

13th

**Patient
Advocacy
Seminar**

REPORT

**February 20 – 23 /2025
ROME – ITALY**



THANK YOU for supporting the 13th ENGAGE Patient Advocacy Seminar in Rome! We were very happy to welcome 60 participants from 34 patient advocacy groups and 27 countries.



We welcomed participants from:

- | | | | | |
|------------------|-----------|-------------------|---------------|-------------------|
| • Albania | • France | • Israel | • Portugal | • The Netherlands |
| • Belgium | • Georgia | • Italy | • Romania | • Turkey |
| • Cyprus | • Germany | • Latvia | • Serbia | • UK |
| • Czech Republic | • Greece | • North Macedonia | • Spain | |
| • Denmark | • Hungary | • Norway | • Sweden | |
| • Finland | • Ireland | • Poland | • Switzerland | |

SESSION

1 Developments

Opening remarks

SPEAKERS: Prof. Philippe Morice (Institute Gustave Roussy, France)
Kim Hulscher (Olijf, The Netherlands)



- » Kim Hulscher and Philippe Morice gave the opening remarks to the conference and welcomed everyone.
- » Philippe, as the ESGO representative thanked Kim and the other patients for advocating for the quality of life of patients. He also stated that their mandate is to reconnect ESGO and ENGAGE more strongly as they work together to serve patients.
- » On that note, he mentioned that ENGAGE and ESGO will lead on developing new guidelines regarding the sexual rehabilitation and sexual quality of life of patients with gynaecological cancer. It highlights how the voice of the patient and their needs must be the focus of medical care.

1 Developments

OC - HRD and non-HRD - Why Do Some HRD+ Tumors Do Not Benefit From PARPi

SPEAKER: Jonathan Ledermann (UCL Cancer Institute, London)



KEY TAKEAWAYS:

- » Jonathan Ledermann introduced the topic of Homologous Recombination Deficiency (HRD), focusing on why some HRD-positive tumors do not benefit from PARP inhibitors. The importance of homologous recombination in DNA repair and its role in cell survival was highlighted.
- » The role of BRCA1 and BRCA2 genes in homologous recombination and the impact of mutations on DNA repair was emphasised. There is a prevalence of BRCA-related dysfunction in high-grade serious ovarian cancer and other gene mutations involved in DNA repair.
- » The Cancer Genome Atlas study shows the distribution of BRCA-related and non-BRCA-related HRD in ovarian cancer. The complexity of testing for HRD is an issue, with the most common test being that of the Myriad myChoice assay, which measures genomic scarring to determine the degree of homologous recombination deficiency.
- » There is a variability in HRD scores within individual tumors, demonstrating the importance of sample selection for testing. There is also variability in PARP inhibitor response, particularly in patients with BRCA mutations.
- » PARP inhibitors showed significant benefits, but resistance remains a challenge with 42% of patients requiring further treatment within four years. There is also the phenomenon of reverse mutations, where a tumor with a BRCA mutation regains functionality, leading to drug resistance.
- » The complexity of drug resistance to PARP inhibitors means there is a need for further research to understand mechanisms of resistance as well as developing strategies to overcome this resistance.

1 Developments

ADCs - Antibody-Drug Conjugate

SPEAKER: Toon Van Gorp (University Hospital Leuven, Belgium)



KEY TAKEAWAYS:

- » Antibody Drug Conjugates (ADCs) are potentially useful in cancer therapy despite the current unavailability of approved ADCs for endometrial cancer.
- » Antibody engineering is the creation of new antibodies to recognize cancer cells. ADC is an antibody with chemotherapy attached, designed to target cancer cells by releasing chemotherapy into the cell.
- » ADCs can attach multiple chemotherapy molecules to an antibody, offering versatility. Various targets are being investigated with ADCs, including HER2, tissue factor, and Claudin-6.
- » However, there are various side effects of ADCs that depend on the target, stability of the chemotherapy, and toxicity of the chemotherapy. Furthermore, each ADC has its own side effect profile.
- » Possible side effects include the release of toxic payloads into the bloodstream, on healthy tissue, and affecting other organs like the liver and kidney. An example was given of when a patient developed cysts on the eye caused by ADC.
- » There is also the possibility of heterogeneous expression, where not all cells in a tumor have the target protein, leading to resistance. The tumor can also downregulate the target protein, making it unavailable for the ADC to attack.
- » Despite these challenges and the complexity of drug resistance, ADCs are seen as promising for endometrial cancer.

1 Developments

Vulvar and Vaginal Epidemiology and Screening

SPEAKER: Mario Preti (University of Torino, Italy)

KEY TAKEAWAYS:

- » Vulvar and vaginal cancers are rarely and poorly diagnosed. There is a need to reduce diagnostic delays and a better understanding of risk factors.
- » Incidences of vulvar cancer are increasing, especially in younger women, while vaginal cancer remains steady but affects older women. Vulvar cancer ranks 29th in incidence and mortality while vaginal cancer ranks 33rd in incidence and mortality.
- » HPV infection is a significant risk factor for vaginal cancer, and previous history of high-grade cervical dysplasia or cervical cancer increases the risk.
- » Vulvar cancer has the longest diagnostic delay. It is divided into HPV-related and non-HPV-related types, with different clinical presentations and prognoses.
- » Education, support, and awareness are crucial for the early detection and management of vulvar and vaginal cancer.
- » The challenges in early detection of vulvar cancer include the discomfort among healthcare providers in examining the vulva which is essential for early detection. Many healthcare providers do not inspect the vulva region before cervical cancer screening.
- » There is a need for improved infrastructure and prioritization of referral pathways to specialized centers for vulvar pathology.
- » There is also a need to promote vulvar self-examination among patients and provide a step-by-step guide. Less than a quarter of women in a study performed vulvar self-examination, but most would like more information.
- » A QR code was provided for accessing a consensus statement on vulvar cancer screening and a guide for vulvar self-examination.



