

2023

Patient Advocacy Seminar Report



ESGO ENGAGe Patient Seminar in Gynaecological Cancers

Sept 29 - Oct 1, 2023

Held during the European Society
of Gynaecological Oncology Congress
in Istanbul, Türkiye.



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About ESGO

Founded in 1983, the European Society of Gynaecological Oncology (ESGO) is a not-for profit organisation and leading forum of professionals from across Europe and all around the world who are dedicated to promoting the highest quality of care for women with gynaecological cancers. ESGO's mission is to improve the health and well-being of women with gynaecological cancers through prevention, research, excellence in care and education.



About ENGAGe

Established by ESGO in 2012, the European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) is a network of European patient advocacy groups representing all gynaecological cancers (ovarian, endometrial, cervical, vulvar, and rare cancers). ENGAGe is committed to empowering a patient-centric approach to gynaecological cancer care, research and prevention through awareness, advocacy, and education.

Objectives

- Facilitate the development of national gynaecological cancer patient groups in Europe and networking and collaboration 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 for patient care policies, practices, and access to appropriate care at both national and European levels.
- Educate patient groups, health professionals, and the public and help decision-makers.

Welcome to Istanbul!

THREE DAYS OF SHARING KNOWLEDGE & FELLOWSHIP!



We were pleased to welcome our patient advocate delegates to our 11th patient advocacy seminar—this time in Istanbul, Türkiye.

Our delegates got together over three days in parallel with the European Society of Gynaecological Oncology (ESGO) 2024 Congress for an inspiring programme of workshops, lectures, roundtables, networking events, knowledge sharing, poster presentations, and HPV and ovarian cancer awareness activities.

The first lecture in our New Approaches and Treatments in Gynae Cancer series, given by Jonathan Ledermann, was a particular highlight on the scientific side of our programme, while the new Come Together workshop helped us share information and unmet needs as well as start to map the situation in our member countries within each gynaecological oncology diagnosis. On the main stage at the ESGO Congress, our voices were represented at the session on the WHO Cervical Cancer Challenge: From Screening to Vaccination to Eliminate the Tumour with Joanna Kacperczyk-Bartnik, Murat Gultekin, and Marc Arbyn.

The awareness events were also big hits! The HPV Awareness Dance by Alya Dormen and moderated by Ayse Arman was a fun and fabulous addition to the “Good for my daughter, good for us” campaign from the PI Women’s Cancers Association. We are very grateful to our Turkish hosts, who also include Kanserle Dans Derneği, for organising it! On Saturday morning, patient advocates wearing purple World GO Day T-shirts represented us at the ESGO Awareness Run and Walk for Health, which had a beautiful view of Istanbul. We also saw the launch of the Olivia digital patient support for ovarian cancer patients in the Turkish language.

Please enjoy this short summary of selected sessions and some photos of the event. We will see you again soon—in Barcelona for the 2024 Patient Advocacy Seminar—for another robust, but different, programme of events for our delegates.

**Save the date for the 2024
Patient Advocacy Seminar, March 8–9, Barcelona, Spain!**

SEE YOU IN BARCELONA!

ENGAGe
ESGO | European Network of Gynaecological
Cancer Advocacy Groups

**12th Patient
Advocacy
Seminar**

March 8 - 9, 2024, Barcelona, Spain



New approaches and new treatments in gynaecological cancer

By Jonathan Ledermann, United Kingdom



*This is the first lecture in a planned series!
Thank you for your expertise,
Professor Ledermann!*

Questions for the future

ENGAGeO
European Network of Gynaecological
Cancer Advocacy Group

*Will Immunotherapy replace
chemotherapy as front-line treatment
for advanced or high-risk endometrial
cancer ?*

- **OVARIAN CANCER.** There has been a paradigm shift with the introduction of PARP inhibitor maintenance therapy. The SOLO1, PAOLA-1, PRIMA, PRIME, ATHENA, and VELIA trials indicate improvement in progression-free survival. Overall survival results are now available from SOLO1 and PAOLA-1.
- **ENDOMETRIAL CANCER.** This cancer (also known as uterine cancer) is the only gynaecological malignancy with a rising incidence and mortality. Patients who are diagnosed early have excellent prognoses, but those who are diagnosed late have a 5-year survival rate of only 17%. Recent studies (KEYNOTE 158, GARNET, PHAEDRA, Konstantinopoulos, KEYNOTE 775) looked at immune checkpoint inhibitors and saw higher overall response rates for MMR-d than MMR-p. The question that will need to be asked by researchers next is if immunotherapy will replace chemotherapy as a front-line treatment for advanced or high-risk endometrial cancer.
- **CERVICAL CANCER.** Recently, the EMPOWER-Cervical 1 trial indicated that cemiplimab improved overall survival over chemotherapy. KEYNOTE-826 looked at combining checkpoint inhibitor pembrolizumab with chemotherapy and found that it improved progression-free survival and overall survival.

Incremental Improvements in Survival (OS) in Treating Metastatic and Recurrent Cervical Cancer with Combinations and Biomarkers

ENGAGeO
European Network of Gynaecological
Cancer Advocacy Group

Chemotherapy backbone (platinum + taxane) 2009

GOG 204 established the global standard with a median OS of 12.9 months¹

Adding bevacizumab 2014

GOG 240 added bevacizumab in eligible patients with a median OS of 17.5 months²

Adding pembrolizumab if biomarker positive (PD-L1 22c3)

KN-826 added pembrolizumab in PD-L1 positive (CPS ≥ 1). Median OS not recached (24.4 months in all comers)³

