ENGAGe

ESGO | European Network of Gynaecological Cancer Advocacy Groups

12th Patient Advocacy Seminar

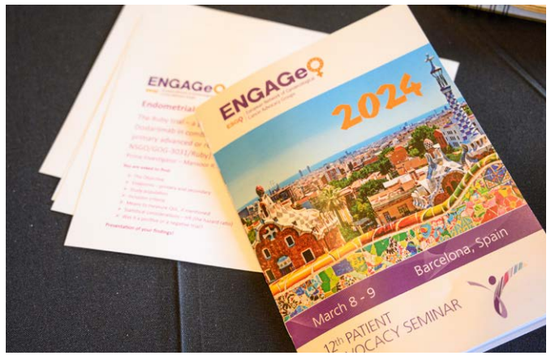
REPORT

March 8 – 9 / 2024

BARCELONA – SPAIN

THANK YOU for supporting the 12th ENGAGe Patient Advocacy Seminar

in Barcelona, Spain. We welcomed 56 active participants from 27 countries.



We welcomed participants from:

- Belgium
- Czech Republic
- Denmark
- France
- Germany
- Georgia
- Greece
- Hungary
- Italy
- Ireland
- Northern Ireland
- Sweden
- The Netherlands
- Turkey
- Finland
- Serbia
- Spain
- Israel
- North Macedonia
- Portugal
- Norway
- Poland
- Latvia
- Albania
- United Kingdom

Opening remarks

ESGO president, Anna Fagotti; President-Elect, Jalid Sehouli; ENGAGe Co-Chair, Kim Hulscher; and past Co-Chair, Petra Adamkova, opened the seminar. The event began on National Women's Day, so the group recognised their female patients and offered congratulations for ENGAGe's accomplishments at a European level.

SESSION 1 Special Lectures

PART 1: Braiding together evidence, equity, and advocacy for cervical cancer prevention

SPEAKER: Prof. Linda Eckert

Professor of Obstetrics and Gynaecology, Adjunct Professor – Global Health
University of Washington (USA)

KEY TAKEAWAYS:

- Cervical cancer is preventable, but factors like misinformation, missed screenings, and low vaccination rates have made enacting that prevention much more difficult.
- Gynaecological cancers also create intergenerational challenges, and working towards lessening deaths from those cancers offers a massive public health benefit.
- Normalising the language and „intangible" elements (like knowledge of treatment and access challenges) of gynaecological cancers can make those issues easier to approach and address.
- Combining data with stories and advocacy can lead to needed policy change, which we've seen throughout the US and UK in the last 30 years, but guidelines alone don't have enough impact.
- Seeking partners and community in advocacy is critical to overcoming issues of stigma, patriarchy, and equity in the field of women's health.

SESSION 1

Special Lectures

PART 2: Implementation of HPV self-collection in cervical screening

SPEAKER: Dr. Matejka Rebolj
Wolfson Institute of Population Health, Queen Mary University of London (United Kingdom)

KEY TAKEAWAYS:

- Cervical cancer is largely caused by the human papillomavirus (HPV). It's extremely common – in fact, HPV16/18 causes about 70% of all cervical cancer cases.
- Cervical cancer can be prevented by a combination of HPV vaccination and effective screening.
- Though prevention is highly effective, cervical cancer hasn't been eradicated because not all women and girls are being vaccinated or screened (due in part to a combination of socioeconomic issues, lack of access, cultural factors, etc.).
- To combat this, HPV tests can serve as better cervical cancer screening than using cytology as the "primary" test. These HPV self-collection options have proven to be as good, or better than, a clinician sample.
- But, does HPV sampling work in routine health care? Approaches in early adapter countries include offering HPV sampling only to under-screened women and as a choice to all, with mixed results (and unclear messaging and system requirements emerging as obvious obstacles).
- Though self-collection is likely a better test than cytology with the potential to detect more cancers, there is still uncertainty surrounding test sensitivity.
- Because effective implementation is complex, and the steps only work if they're all completed, further communication and mitigation are critical to designing a service that women will choose to use and complete.