1 Developments

Cervical cancer: Recent Advances in Treatment and Prevention

SPEAKER: Maria Kyrgiou (Imperial College London, United Kingdom)

KEY TAKEAWAYS:

- » There has been considerable progress made in the prevention and treatment of cervical cancer. However, there is still the need for optimizing treatment to ensure high cure rates without adverse impacts on survival, reproductive function and quality of life.
- » There are a range of abnormalities associated with cervical disease, from HPV infections to invasive cancer.
- » The prevalence of high-risk HPV infections in different age groups highlights the need for accurate screening. Current tests are limited in predicting which mild changes will lead to cancer.
- » The transition from cytology to DNA/RNA testing for HPV offers greater protection against cervical cancer. A study from Sweden showed lower cervical cancer risk in women screened with HPV compared to cytology. There is also the potential of self-sampling for HPV testing, which helps to address issues like avoiding gynaecological examinations and cultural factors.
- » Vaccines are important in preventing HPV infections and cervical cancer. Data from Sweden and the UK demonstrate the impact of vaccinations on reducing cervical cancer and associated morbidity. There is a need for organized vaccination programs and the potential for herd immunity to reduce infection rates.
- » There is a poor uptake of vaccines in some countries and a need for more equitable global access. A high burden of cervical cancer in low and middle-income settings, including lack of access to treatment.
- » There is an inverse relationship between cervical cancer and endometrial cancer, with the latter being more common in affluent societies. A need for better prevention and cancer care education in low-income countries.
- » Advances in surgical treatments for cervical cancer includes fertility-sparing techniques and sentinel lymph node mapping. Well-designed clinical trials are needed in assessing new surgical techniques.
- » The major barriers in women's cancer care includes shortages in screening infrastructure and lack of access to basic surgical procedures. Digital technologies and telemedicine are playing a significant role in improving care in low-resource settings.
- » The World Health Organisation has a goal of eliminating cervical cancer by 2030.



2 Preventions and Innovations →

How Can AI Help GO Field

SPEAKER: Frédéric Amant (UZ Leuven, Belgium)

KEY TAKEAWAYS:

- » The growing importance of AI in the medical field is revolutionizing oncology with its potential and limitations.
- » General concepts of AI that can be applied to healthcare including machine learning, natural language processing, and semantic entropy. Various chatbots are available that generates answers to medical queries such as Copilot from Microsoft and ChatGPT from OpenAI. Semantic entropy measures the degree of uncertainty in AI-generated responses.
- » There are limitations of AI in handling long documents. A context window which limits the amount of text AI can handle in a single interaction.
- » The issue of privacy and ethics in AI, with some chatbots retaining user information while others do not. In addition, the information fed into AI systems is not comprehensive and are influenced by the biases of those managing the systems.
- » AI can assist in patient education, clinical support, administrative aid, training, and awareness in gynaecological oncology. However, there is a need for clear guidelines on how AI can assist and where it cannot in medical research and clinical practice.
- » The importance of disclosing the use of AI in manuscript preparation and the need for journals to train editors to recognize AI-generated content.
- » ChatGPT's references can be incorrect or non-existent. For example, there was a case study where ChatGPT suggested a radical hysterectomy which is no longer the standard of care due to newer data. There is a need for transparency and up-to-date information in AI-generated responses, and the verification of its advice by expert knowledge.
- » AI plays a role in improving patient care and clinical decision-making, but has limitations in providing accurate individualized clinical advice. There will be always be a need for expert input, continuous updates and guidelines.



2 Preventions and Innovations →

RISCC Project

SPEAKER: Richard Tóth (Semmelweis University, Hungary)

KEY TAKEAWAYS:

- » The RISCC project is a risk-based cervical screening approach considering factors like age, smoking history, and HPV vaccination. The project collected risk profiles to provide tailored screening recommendations, and assessing their cost-effectiveness and feasibility through pilot testing. Education and open-source tools were developed to facilitate implementation across different centers.
- » Amsterdam Lab Project focused on risk profiles for unvaccinated individuals, analyzing data from HPV screening in the Netherlands over 15 years. High-risk HPV positivity was found to increase the risk of developing cervical pre-cancer, leading to higher colposcopy referrals. The project advised using HPV DNA tests to identify high-risk HPV, followed by cytology and methylation testing to determine further management.
- » Brussels Group Project: compared HPV self-sampling with clinician-collected tests. They found no difference but noted reliability issues with mRNA tests. Proper sample handling is crucial for test accuracy, but self-sampling can increase screening response rates.
- » Stockholm-Based Project developed a risk-based screening system, sending self-sampling kits to high-risk individuals and recommending tests for those with lower risks. An application was created to manage patient data, send self-sampling kits, and provide results via email or the application.
- » The RISCC project aims to build a well-informed workforce capable of answering patient questions and promoting screening programs. Key messages included the importance of HPV DNA testing, gender-neutral vaccination, and HPV genotyping for risk management.
- » A model framework was developed for implementing a cost-effective risk-based screening program in 27 EU countries. A 500-page document was presented to the European Commission for implementation.
- » The project emphasized the need for regular data collection and monitoring to implement risk-based screening effectively.

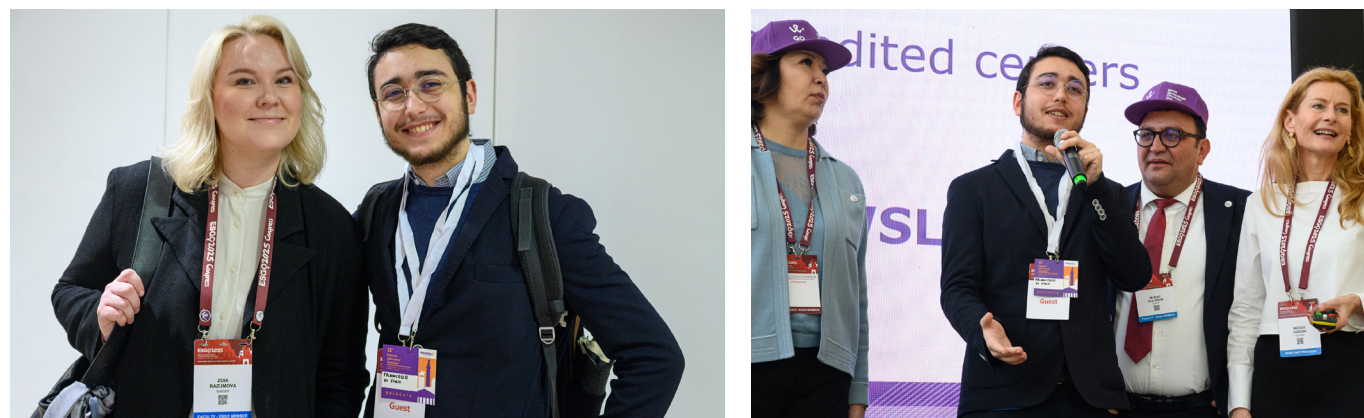


SESSION

2 Preventions and Innovations →

ENGAGe TEENs

SPEAKERS: Francesco Di Fino, Dr. Zoia Razumova (Karolinska Institutet, Sweden)



