

2018 Patient Seminar Report



ENGAGe Patient Seminar in Gynaecological Cancers

Oct. 5–6 2018, LYON, FRANCE

Held during the European Society of Gynaecological
Oncology State of the Art Conference on New Insights
in Rare Gynaecological Malignancies
in Lyon, France



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PROGRAMME

Patient Seminar 2018

Palais de la Bourse Salle Jacquard		
DAY 1: October 5th		
Chairs: Esra Urkmez, Murat Gultekin		
9:00 - 9:15	Patient Seminar Welcome Remarks	Denis Querleu (France), Murat Gultekin (Turkey), Esra Urkmez (USA)
9:15 - 10:45	Introductions and Short Summary Of Local Campaigns and Achievements	Participating Patient Organizations*
10:45 - 11:00	<i>Coffee Break</i>	
11:00 - 11:30	What Have We Learned from 2017 ESGO Congress in Vienna	Murat Gultekin (Turkey), Kamil Zalewski (Poland)
11:30 - 12:00	Hereditary Syndromes, Genetic Testing and Gynaecological Cancers	Nicoletta Colombo (Italy)
12:00 - 12:45	<i>Lunch Break</i>	
BLOCK 1 - What is New in Gynaecological Cancer?		
Chairs: Esra Urkmez, Murat Gultekin		
12:45 - 13:30	What is a Rare Tumour and Its Treatment Options	Domenica Lorusso (Italy)
13:30 - 15:30	What is New in Gynaecological Cancer? Roundtable Discussions	
	Table 1: Ovarian Cancer	Jonathan Ledermann (UK)
	Table 2: Cervical Cancer	Jalid Sehouli (Germany)
	Table 3: Vulvar & Vaginal Cancer	Ate van der Zee (The Netherlands)
	Table 4: Uterine Cancer	Mansoor Raza Mirza (Denmark)
15:30 - 15:45	<i>Coffee Break</i>	
BLOCK 2 - Quality of Life and Fertility in Cancer		
Chairs: Maria Papageorgiou, Murat Gultekin		
15:45 - 16:15	Quality of Life and Late Treatments Effects	Florence Joly (France)
16:15 - 16:45	Cancer in Pregnancy and Fertility Sparing Surgery	Frédéric Amant (Belgium)
16:45 - 17:15	Recap of the Day	
19:30	Dinner for ENGAGE NGOs - Exchange of the Experience	

DAY 2: October 6th		
BLOCK 3 - How to collaborate with other networks and make a poster		
Chairs: Simona Ene, Dina Kurdiani		
8:00 - 8:10	What is ENGAGE	Esra Urkmez (USA)
8:10 - 8:20	What is ENYGO	Kamil Zalewski (Poland)
8:20 - 8:30	What is ENGOT	Antonio Gonzalez (Spain)
8:30 - 8:50	How to Make a Patient Organization Poster	Karina Dahl Steffensen (Denmark)
8:50 - 9:10	How to Search in PubMed and the ESGO Journal	Dina Kurdiani (Georgia)
9:10 - 9:30	Discussion	
9:30 - 9:45	<i>Coffee Break</i>	
9:45 - 10:15	Awareness Campaign - Cervical and Ovarian Cancer	Birthe Lemley (Denmark), Icó Tóth (Hungary)
10:15 - 12:15	Best Practices from ENGAGE Members - "How to" Roundtable Discussions	
	Table 1: Prevention/Early Detection, Education materials	Ross Little (UK), Linda Snoep (The Netherlands)
	Table 2: Fundraising, Grant Submissions, Communication with Sponsors	Esra Urkmez (USA)
	Table 3: Clinical Trials	Birthe Lemley (Denmark)
	Table 4: Palliative Care	Charo Hierro (Spain)
12:15 - 12:45	<i>Lunch</i>	
12:45 - 13:45	ENGAGE General Assembly	For members only
	- Ideas for Greece Patient Seminar 2019	Maria Papageorgiou (Greece)
	- ENGAGE Products	Esra Urkmez (USA), Eva Streglova (ENGAGE Office)
	- Feedback from Members	
14:00	End of the Meeting	
14:30 - 17:00	EEG meeting	only EEG members attending

SUMMARY OF SESSIONS

About ESGO

The European Society of Gynaecological Oncology (ESGO) is the leading European organisation in the field, with more than 1,800 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.

Welcome Remarks



“At the end of these two days, you will be much more knowledgeable about rare tumours than most of the doctors in Europe.”

Denis Querleu

ESGO President Denis Querleu; WHO International Agency for Research on Cancer, Head of Communications, Nicolas Gaudin; ENGAGe Co-Chairs Esra Urkmez (USA) and Murat Gultekin (Turkey)

Key messages

- The ENGAGe patient advocacy network is a full part of the European Society of Gynaecological Oncology. President Denis Querleu and the ESGO Council look forward to continued close collaboration with patient advocates.
- Part of patient advocacy is to reach women before they become patients. ESGO and ENGAGe are working on initiatives to encourage prevention of women's cancers. Nicolas Gaudin, the director of the International Agency for Research on Cancer, which is the Lyon-based cancer research arm of the World Health Organisation, is pleased to join ESGO and patient advocates in their efforts to prevent cancer on an international level and raise awareness among at-risk women. The recent international success of the adoption of the HPV vaccine to reduce cervical cancer is an indicator of the potential of these movements.
- In addition to all the usual positive points of the patient seminars, this year's event benefits especially from the focus of the ESGO State of the Art Conference on rare gynaecological malignancies. The patient advocates are learning about little-discussed tumours while also seeing what their peers have achieved across Europe.
- The next ENGAGe Patient Seminar will be held at the ESGO Congress in Athens, Greece Nov. 2–5, 2019.

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 (ovary, 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.

Introductions and a Short Summary of Local Campaigns and Achievements



"I share that they are not alone. We celebrate life and giving and caring for each other."

*Slavica Periskic (Serbia),
Anti Cancer Society SOMBOR representative*

"We're working hard so that all women with ovarian cancer get the test."