Endometrial cancer screening options and diagnostics

By Pawel Knapp, Poland

- There are around 415,000 new cases of endometrial (also known as uterine) cancer each year and more than 95,000 deaths.
- Europe has a high incidence rate.
- Endometrial cancer can be recognized in the early stages (FIGO 1a, 1b) because there are very early symptoms.
 - The classic symptom of endometrial cancer is abnormal uterine bleeding, but there is no standard or routine test for it.
 - Diabetes is not an independent risk factor.
 - Genetic risk factors include Lynch Syndrome, Hereditary Non-Polyposis Colorectal Cancer—mutation in DNA mismatch repair genes MLH1, MSH2, MSH6, and PMS2.
- Diagnosis follows a pelvic examination and ultrasound scan to rule out ovarian disease.
- Dilation and curettage or office endometrial biopsy (both are adequate) can be used to rule out other causes of symptoms, including chronic endometriosis, atrophy, polyps, cervical cancer, and other unusual factors, including carcinosarcoma, serous carcinoma, placental nodule.
- In cases of stage 1, an MRI should be performed to evaluate myometrial invasion. Advanced cases should have MI, CT, PET-CT scans with an expert sonographer.
- Therapeutic strategy is based on stage, grade, and histotype.
- While historically, this cancer was treated with chemotherapy, hormone therapy, and radiation, and current treatment includes immunotherapy and targeted therapy, future treatments will involve personalized, combination treatments.

Resources:

- <https://www.iarc.who.int/>
- <https://guidelines.esgo.org/uterine-cancer/guidelines/recommendations/>

Pre-operative pathological information is crucial for establishing the surgical plan.

The final therapeutic strategy could be based on the information available before surgery:

- Stage (apparent I or more advanced stage)
- Grade (G1, G2, G3)
- Histotype (endometrioid or non-endometrioid tumour)

engage.esgo.org



Communication with family during cancer treatment

By Volkan Aykac, Germany



- A cancer diagnosis and treatment are psychological trauma and, therefore, can affect cognitive function and the decision-making process.
- Communicating not only transmits information, but it also promotes cooperation and peace, is the basis of coordination and cooperation and acts as the basis for decision-making.
- Although we may think of communication in terms of content or speech, in fact, 55% of the effects of communication are non-verbal.
- For effective communication with family during cancer treatment, several tactics can be used:

- Verbal: strong, confident speaking voice, active listening, no filler words, medical jargon only when appropriate.
- Nonverbal: be intentional, mimic those you find to be effective, and notice how your emotions feel physically.
- Visual: Ask others before you use visuals, consider your audience, only use them if they add value, and make them clear and easy to understand.
- Written: Strive for simplicity, don't rely on tone, take time to review written communications, and keep a file of writing you find effective or enjoyable.
- Benefits of effective communication include:
 - Encouraging patients to share information.
 - Motivating people to take medicines as prescribed.
 - Giving patients more understandable information.
 - Helping people live a healthier lifestyle.
 - Positively influencing a person's mental state.
- Tips for medical professionals and patient advocates arranging a good setting for communicating with family during cancer treatment:
 - Include (gyn-)oncologists.
 - Have preliminary information about the family.
 - Create a private space.
- Tips for medical professionals and patient advocates on communicating with family:
 - Use simple and effective language.
 - Use more open questions than yes/no language.
 - Use brief, clear, and concise comments, tips, and suggestions.
 - Summarize ("teach-back").
 - Use active listening.
 - Pay attention to non-verbal communication.
 - Be accurate and avoid mistakes.
 - Use their everyday language (translate medical terms).
 - Don't be too intrusive.
 - Allow moments of silence.

Our soul

By Icó Nagy-Tóth, Hungary

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*"If you hold my hand and it's squeezed by another.
We all know what it means to be together.
I support you, and you support me forever.
We all know what it means to be together."*

– from "Stay Silent, Please!" a poem by Icó Tóth.

- **To My Soul workbook.** What is our soul? How does it connect with our body? ENGAGe Past President Icó Tóth described the ongoing ENGAGe quality of life project to create a "to my soul" workbook that aims to help women who have no chance to connect with a psychologist to help them through a cancer diagnosis. Professional psychological help can be expensive, difficult to schedule, or it may be that women are ashamed to seek out a therapist. This workbook should be able to fill some of the gaps. Psychology experts, storytellers, and patients are creating the content.
- **Diagnoses Delivery Images.** These one-sheet brochures created with ISGOPPI will provide at-a-glance information about gynaecological cancers, including procedures, surgical complications, and common treatment side effects, as well as diagrams that can be marked up with the patient's specific tumour sites and other relevant information.
- New **"Endorsed by ENGAGe" brochures** that will bring member groups' brochures to a wider audience.

Resources:

- <https://engage.esgo.org/brochures/to-my-soul/>

ENGAGe TEENs project presentation

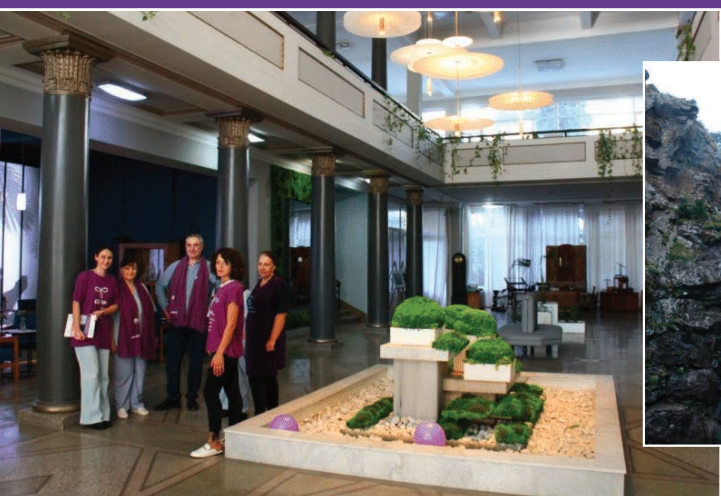
By Francesco Di Fino (IT) and Mako Museridze (GE)



Francesco Di Fino
ENGAGe TEENs
Project Leader

A video from the Teens in various countries explained why they are involved in helping raise awareness about HPV vaccination with their peers!

