification that they meet the criteria outlined in the guidelines. They may apply for a five-year certification.

Resources

<https://www.ncbi.nlm.nih.gov/pubmed/19476798>

<https://www.ncbi.nlm.nih.gov/pubmed/21414656>

<https://www.esgo.org/explore/esgo-accreditation/>



HYPE or HIPEC in ovarian cancer?

Giovanni Scambia (IT), Andreas du Bois (DE)

"The most important thing when treating ovarian cancer is to know what you're doing and always do your best."

Andreas du Bois

Key messages

- Intraperitoneal hyperthermic chemoperfusion, or HIPEC, is a hyperthermic therapy that uses heated chemicals injected in the peritoneal cavity. It is used in the treatment of several cancers, most often in combination with surgery.
- Whether it is a promising new technique for the treatment of ovarian cancer or a risky and unproven method that still requires further study is a matter of debate.
- In this special debate session at the Patient Advocacy Seminar, experts Scambia and du Bois discussed the pros and cons of HIPEC.

Pro-HIPEC arguments with Giovanni Scambia

- It is difficult to argue for HIPEC as a standard procedure, but it has a lot of potential for future treatments in ovarian cancer as the field evolves.
 - It can safely be combined with bevacizumab in ovarian cancer, and there are several other emerging drugs that may be compatible with it.
- Before January 2018, most data was from retrospective studies, with higher costs, heterogenous studies, poor quality of data, higher toxicity, different drugs, temperatures and techniques, no survival advantage and it wasn't competitive with other drugs. But then, in their multicentre, open-label, phase 3 trial, van Driel et al. showed that the addition of HIPEC to interval cytoreductive surgery, compared to surgery alone, resulted in longer recurrence-free survival, longer overall survival, and that it did not result in higher rates of side effects.
- Still, even after the van Driel study, there were not enough other quality studies. OVHIPEC-1 had poor quality of data; OVHIPEC-1 showed higher toxicity; GOG 218, GOG 240, and Study 19 showed toxicity.
- It is still unclear which patients may benefit most from HIPEC.
- At present HIPEC remains an investigational approach and should be administered only in the context of clinical trials in tertiary gynaecological oncology centres.
- A challenging task for gynaecologic oncologists is to find space for the design of trials involving HIPEC in an era in which several new drugs could be introduced in the management of ovarian cancer.
- However, primary debulking surgery with HIPEC is feasible and can be combined with the upfront therapy of advanced epithelial ovarian cancer consisting of primary debulking and carbo-taxol-bevacizumab chemotherapy.

- As for it not being compatible with other drugs, in case of BRCA2-mutation carriers, combining hyperthermia with PARP1-i may boost the treatment efficacy. This combination therapy would be effective for all patients with PARP1-i regardless of their BRCA status.
- Immunostimulation by hyperthermia involves both direct effects of heat on the behaviour of immune cells as well as indirect effects mediated through heat shock protein release.
 - Indirect effect: heat shock proteins, produced in abundant quantities in cells exposed to heat, are potent immune modulators and can lead to stimulation of both the innate and adaptive immune responses to tumours.
 - Direct effect: dendritic cells have enhanced stimulatory function and migration, enhanced by heat.
- New evidence should soon be forthcoming from the Chorine trial. The HORSE trial and OVHIPEC-2 trial are also ongoing and may bring new promising results.

Anti-HIPEC arguments with Andreas du Bois

- It is important to put all of our knowledge together and use what we have. At this moment, HIPEC is not the best technique we have.
- HIPEC offers a higher dose without any benefit in advanced ovarian cancer. Though it includes the advantage of intraperitoneal administration directly where the tumour grows, that route is significantly more toxic and has no benefit in advanced ovarian cancer.
- It also shows drawbacks in other fields. HIPEC in colon cancer has already shown poor results, including high morbidity at 60 days (Verwaal et al.).
- In the van Driel study, HIPEC may add some benefit to selected patients with advanced ovarian cancer; however, the results of the Dutch trial cannot be generalised and the exact identification of the subset of patients who may benefit and the optimal setting /timing of HIPEC has to be elucidated further.
 - No criteria were defined, and the recruitment period may have resulted in hyperselection.
 - Also the selection of sites and surgeons was perhaps not rigorous enough, with the only qualification criteria being that HIPEC equipment was available.
 - There was no information about surgeons' qualifications, or data about surgical complications (e.g., Clavin-Dindo); there was no data on patient-reported outcomes.
- Future studies are urgently needed and should avoid the potential biases inherited in the present trial, e.g., compare HIPEC against heated saline.
- An ideal HIPEC trial design might involve statistical planning with independent review from a HIPEC-sceptic and strict centre selection by defined and transparent quality criteria and audit (independent quality assurance team strata: residual tumour, BRCA, histo-type, morbidity score evaluation, during- and post-operation complications, stoma-rate, long term sequelae, quality of life and patient reported outcomes, progression-free survival, and overall survival).