Birthe Lemley (Denmark),

Key messages

- Representatives of the following participating patient advocacy groups introduced themselves and shared highlights of their work, including outreach and awareness, funding appeals and ways in which their organisations touch women who have been diagnosed with gynaecological cancers and need support.
- Onko Unie o. p. s., Czech Republic
- Veronica, Czech Republic
- KIU—Women with gynaecological cancer, Denmark
- Association of Cancer Patients, Finland
- Imagyn—The Patient Advocacy Group, France
- German Foundation for Ovarian Cancer, Germany
- Georgia Patient's Union (GPU), Georgia
- K.E.F.I. of Athens (Association of Cancer Patients of Athens), Greece
- Mallow Flower Foundation, Hungary
- "Together it's easier" for Women's Health Foundation, Hungary
- OvaCare, Ireland
- ISGO PPI, Ireland
- BRACHA – Living with a high risk of hereditary cancer, Israel
- Acto Onlus – Alleanza contro il Tumore Ovarico, Italy

- BORKA, Macedonia
- HomeCare Association, Romania
- Anti Cancer Society Sombor, Serbia
- Women's centre Milica, Serbia
- ASACO, Spain
- Network against Gynaecological Cancer, Sweden
- Gynsam - The Gynaecological Cancer Patient National Coalition), Sweden
- Stichting Olijf/Olijf Patient Foundation, The Netherlands
- Dance With Cancer, Turkey
- Ovarian Cancer Action, UK

What We Learned from the 2017 ESGO Congress in Vienna



Murat Gultekin (Turkey) and Kamil Zalewski (Poland)

"Even if [a study does not] have positive results, it's still important to share the negative results."

Murat Gultekin

"Every time we go to one of these meetings, we get a burst of energy to go forward."

Kamil Zalewski

Key messages

- The Best of ESGO is a new ENYGO project that helps doctors, patient groups, and others who were unable to come to the conference get a feel for the information that they missed. It collects the best slides and updates from the Congress and compiles them into a summary that can be shared with interested parties.

- One of the most interesting ESGO2017 papers, from the viewpoint of patient advocacy, is the report on a randomised controlled trial on pre-surgical metformin use. The objective was to evaluate the effect of metformin in women with atypical hyperplasia or endometrioid endometrial cancer.
 - Vomiting, diarrhoea, and anorexia were significantly higher in the metformin arm. Furthermore, unfortunately, there was no overall reduction in endometrial cancer cell proliferation with short-term metformin treatment, although patients with a BMI <30 kg/m² may have a beneficial effect. The speakers note that this is an example of a study where the results were not positive, but still useful.
- Another relevant study examines the prognostic value of lymph nodes for patients with vulvar cancer. The authors examined what the ratio of positive to negative lymph nodes in the groin may predict in vulvar cancer patients. Previous literature had reported five-year survival ranges from 70%–93% for patients with negative nodes to 25%–41% for those with positive nodes. Other prognostic factors include stage, size, capillary lymphatic space invasion, and older age.
 - A high ratio of positive nodes was associated with larger tumour size and higher tumour grade. Meanwhile, patients with no positive lymph nodes had a 90% five-year overall survival rate while patients with more than 20% positive nodes had a 61.8% rate.
 - Patients with a ratio over 20% benefit from adjuvant radiotherapy. Lymph node ratio is an independent prognostic parameter in vulvar cancer. Measuring lymph node positivity allows for more accurate prognostic stratification of patients than number of positive nodes and seems useful for selecting appropriate candidates for adjuvant radiation.
- The LION study, which looked at lymphadenectomy in ovarian cancer, is another the speakers recommend patients and patient advocates read. Surgery is the main treatment for ovarian cancer. This prospective, randomised study looked at the effect of lymph node dissection in patients with advanced ovarian cancer and asked the question, should we do lymphadenectomy or not?
 - The answer was, probably not. The LION study data do not support systematic lymphadenectomy of clinically negative lymph nodes in patients with advanced ovarian cancer receiving macroscopic complete resection. If such a patient has no suspicious lymph nodes, then lymphadenectomy should be omitted, and chemotherapy will be sufficient.
- The speakers also recommend a recent study about HIPEC, which stands for “hyperthermic intraperitoneal chemotherapy” and is a heated chemotherapy treatment that delivers chemotherapy directly to cancer cells instead of circulating it through the whole body. The authors investigated if HIPEC along with cytoreductive surgery would improve outcomes for stage 3 epithelial ovarian cancer patients being treated by neoadjuvant chemotherapy.
 - Though HIPEC is considered to be highly toxic, the patients who received it are living better than those who received interval debulking surgery. The authors concluded that adding HIPEC to complete or optimal IDS for FIGO stage 3 ovarian cancer prolongs RFS and five-year overall survival, with no severe toxicity or worsening of quality of life.
 - The speakers noted that, based on these results, HIPEC should be a standard of care, but as certain equipment is necessary to perform it, it may not be quickly adopted.

Resources

Request a copy of the Best of ESGO presentation at <https://www.esgo.org/best-of-esgo-2017/>

Study on Metformin: Pre-Surgical Metformin in Uterine Malignancy – Results of The Premium Randomised Controlled Trial by S. Kitson et al.

Study on Lymph nodes: Prognostic Value of Lymph Node Ratio and Number of Positive Inguinal Nodes in Patients with Vulvar Cancer by S. Polterauer et al. <https://www.ncbi.nlm.nih.gov/pubmed/28797698>

LION – Lymphadenectomy in Ovarian Neoplasms. A Prospective Randomized Ago Study Group Led Gynecologic Cancer Intergroup Trial D. Lorusso et al.

<http://eacademy.esgo.org/esgo/2017/20th/202722/domenica.lorusso.lion.lymphadenectomy.in.ovarian.neoplasms.a.prospective.html>

HIPEC: Hyperthermic Intraperitoneal Chemotherapy (HIPEC) for Ovarian Cancer, by WJ van Driel et al. <https://www.nejm.org/doi/full/10.1056/NEJMoa1708618>

Hereditary Syndromes, Genetic Testing and Gynaecological Cancers



“BRCA mutation provides us, as a physician, information about the prognosis and clinical outcome.”