SESSION 2

Clinical Trials Education Workshop

WORKSHOP PART 1: How to read and understand a clinical trial protocol

SPEAKER: Birthe Lemley
Member of KIU (Women with Gynaecological Cancer, Denmark)
and Head of ENGAGe Clinical Trial working group

The clinical trials project, administered by ENGAGe and ENGOT, is an ongoing effort to involve both patients and patient advocates in clinical trials to incorporate patient perspective into their final design.

The program's facilitators are: Professor Jalid Sehouli, co-chair of ESGO ENGAGe on behalf of ENGOT (Charite Universitatsmedizin, Berlin); Birthe Lemley, a patient and EEG member of ESGO ENGAGe; and Petra Adamkova, past co-chair of ESGO ENGAGe and patient advocate.

KEY TAKEAWAYS:

- The Clinical Trials Project began three-and-a-half years ago, and includes 21 patients as well as patient advocates. The initiative has also produced three study books, which summarise a series of educational webinars presented by ENGOT representatives.
- The purpose of clinical trials is to answer a primary question or hypothesis posed by a study. This question or hypothesis is called the Objective. The study Endpoints are specific variables chosen to evaluate this objective.
- A randomised clinical trial has three "phases:" 1. A small number of patients (20-60) are tested to evaluate drug safety and maximum dosage. 2. Focuses on drug efficacy. 3. Focuses on comparing the standard of care with study drugs (which also includes a larger patient pool, usually about 200-2000).
- We have to take care to get the same number of patients into each arm of the trial; otherwise, the results of the trial won't be reliable.
- Defining key inclusion and exclusion (aka, eligibility) criteria – or pre-existing conditions that could involve or eliminate patients from the study - is also critical to correctly interpreting clinical trial results, and therefore, the future of the drug's development.
- Only studies with a Hazard Ratio (HR), which evaluates risk of complications, below 1 are positive trials, and therefore offer patient benefit.

SESSION
2 Clinical Trials Education Workshop

WORKSHOP PART 2: CT statistical endpoints and their interpretation

SPEAKER: **Prof. Jonathan Ledermann**
UCL Cancer Institute, University College London (United Kingdom)

KEY TAKEAWAYS:

- A clinical trial is a scientific evaluation of a medical intervention to determine whether a treatment is effective based on the outcome in a specific study population.
- We need clinical trials because they're important for new treatments for patients.
- There are three phases of clinical trials: Phase 1: is the drug useable and safe? Are there signs of clinical activity? Phase 2: Expands the treatment in a selected group of patients, which is often randomised. Phase 3: A trial that looks at whether the new treatment (currently available) is better than the ones you're trying. Phase 3 trials are predominantly used for licensing of drugs.
- Progression-free survival (PFS) is often used as the endpoint of many clinical trials because: it's a shorter endpoint than overall survival; you need fewer patients; and it's a cheaper trial to run.
- An improvement in PFS doesn't always mean overall survival benefit, as patients can cross over to another group in the middle of the trial or be affected by later treatments.
- Patients can also be lost to follow-up or experience a negative effect of a PARP-inhibitor, both of which can affect trial results.
- PFS2 (the period just after PFS and prior to any additional treatments) can be a good indicator of the trial's actual outcome.
- Not all trials are randomised when there's a very strong biomarker associated with the result.

WORKSHOP PART 3:
New clinical trials in OC, CC, and EC

Participants were divided into three groups to analyse and present findings of three example clinical trials.

SESSION
3 Treatment Innovations

PART 1: New FIGO staging for endometrial cancer ("the evolution of the revolution")

SPEAKER: **Prof. Nicole Concin**
Department of Gynaecology and Gynaecological Oncology,
Medical University of Vienna (Austria)

KEY TAKEAWAYS:

- Endometrial carcinoma can be classified into four distinct diseases via molecular biology, and each type has a different prognosis.
- The new 2023 FIGO system critically integrates molecular markers into prognostic groups in international guidelines, which is a paradigm shift from the previous structure.
- FIGO is a prognostic classification used all around the globe and is based on the anatomical spread of the cancer. To integrate tumor biology into this system is a huge step!
- The main goal of the new system – and for patients – is for higher prognostic precision.
- If it's known, the molecular subtype changes the FIGO stage in two specific situations pertaining to early disease and should be recorded in all other circumstances.
- Higher prognostic precision has been demonstrated in five validation studies (to date).
- New FIGO staging also allows for new treatment plans.
- Integrating molecular classification into international medical guidelines and FIGO leverages this approach to benefit patients with endometrial cancer.