KEY TAKEAWAYS:

- » ENGAGe TEENs is a youth-led group focused on HPV and cervical cancer prevention, using peer-to-peer education to engage teens aged 13-18.
- » The group is assisted by professional medical staff. The primary goal is to educate peers about HPV and its risks, especially among teens who are starting to have their first sexual experiences.
- » Teens face challenges in trusting adults, leading to the need for peer-to-peer education. The team aims to address the fear and guilt teens might feel when discussing HPV.
- » They create innovative content like comics, brochures, and quizzes to raise awareness. Efforts include collaborations with schools, families, and communities, and they plan to expand also into different support groups.
- » The team has also developed social media campaigns, short reels, and other materials to spread awareness. These materials are certified by professional doctors and serve as effective communication tools.
- » A successful pilot in Hungary involved interactive lectures and discussions. The team has also finalized collaborations with three schools in Italy and a Catholic Church organization to reach children in need of information.
- » Future plans include an educational programme for schools and a support program for families affected by gynaecological cancer. They aim to increase vaccination rates and awareness across Europe.
- » They also intend to translate the existing educational comics and brochures to more languages, and encourage people to follow the ENGAGe TEENs' social media channels and share their educational materials.

SESSION

3 Fertility sparing →

Fertility Sparing - Patient Story

SPEAKER: Kyriaki Melliou (Erifyle, Greece)



KEY TAKEAWAYS:

- » Kyriaki Melliou from Greece shared her journey with endometrial cancer when she was diagnosed in February 2020 at age 35.
- » She highlighted her high-risk factors, including polycystic ovary syndrome and being overweight. She was initially treated with progesterone and letrozole but faced severe side effects and changed doctors. Her new doctors supported her lifestyle changes including adopting a ketogenic diet, intermittent fasting, Wim Hof breathing, and acupuncture. Despite challenges, she achieved a clear biopsy three months after refusing a hysterectomy.
- » She emphasizes the importance of self-advocacy, even when faced with medical advice to undergo a hysterectomy. She attributes lifestyle changes and psychotherapy as crucial to her recovery.
- » Her support system, including her family and the understanding and support from her work environment, was also vital to her success.
- » Her cancer experience has shaped her identity and motivates her to help others. She shares her personal struggles with maintaining a healthy lifestyle and the importance of self-acceptance. She continues to work with the patient advocacy group to support others in similar situations.

3 Fertility sparing

Fertility Sparing Balance Between the Risk and the Wish

SPEAKER: Philippe Morice (Institute Gustave Roussy, France)

KEY TAKEAWAYS:

- There are ethical and medical implications of fertility-sparing strategies in cervical cancer treatment. In particular, the balancing of oncological safety with patient's wishes means that fertility-sparing strategies should never compromise patient survival.
- An overview of six current surgical strategies to preserve the uterus and allow pregnancy were outlined, including simple cone biopsy and radical trachelectomy.
- There are also ongoing trials to evaluate the safety of neoadjuvant chemotherapy in patients with tumors between 2-4 cm.
- Abdominal radical trachelectomy is considered as the safest management approach for patients with 1B2 disease, reserving neoadjuvant chemotherapy only for the clinical trial context.
- Current management guidelines for fertility sparing surgery emphasizes the importance of accurate tumor size measurement.
- The two different stages of cervical cancer eligible for fertility sparing surgery are: stage IB1 (tumor size below two centimeters) and stage IB2 (tumor size between two and four centimeters).
- A recent paper from Italy reported a high recurrence rate after cone resection alone. However, the characteristics of the recurrent disease were questioned, and the importance of strict inclusion criteria was emphasized.
- There is a debate between following strict inclusion criteria and patient wishes, highlighting the ethical issues involved.
- There is a need for the centralization of care and for multidisciplinary teams to achieve the best results.
- Concludes by highlighting the optimistic results in terms of pregnancy obtained through different procedures.

3 Fertility sparing

Fertility Sparing Not Feasible

SPEAKER: Nadeem R. Abu-Rustum (Memorial Sloan Kettering Cancer Center, United States)

KEY TAKEAWAYS:

- There have been significant changes in cancer treatment over the past 30 years, particularly in cervical and endometrial cancer.
- The increasing role of patient wishes in treatment decisions, with many patients preferring less invasive options. This highlights the importance of patient autonomy and patient-centric care, and the need to balance safety while respecting patient choices.
- The challenges of treating young patients with endometrial cancer includes the need to balance early treatment with patient readiness for pregnancy.
- There is difficulty in treating patients with extensive tumor growth, including the formation of adhesions and the potential for scarring. Molecular testing can be used to identify patients who may respond better to progesterone therapy.
- The use of hysteroscopy and the receptor scope to remove tumors and treat with progesterone. Different responses to progesterone are based on tumor makeup. The importance of negative biopsies before attempting pregnancy.
- The role of lifestyle modifications, including the use of GLP-1 agents and bariatric surgery in reducing the risk of endometrial cancer.
- The potential for new drugs in advanced endometrial cancer to preserve fertility. The importance of monitoring the impact of treatments on the uterus and the potential for scarring.
- The use of conization for small cervical cancers, which maintains the uterus and allows for future pregnancy.
- The importance of reproductive endocrinology in egg freezing. Refer patients to reproductive endocrinology for egg/embryo freezing if they cannot undergo fertility-sparing surgery.
- The evolution of surgical techniques for cervical cancer, including the shift from abdominal to vaginal approaches.
- The use of sentinel node mapping and the importance of lymph node removal.
- The importance of ongoing research and the need for continued advancements in fertility preservation.

4 Quality of life

Minimal Invasive Surgery & Physical Activity

SPEAKER: Houssein El Hajj (Institut Gustave Roussy, France)

KEY TAKEAWAYS:

- » There is a notable lack of research on physical activity in gynaecological oncology.
- » Physical activity guidelines in gynaecological surgery have historically advised patients to rest, with concerns by surgeons of the risk of hernia or wound opening. However, with the advent of minimally invasive surgery, and recent studies that suggest pelvic loading through activity may promote tissue remodeling and improve surgical outcomes, this advice may need to be revised.
- » There is a discrepancy in post-operative activity recommendations among surgeons, with some recommending up to six weeks of restriction. The potential benefits and harms of post-operative activity restrictions need to be interrogated, as everyday activities exert similar pressure as exercise.
- » The importance of early mobilization and the potential harm of prolonged inactivity, including decreased muscle mass and increased risk of thrombosis.
- » With the increasing number of cancer survivors, physical activity plays a significant role in cancer survivorship. There is a difference between structured exercise and adapted physical activity; for cancer survivors there is a need for customized programs.
- » There are benefits of physical activity in improving outcomes after cancer diagnosis, with data showing that physical activity improves survival and reduces mortality, especially when started after diagnosis.
- » Lack of knowledge, time and resources are barriers to implementing physical activity interventions in gynaecological oncology. There is also a need for culturally adapted questionnaires, as well as creating programs that are adapted to patients' physical and medical conditions.
- » Practical tips for staying active, such as taking the stairs or walking instead of driving. Every little bit of effort makes a difference.