"In Georgia, the Reach the Mountains Campaign held HPV tours to target the general population and school pupils."



Resources:

- <https://engage.esgo.org/engage-teens-project/>

HPV awareness dance

Alya Dormen, hosted by PI Kadin Kanserlei Dernegi & Kanserle Dans Dernegi

A big thanks to these talented dancers for using their moves to raise awareness about HPV vaccination! Our delegates loved learning some steps, too!



WHO Cervical Cancer Challenge: from screening to vaccination to eliminate the tumour

(ENYGO & ENGAGE Session)

By Joanna Kacperczyk-Bartnik, Poland; Murat Gultekin, Türkiye; Marc Arbyn, Belgium

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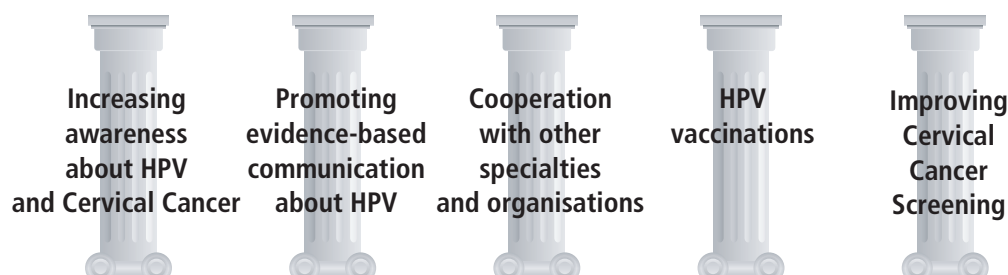
Khayal Gasimli

Joanna Kacperczyk-Bartnik shared the Manifesto of Young Gyn Oncologists for the Cervical Cancer Elimination project.

● To **increase awareness** about HPV and cervical cancer, it's important to educate communities, encourage participation in vaccination and screening programmes, introduce public health campaigns, promote cervical health as a trending topic (like anti-tobacco trends), and understand the role of social media and influencers.

- To promote **evidence-based communication about HPV**, it's important that **healthcare providers offer guidance in line with evidence-based data and convey it to the patient in simple language**. Understand that vaccine hesitancy is the result of insufficient or misinformation and the role that cultural beliefs play in people's perceptions about health-related topics. Include community figures like religious or cultural leaders in the action.
- To promote **cooperation with various medical specialties**, recognize that primary care plays a pivotal role, and continuous education is crucial. Cervical cancer survivors can serve as advocates for education about vaccination, screening, and treatment. Strong cooperation is necessary with the education system, national healthcare services, and the private sector.
- To promote **HPV vaccination**, ESGO supports gender-neutral vaccination programmes for children and adolescences with a catch-up programme for young adults and vaccination on an individual basis. In addition, ESGO and the European Federation for Colposcopy are committed to providing appropriate information and education for women, not only in their role as patients but also as mothers of the next generation. Vaccine affordability is also a crucial topic. Data needs to be shared, ideally with the participation of national HPV elimination board.
- To improve **cervical cancer screening**, there should be attention paid to migration health to overcome inequality in HPV-disease prevention, as well as to measures to increase equity for vulnerable populations. Self-sampling is another route to improving access, as are investments in healthcare infrastructure, healthcare workforce training and health system strengthening. Increased funding and resources for cervical cancer prevention programs, including research and new tech development, should be addressed. Introducing HPV testing in countries and populations that are underserved is important, as is the implementation of unified national and international registries.

5 PILLARS OF CERVICAL CANCER ELIMINATION



HPV prevention policy atlas

By Leonidas Galeridis, European Parliamentary Forum



9 Key recommendations

States should:

1. Include **HPV vaccination** into routine state vaccination schedules
2. Establish **gender neutral vaccination** by including **boys** into HPV vaccination coverage (which also serves protection of the girls)
3. Offer the HPV vaccine **free of charge**
4. Provide mature **population-based screening** programmes which are the **only way** to reach the entire population and achieve results in saving women's lives
5. Ensure that screening is offered **free of charge**
6. Increase considerably the **VCR and screening levels** and make them **publicly available**
7. Offer screening by **HPV testing and self-sampling options**
8. Provide their citizens with **reliable evidence-based information** about HPV screening and vaccine and where to reach them
9. Ensure **better data collection** for HPV screening and coverage rate

- Joint project from European Parliamentary Forum for Sexual & Reproductive Rights and ECO. The 30 parliamentary groups throughout Europe are uniquely positioned to influence the shape and content of their countries' public health agendas.
- Every year in the WHO European Region, more than 66,000 women are newly diagnosed with cervical cancer and 30,000 women die. But cervical cancer is a preventable disease, and we have the tools to eliminate it.
- The HPV Prevention Policy Atlas is a comparative map that scores 47 countries across geographical Europe on prevention policies of cervical cancer. The Atlas focuses on primary (vaccination) and secondary (screening) prevention and online information on HPV, cervical cancer and accessing vaccination. It aims to provide a living document that introduces a common baseline on prevention policies for HPV-related cancer in Europe.
- There is an evident division between western and eastern Europe regarding these policies, though there is also proof that policies are improving.
- Denmark, Sweden, and Finland are policy champions in primary and secondary prevention and also online information.
- Azerbaijan and Bosnia-Herzegovina have the worst ratings on the atlas.
- Internal mechanisms driving progress include the EU Beating Cancer Plan and the WHO Global Strategy to eliminate cervical cancer.