SESSION
3 Treatment Innovations

PART 2: A cinderella story

SPEAKER: **Dr. Mansoor Raza Mirza, MD**
Chief Oncologist, Copenhagen University Hospital (Denmark)
and Medical Director of Nordic Society of of Gynaecological Oncology (NSGO)

KEY TAKEAWAYS:

- For the last decade, we didn't have many other therapies other than hormonal and chemotherapy for endometrial cancers, and chemotherapy isn't as effective as patients need it to be.
- Endometrial cancer is susceptible to immune therapy.
- Immune checkpoint inhibitor therapy has far-reaching efficacy of treatment.
- By understanding the biomolecular nature of this disease, physicians can make real progress in treatment!
- Scientists can also cater their test patient populations based on desired disease alterations/mutations in order to find the best treatment for that cancer.
- Antibody drug conjugates will likely further the progress of patients' output moving forward.

SESSION
3 Treatment Innovations

PART 3: Treatment innovations in ovarian cancer

SPEAKER: **Dr. Antonio Gonzalez-Martin, MD PhD**
Cancer Center Clinica Universidad de Navarra (Spain)

KEY TAKEAWAYS:

- Ovarian cancer is the number one cause of death in terms of gynaecological cancers, because upwards of 80% of diagnoses are advanced.
- There are at least five different subtypes of epithelial ovarian cancers. The most frequent is High-Grade Serous Ovarian Cancer, which accounts for about 70% of all cases.
- When patients with advanced ovarian cancers are treated, four general options are considered: surgery, molecular diagnostic, chemotherapy +/- Bevacizumab, and PARP-inhibitor maintenance. But, there's still some doubt regarding best sequence (e.g., deciding whether to use surgery or chemotherapy first) if the patient is a good candidate for surgery and could have all cancer removed.
- The NACT-ISD platform is a platform for translational research, because scientists have tumor tissue before and after chemo.
- PARP-inhibitors are an effective maintenance in front-line treatments of patients with BRCA mutations, but physicians are also working on new protein inhibitors to achieve that goal (i.e., to stop tumor cells from damaging DNA).
- There's still some question surrounding the efficacy of combining checkpoint inhibitors with other ovarian cancer treatments.
- New and successful drugs with manageable side effects, like antibody drug conjugate Mirvetuximab, are on the rise in Europe.

SESSION 3 Treatment Innovations

PART 4: Treatment innovations in cervical cancer

SPEAKER: **Prof. David Cibula**
Charles University, Prague (Czech Republic)

KEY TAKEAWAYS:

- New innovations allow for de-escalation of radical surgical treatment in early stages of cervical cancer, including: only conization in very small tumors; the removal of sentinel lymph nodes instead of pelvic lymphadenectomy; and simple hysterectomy instead of radical hysterectomy in very small tumors.
- Fertility-sparing treatments in cervical cancer therapies are now the standard, instead of an industry exception.
- There have been significant improvements in radiotherapy, which improves quality of life as well as oncological outcome – especially for large tumors.
- Immunotherapy is now available for advanced and recurrent tumors and improves prognosis dramatically. Immunotherapy also works in combination with chemoradiation.
- Moving forward, more accurate detection of metastases through AI is anticipated, as well as new prognostic markers, including radiomics and tumor microenvironment. The field is also looking forward to active immunotherapy (vaccines) and antibody drug conjugates.

SESSION 4 Best Practice Sharing 1

How to collaborate with doctors

SPEAKERS: **Bar Levy, Prof. Zvi Vaknin**

Bar Levy, of HaBait Shel Bar (Israel's Women's Cancer Association) and Professor Zvi Vaknin (Assaf Hrof Medical Center) teamed up to discuss how Patient Advocate Groups can collaborate with doctors in Israel and beyond.