Nicoletta Colombo (Italy)

Key messages

- The most common genetic mutations that are discussed signal breast and ovarian cancer. However, hereditary syndromes and genetic testing also have implications for other gynaecological cancers. For example, while the BRCA1 and BRCA2 genes are associated with hereditary breast and ovarian cancer, endometrial and ovarian cancer are associated with MLH1, MSH2, MSH6, PMS2 (EPCAM); endometrial carcinoma is associated with PTEN; ovarian small cell carcinoma with SMARCA4; Sertoli-Ledig ovarian tumours with DICER1; and sex cord tumour with annular tubules (SCTAT), MDA cervix, endometrial carcinoma with STK11. Though these are rarer than what we usually talk about, they are important tools for prevention. The most important gynaecological cancer susceptibility syndromes include hereditary breast-ovary, and Lynch, Cowden and Peutz-Jeghers syndromes.

- BRCA testing in the patient population informs patient management decisions and should be performed in all patients with ovarian cancer. The BRCA1 and BRCA2 genes have clear associations with cancer: an up to 25% lifetime risk for BRCA2 carriers and up to 53% risk for BRCA1 carriers¹. Other associations with various genes are being studied, but evidence so far does not yet indicate if they are clinically actionable or not. For example, studies show the BRIP1 gene as having only a 1.4% frequency in ovarian cancer and representing a 10–15% lifetime risk for carriers.²
 - For more on this topic, the speaker recommends a paper by BM Norquist et al. which summarises germline DNA mutations in ovarian cancer.
- Internationally, genetic testing is gaining traction. The NCCN, SGO, and ASCO societies recommend testing all women with ovarian cancer for possible genetic mutations³. And in the ESMO Guidelines, all patients with high-grade tumours should be tested for a germline BRCA mutation⁴.
- Mutation testing has an evolving role in cancer prevention and treatment. It's a risk assessment that allows patients to take preventative action and it offers the medical team a prognostic value, giving insight into survival rates. It helps guide care decisions, such as identifying which patients are likely to be treatment sensitive. Perhaps most importantly for prevention is the waterfall effect—testing one member of the family may also help other family members take measures to reduce their own risk.
- Confirmed carriers have several preventative options:
 - Chemoprevention, through birth control pills, reduces ovarian cancer risk by up to 46% and protection can last up to 30 years. However, there is an elevated risk of breast cancer with chemoprevention.
 - Prophylactic surgery—such as that made famous by actress Angelina Jolie, who had both preventative mastectomy and her ovaries and fallopian tubes removed—is also an option proven to improve survival. Hormone replacement therapy (HRT) in the first year after risk-reducing salpingo-oophorectomy (RRSO) has beneficial effects in terms of minimising endocrine symptoms and sexual symptoms in premenopausal women who have had prophylactic surgery⁵.

¹ Kuchenbaeke KB, et al. JAMA 2017;317:2401-16

² Rafnar et al., Nature Genet 2011; Ramus et al. JNCI, 2015

³ NCCN Guidelines; Lancaster JM et al. Gynecol Oncol. 2015;136:3-7; Lu JF et al. J Clin Oncol. 2014;32:833-840.

⁴ <https://www.esmo.org/Guidelines>

⁵ Hormone replacement therapy after risk-reducing salpingo-oophorectomy minimises endocrine and sexual problems:

A prospective study, Vermeulen, Ravi FM, et al. European Journal of Cancer, Volume 84, 159 – 167

<https://www.ejca.com/action/showCitFormats?pii=S0959-8049%2817%2931138-3&doi=10.1016%2Fj.ejca.2017.07.018>

- Current National Comprehensive Cancer Network guidelines recommend RRSO and/or hysterectomy for BRCA1 and 2 and also for BRIP1, RAD51C, RAD51D, +/- STK11/Peutz-Jeghers, Cowden, and Lynch carriers⁶.
- PARP inhibitors, in particular, olaparib for ovarian cancer, are another treatment avenue for patients with genetic mutations. Some PARP inhibitors are approved by the US Food and Drug Administration (and some also by the European Medicines Agency) for maintenance of ovarian cancers, regardless of BRCA status. However, the speaker notes this treatment has a greater magnitude of benefit for BRCA carriers, and so we need to continue testing for BRCA. It's also important that BRCA status is a significant predictive biomarker for PARP inhibitor efficacy.
 - Study 19 showed the results of olaparib treatment on a subpopulation of high grade serous ovarian cancer patients with BRCA mutations⁷. There was clear evidence of 'super-responders' to the treatment. Another notable study on olaparib was SOLO2/ENGOT-Ov21⁸. The US Food and Drug Administration approved olaparib tablets as maintenance for high grade serous, platinum-sensitive ovarian cancer, regardless of BRCA status.
 - Niraparib⁹ and rucaparib¹⁰ are other FDA-approved PARP inhibitor options used for ovarian cancer treatment maintenance, regardless of BRCA status.
- Patients and patient advocates should understand the two kinds of mutations, germline or somatic.
 - Germline BRCA mutations can be detected in a blood sample. These mutations are present in all of the body's cells¹¹.
 - Somatic BRCA mutations must be detected in a tumour sample. The mutations are present only in the tumour cells^{12,13}. From 5–8 % of ovarian cancer patients have this kind of mutation.
- Another prevention tool is the identification of patients with Homologous Recombination Deficiency (HRD), a genetic mutation linked to cancer. An extensive gene panel (several types are commercially available) or the 'genomic scar', which is HRD's effect on the patient's DNA, help clinicians understand which patients will most benefit from PARP inhibitors. As the price of sequencing decreases, direct germline testing of endometrial cancer patients may become a reality.
- Lynch Syndrome is the most famous genetic mutation linked to endometrial cancer risk (it also is a risk factor for ovarian cancer and colorectal, stomach, hepatobiliary, urinary tract, small bowel, brain, sebaceous neoplasms, and pancreatic cancers). It is present in the general population at about 1/500–1/1000, but in patients with endometrial and colon cancers, about 2/100–3/100. Lynch Syndrome carriers have a 'mismatch repair' in one of several genes that can represent from about 25% (PMS2 gene) to 50% (MSH2 gene) lifetime risk of endometrial cancer.
- A simple test for endometrial cancer is a pathologist-performed staining screen. It is now recommended for all patients with endometrial cancer, not the least because Lynch Syndrome carriers have an elevated risk for developing a second cancer, particularly colon (48%).
- The following recommendations from the NCCN concern patients carrying Lynch Syndrome:
 - Educate patients about abnormal vaginal bleeding and unusual vaginal discharge and use EMB for diagnosis if symptoms develop; consider screening every 1–2 years; consider transvaginal ultrasound; limitations in premenopausal women due to changes in endometrial stripe in normal menstrual cycle; consider risk-reduction agents (i.e., oral contraceptives, progestin, risk-reduction surgery).