Key Findings (2023) Countries' Ranking

Excellent (>95%)	Very good (85-95%)	Medium (75-84%)	Poor (65-74%)	Very poor (50-64%)	Exceptionally Poor (<50)
5 champion countries	12 countries	7 countries	9 countries	7 countries	7 countries
Denmark 97,4 Sweden 97,4 Finland 96,1 UK 95,8 Ireland 95,2	Netherlands 94,2 Iceland 93,9 Germany 93,4 Norway 93,1 Malta 92,9 Switzerland 92,3 Estonia 91,7 Belgium 90,5 Latvia 88,8 France 86,6 Czech Republic 86,5 Italy 85,2	Poland 84,4 Hungary 84,3 Croatia 84,0 Portugal, 83,7 Austria 83,6 North Macedonia 80,7 Slovenia 80,7	Spain 78,1 Lithuania 73,9 Serbia 72,1 Andorra 70,5 Cyprus 70,1 Slovakia 66,4 Romania 65,7 Greece 65,5 Georgia 65	Armenia 64,4 Monaco, 63,5 Luxembourg 61,8 Moldova 61,7 Bulgaria 60,9 Montenegro 60,5 San Marino 54,1	Albania 39,5 Russia 37,4 Ukraine 33,8 Türkiye 31,6 Belarus 30,0 Bosnia-Herzegovina 21,5 Azerbaijan 6,4

RISCC project communication & dissemination

By Claudia Robles, Spain



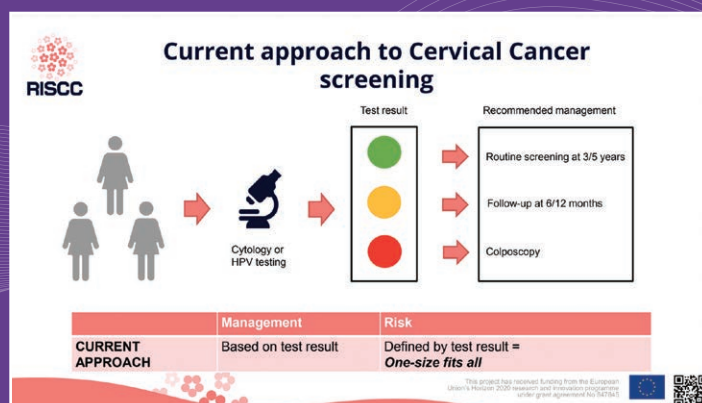
- The RISCC project aims to implement risk-based screening for cervical cancer in Europe. It is currently developing the first European risk-based cervical cancer screening proposal.
- Currently there are many differences in prevention strategies and policies within regions in Europe. Even in countries that have a high score, there is room for improvement.
- Advantages of risk-based cervical cancer screening include:
 - Less unnecessary activity for those with low risk
 - Expedited follow-up for higher risk cases
 - Easier to incorporate new screening methods.
 - Significant cost-reduction
 - +2 EUR per woman avoids 12,500 annual cervical cancer deaths in Europe.
- The current project implementation tools are:
 - Cost-effectiveness assessment.
 - Pilot testing of a risk-based screening programme.
 - Open-source tools to facilitate clinical management.
 - Education in the form of free online training for personnel in the screening and dissemination and communication activities.
- The results so far:
 - Must only use validated HPV tests (including 13 DNA tests and 1 mRNA test)
 - High-volume procurements can obtain these tests for lower costs.
 - Self-sampling data (versus clinician samples) is being updated, including the first real-world performance data from the Netherlands.
 - P16 staining, extended genotyping and viral load management in HPV positive women show similar performance to cytology.

management in HPV positive women show similar performance to cytology.

- The methylation test in HPV-positive patients with low-grade cytology allows the reduction of colposcopy referrals (and therefore costs).
- In Norway partial genotyping is being studied.
- Combined triage with HPV genotyping, cytology, and dual staining offers higher protection against future lesions.
- Methylation testing could identify women with lesions who don't need treatment and predict lesions at a higher risk of progression in vaccinated women.
- Among many other dissemination activities, an e-learning program in English and Spanish has rolled out for primary care physicians, cervical cancer prevention, and HPV vaccines.

Resources:

• Risc-h2020.eu • e-oncologia.org • hpwworld.com



PARTICIPANT
PHOTOS

End of life medical input & social input

By **Jalid Sehouli, Germany; Andrea Krull, Germany; Volkan Aykac, Germany**

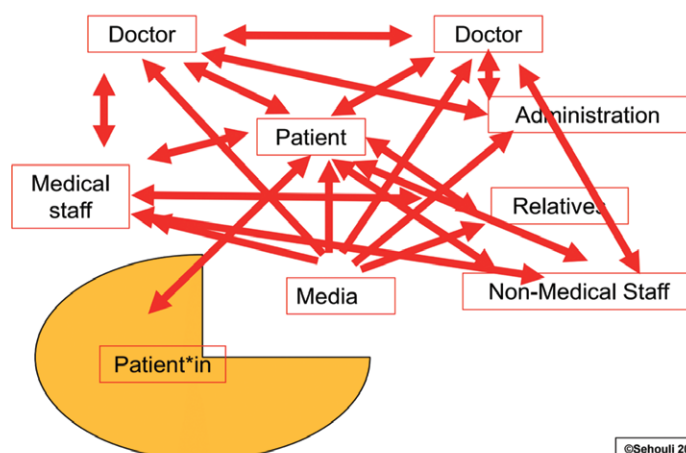
- End of life is the time before death. It can be measured in months, weeks, days or even hours.
- Medical personnel should take time for communication with the patient and family to find out the patient's plan and wishes for the end of their lives. A discussion of the treatment choices and plans can reduce stress on the patient, their family, and their health care providers.
- Unfortunately, as one study shows, although patients wish for information about end-of-life care from their physician, active conversations about end-of-life care by physicians can be extremely rare.
- The knowledge gap concerning advance directives for end-of-life care is particularly significant for patients with a migration background; they often have trouble getting information in their native language.
- Death within the next 12 months is not always possible to predict; however, advanced incurable illness (such as cancer, dementia) and frailty or multimorbidity, or life-threatening acute conditions caused by a sudden catastrophic event, such as an accident or a stroke, may be the right time to begin discussions about end-of-life care.
- A common question about morphine is if its use hastens death; there is no evidence to support this. Rather, morphine improves the quality of life of patients who are suffering from physical pain or shortness of breath.