Key points included: the importance of collaboration in patient care; that regulators should have united purpose to leverage for patient care; and working towards recognising medical professionals' "dark spots" (or specific lacks in awareness).

SESSION 5 MEDICAL EDUCATION

PART 1: Preventative operations for BRCA and Lynch mutation

SPEAKER: **Prof. Ranjit Manchanda**
Professor of Gynaecological Oncology, Wolfson Institute of Population Health, Queen Mary University of London (United Kingdom)

KEY TAKEAWAYS:

- **Though ovarian cancers, in particular, are known to have poor survival prognosis, they are potentially preventable - especially if we can identify high-risk patients, like those who carry BRCA and Lynch Syndrome mutations.**
- **Guidelines today recommend testing for known cancer-causing gene mutations.**
- **A whopping 50% of annual women's cancer rates are breast, ovarian, bowel or endometrial; with the number of instances and deaths slated to increase significantly over the next 20 years.**
- **About 20% of ovarian cancers and one-third of womb cancers are linked to common gene mutations, like BRCA and Lynch Syndrome.**

BRCA:

- Removal of tubes and ovaries is the most effective strategy for ovarian cancer prevention, yielding upwards of 80% reduction in ovarian cancer incidences.
- It's important to consider such variables as patient age, fertility, what the gene is, and implications of menopause before performing preventative surgery (including both BRCA and Lynch Syndrome mutations).
- SEEFIM special pathology is essential for RRSO, as it detects early cancer or pre-cancer in one-in-five individuals, which can then be treated.
- Whether or not to perform a hysterectomy as a means of ovarian cancer prevention is an area that requires more research.
- HRT can be beneficial for women up to age 51 for premenopausal RRSO, unless there are other contra-indications.
- Early salpingectomy remains best undertaken in research studies.

Lynch Syndrome:

- Removal of the uterus, tubes, and ovaries is effective for preventing both womb and tubo-ovarian cancers women with Lynch Syndrome.
- Preventative surgery for Lynch Syndrome carriers makes most sense for women aged 40 and over, is usually minimally-invasive, and provides almost full protection from developing cancer.

SESSION 5 MEDICAL EDUCATION

PART 2: Biopsies and liquid biopsies

SPEAKER: Prof. Murat Gultekin, MD
ESGO Prevention Committee Co-Chair (Turkey)

KEY TAKEAWAYS:

- Biopsies are critical to confirming types of gynaecological cancers.
- The punch biopsy, or taking a "small bite," is the most common method of sampling vulvar tissue.
- Possible cervical biopsy methods include: cervical (e.g. "pap") smear, colposcopies – these often follow an abnormal pap-smear, cervical punch biopsies, Endocervical Curettage (ECC) for when the lesions extend into the canal, LEEP/LLETZ procedures (which apply electricity to excise a lesion), and conization for larger swaths of tissue.
- Endometrial biopsy methods include: Dilation and Curettage (which is standard), Karman or Pipelle Aspiration Biopsy, and Hysteroscopy (e.g., cameras).
- Though ovarian biopsies aren't common – mostly for inoperable patients – laparoscopy is standard, though needle biopsies are gaining popularity.
- The future is liquid biopsies! These involve evaluating blood with tumor DNA.
- Liquid biopsy can give us the possibility for early diagnosis, as well as offer information on possible cancer mutation and treatment adjustment.
- The new ERA-PerMED CytoMark Project (partners include: Spain, Luxembourg, Estonia, and Turkey) aims to further a personalised and less-invasive tool for diagnosing endometrial cancer by evaluating uterine aspirates.