- Research into therapies for microsatellite instability high-cancer (MSI-H) may become more popular. In the same way that BRCA became very popular after PARP inhibitors, now FDA-approved pembrolizumab for MSI-H tumours is pushing assessment of MSI status to become the standard of care in advanced colon and endometrial cancer. This is helping to identify individuals with Lynch Syndrome.
- For the future: ENGOT is currently running a stage III clinical trial (ENGOT-en7/MaNGO/AtTEnd) on paclitaxel.

⁶ https://www.nccn.org/professionals/physician_gls/default.aspx

⁷ Ledermann J et al. N Engl J Med 2012 <https://www.ncbi.nlm.nih.gov/pubmed/22452356>

⁸ Article in The Lancet about SOLO2/ENGOT-Ov21: [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(17\)30469-2/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(17)30469-2/fulltext)

⁹ Niraparib Maintenance Therapy in Platinum-Sensitive, Recurrent Ovarian Cancer. Mirza MR et al. N Engl J Med 2016 <https://www.ncbi.nlm.nih.gov/pubmed/27717299>

¹⁰ Rucaparib maintenance treatment for recurrent ovarian carcinoma after response to platinum therapy (ARIEL3): a randomised, double-blind, placebo-controlled, phase 3 trial. Coleman RL, et al. Lancet Oncol 2017 [Epub ahead of print].

¹¹ National Cancer Institute. <http://www.cancer.gov/dictionary?cdrid=46384> [accessed January 2018].

¹² National Cancer Institute. <http://www.cancer.gov/dictionary?CdriD=46586>.

¹³ Vergote I et al. Euro J Cancer 2016; 69: 127-1

Resources

Inherited Mutations in Women with Ovarian Carcinoma. Norquist BM, et al. JAMA Oncol. 2016;2(4):482-490. <https://www.ncbi.nlm.nih.gov/pubmed/26720728>



Ate van der Zee (The Netherlands), Jalid Sehouli (Germany), Jonathan Ledermann (UK), Mansoor Raza Mirza (Denmark), Murat Gultekin; photo taken by Maude Andersson

BLOCK 1: WHAT IS NEW IN GYNAECOLOGICAL CANCER

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

What Is a Rare Tumour and Its Treatment Options?



"What will change the future is organisation. We finally understand we need to [create] a network on rare tumours."

Domenica Lorusso

"Rare cancers are not so rare as we believe."

Domenica Lorusso

Key messages

- "Rare" cancers are defined as having an incidence of fewer than six patients from every 100,000 patients every year. More than 4.3 million people in the European Union are living with a rare cancer. In fact, when added together, the 198 rare cancers represent about 22% of all cancer cases.
- Also, rare cancers are not that rare within the subset of gynaecological tumours. They represent 53% of all gynaecological tumours. For someone like the speaker, who only treats gynaecological cancers, one out of two patients falls into the definition of rare.
 - With the exception of high-grade serous tumours of the ovary, high-grade endometrioid tumour of the endometrium, and squamous cell cancer of the cervix, all the other gynae malignancies are defined as rare tumours.
- In terms of rare ovarian cancer, we distinguish two categories: rare epithelial tumours of the ovary and non-epithelial tumours (including sex cord tumours and germ cell tumours of the ovary).
 - Germ cell tumours are the most frequent tumours in women younger than 27 and represent about 2 or 3 percent of all ovarian tumours. It's highly chemo-sensitive, and 85% are cured.

- Meanwhile, stromal tumour and rare epithelial cancer are more frequent in older patients.
 - The best five-year survival is for germ cell tumour of the ovary and for sex cord tumours and rare epithelial tumours.
 - The Mullerian mixed tumour has the worst prognosis.
- The RARECAREnet project of surveillance of rare cancers in Europe covers the data of 94 cancer registries in 27 European countries. The biggest registry of tumours in Europe, more than 48% of cancer patient diagnoses are included.
 - Patients treated in Eastern Europe have worse survival than patients in northern or Western Europe; older patients experience the worst prognosis, true for all tumours.
 - In 2008 in Europe, 119,000 women were expected to be living with a past diagnosis of a rare ovarian cancer.
- Rare cancers are a problem for clinicians because they enter into what is nicknamed a “fatal spiral”. As knowledge is lacking, there is no evidence-based medicine. Without competition, there is low interest from agencies and pharmaceutical companies to trial these medicines. In short, there is little support for rare tumours. The result is that survival rates for rare cancers are lower across all age ranges than they are for the most common cancers. Further complicating the push for evidence-based medicine is that when trials do get off the ground, they may close due to insufficient enrolment.
- The answer may lie in trials across networks rather than from one pharmaceutical company or research institution. For example, the ALIENOR (ENGOT-OV7) international trial looked at bevacizumab and paclitaxel in relapsed sex cord stroma patients. A collaboration of five countries, it recruited patients across sites. It was a success because of a strong international collaboration. It was presented at ESMO18 in October 2018.
- Low-grade serous carcinoma (6–10% of all ovarian carcinoma) represents a challenge because it’s more frequent in younger patients but responds poorly to chemotherapy. A proposed clinical trial for this cancer will turn the tables for the scientific community because it removes chemotherapy as the first-line treatment for ovarian cancer.
- The scientific community is looking to identify another way to study rare cancer. While randomised trials offer high-quality scientific data, it is difficult to enrol enough rare cancer patients. It’s better for patient care to have any data than no data at all.
 - Mucinous ovarian carcinoma (2% of all epithelial carcinoma) has an excellent prognosis when localised but is not responsive to chemotherapy if it is located outside of the ovaries. The mEOC randomised trial was created—it was very important because of the difficulty of the cancer—but since it was impossible to do a truly randomised trial on such a rare cancer, it closed with only 50 patients enrolled.
- Basket trials may be an answer. These study the effect of one drug but on a variety of tumour types. An example is the randomised phase II study NiCC (ENGOT-GYN1) on clear cell carcinoma in ovarian, uterine, and epithelial tumours. This trial offers a look at a potential model for other trials to serve rare cancers—select a biomarker and a tumour and enrol depending on those characteristics rather than on the cancer’s location in the body.
 - The breaking news for clear cell carcinoma is that it’s chemo-resistant but if radiation treatment (not typically used in ovarian cancer) is done on stage 1 or 2 clear cell when it’s localised in the pelvis, survival increases.