- » **Palliative care** encompasses **end-of-life care**, which in turn encompasses **terminal care**.
- » Palliative care aims to maximize quality of life, though symptom management, palliative surgery, psychosocial support, etc.
- » End-of-life care does the same as palliative care but on a more condensed scale, when there are weeks or months to live.
- » Terminal care focuses on symptom management, psychosocial support of the patient and their family, and spiritual care.

COMMON SYMPTOMS AT THE END OF LIFE ARE:

- Death rattle
- Fatigue
- Pain
- Coughing
- Skin irritation
- Trouble swallowing
- Digestive problems
- Shortness of breath
- Depression
- Delirium

Interpersonal and interinstitutional Communication and challenges regarding breaking bad news and complications



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Resources:

- hpc.providencehealthcare.org/about/what-palliative-care
- NOGGO-expression X study "Prevalence, expectations, and barriers of advance directives in 736 patients with gynecological cancer with and without a migration background." <https://pubmed.ncbi.nlm.nih.gov/34511112/>

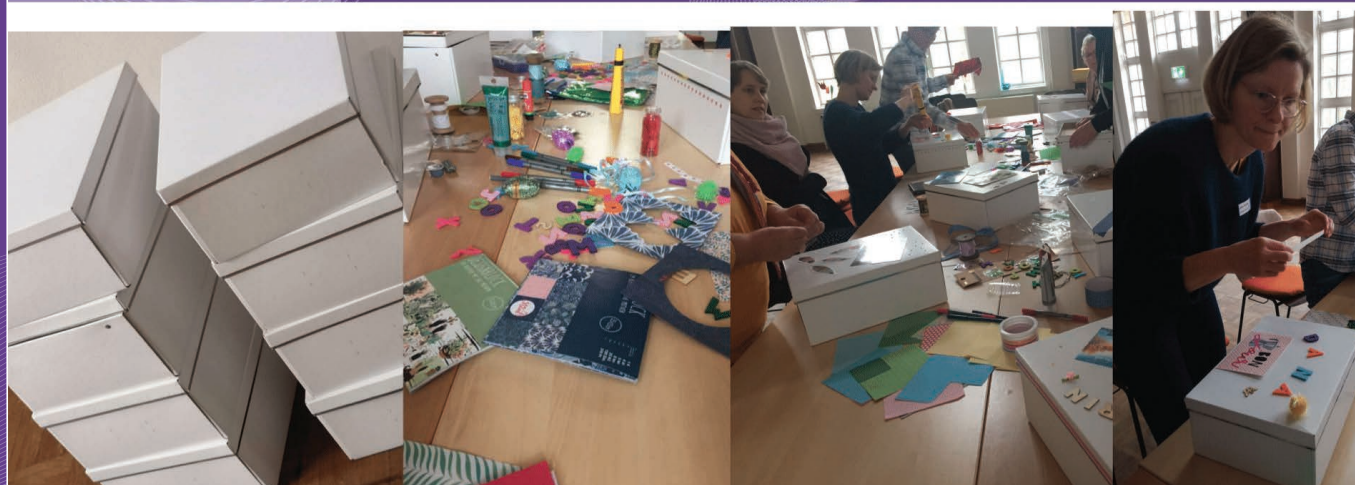
When healing is no longer possible

By Andrea Krull, Germany

When healing is no longer possible



Farewellbox as a Transporter - Diegnfied saying goodbye, leaving memoies, talking about dying - Last Aid Program



“Human dignity is inviolable—even in dying. This encounters farewells, new beginnings, happiness and laughter, grief, pain, and anger. Palliative work and knowledge about it are therefore always permeated by doubts and uncertainty, but also by hope and trust.”

- Andrea Krull invented “Farewellbox” after her own diagnosis with stage 4 ovarian cancer. She had been under the impression that “high-quality dying” was not possible. The “Farewellbox” is a shoebox filled with brochures and information for the patient and family about palliative care, patient rights, wills, hospice care, etc. and a “Last Aid” workshop offer. The box is decorated by the patient and filled in the support group or brought by a palliative care nurse.
- The Last Aid workshops empower family members to be fully prepared for a death. It is aimed at all people who want to learn about issues surrounding death, dying and palliative care. It can be useful for individuals, groups, associations, and companies.
- Last Aid includes four modules: dying as a part of life, provision and decision-making, alleviating suffering, saying goodbye.

Resources:

- <https://www.letztehilfe.info/last-aid/>

ADC's: What are they?

By Toon Van Gorp, Netherlands

- Antibody Drug Conjugates (ADC) target the proteins on cancer cells that identify them as different from normal cells so that the cancer cells can be destroyed by chemotherapy.
 - Antibodies are produced by specialised white blood cells "B cells". They signal the immune system to attack harmful things that enter the body.
- Possible side effects of ADCs include the toxic payload (the chemotherapy) being released in the bloodstream, the target being present also on healthy cells, and non-specific uptake into the healthy tissues. These side effects depend on the target, the stability, the toxic payload, and the stability of the "linker" that connects the cytotoxic payload to the antibody and antigen. Each ADC unique and will have its own side effects.
- Some ADCs such as Mirvetuximab-Soravtansine have been approved in other countries (US) but are not yet available in the EU. According to current research, Mirvetuximab improved progression free survival and has a more tolerable safety profile when compared to chemotherapy.