4 Quality of life

Lymphoedema

SPEAKER: Ane Gerda Eriksson (Oslo University Hospital The Norwegian Radium Hospital, Norway)

KEY TAKEAWAYS:

- » The discussion focused on lymphoedema in endometrial cancer survivors, emphasizing its impact on health-related quality of life.
- » Lymphoedema is defined as chronic swelling caused by the accumulation of protein-rich fluid in the tissue, typically developing after lymph node removal but also after radiotherapy or chemotherapy. There is the need to prevent lymphoedema rather than treat it, as limited treatment options are available.
- » The Lower Extremity Lymphoedema Screening Questionnaire (LaLSQ) was a study that included a cross-sectional survey sent to over 2,000 women who had undergone surgery for endometrial cancer. The study found that women who had undergone lymphadenectomy had a higher incidence of self-reported lymphoedema compared to those who had sentinel lymph node biopsy or hysterectomy alone.
- » The study also found that musculoskeletal complaints, such as back pain and arthritis, may overlap with symptoms of lymphoedema, complicating the interpretation of questionnaire results. The study highlights the need for prospective data collection to better understand the baseline risk of lymphoedema and its impact on quality of life.
- » The negative impact of self-reported lymphoedema on various domains of health-related quality of life includes physical, emotional and social functioning.
- » Women who met the physical activity recommendations as outlined by the World Health Organization (WHO) had better health-related quality of life and a lower risk of lymphoedema. Similarly, women who had a normal BMI reported a better quality of life. The study concluded that being physically active can reduce the odds of lymphoedema by 37%.
- » A need for further research to understand the impact of physical activity on lymphoedema risk, and to explore ways to prevent and manage lymphoedema in cancer survivors.



SCIENTIFIC SESSION: How to Improve the Sexual Health During and After Treatment of Gynaecological Cancers

(organized by ENGAGe and ENYGO)

Mapping Patient Needs: Insights and Actions From Sexual Health Survey in Gynaecologic Oncology

SPEAKER: Dr. Zoia Razumova (Karolinska Institutet, Sweden)

KEY TAKEAWAYS:

- Sexuality is a crucial part of quality of life regardless of age
- ENYGO-ENGAGe Survey on Sexual Health after Gynaecological Cancer: the objectives of the survey were to **1)** Assess sexual health care experiences of gynaecological cancer survivors in Europe **2)** Identify areas for improvement in post-treatment support.
- The survey included patient-driven questions that were developed with the help of psycho-oncologists and clinical psychologists; collected demographic data, pre-and post-cancer sexual health information and Female Sexual Function Index (FSFI); and was translated into 10 languages.
- Participants were women diagnosed with a range of cancers including ovarian, uterine, cervical, vulvar, vagina, and rare cancer.
- Some responses to the health survey include incidences of vaginal bleeding, vaginal dryness, vaginal shortening or tightening, pain, lack of sexual desire, mental distress during sexual activity and difficulties in reaching orgasm.
- Vaginal intercourse decreased, post-treatment masturbation decreased and sexual inactivity increased.
- Summary of findings from survey: **1)** there is a high prevalence of sexual dysfunction among survivors **2)** there is limited access to sexual health resources and counselling **3)** the clinical implication is that there is a need for routine sexual health assessments and discussions in post-treatment care.
- Gynaecological cancer survivors face significant sexual health challenges. Improved communication and tailored care are essential.

Empowering Care: The Mallow Flower Collaborative Approach to Sexual Health Education and Support

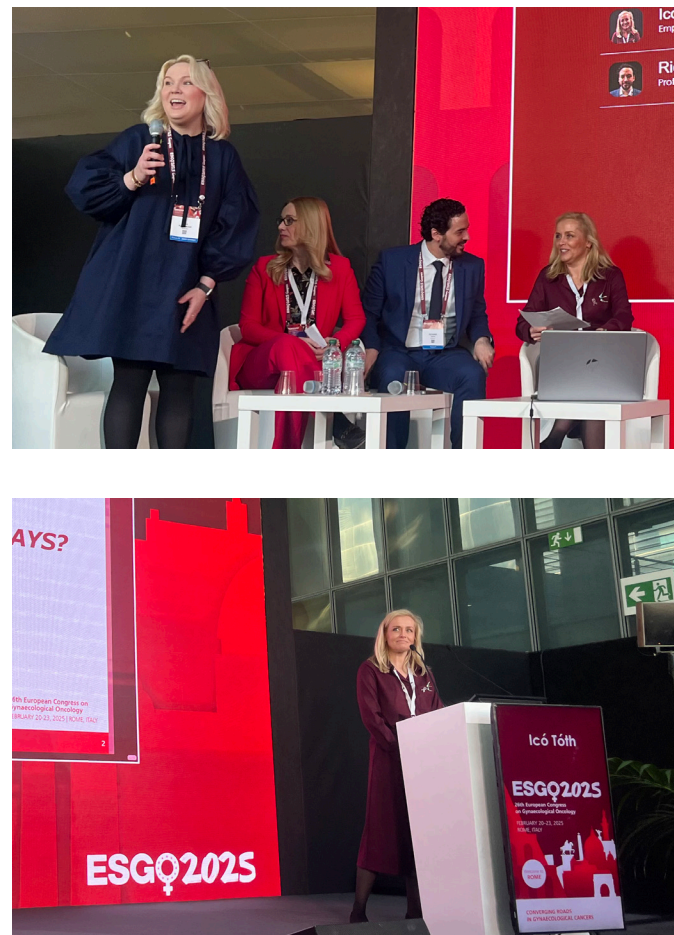
SPEAKER: Icó Tóth (Mallow Flower Foundation, Hungary)

KEY TAKEAWAYS:

- Research shows that up to 90% of gynaecological cancer survivors experience sexual dysfunction. Yet less than 30% receive any guidance or medical intervention.
- Key aspects of sexual health rehabilitation include: medical interventions that involve hormonal and non-hormonal treatments; physical therapy with pelvic floor exercises and vaginal dilators; psychological support that addresses body image and emotional barriers; partner communication guidance in navigating changes in intimacy.
- Patients assume sexual dysfunction is an inevitable side effect. Many give up on their intimate lives, unaware of available help. Anxiety, frustration and relationship difficulties follow.
- But sexual dysfunction is treatable. Addressing it improves patient satisfaction, mental health and relationships.
- Patients expect doctors to start the conversation. Oncologists play a key role in initiating this conversation.
- How the Mallow Flower Foundation is changing the narrative around sexual health education and support for gynaecological cancer patients: 1) translating ENGAGe brochures 2) Creating a sexual health subpage and providing reliable online resources (<https://szexualisegeszseg.malyvavirag.hu/>) 3) Organising a Sexual Health Conference.
- The patient-doctor process at the Mallow Flower Foundation: 1) the doctor assesses the condition of the vagina and gives a recommendation 2) the patient attends a consultation at Mallow Flower and discusses assistive devices such lubricants, penis rings, vaginal moisturizer and other options 3) psychological counselling is integrated into cancer care if needed 4) ongoing contact and communication with the patient.
- A European-level goal for the Mallow Flower Foundation is integrating 'sexual health training after gynaecological cancers' into existing medical programs, as well as collaborating with national medical societies to incorporate sexual health education into standard oncology and gynaecology curricula. Developing ESGO Guideline of sexual health after gynaecological cancers.
- National goal includes establishing a Sexual Health Outpatient clinic in hospitals to provide comprehensive care.

How to Improve the Sexual Health During and After Treatment of Gynaecological Cancers: The Patient's Pathway

SPEAKER: Kim Hulscher (Olijf, The Netherlands)



KEY TAKEAWAYS:

- The impact on patients' sexual health after gynaecological cancer treatment are multiple: mental, physical and social consequences.
- Mental: the transformation needed to become a sexual human being again, a lack of interest in sex, fear of HPV.
- Physical: pain, dryness, bleeding.
- Social: as a single woman (how to talk about it to new partners etc), or in a relationship (fear that partners will leave them if they can't have sex anymore); the effects are different.
- Doctors need to explain these possible consequences on a patient's sexual health when undergoing treatment. It needs to be repeated at every consult or in writing. Talk about it in general terms if it is difficult for the patient to talk about it. Acknowledge the pain of loss of sexual health, and refer patients to sexologists if necessary as well as to patient advocacy groups for support.

Protecting Vaginal Health: Practical Strategies after Gynaecological Cancer Treatment

SPEAKER: Richard Tóth (Semmelweis University, Hungary)

KEY TAKEAWAYS:

- Sexual health is a difficult topic to address both by doctors and patients.
- Lack of offering of a sexual health consultation after a cancer diagnosis and treatment. Addressing sexual health issues are more common, but not that typical. Younger people are more at ease in talking about their sexuality with doctors and family.
- Preventive measures are possible during surgery. These include the role of minimally invasive and nerve-sparing approaches and the awareness that combination of radiation therapy and surgery give the worst outcomes.
- Ovarian transposition is a way to maintain hormonal balance during radiation. There are various ways of preventing radiation toxicity to reduce the harm in radiation treatment.
- Described the process of a sexual health consultation after cancer diagnosis. This includes presentation of informational leaflets by the doctor to open the topic before asking some screening questions. Various treatments can then be proposed.
- Topics that can be addressed during sexual health counselling include: symptoms of menopause; vaginal dryness; problems with desire, libido or intimacy; painful sexual activities; problems with orgasm; and global symptoms of distress, anxiety and depression.
- A sexual health management plan should include: regularly identifying and evaluating symptoms; normalizing the symptoms; thinking holistically about the patient's physical, mental, emotional and social health; and continually reassessing symptoms during oncologic care.

5 ENGAGE - Ovarian Cancer Commitment

Don't Overlook - Wrap Up

SPEAKER: Linda Snoep (Olijf, The Netherlands)

KEY TAKEAWAYS:

- » The Ovarian Cancer Commitment (OCC) is a collaboration between ESGO, ENGAGe and AstraZeneca that aims to improve ovarian cancer patient experience and survival.
- » Olivia is a comprehensive digital resource created by OCC for ovarian cancer patients and their support networks. The platform contains information reviewed by medical experts to address the needs of ovarian cancer patients. It has been translated into multiple languages.
- » The "Don't Overlook" initiative aims to raise awareness about ovarian cancer symptoms by focusing on early diagnosis. The project includes a digital campaign, live and virtual workshops for primary care physicians and patient advocacy groups (PAGs).
- » The project emphasizes the need for centralized, specialized care for ovarian cancer patients, especially in countries without adequate healthcare systems. It also aims to help PAGs improve healthcare situations in their own countries.
- » The OCC organised a series of online touchpoint meetings that covered various topics. Recordings are available on the ENGAGe website.
- » Six PAGs presented their achievements, showcasing creative ways they improved healthcare in their countries.
- » Common challenges faced by PAGs include securing extra finances and finding additional support.
- » The role of PAGs in driving healthcare changes was highlighted and the importance of small changes in making a difference.



5 ENGAGE - Ovarian Cancer Commitment

Don't Overlook - Best Practice Sharing

SPEAKER: Małgorzata Kretowska (Eurydyki, Poland)



KEY TAKEAWAYS:

- » Eurydyki is a Polish association operating in Białystok near the Belarus border. The organization was founded in 2014 initially for ovarian cancer patients but expanded to support women with all types of cancer. The primary goals are to support women post-diagnosis and to educate on cancer prevention.
- » They organize annually an Ovarian Cancer Day walk in the city center to raise awareness about ovarian cancer, with press coverage and distribution of educational materials.
- » The "Don't Overlook" Campaign organized by the OCC faced local challenges such as the need to translate materials and hire a professional graphic designer for changes. Not all material was approved by local AstraZeneca so they had to be discarded.
- » "Plan Your Health" workshops were organised to educate women on the symptoms and prevention of gynaecological and breast cancers. Since 2018, they have held 28 workshops with over 1,000 participants.
- » The organization's efforts were noticed by local authorities and the Medical University of Białystok, leading to meetings with medical students.
- » Two workshops were organized in secondary schools for teenagers. The local government promised funding for future workshops for teenagers, seen as a positive step for the future.
- » The organization plans to continue its efforts in educating and supporting women and teenagers on cancer prevention and awareness.