SESSION 5 MEDICAL EDUCATION

PART 3: The role of the pathologist in the diagnosis of gynaecological cancer

SPEAKER: Prof. Xavier Matias-Guiu
President of the International Society of Gynaecological Pathologists;
Chairman of Pathology – Hospital U de Bellvitge and Hospital U Arnau de Vilanova,
Universities of Barcelona and Lleida (Spain)

KEY TAKEAWAYS:

- Pathologists are medical doctors that make diagnoses of diseases based on microscopic examination of tissue samples or cells and perform tests on those samples. As such, they're largely responsible for making formal cancer diagnoses and determining the type of cancer a patient has.
- Pathology reports contain diagnoses based on molecular analysis, and are standardised following international consensus (for example, those of the ICCR).
- Tissue handling is critical to accurate pathology, as time between resection of tissue samples, the amount of tissue a biopsy contains, and its informative area are critical to making correct diagnoses.
- If and when microscopic images are unclear, pathologic diagnoses can require more time or more tumor tissue, which allows for detection of proteins or DNA/RNA sequences (some of which are called biomarkers and indicate distinct types of tumors).
- Digital pathology offers opportunities in nuanced tissue distinction, but comes with challenges.
- The patient (history, reports, etc.) is always at the center of pathology practice.
- Molecular analysis, in cases of HRD or determining cell type, must be integrated into pathology practice to ensure accurate diagnoses and treatment.

SESSION

5 MEDICAL EDUCATION

PART 4: History of surgeries in cervical cancer

SPEAKER: **Dr. Henrik Falconer**
Karolinska University Hospital (Sweden)

KEY TAKEAWAYS:

- Cervical cancer treatments have seen significant advancements in the past century. Rates of cervical cancer are dropping, and medical institutions are detecting it much earlier, thanks in large part, to improved screening and vaccination.
- Ernst Wertheim performed the first radical abdominal hysterectomy for cervical cancer in the late 1890's (which later became known as Wertheim's hysterectomy), and was responsible for the critical discovery that a wide excision is necessary to remove cancer that's spread outside the uterus.
- Wertheim paved the way for surgical overhaul in areas of screening, diagnostics and imaging, and improved radiotherapy.
- But, classification of the radical hysterectomy is difficult; and as cervical cancer is becoming less common, surgeries are becoming less radical – including options like fertility and nerve-sparing surgeries (in particular the radical trachelectomy, which was developed in the 1990's).
- Minimally invasive surgeries are also on the rise, like video laparoscopy in the 1980's and robot-assisted surgery in the early '00's, though clinical trials are still taking place.

SESSION

6 PATIENT ADVOCACY AND POLICY CHANGES

PART 1: Policy change 101

SPEAKER: **Bar Levy**
CEO of HaBait Shel Bar
- Israel's Women's Cancer Association (Israel)

KEY TAKEAWAYS:

- Everyone's always talking about policy change, but it's hard!
- Policies are plans of action that serve as written or unwritten guidelines that groups of people (like governments, communities, institutions, and individuals) use to direct their response to certain issues or situations.
- The best policy changes start with patients! It's our responsibility, as patient advocates, to help guide them towards that change.
- To start that change, it's important to think about what policies and adjustments your home country needs. Begin by identifying your stakeholders (e.g., parliament, bureaucracy, press, etc.) and create connections! Next, identify what change is needed – be sure it's backed by data! – and identify any disconnect between what's needed and what's available. From there, express your opinion: write papers, create proposals, participate in committees – and be sure to do it in person!
- Promoting shared goals is important for change.
- Data is critical! In a 2023 cervical cancer patient study in Israel, only 8% of respondents were HPV vaccinated (and 19% didn't know about the link of HPV to cervical cancer), and a huge majority left their doctor's offices feeling like they needed more information.
- As an example, the Pembro-Lenva treatment phase received funding by February, 2023 after following these steps, laid out by the START process. The group's short-term goal is to encourage catch-up vaccines and change vaccination in a way that will lead to their overall increase. The long--term goal is elimination of cancer-causing HPV.