- Uterine sarcoma most often affects women between the ages of 40–60 and represents 5–10% of uterine corpus malignancies. It can be stratified into three histologies and prognoses: low-grade endometrial stromal sarcoma (ESS) and adenosarcoma, which have a good prognosis; leiomyosarcoma (LMS), which has a bad prognosis; and high-grade undifferentiated sarcoma, ESS, and adenosarcoma with sarcomata's overgrowth, which have very bad prognoses.
 - For low-grade ESS, in 20% of cases, the diagnosis is wrong. It shouldn't be treated with chemotherapy, but rather a hormone blocker. However, high-grade ESS need to be treated with chemotherapy. So, when diagnosed with ESS, it's important for patients to ask for a second opinion.
 - For now, surgical excision is the only established treatment for uterine LMS. When laparoscopy is used for surgical treatment, sometimes the LMS is morcellated, which ends up as a worse situation for the patient. The GOG 277 trial set out to evaluate combination therapies for LMS. However, this randomised trial closed with only 38 patients. The tumour needs more data .
- High-grade undifferentiated uterine sarcoma often has hidden metastases (74%); 50% are discovered at stage 4. There is no clinical standard for it except radical surgery and adjuvant treatment if accepted.
 - The EORTC 62113-55115 trial is being carried out at an international level, trying to understand if maintenance treatment will help with this difficult cancer. To date, the trial is enrolling quite well.
- National and international networks can help facilitate trials and knowledge exchange to bring more options for rare tumour treatment. The European Reference Networks move knowledge not the patient, allowing patients the right to cross borders for health care and help them identify referral networks where those tumours could be treated. Examples of functioning national networks are in France and Italy.
 - Internationally, the RARECARE project involved ten rare tumours and created a dedicated network for gynaecological oncologists. It also involved patient advocacy groups, which are needed because they represent the patient voice and are better often than clinicians at creating a patient-centric strategy.

Resources

<http://www.rarecarenet.eu>

BLOCK 2: QUALITY OF LIFE AND FERTILITY IN CANCER

Chairs: Maria Papageorgiou (Greece), Birthe Lemley (Denmark)

Quality of Life and Late Treatment Effects



Florence Joly (France)

"If I have only one message, it is, 'practice physical activity'."

Florence Joly

Key messages

- Some rare tumours have very good prognoses. After treatment, these patients have good quality of life. In particular, tumours that affect mainly young women and ones that call for conservative surgery followed by chemotherapy have a good prognosis. The most frequent chemotherapy regimen used is BEP: bleomycin, etoposide, cisplatin.
 - Germ cell tumours have 85% five-year overall survival.
 - Sex cord tumours have 80%.
 - And trophoblastic tumours more than 80%.
- Even with a good prognosis, common long-term toxicities for women treated with chemotherapy exist, including hearing loss neurotoxicity; pulmonary, cardiovascular, metabolic and menopausal issues; and the risk of second cancers.
- When seeking answers for rare gynaecological cancers, there are some lessons that can be learned from testicular cancer and childhood cancer survivors. They have some of the same long-term survival issues and the chemotherapy regime for testicular cancer is the same.
 - Quality of life and psycho-social issues, especially, can be compared with testicular cancer survivors. Many of these are quite positive, for example, testicular cancer patients have a long-term quality of life similar to the global population. However, they also have higher levels of anxiety, fatigue, and cognitive

complaints with memory. There is also the implication of some socio-economic factors such as youth, substance abuse, unemployment, and low education levels.

- Young cancer survivors, particularly, exhibit higher psychological impairment, anxiety, post-traumatic stress, and suicide.
- Some 20% of testicular cancer patients had high cumulative late effects in relation to chemotherapy. After cisplatin-based chemotherapy, patients reported higher rates of hearing damage/tinnitus, dyslipidaemia, diabetes, high blood pressure, neuropathy, pain, cardiovascular issues, thyroid problems, and anxiety/depression. The factors associated with these side effects included older age, disability leave, type and number of cycles of chemotherapy, and overall health (smoking, drinking, weight).
- Second malignancies are always a concern for patients. For testicular cancer patients, there is a small increase in the risk (1.5 %–2.1%) that remains elevated up to 35 years after treatment. In the case of platinum area chemotherapy, there was an increase in leukaemia, thyroid, and soft tissue cancers.
- Unfortunately, there are few data about women with good prognosis after rare gynaecological cancer. After chemotherapy, depending on age at diagnosis, type of chemotherapy, history of smoking, and time since ceasing chemotherapy, patients report the following quality of life issues and late side effects:
 - No difference in general health, mood, vitality.
 - Significant differences in high blood pressure, hearing loss, Raynaud syndrome, sensitive neuropathy, induced nausea.
- There is reassuring data regarding fertility after conservative surgery followed by chemotherapy. Only 3% of patients report premature menopause and 71%–95% preserve their menstrual function within about eight months. However, compared to women from the general population, cancer survivors report more reproductive concerns, less sexual pleasure and less sexual activity while also having better relationships with their partners. Note that there are greater reproductive concerns and sexual discomfort with infertile patients compared to fertile ones.
- More reassuring data for women with rare gynaecological cancers comes from the Norway Cancer Registry, which shows a very low risk of second cancer, mainly when chemotherapy was combined with abdominal irradiation .
- The next steps that can be taken to further minimise long-term side effects are to evaluate the patients better, centralise the treatments, and stage interventions to help cope with the disease and the treatments.
- Researchers are currently working on better evaluating rare tumours, for example in the INCa French Network for Rare Malignant Ovarian Tumours (TMRO)-GINECO study.
- A promising trend for patients is care centralisation. Testicular cancer patients have shown better outcomes when treated in high-volume centres, and ovarian cancer patient data suggests the same.
- To additionally minimise late effects of treatment, there are several interventions. A survivorship care plan, fertility, and menopausal concerns, and the promotion of a healthy life are all recommended.
 - A survivorship care plan is a plan for long-term follow up. It summarises treatment and follow-up steps and provides recommendations for the patient's general practitioner.
 - Fertility and menopausal concerns are often a worry for women's cancer patients. Patients should have access to specialists and information about their concerns. In most cases, fertility preservation steps are an option, and, on the other side, there is no contra-indication to normal contraception methods and no contraindication to having treatment for menopausal symptoms for rare cancer patients.