5 ENGAGE - Ovarian Cancer Commitment

Presentation of Italian Version of Olivia

SPEAKER: Manuela Bignami (LOTO ONLUS, Italy), Marta Manna (LOTO ONLUS, Italy)



KEY TAKEAWAYS:

- » The Italian version of Olivia was introduced. Olivia is a digital patient support resource that aims at providing comprehensive information and support for women with ovarian cancer. It features high-quality and accessible information for patients, caregivers, and healthcare teams, with a focus on practical lifestyle advice.
- » It has interactive tools designed to support women at every stage of their ovarian cancer pathway, with features like dedicated sections for newly diagnosed patients and interactive pathways for those undergoing treatment.
- » The main purpose of Olivia is to serve as a trustworthy source of information and support for women with ovarian cancer at every step of their experience.
- » Olivia is now accessible via a dedicated URL and through the ESGO and ENGAGE websites, including the Italian version.

5 ENGAGE - Ovarian Cancer Commitment

Presentation of Every Two Minutes Initiative

SPEAKER: Nicoletta Cerana (ACTO, Italy), Elisabetta Ricotti (ACTO, Italy)

KEY TAKEAWAYS:

- » The campaign is an initiative by AstraZeneca in collaboration with patient associations and clinicians across Europe, including Italy. The campaign aims to promote advanced treatments and standard adoption in hospitals, addressing the lack of diagnostic competence and hospital certification.
- » The campaign emphasizes the need for certification of hospitals, as only three in Italy treat more than 100 patients surgically, while many others handle fewer cases.
- » The campaign started in 2003 and a policy paper was presented at a press conference, as well as at a closed round table with political representatives.
- » The campaign also includes a media campaign and a series of podcasts to raise awareness about ovarian cancer: its symptoms, treatments, genetic testing, and therapies.



6 ENGAGE best practice sharing

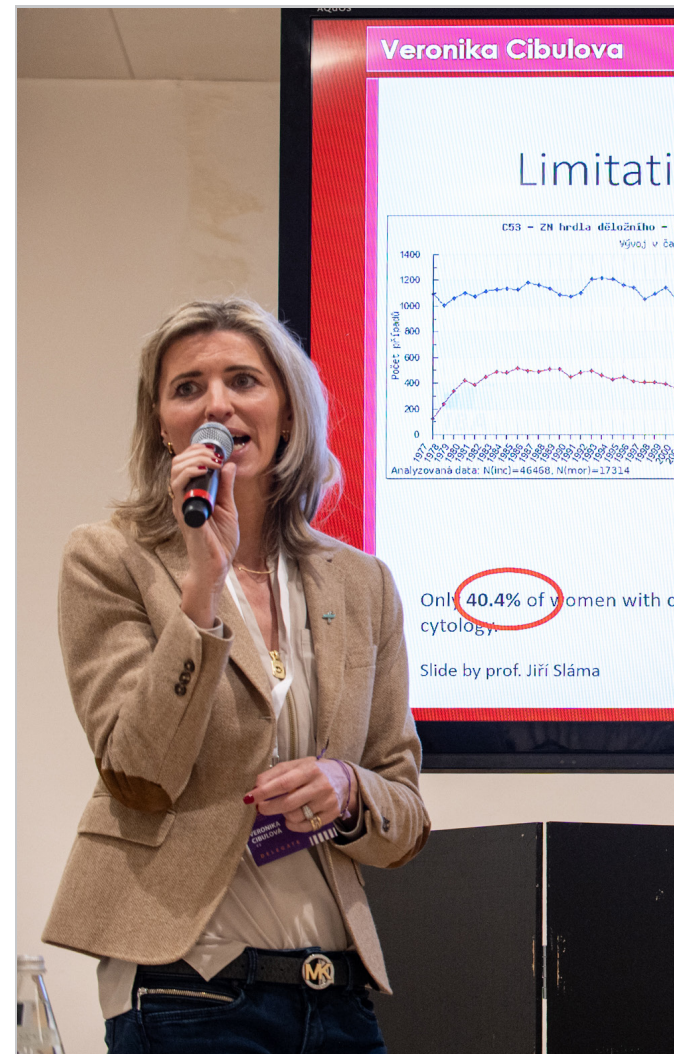


ASTRA project

SPEAKER: Veronika Cibulová (Veronica, Czech Republic)

KEY TAKEAWAYS:

- Project Astra in the Czech Republic aims to improve cervical cancer screening by increasing the efficiency and coverage of HPV DNA tests.
- Only 50% of women over 55 years old visit gynaecological offices. Despite a decrease in incidence, mortality rates remain unchanged.
- Studies from developed countries show that HPV DNA tests have higher sensitivity than cytology, with an average difference of 35%.
- The project is involved in ongoing efforts to raise awareness, including talks with stakeholders, the Ministry of Health and media campaigns.
- The project aims to catch the cohort of women who never show up at gynaecological offices by targeting them through GP offices. Nurses were trained to ask patients about their last HPV DNA test and offer self-sampling kits.
- The main obstacles faced in implementing the project include financial barriers for patients and time constraints for nurses. The lack of an option for home self-sampling is a significant issue, as samples must be done on-site. Despite efforts, only 25 samples were collected in one fiscal year.
- There is also a patient center in a major hospital in Prague, managed by Czech patient association Veronica, where patients receive comprehensive care and support, including educational materials and self-sampling options. The patient center provides a supportive environment for patients with suspicious tumors, including expert consultations and community support.
- There is a need for continued efforts to improve cervical cancer screening and awareness, and for innovative strategies and collaboration to address the challenges in the current system.



6 ENGAGE best practice sharing



Successful World Gynecologic Oncology Day Campaign

SPEAKER: Sharon O'Toole (Ovacare, Ireland)



KEY TAKEAWAYS:

- The Irish Network for Gynaecology comprises of over 30 groups across Ireland, from large cancer charities to small support groups. They coordinate awareness campaigns including the World Gynaecological Oncology (GO) Day.
- The first World GO Day began in 2019, with T-shirts and awareness desks at Daffodil centres. In 2020, buildings lit up in purple for World GO Day. In 2021, a podcast was created featuring patients and clinicians.
- The 2022 theme focused on physical activity and reducing the risk of endometrial cancer, leading to the creation of the Dipper Dance. Over 20 swims across Ireland were organized to raise awareness.
- In 2023, the campaign included a webinar featuring five patients from each of the five gynaecological cancers, and their stories were promoted in the media.
- The website <https://thisisgo.ie/> was created as a comprehensive resource for information on gynaecological cancers.
- The campaign has won several awards, including the Irish Healthcare Award for the best patient organization healthcare campaign.
- The campaign continues to evolve, with plans for future events and collaborations with other organizations. The courage and trust of patients who share their stories has been pivotal in their success of raising awareness.