SESSION 7 GUIDELINES

PART 1: PRE helps RE – guidelines of prehabilitation

SPEAKER: Prof. Christina Fotopoulou
Professor of Gynaecological Cancer Surgery, Faculty of Medicine,
Imperial College, London (United Kingdom)

KEY TAKEAWAYS:

- Like a marathon, surgery is its own journey – and preparation is key for success!
- Preparing the body for surgery contributes to a successful recovery and reduces the risk of complications.
- Peri-operative care guidelines, updated in 2023, now include implementation for prehabilitative care.
- Though prospective data is still incomplete, the concept of prehabilitation was so strong that experts have concluded that patients will clinically benefit from it.
- We're defining "prehabilitation" as the continuum of care that takes place between a cancer diagnosis and the beginning of treatment. It could include physical or psychological assessments to establish a patient's baseline condition, and targets existing impairments with the aim of optimising a patient's overall health prior to surgery, rather than adjusting for reactive treatment.
- Though there's no widely-accepted baseline definition for prehabilitation, a multi-pronged approach is gaining popularity. It includes: aerobic and resistance exercise; targeted functional exercises to minimise impairments; as well as dietary and psychological intervention to mitigate potential complications and support overall health.

SESSION 7 GUIDELINES

PART 2: Patient-related key points from ESGO Guidelines

SPEAKER: Prof. Ignacio Zapardiel, MD, PhD
Chief Gynaecologic Oncology Unit, Associate Professor UAM University,
ESGO Council Member, La Paz University Hospital (Spain)

KEY TAKEAWAYS:

- Most ESGO guidelines are developed by experts, for expert use, even in the case of guidelines created to improve patient management. Because of this, there's not much patient participation in these guidelines. It's time to change that!
- For example, 46 participants from 15 countries across Europe, Asia, and the US contributed to the ESGO-ESMO-ESP consensus conference, which discussed recommendation and treatment for specific ovarian cancer groups – but there was no external review, no patient integration in working groups, and no evaluation of the consensus by patient groups.
- In an updated 2023 study of management guidelines for patients with cervical cancer, ESGO/ESTRO/ESP added external evaluation and integration of international reviewers' comments to their guideline development process.
- Overall, the consensus recommended that cervical cancer patients should be carefully advised on the risks and benefits involved in their possible treatment plans. Example groups included the surgical management of tumors of all sizes, treatment of recurrent disease, cervical cancer and pregnancy, and follow-up procedures.
- Moving forward, more patient involvement and input in devising cancer treatment plans is highly recommended.

SESSION 7 GUIDELINES

PART 3: How can patients be involved in guidelines?

SPEAKER: **Yael Biegun**
Member of HaBait Shel Bar - Israel's Women's Cancer Association (Israel)

KEY TAKEAWAYS:

- There's a gap between how medical providers understand the effects of having cancer and its treatment and the patient's experience.
- Cancer treatment affects many aspects of life for the patient, including: parenthood, friends and family, sexuality, work, economic stability, and general well-being.
- ENGAGe's role is to help fill in the gaps by offering psychological resources, community, and media for those experiencing cancer, as well as connective outlets for conversation and support.
- To best support other women experiencing gynaecological cancer, patient guidelines need to be implemented in each aspect of life. That's why ENGAGe exists, and this is the organisation's primary role.

SESSION 8 BEST PRACTICE SHARING 2

PART 1: Empowering women's health: understanding ovarian and cervical cancers

SPEAKER: **Donjeta Zeqa**
President of Europa Donna Albania

KEY TAKEAWAYS:

- Europa Donna Albania (EDA) is part of breast cancer coalition, Europa Donna, which now includes 48 member countries. Europa Donna Albania was founded in 2008.
- Ovarian cancer is often more prevalent in women who have had breast cancer, making OC screenings especially important in this population. Doctors and patients, especially in Albania, should be more aware of this.
- Though almost 80-percent of OC diagnoses are in post-menopausal women, it's important for diagnoses to be individual.
- EDA has raised awareness about cervical and ovarian cancer through initiatives like peaceful protests and media outreach.
- EDA is the brains behind the "Cancer Care Albania" initiative, which is also focused on other cancers. Its implementation also marks the first time that all stakeholders were gathered in one place to discuss cancer and oncology. Primary topics included funding for diagnosis and treatment, as well as the provision of essential drugs aligned with international protocols.