- Intervening with patients to help them foster a healthy life is also a good way to minimise late effects. A recent clinical trial in the USA on the effect of exercise on ovarian cancer patients indicates physical activity reduces fatigue and improves quality of life.

¹⁵ Ray-Coquard et al Eur J Surg Oncol, 2018, Gatta et al EJC 2011

¹⁶ Solheim, Gyn Oncol 2013

¹⁷ Collette JNCI 1999, Dubois Gyn Oncol 2009, Huguet BMC health services Res 2018

¹⁸ Women's Activity and Lifestyle Study in Connecticut (WALC) <https://clinicaltrials.gov/ct2/show/NCT02107066>

Cancer in Pregnancy and Fertility-Sparing Surgery



Frédéric Amant (Belgium)

"You need sufficient expertise in the centre, and that can only be provided when you have sufficient volume."

Frédéric Amant

Key messages

- For women who are diagnosed with cancer while pregnant, surgery, radiotherapy and chemotherapy treatments are possible even during the pregnancy. Even at the risk of antenatal exposure to chemotherapy, this risk is preferable to premature delivery.
 - For example, the diagnosis of breast cancer in pregnancy is difficult and different from usual, but still possible. It is also possible to use sentinel lymph nodes for cancer detection, since the exposure to radioactivity is very low.
- During the first and second trimesters, the application of chemotherapy has no larger risk of malformations for the baby. During the early stages of pregnancy, it's possible to provide the upper body with treatment from radiotherapy.
 - In particular, chemotherapy must be adapted carefully to pregnant women because each time the woman comes back for the therapy, she will weigh a different amount, so the dosages are going to be different.

- After 37 weeks, therapy is not recommended since the baby's liver may not be able to handle it.
- Cancer in pregnancy is diagnosed only in one out of thousand or two thousand cases. A European Registry collects data about these incidences. Each year, there are 2,500–5,000 new cases in Europe. The four most frequently diagnosed are breast cancer (35%), lymphoma (13%), cervical cancer (11%), and ovarian cancer (8%).
 - Breast cancer in pregnancy is most often symptomatic, and diagnosis is often delayed. Every suspect mass should undergo a core biopsy.
 - Cancer screening through sonography and MRI is safe and preferred, especially for the pelvis, though X-rays and other exams are also performed. The threshold radiation dose for foetal damage is estimated to vary between 10–20 cGy. Most of the common scans have a much lower exposure rate than that; the highest risk is a CT scan of the pelvis, which can contribute up to 8.9 cGy.
 - SLN biopsy during pregnancy has a low axillary recurrence rate. This staging method can be considered during pregnancy instead of standard ALND for early stage, clinically node-negative breast cancer¹⁹.
- In cases of a mastectomy or other surgery during pregnancy, the foetal heart rate is monitored with special equipment during the surgery.
- A 2010 study on congenital malformations on 173 babies whose mothers had cancer during pregnancy found that a physical abnormality was diagnosed at birth for just 13 children. This reflects the background risk in the general population, and the authors conclude cytotoxic treatment does not increase the risk of malformations²⁰.
 - In the results of a multicentre case-control study published in the *New England Journal of Medicine* in 2015, 129 children with cancer patient mothers were compared with the same number of children whose mothers were not patients. The incidence of medical and cognitive problems was the same between the study group and the control group²¹.
 - There is some evidence that babies whose mothers are treated with cisplatin during pregnancy are at higher risk for hearing loss. For example, one case report mentioned a boy who had severe bilateral perceptive hearing loss²².
- Providing support for psychological distress and coping with the psycho-social and quality of life issues is also vital for pregnant patients.
- A recent (2018) retrospective study looks at patients registered in the International Network on Cancer, Infertility and Pregnancy (INCIP)²³. Due to the complications present in a pregnant cancer patient's treatment, the authors' recommendation was that it is best if pregnant cancer patients are able to join a pregnancy high-care group where there will be sufficient expertise in the centre. That expertise can only be found where there is sufficient volume. Multidisciplinary care is especially important for pregnant cancer patients. There will be many more people included on the care team, including a breast surgeon and breast nurse.