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Social Media in 2025 - Tips and Tricks

SPEAKER: Beth Green (ENGAGE, the Czech Republic)



KEY TAKEAWAYS:

- » The importance of social media in patient advocacy, especially the use of platforms like Instagram, LinkedIn, and TikTok to raise awareness and engage with patients. Different platforms are recommended for different audiences.
- » The September campaign will focus on stigma in gynaecological cancers, and WGOD 2025 is a significant event which will utilise extensive social media.
- » Authentic content, particularly video, remains essential for engagement. However, it is important to note that the use of hashtags is no longer prioritized by platform algorithms. Overuse of hashtags can reduce the effectiveness of posts; therefore, any use should be limited, strategic, and focused on only the most relevant tags, such as #WorldGODay2025 or #GOAgainstStigma, when appropriate.
- » Patient stories shared on social media need to be done with the full consent and protection of the individuals involved. There is a need for alternative ways for patients to contribute.
- » The increasing value of long-form content, for example Tik Tok and Instagram's shift towards longer reels. The importance of posting regularly and frequently.
- » A crisis management plan is needed to address any potential issues or negative comments on the organization's social media channels. The importance of diffusing frustration and addressing immediate needs in a crisis situation.

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GO HILDAS

SPEAKER: Jacqueline Mills (GO HILDAS, UK)

KEY TAKEAWAYS:

- » GO HILDAS' mission is to promote fairness and equality in gynaecological cancer care, particularly in underserved communities. The group consists of diverse members, including patients, community leaders, doctors and researchers.
- » The group conducts workshops three to four times a year, with topics such as updates on initiatives, patient-led training, and working on ideas like the Power of Narrative.
- » The Power of Narrative aims to capture and use patient stories to change health behaviors, going beyond emotional responses to effect real change. The idea originated organically from conversations with patients and professionals. They collaborated with a local theater group, Women in Theater, to turn patient stories into monologues.
- » The first public pilot of the monologues was held at a Yemeni women-only community event. It included a Q&A panel with doctors and nurses on the theme of genetic testing.
- » The second series of monologues will focus on early diagnosis. They are actively seeking funding and completing community grants for this.
- » Performance of a Monologue: "Breaking the Chain" performed by the artistic director of the Power of Narrative. The monologue tells the story of a couple who face the challenge of a BRCA2 gene diagnosis, and who decide to start their family early to avoid passing on the gene. The monologue highlights the importance of genetic testing and early diagnosis, as well as the emotional impact of that diagnosis on the family.



7 ENGAGE - new projects I.



Quality of Life - Panel Discussion

SPEAKERS: Icó Tóth, Kim Hulscher, Bar Levy, Dr. Stephanie Christodoulidou, Dr. Zoia Razumova



- » The session on quality of life was divided into two parts: a panel discussion and round tables.
- » The panel members included Icó Tóth as a moderator; Kim Hulscher, cervical cancer survivor, co-chair of ENGAGE and social worker at the Salvation Army; Bar Levy, CEO of Ha Bait Shel Bar, an Israeli women's cancer association; Dr Stephanie Christodoulidou, head of psycho-social services at Europa Donna Cyprus and Dr Zoia Razumova, Gynaecologic Oncology specialist from the Karolinska Institute in Stockholm, Sweden.
- » The quality of life project emphasizes the importance of taking care of the soul, emotions and psychology. Each panel member was asked to reflect on different aspects of these.
- » Kim shared a moment of feeling seen and understood during her cancer journey, emphasizing the importance of community. She also recounted a practical experience where she felt unheard by her colleague, highlighting the challenges of being a cancer patient.
- » Stephanie discussed the pressure on patients to stay strong and the importance of emotional support.
- » Bar reflected on the impact of caring for her mother with cancer and the importance of self-care for caregivers.
- » Zoia discussed the emotional and professional challenges faced by doctors, emphasizing the importance of empathy. She highlighted the need for trust and collaboration between doctors and patients.
- » The panel members shared their reflections on some of the key emotions in a cancer pathway: empathy, fear and hope.

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Quality of Life - Roundtables



- » The roundtable discussion focused on improving communication between patients and medical teams, patients and caregivers, and patients and employers.
- » There is a need especially for empathy and clear communication between patients and medical teams.
- » Groups identified key challenges in discussing emotions, treatment choices, and support between patients and caregivers. Proposed solutions for better support included creating WhatsApp groups and Facebook channels for communication.
- » The importance of involving professionals like psychologists and providing diagnosis cards for families.

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World Gynecologic Oncology Day Plans for 2025

SPEAKER: Elisabetta Ricotti (ACTO, Italy)



- » WGOD 2025 will highlight stigma in gynaecologic cancers, including the long-term effects of treatment and their impact on fertility, motherhood, sexuality, and participation in the workplace and society.
- » The campaign will carry forward two central messages: #GOAgainstStigma and #GOFORPrevention, promoting HPV vaccination, risk awareness, and the importance of early detection through screening.
- » Engagement opportunities include subscribing to the ENGAGE newsletter, attending a dedicated webinar on April 15th at 18:00 CET, and using social media as the main platform for campaign outreach, with toolkits provided to local advocacy groups and partner organizations.

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Mentorship Programme

SPEAKERS: Bar Levy (Ha Bait Shel Bar, Israel), Kim Hulscher (Olijf, the Netherlands)



- » The aim of the mentorship program is to help advocacy groups enhance various aspects of their activity and to strengthen the collaboration between them, including best practice sharing and knowledge exchange.
- » Nine possible areas of focus: **1)** capacity building and volunteer management **2)** fundraising and grant applications **3)** policy and advocacy work **4)** public awareness and campaigns **5)** patient support services **6)** digital outreach, social media and media relations **7)** scientific and medical collaboration **8)** legal and ethical aspects of advocacy **9)** crisis management and resilience in advocacy.
- » A link to a survey will be sent out to all members for further ideas and suggestions. Then a call for applications will be put out for the program.
- » Depending on funding, the idea is for people to be able to travel from one country to another, to meet and see each other, not only at the annual Patient Advocacy Seminar.
- » Some participants suggested additional areas of focus like volunteer management and the importance of matching based on chemistry and expertise. Participants also discussed the potential for funding through programs like Erasmus and the need for personal support within the mentorship program.
- » There will be an online meeting organised dedicated to this project later this year.