SESSION

8 BEST PRACTICE SHARING 2

PART 2: Let's change direction - cambiamo rotta

SPEAKER: **Nicoletta Cerana**
President, ACTO Italia, Alleanza Contro il Tumore Ovarico (Italy)

KEY TAKEAWAYS:

- Let's Change Direction (Cambiamo Rotta) is an advocacy campaign for the unmet needs of Italian women affected by ovarian cancer.
- New ovarian cancer therapies have increased patient survival rates, but have also created new patient needs. The advocacy project has three main goals: 1. To identify new unmet needs of patients 2. To draw the attention of national health institutions and the general public to these needs, and 3. To open public discussion for new care pathways.
- To identify new unmet needs, the organisation launched a quantitative survey in June and July 2023 to 109 patients in 13 hospitals. According to that survey, primary needs include: disease and onco-fertility care awareness, information about specialised care and diagnostic tests; as well as support for patient relationship with sexuality and access of information for working women.
- To draw attention towards these unmet needs, CR collected this data in a white paper," which they've called Let's Change Direction. It's a 94-page book that reflects the campaign's qualitative and quantitative data. It also includes 18 comments from clinicians and 9 editorial contributions, and was signed by prominent opinion leaders.
- The group has also published a 2.0 Manifesto, which summarises (in 7 points) the major needs of patients.
- Both publications were launched at a national event in Rome through the Ministry of Health, including nearly 700 participants and a 16.5 million-person readership.
- The project has two main values: it targets medical professionals and institutions to provide concrete answers to national regional needs, and also guides ACTO Italia towards the new direction that services and support activities for patients should take.

SESSION

8 BEST PRACTICE SHARING 2

PART 3: Esperanza and the making of videos

SPEAKER: **Sonia Rademaekers**
Founder *Esperanza* (Belgium)

KEY TAKEAWAYS:

- Esperanza is a patient organisation in Flanders, Belgium. It's a small organisation with an extensive social media presence and hosts many activities and symposia.
- Esperanza's videos promote their own events, as well as patient experience videos, and offer information on health topics from doctors and other health professionals.

PART 4: A social farm for integrated oncology (Il Ranch delle Donne, ACTO Piemonte)

SPEAKER: **Elisa Picardo / Marco Mitidieri**
President of Acto Piemonte (Italy)

KEY TAKEAWAYS:

- This ranch in Piemonte has a focus on oncological and traumatic recovery in a context that celebrates sensory experiences through the earth, water, lights, sounds, etc., and it's open to all.
- The farm has two main objectives: to study and facilitate cancer treatments and recovery through integrated therapies, and to educate oncologists, patients, and practitioners on these therapies.
- The farm offers three organised activities per week, and sees about 500 patients and more than 1000 caregivers and supports per year.

SESSION

9 ENGAGE PROJECTS AND FEEDBACK SESSION

PART 1: 2023 and 2024 ENGAGe projects

SPEAKER: **Kim Hulscher**
ENGAGe Co-Chair, et. al.

KEY TAKEAWAYS:

- ENGAGe welcomes a second new Co-Chair, Prof. Phillippe Morice (France).
- ENGAGe introduces ENGAGe Executive Group (EEG) members: Petra Adamkova, Anne de Middelaer, Birthe Lemley, Bar Levy, Icó Tóth, Murat Gultekin, Zoia Razumova, Jalid Sehouli, and Houssein El Hajj as a host member.
- The following projects will be carried out by ENGAGe members: Clinical Trials (Birthe Lemley), Quality of Life (QoL) Series (Icó Tóth), TEENs (Zoia Razumova), Membership (Bar Levy), Webinars (Anne de Middelaer), World GO Day (Elisabetta Ricotti/Petra Adamkova from EEG), and PAS (Kim Hulscher).
- Notable updates for ENGAGe members include: a renewed connection to the EEG and monthly EEG summaries for ENGAGe members; catering participation towards individual strengths and interest; and increased collaboration between patient advocacy groups.
- ENGAGe also plans to reestablish gynaecological cancer committees - each devoted to endometrial, cervical, ovarian, and rare cancers – to be the advisory bodies in different topics and projects.
- In the ENGAGe Office, Eva Streglova serves as Director, while Zuzana Santamaria and Radka Skranka Hlavackova are Project Managers.

ACKNOWLEDGEMENTS

We are grateful to our sponsors for their support!

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Save the date for the 2025
13th Patient Advocacy Seminar, February 20-23 in Rome!

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