What's in the name



• FR α :	Mirvetuximab	- Soravtansine	(Mirv)
• FR α :	Farletuzumab	- Ecteribulin	(FZEC)
• TF:	Tisotumab	- Vedotin	(TV)
• HER2:	Trastuzumab	- Emtansine	(T-DM1)
• HER2:	Trastuzumab	- Deruxtecan	(T-Dxd)
• NaPi2b:	Upifitamab	- Rilsodotin	(UpRi)



Toon Van Gorp

Sexual health survey

By Zoia Razumova, Sweden



- The European Network of Young Gynae Oncologists (an ESGO network) and ENGAGe administered a survey on sexual health and gynaecological cancer patients. The survey consisted of patient-driven questions and was developed with a psycho-oncologist and clinical psychologist. It was translated into 10 languages.
- Sexuality is a crucial part of life. However, a majority of patients surveyed reported their sexual life got worse after their diagnosis.
- The top three problems related to sexual health that were reported were lack of sexual desire (93.3%), vaginal dryness (91.1%), and difficulties in reaching orgasm (84.7%).
- 49% of the oncological patients surveyed thought that sexual health counselling was very important, and a further 31% said it was important. However, only 21% reported having their information about sexual function collected often or always and 19% had never or rarely had it discussed with them.
- For patients who were offered, 60% accepted sexual counseling. Those who did not accept it did so for the following reasons: I didn't need it (42.1%), no interest in a sexual life (15.8%), ashamed to talk about it (18.4%), it was offered at the wrong time (26.3%) and other (18.4%).
- Thanks to this project, the ESGO Exam (for gynae oncologists) now includes questions on sexual health. There are also new modules on the ESGO eAcademy video portal about sexual health and psychological oncology.

ENYGO survey on sexual counselling

Kacperczyk-Bartnik et al.

Clinician attitude towards sexual counselling in women with gynecologic malignancies: European Network of Young Gynaecological Oncologists (ENYGO) survey

Abstract

Background: Sexual health is a major component of quality of life and well-being. However, it is often neglected in clinical practice. The aim of this study was to assess the attitudes and knowledge of gynecological oncologists regarding sexual health counselling.

Methods: A cross-sectional survey was conducted among 100 gynecological oncologists from 10 European countries. The survey included questions on demographic data, clinical practice, and attitudes towards sexual health counselling.

Results: The majority of respondents (49%) considered sexual health counselling as very important, while 31% considered it as important. However, only 21% reported having their information about sexual function collected often or always, and 19% had never or rarely had it discussed with them.

Conclusion: Sexual health counselling is a crucial part of life, but it is often neglected in clinical practice. The survey results highlight the need for more structured approaches to sexual health counselling in gynecological oncology.

✓ 'Sexual counselling of oncological patients is very important (49%) or important (31%).'

BUT

✓ 'Collecting information concerning sexual function is performed often or always by only 21% of respondents and 19% discuss the topic rarely or never.'

ESGO European Society of Gynaecological Oncology

24th European Congress on Gynaecological Oncology
Sep 28 - Oct 1, 2023 | Istanbul, Türkiye

Rare cancers, EURACAN

By Isabelle Ray-Coquard, France

- “Rare” cancers are more frequent than it might seem. Rarity may be due to unusual histology (e.g., sex cord, trophoblastic), localisation (e.g., vaginal melanoma), or histological subtype (e.g., mucinous, clear cell carcinoma).
- Education for physicians and patients is key to making sure that the best care is given. Centres must streamline decision making, with expert pathologists, an expert multidisciplinary tumour board, and receive national support from a dedicated rare cancer network. International cooperation is a must.
- The most important challenges for patients are: to identify the right diagnosis, define the prognosis, define the best standard for care and the best option in case of relapse, then to follow sequelae and late toxicities including psychological aspects. For stakeholders and scientists, the key challenges are routine management and quality of care, developing regional and national networks and national databases, coming together on guidelines and levels of evidence and clinical trials, international collaboration, and national management.
- There usually aren’t sufficient quantities of patients with a rare disease to be able to hold a large-scale clinical trial. Without clinical trials, it’s difficult to have innovation or improvement in terms of overall survival. Pharmaceutical companies are not often interested in giving financial support to studies on this smaller scale.
- European multi-disciplinary tumour boards support cross-border networking and increase treatment options for patients with rare tumours.
- **Some notes on individual rare gyn cancer types:**
 - For rare epithelial carcinoma patients, which are often in the early stages, the most common question is if there is any place for conservative surgery, and any indication of adjuvant chemotherapy.
 - For low grade serous carcinoma (6–10% of all ovarian carcinoma cases), the tumour is usually less sensitive to chemotherapy, so first-line treatment includes maximum debulking surgery and adjuvant chemotherapy (+/1 bev) for advanced disease.
 - Mucinous ovarian carcinoma treatment remains problematic. Some improvements include the possibility of new drugs with the BOUQUET trial.
 - Clear cell carcinoma is the second most common sub type of endometrial cancer and is more often diagnosed in Asia than in Europe.
 - Sex cord stromal tumours make up 7% of ovarian cancer cases. They require surgery (fertility sparing for early stage and radical for advanced disease). Postoperative chemotherapy should be discussed.
 - Ovarian germ cell tumours have had significant improvements in treatment. 85% of patients are cured today. This subset makes up 2–3% of ovarian tumours and are usually found in adolescents or young adults.

» Put together, the number of “rare” gynaecological cancers isn’t that rare! About 55% of all gynae cancer patients have rare gynae tumours!

» EURACAN is the European Reference Network for rare or low prevalence complex diseases Adult Cancers network. It aims to establish a world-leading, patient centric and sustainable network of multi-disciplinary research-intensive clinical centres focused on Rare Adult Cancers.