Resources

<https://www.ncbi.nlm.nih.gov/pubmed/14551293>

<https://www.nejm.org/doi/full/10.1056/NEJMoa1708618>

<https://ascopubs.org/doi/10.1200/JCO.2003.04.187>

Patient perspectives in the main hall

Maria Papageorgiou (GR), Charo Hierro (ES), Esra Urkmez (USA) and Birthe Lemley (DK) spoke to the main audiences at the Congress.



Patient Board meetings

Esra Urkmez (USA)



"This will help companies understand the unmet educational needs related to a specific cancer."

Esra Urkmez

- A new ENGAGe project to provide patient perspectives to industry contacts launched concurrently to the Patient Advocacy Seminar this year. The Patient Board meetings are focus group sessions that create an intimate, safe setting for patients to advise organisations face-to-face on specific topics. Patients will give insights on
 - their cancer experience, including the impact that living with cancer has on patients, caregivers and families, and
 - the treatment decision-making process for women living with specific types of cancer.
- Additional Patient Board meetings will be planned to coincide with the next Patient Advocacy Seminar and potentially at other times during the year.

ROUNDTABLES

Day One:



Table 1:
Ovarian cancer campaign with Elisabetta Ricotti (IT)

Table 2:
Campaign – lobbying with Charo Hierro (ES)

Table 3:
Campaigning – HPV vaccination and World GO Day with Icó Tóth (HU), Esra Urkmez (USA)

Table 4:
WHO cervical cancer elimination campaign with Elena Fidarova (WHO)

Day Two:



Table 1:
Ovarian cancer with Jonathan Ledermann (UK), Esra Urkmez (USA)

Table 2:
Cervical cancer with David Cibula (CZ), Simona Ene (RO)

Table 3:
Endometrial cancer with Mansoor Mirza (DK), Birthe Lemley (DK)

Table 4:
Quality of life with Jalid Sehouli (DE), Icó Tóth (HU)

ESGO RUN

ENGAGe representatives wearing World GO Day shirts cheer on the participants of the ESGO Run on November 2, 2019, in Athens. The run raised awareness about early detection of Cervical Cancer and HPV vaccination programmes.



HAPPENING IN SYNTAGMA SQUARE

Maria Papageorgiou (GR)



"What has cancer taken away from me and what has cancer given me back? Cancer is in every family. Everybody has an experience with cancer. We want people to think about the impact on their lives."

Maria Papageorgiou

Patient Advocacy Seminar attendees wore their World GO Day shirts and travelled to Syntagma Square in the centre of Athens on Saturday afternoon to take part in an awareness outreach activity that asked passers-by to consider how cancer has affected their lives.



MaRla's Dance

Maria Papageorgiou (GR)



What is it like to be a patient undergoing an MRI? On Saturday evening during a networking event at the ESGO Congress, ENGAGe presented MaRla's Dance, conceptualised by Maria Papageorgiou, president of Erifyle K.E.F.I. of Athens. Dancers performed to the rhythm of the MRI.

*I lie in a confined place
frozen
like I am under water,
breathless,
absent
I need air.....to breathe
to live
to connect
I try to imagine open spaces
the sea.....the sun
being with my loved ones*

*the sound is hammering my soul
I transform it into a rhythm
I can dance to
I breathe
I am alive
I am here
life is here*

Maria Papageorgiou

ACKNOWLEDGEMENTS

*Many people have been responsible for the success
of this Patient Advocacy Seminar.*

*ENGAGE would like to thank to all who actively took part
in the preparations and Patient Advocacy Seminar itself.*

*We would like to take this opportunity to thank our educational partners
for providing generous educational grants
to support the ENGAGE Patient Advocacy Seminar.*

*The educational partners had no influence
on the content and program of the event.*