¹⁹ Han et al., Br Ca Res Treat 2018

²⁰ Van Calsteren et al., J Clin Oncol 2010

²¹ Amant et al. Pediatric Outcome after Maternal Cancer Diagnosed during Pregnancy N Engl J Med 2015; 373:1824-1834
<https://www.nejm.org/doi/full/10.1056/NEJMoa1508913>

²² Geijteman E et al., Obstet Gynecol 2014

²³ de Haan et al. Oncological management and obstetric and neonatal outcomes for women diagnosed with cancer during pregnancy: a 20-year international cohort study of 1170 patients. Lancet. Vol 19, Issue 3, P337-346, MARCH 01, 2018
[https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(18\)30059-7/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(18)30059-7/fulltext)

Resources

CancerinPregnancy.org

BLOCK 3: HOW TO COLLABORATE WITH OTHER NETWORKS AND MAKE A POSTER

Chairs: Simona Ene (Romania), Dina Kurdiani (Georgia)

WHAT IS ENGAGe



Esra Urkmez (USA)

- The European Network of Gynaecological Cancer Advocacy Groups is the only umbrella organization for patient groups committed to gynaecological cancers.
- The objectives of the group are:
 - To facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate networking and collaboration between them.
 - To disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
 - To build public awareness and mobilise the best care of women with gynaecological cancer at national and European levels.
 - To increase patient representation in ESGO activities by education on current research and health policy.
 - Advocate patient care policies, practices, and access to appropriate care of both national and European levels
 - To educate and build the capacity of patient groups, and facilitate their communication with health professionals, the public and health decision makers
- ENGAGe is governed by an executive group that consists of representatives of patient advocates and clinicians. The Executive Group reports to the ESGO Council and to the Assembly of ENGAGe members. The Patient Advocate co-Chairing the executive group has been appointed as ESGO Council member to represent the patient voice at ESGO.

WHAT IS ENYGO



Kamil Zalewski (Poland)

- The ESGO European Network of Young Gynaecological Oncologists (ENYGO) is a network for juniors and trainees in gynaecological oncology and its related subspecialties. ENYGO was created in 2008, and its activities are supported by ESGO. Members are young professionals younger than 40. There are currently over 700 members in Europe, and 35 countries are represented.
- The network was founded because young people at conferences didn't know each other and were listening but weren't approaching experts. The ESGO leadership realised that the young professionals today will be the future leaders tomorrow. ENYGO helps prepare them for leadership.
- ENYGO activities include educational workshops, the LiFE report which helps members stay up-to-date with recent publications, online scientific surveys, ESGO accreditations, the ESGO eAcademy, cooperation with ENGAGe (translations), the Best of ESGO Project, and the eLOG BOOK
- ENYGO has a president, vice president, and five members-at-large.

WHAT IS ENGOT



Antonio González Martín (Spain)

- The European Network for Gynaecological Oncological Trial groups (ENGOT) is a research network of ESGO that was founded in Berlin in October 2007. It coordinates and promotes clinical trials within Europe on patients with gynaecological cancer. 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.
- There are now 20 groups from 25 countries.
- ENGOT is a platform that guarantees 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. The ultimate goal is to bring the best treatment to gynaecological cancer patients through the best science and enable every patient in every European country to access a clinical trial.
- ENGOT leadership consists of a clinical and an operational co-chair, a strategic group of the nine biggest groups, the administration chair, the GCA Chair, and an ESGO council representative.

Resources

<https://engage.esgo.org>

<https://enygo.esgo.org>

<https://engot.esgo.org>

How to Make a Patient Organisation Poster



Karina Dahl Steffensen (Denmark)

"Posters are an excellent way of showcasing your work. For example, if you had a poster here at the exhibition area, you could tell everyone what you were doing at your home organization and gain interest, maybe even be able to raise funds."

Karina Dahl Steffensen

Key messages

- An academic poster presentation summarises a project into a concise format and is displayed at congresses, conferences, and other events. They represent one effective way to get eyes and influence on a patient advocacy organisation.
- Follow basic design rules when preparing a poster: keep it simple while making important information stand out and use the space you have but do not make it crowded.
- Check the guidelines provided by the target conference or event. The guidelines may be quite specific and adhering to the guidelines will mean your poster may be considered for an award or other accolade at the event that will bring further visibility.
 - Guidelines may address poster size, orientation, required sections, and other important points.
- The headline is one of the most important parts of your poster. It should be concise and catch the attention of the viewer. Make the font large enough that a viewer can see it from a few meters' distance. Subheadings will also help the viewer orient themselves within the information on the poster. Other headings will be necessary, including authors and affiliations.
- The main body of your poster should include an introduction (with a short background of the topic, aim, and objectives), methods, results, conclusion, and references. The information presented should be minimal and written more in the style of a slide deck or presentation than a report—full sentences are not always necessary.
- Graphic elements such as tables, charts, and other figures are good to include. They are attractive and provide information in a way that's quick to absorb.
- The poster background is best kept simple. White or a light colour is best. Choose one or two font colours as well but avoid using too many. When choosing a colour for background or text, print out a test version before the event to make sure it looks good on paper as well as on the screen.

- Before the event, do a final check: Do my poster sections flow logically? Is all my text readable? Are all my graphics good quality? Is my data understandable? Does the most important information stand out? Then, get someone to review it for you.
- At the event, when displaying the poster, make sure you have prepared simple and clear talking points. Similar to oral presentations, successful posters can generate discussion amongst the audience members. It is therefore important to have a clear plan of what to say when standing alongside your poster.

How to Search in PubMed and the ESGO journal



"Patients can find important information on PubMed."

Dina Kurdiani

Key messages

- PubMed is a free resource that provides access to MEDLINE, the National Library of Medicine database of citations and abstracts in the fields of medicine, nursing, dentistry, veterinary medicine, health care systems, and preclinical sciences.
- Searching PubMed is similar to other Internet search engines. Type a search term, such as "ovarian cancer" into the search box and click "search." It's not necessary to use any punctuation.
- Search results are shown organised by "most recent" as a default, but you can click the "sort by" menu at the top of the results to customise this. For example, you could select "best match" or limit the search to particular journals.