Rare ovarian non-epithelial tumours

- Germ cell
- Sex cord stromal
- Small cell carcinoma

Rare epithelial carcinoma

- Low grade serous carcinoma
- Mucinous carcinoma
- Clear cell carcinoma
- Carcinosarcoma

Resources: • euracan.eu • ovaire-rare.org

Olivia Turkish language launch

Olivia, the digital support platform created to offer support to all those affected by ovarian cancer, is now available in the Turkish language. Because language should never be a barrier to accessing disease information and support!



Resources:

- <https://ovarian.gynecancer.org/tr/>

World GO Day wrap up

By Petra Adamkova, Czech Republic

- World Gynecologic Oncology Day 2023 was another great event.
- The topic this year was #GOforTesting, #GOforPrevention, #GOforTreatment
- This connects Testing and Tasting—the perfect recipe for your healthy lifestyle.
- This year's event had more than 60 partners from 20 countries (on every continent!)
- Over 30 videos from clinicians, patients and teens were shared.
- We had a huge impact on social media, reaching 44.1 million with 11.3 million unique views!

World GO Day World Gynaecologic Oncology Day



Some pictures tell more than a thousand words....



World GO Day World Gynaecologic Oncology Day



5th World GO Day topic:

- ✓ #GOForTesting, #GOForPrevention, #GOFor (right) Treatment
- ✓ Connecting Testing and Tasting – Perfect recipe for your healthy lifestyle

Some 2023 numbers:

- ✓ More than 60 partners from 20 different countries (covering all continents!)
- ✓ Over 30 videos from clinicians, patients and Teens
- ✓ Total social media impact: **44,1 million** (FB, IG, Twitter), **11,3 million unique views** (FB, IG) – best result ever!
- ✓ Parallel posting on ESGO / ENGAGE channels with our own branding
- ✓ Involvement of IGCS and IJGC in campaign support for the first time!



Patient advocate posters

KIZIMA İYİ GELECEK, BİZE İYİ GELECEK
GOOD FOR MY DAUGHTER, GOOD FOR US
BİR YILDA 1000 AŞI
1000 VACCINES IN ONE YEAR

20 Eylül 2022 Dünya Jinekolojik Kanseler gününde kolumuza 1000 aşı için başladığımız KIZIMA İYİ GELECEK BİZE İYİ GELECEK ücretsiz HPV aşı kampanyamızın tamamlandığını gururunu yaşıyoruz. On September 20, 2022 World Gynecological Cancers Day, we are proud to complete our free HPV vaccination campaign that we started for 1000 vaccines for our girls.

Proje için genç üyelerimizden Ayşe Demirel, tüm ailesi ile birlikte HPV aşı kampanyasını destekleyerek kampanyanın kendilerini hissettirdiği HPV aşı kampanyası medyasından bir anıyı paylaşmış. Başarıya Kızımın HPV aşı kampanyası için bir anıyı paylaşmış. Başarıya Kızımın HPV aşı kampanyası için bir anıyı paylaşmış.

Ayşe Demirel, the young face and heroine of our project, organized a dance workshop, all proceeds of which were donated to the HPV vaccine. By teaching the HPV dance, which she choreographed, to thousands of people on social media, she helped us raise awareness among young people against Cervical Cancer.

Yüksek kaliteli bir HPV aşı kampanyası için toplumun müdahale etmesi. We are happy to protect hundreds of girls against cervical cancer.

Proje için ilk randevu ve destek, yolları Instagram ve TikTok'ta yayınladı. Ayşe Demirel, kampanyanın Sosyal Medya'daki ilk randevusunu yayınladı. The first promotion of our project and the call for support was made by Instagram and TikTok phenomenon Ayşe Demirel on Social Media.

Kampanya ile birlikte 1000 aşı kampanyası kapsamında bir anıyı paylaşmış. We explained the importance of HPV vaccine in the awareness-raising meetings of the employees of national and international companies in our country, accompanied by our esteemed professors.

Yaptığımız çalışmaların bir anıyı paylaşmış ve gelen destekleri de bir anıyı paylaşmış. HPV aşı kampanyası için 1000 aşı kampanyası kapsamında bir anıyı paylaşmış. Our calls did not go unanswered and with the invitations we received, we participated in shopping mall organizations to raise awareness about Cervical Cancer in order to provide HPV vaccination to more girls.

BİR YILDA 1000 AŞI
1000 VACCINES IN ONE YEAR

kadinkanserlerdernegi.org
 @kadinkanserleri #kadinkanserlerdernegi



ORANGE MEETS PURPLE

4 initiatives by Esperanza in Flanders to support gynecological cancer patients

- 1 Brochure on Sexuality and Intimacy**
 - Written by Hilde Toelen, onco sexologist of UZ Leuven.
 - Distributed in Flanders' hospitals.
 - Used as a basis for Sexuality and Intimacy sessions for gynecological cancer patients through Flanders.
 - Translated by Esperanza and adapted by Engage to a generic European version for European Patient Groups.
- 2 Ovarian Cancer Campaign 8th of May 2023**
 - Ovarian Cancer-World Day (WOD) with AstraZenca
 - Focus on the symptoms and early referral to specialist care.
 - Interviews with Esperanza, specialized doctors and with patients.
 - On VRT-radio, digital health websites, in digital and paper magazines, via a video of a patient, a podcast for well-known newspaper and via distribution of posters in hospitals.
- 3 Symposium with UZ Ghent**
 - In order to inform patients on innovative treatments and answer pertinent questions in a round-table conversation setting with specialists.
 - To enhance contact with fellow patients.
 - In a relaxed atmosphere with attractive workshops and drinks and snacks.
- 4 Symposium in March 2024 regarding BRCA**
 - In March 2024 symposium on BRCA (together with other organizations and with University Hospital of Antwerp)
 - based on a video initiated by Esperanza on the experience of a BRCA patient and interview of a Medical Geneticist on BRCA
 - with lots of lectures, testimonies, panel discussion and workshops

ESPERANZA
 Hope that always matters

Formation of an Academy for Education experienced Consultants and Field Associates

National Center for Education and Support for Women with experience of Breastcancer and Gynecological Cancers

In Serbia, **7,000** people get breast and cervical cancer every year

The health system does not have enough capacity to support the patients, so they are left without information and support during treatment. Only 20% get information from doctors, the rest look for information on the internet, which is very dangerous. Going through the process of treatment, these women often cannot take care of themselves and their families, and they do not have the right to use the services of Social work centers, help at home, transportation to therapy and snacks. The system does not recognize cancer survivors as a group that needs social and psychological services during treatment. Palliative care is still not working.