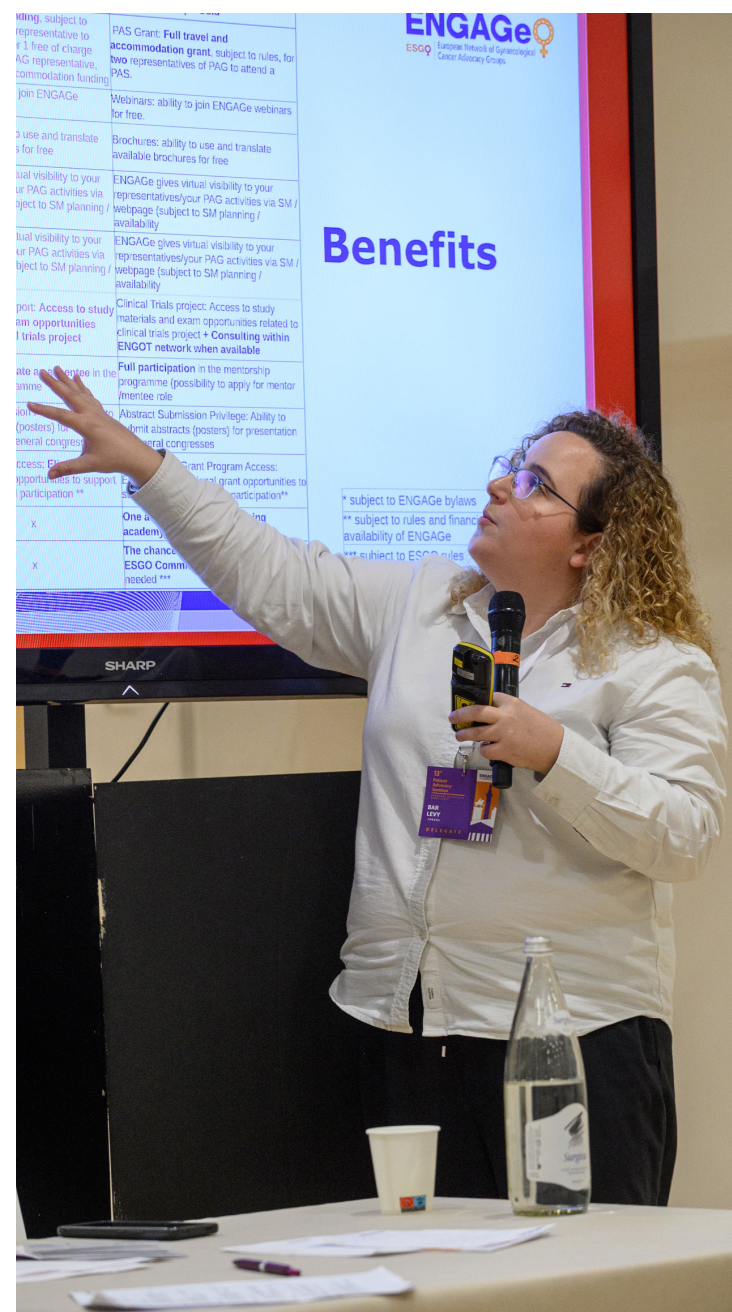
8 ENGAGe new projects II.

Membership Project Introduction

SPEAKER: Bar Levy (Ha Bait Shel Bar, Israel)

KEY TAKEAWAYS:

- The new membership project is focused on enhancing member engagement by providing more benefits to more active members.
- It uses a tiered membership programme that is comparable to a frequent flyer programme. Three tiers will be established, each offering specific benefits and responsibilities.
- Members are encouraged to participate in activities and receive a mix of financial and academic support along with a strong network and mentorship program.
- Members in the most prestigious tier of the programme will have access to additional PAS travel grants, opportunities to join various ESGO committees, and other exclusive benefits.
- An online meeting will be held to give all members the opportunity to present and discuss the newly established project in more detail.
- An emphasis on the fact that the programme, which is and ENGAGe project, is not meant to exclude anyone but to reward active members with additional benefits.
- In response to members' questions and discussion, it was clarified that, as this is a project-based initiative that does not affect the structure of ENGAGe, there is no requirement for it to be voted on at the General Assembly



8 ENGAGe new projects II.

Visibility and Campaigns

SPEAKER: Kim Hulscher (Olijf, the Netherlands)



- Various awareness campaigns are taking place not only on WGO in September, but also on other awareness days. These are done in collaboration with the various patient cancer committees, for example Cervical Cancer Awareness Week in January, World Ovarian Cancer Day in May, HPV day in March and Endometrial Cancer Awareness month in June.
- The campaigns focused on the myths around the cancers and countering it with videos from a doctor with the facts. Working with doctors on these campaigns have been really beneficial.
- Activities include social media campaigns, webinars and brochures. A new ENGAGe website will be in effect later this year, which will make it easier to use the tools and resources available.

8 ENGAGe new projects II.

ENGAGe Involvement in the ESGO Guidelines

SPEAKER: Icó Tóth (Mallow Flower Foundation, Hungary), Anne de Middelaer (Gynca's, Belgium)

KEY TAKEAWAYS:

- » ESGO guidelines are evidence-based recommendations for managing gynaecological cancers. It aims to improve outcomes and quality of life for patients, standardize best practices and ensure multidisciplinary collaboration between oncological specialists and patients.
- » The process of developing and submitting guideline proposals are passed through the multidisciplinary International Development Group as well as through external evaluation.
- » In 2024, two members were actively involved in the guidelines for endometrial cancer and pregnant women with gynaecological cancers.
- » The importance of patient input in the guidelines. The future will include more patient representative involvement in the guidelines and the potential for guidelines to be published in lay language was highlighted.

Evaluation Survey and Closing Remarks

SPEAKER: Kim Hulscher (Olijf, the Netherlands), Anna Fagotti (President, ESGO)

KEY TAKEAWAYS:

- » The President of ESGO, Anna Fagotti, gave the closing remarks. She emphasized the importance of patient advocacy groups in medical settings, often being the bridge between a doctor and patient.
- » The goal is not only to do science, but also to change practice. Working together in continued collaboration can change practice and improve outcomes.

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Contact ENGAGe

Webpage: <https://engage.esgo.org/>

Email: engage@esgo.org

Facebook: <https://www.facebook.com/engage.esgo>

Instagram: <https://www.instagram.com/engage.esgo/>

LinkedIn: <https://www.linkedin.com/company/esgo-engage>

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**14th Patient Advocacy Seminar,
February 24-26
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