- You can also take advantage of the search details function. PubMed maps search terms with the medical subject Headings (MeSH) to match the terms with the vocabulary that indexers use to describe articles in PubMed. Including MeSH terms enhances your PubMed search results. To access MeSH searches, select it from the drop-down menu on the left of the search bar. You can now select other terms included within your original search. For example, from the original search for "ovarian cancer", you may now have results that have the further sub-classification "ovarian neoplasms".
- PubMed also allows you to search for recent developments and therapies. On the home page, select "clinical queries." On the next page, enter the topic you are interested in, for example, "ovarian cancer". On the results page, you'll be able to filter by type and scope (broad and narrow scope); of particular interest to patients and patient advocates may be "therapy".
- When you click on a result, you go to that page. For some articles, you may be able to go to the full text on the publisher's homepage. For others, you can only see the abstract. On the right, you'll see a sidebar with similar articles to the one you have selected.
- Organise the articles you want to read with the "favourites" function. At the top right, you can select "add to favourites" under the "save items" heading.
- Articles from the *International Journal of Gynecological Oncology* can also be searched easily on its website. You can choose to search by Articles and Issues, by selecting the menu on the far left or you can enter a search term in the search bar on the top right.

Resources

www.pubmed.com

<https://journals.lww.com/ijgc>

Awareness Campaign - Cervical and Ovarian Cancer



"Social media is where we get the most response."

Birthe Lemley (Denmark)

"We usually take our programmes into big places like shopping centres, and there we meet lots of women."

ÍcÓ Tóth

Key messages

KIU (Denmark)

- They put effort into ovarian cancer awareness campaigns because the disease is too often diagnosed too late in Denmark and because women don't know the symptoms.
- The group organises awareness campaigns both on- and off-line and actively collaborates with patient advocates in other countries to share ideas and inspiration. For example, inspiration for a recent large public awareness campaign that lit up a public building with teal-coloured lights came from Ovarian Cancer Canada. Lighting up the building garnered a lot of attention, including footage and interviews on the news, which guaranteed a lot of the public saw the campaign.
- Another campaign that reached many was an interview with a famous actress, Ghita Nørby, who is a cancer survivor, in a popular magazine that is widely read among women.
- A more targeted campaign was the production and distribution of a short video to be displayed at pharmacies. Though the video itself has an upbeat and positive ending, it deals with a heavy topic: finding out that you have ovarian cancer. The aim of the video was to encourage women to fill out a questionnaire about ovarian cancer symptoms and take it to their doctor if their answers indicated they might be at risk for the disease.
 - The film has now been translated into Spanish and Norwegian and has run in the underground in Mexico City as well, which was made possible through international collaboration.
- KIU runs an annual awareness discussion campaign on Facebook as well, with the same aim of teaching women about ovarian cancer symptoms and encouraging them to take the self-screening questionnaire.
 - KIU uses Facebook's paid boosting service to promote the posts and get them in front of larger numbers of women.
 - One tip for running similar awareness discussions on social media is that questions will come in that should be answered by a medical professional. Before the event, get a doctor involved who is willing to answer questions.

The Mallow Flower Foundation (Hungary)

- The Mallow Flower Foundation is a five-year-old organization in Hungary that advocates for cervical cancer patients and disease awareness and prevention, as well as ovarian, vulvar, and vaginal cancers. The foundation's unusual branding was created by the founder as a "lovemark" (see Resources).
- Since cervical cancer can be eradicated with the HPV vaccine, the foundation has put extra energy into making sure all women know about this important tool against cancer. One of the most recent campaigns, encouraging teenagers to talk to their parents about getting the HPV vaccine, was a short video with Hungarian teenage influencers that used a special hashtag. The video had good reach and fostered discussion amongst teenagers about HPV vaccines and cervical cancer.
- The foundation often organises artistic, interactive campaigns. Most take place in large public venues like shopping centres, where they can meet lots of women. Their philosophy for awareness campaigns is to create "unobserved education" by striking up conversations with people who come to the event but avoiding lectures.
- This year, the Ride4Women event came to Budapest and partnered with Mallow Flower Foundation.
- During European Cervical Cancer Week in January, they set up mannequins with empty abdomens, where participants could place a pearl as a symbol of HPV protection. In a separate event, they also helped participants make pearl bead bracelets to distribute to hospital patients.
- Many of the campaigns are natural for participants' social sharing, for example, a large wall decoration of mallow flowers where people can stop to take pictures and start conversations. At another event, they created a huge colouring wall that was three meters high and nine meters long. When people came by and helped colour in the design on the wall, the foundation could start a conversation with them about cancer.
- On the World Ovarian Cancer Day, the foundation applied body paint to famous actresses and other participants and posed them in shop windows for cancer awareness.
- On May 8, the foundation gathered patients together in a park in Budapest to plant mallow flowers with signs informing the public who walk through the park about the foundation and the flowers' symbolism.
- An art exhibition featuring portraits of patients depicting the emotions that guided them through their illness has been touring Hungary for two years to date. It has been exhibited in municipal buildings and schools.
- The Powwow and Panties campaign put stickers in the shape of underpants on public toilet doors, and in restrooms in Decathlon sports stores, and in schools. Each of the stickers has a cancer prevention-related message. This campaign also featured a public talk and a photo session with large cut-outs of underpants.
- Some tips for running similar campaigns are to include an expert panel to make sure that there is someone on hand to answer medical questions and to help the medical community and patient community to share knowledge and to make a men's wall or men's focussed part of the event so that they are not left out of the event and women who are passing by with family or friends feel they can stay longer.

Resources

KIU's video campaign: <http://opdag.nu>

Lovemarks: <https://en.wikipedia.org/wiki/Lovemark>

<https://www.facebook.com/malyvavirag/videos/295480171231933/>

<http://www.malyvaviarg.hu>

ROUNDTABLES

Day One: What is New in Gynaecological Cancer



Table 1: Ovarian Cancer

with Jonathan Ledermann (UK)

Table 2: Cervical Cancer

with Jalid Sehouli (Germany)

Table 3: Vulvar and Vaginal Cancer

with Ate van der Zee (the Netherlands)

Table 4: Uterine Cancer

with Mansoor Raza Mirza (Denmark)

Day Two: Best Practices from ENGAGe Members – “How To”



Table 1: Prevention/Early Detection, Education Materials

with Ross Little (UK) and Linda Snoep (the Netherlands)

Table 2: Fundraising, Grant Submissions, Communication with Sponsors

with Esra Urkmez (USA)

Table 3: Clinical Trials

with Birthe Lemley (Denmark)

Table 4: Palliative Care

with Charo Hierro (Spain)

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