That is why this project, for the first time in Serbia, will create the group of experienced patients to receive full support during treatment, by initiating two types of services - health and education in an educated team of experienced consultants and field associates.

Within the National Center for education and support for women with experience of breast cancer and gynecological cancers there will be:

- 1) An academy for education experienced consultants and field associates
- 2) A network of local support centers

The National Center will conduct an accredited education of experienced associates and field assistants. Their services will be available to female patients within the network of centers in the local units of the healthcare system throughout Serbia.

The first Support Center was formed in 2023 in Belgrade and in 4 months of work it achieved the following results:

- 350+ Telephone Consultations
- 100+ Visitation To Our Facility
- 40+ Online Consultations

Types of service:

- 1) Experiential support within the premises of the center
- 2) Field support that can be experienced, health, home help, nutrition advice, follow-up of the user with another service provider, connection to primary care on terms of scheduling controls, leaving instructions, etc.

Two additional support centers will be established next year, in Sabac and Vrnjaka Banja.

A Network of Local Support Centers

The network of support centers consists of centers formed within health centers at the local level.

Support providers will have previously passed the Academy certified program.

Types of service:

- 1) Experiential support within the premises of the center
- 2) Field support that can be experienced, health, home help, nutrition advice, follow-up of the user with another service provider, connection to primary care on terms of scheduling controls, leaving instructions, etc.

Two additional support centers will be established next year, in Sabac and Vrnjaka Banja.

Zenski centar "Milica" | Telefon brojevi: 20, Ambulancija DZ Start (sred.) 10000 Beograd | Koordinator Phone Number: 060 66 12 672 Email: zenski@opg.milica.rs | www.milica.org.rs

Surgical treatment of gynaecological cancer and the need for specialised care centres

» OVERVIEW OF SURGICAL APPROACHES

by David Cibula (CZ)

- When surgery is necessary to treat cervical or vulvar cancer, the surgeon must decide how best to reach the tumour. Choices include open surgery, laparoscopy, or robotic surgery. They must also decide if an abdominal or vaginal approach is better. These decisions must consider multiple factors related to the patient, including her preference, any previous treatment or existing other respiratory diseases, and weight. Other factors include ones related the institution, the surgeon, and the disease.
- Professor Cibula presented several cases as examples and discussed the decision-making process for each.

Resources:

- https://esgo.org/media/2019/03/Pocket-Guidelines_VULVAR-cancer.pdf
- https://esgo.org/media/2019/03/Pocket-Guidelines_Cervical-cancer_June2023.pdf



» MINIMALLY INVASIVE SURGERY

by Valentina Ghirardi (IT)

- Minimally invasive surgery (MIS) was first used in gynae oncology about 50 years ago. In 1975 peritoneoscopy was used for a pretreatment evaluation in ovarian cancer. The laparoscopic pelvic lymphadenectomy in cervical cancer was in 1993.
- Benefits of MIS include smaller incisions, a shorter hospital stay, quicker recovery, a lower risk of complications, a lower need of postoperative analgesics and a shorter time to start adjuvant treatment.
- MIS can be used for treating endometrial, cervical, ovarian, and vulvar cancers.
- Minimally invasive surgery is the preferred surgical approach for endometrial cancer according to the ESGO Guidelines. Used since 1988 for this cancer, MIS has been associated with fewer complications and better quality of life for all patients, including better outcomes in elderly patients and obese patients.
- But, for cervical cancer, MIS hysterectomy has been associated with lower rates of disease-free survival and overall survival than open hysterectomy. (LACC trial). Now MIS can still be used for patients who have micro-invasive cervical cancer and in certain cases for patients with tumours less than 2 cm. Other trials are ongoing.
- In ovarian cancer, MIS has been associated with better perioperative outcomes for early-stage disease and for patients with recurred disease. Trials are ongoing.
- In vulvar cancer, some reports claim MIS can be used for inguinal lymphadenectomy with favourable results, but further research in larger studies is needed.

» Specialised Care Centres: Quality Indicators

by Nicolò Bizzarri (IT)

- Quality cancer care requires a multidisciplinary care team, including not only the surgeon, but the primary care providers, radiologists, radiation oncologists, medical oncologists, pathologists, genetic counselors, research team, plastic surgeons, nursing team, patient support groups, nutritionists, social workers, and physical therapists.
- Centres that specialise in patient care for particular types of disease may have higher survival rates or other metrics than general care centres. The surgeons who operate in these centres have more data and more experience with relevant cases.
- Some countries have their own certifications for cancer centres. There are also ESGO Accredited Centres, which follow the ESGO Quality Indicators and Guidelines and demonstrate high standards of care.
- Currently, ESGO has accreditations for ovarian cancer and endometrial cancer surgery. An accreditation for cervical cancer surgery is being prepared.

Resources:

- <https://guidelines.esgo.org/ovarian-cancer/quality-indicators/indicators/>
- <https://esgo.org/explore/esgo-accreditation/>

ESGO Awareness Run and Walk for Health



ACKNOWLEDGEMENTS

We are grateful to our sponsors for their support!



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