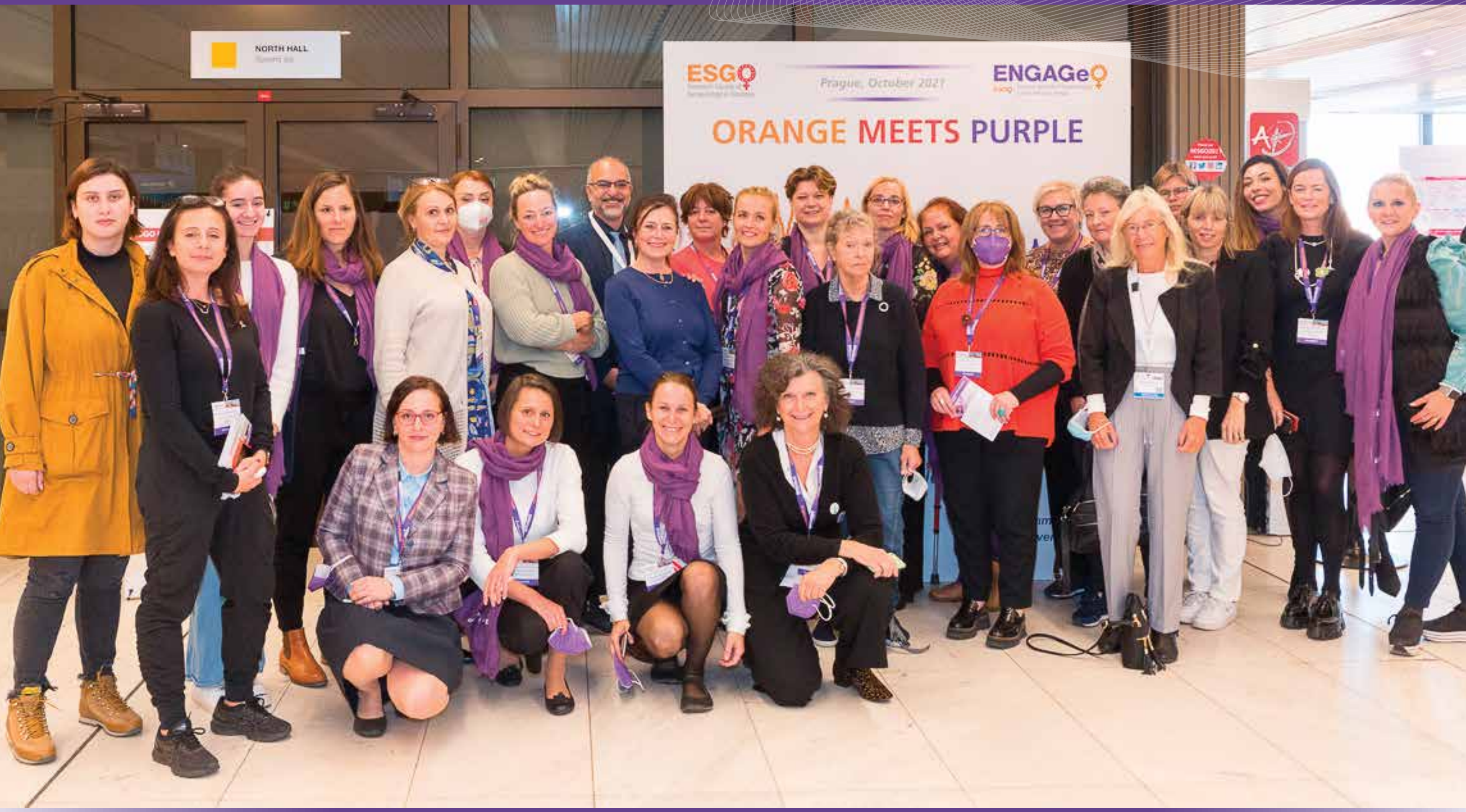
# 2021

# Patient Advocacy Seminar Report



# ESGO ENGAGe Patient Advocacy Seminar in Gynaecological Cancers

## October 22–24, 2021

Held during the European Society of Gynaecological Oncology Congress in Prague, Czech Republic

ENGAGe
ESGO | European Network of Gynaecological Cancer Advocacy Groups

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# PROGRAMME

## Venue: Prague Congress Centre, 5. května 1640/65, Praha 4-Nusle, Czech Republic

| DAY 1: Friday, October 22nd | | | |
|---|---|---|---|
| *Time* | *Lecture name* | *Speakers* | |
| **Chairs: Icó Tóth (HU), Murat Gultekin (TR)** | | | |
| 10:00 - 12:00 | EEG Meeting | | |
| ***12:30*** | ***Beginning of the PAS*** | | Club H |
| 12:30 - 12:40 | ***Welcome word*** | *ESGO President + ENGAGe Co-Chairs* | Club H |
| 12:40 - 13:10 | Stigma that we have to break down together- building a new communication on HPV (risk for wmn and men) | *Murat Gultekin (TR), Icó Tóth (HU)* | Club H |
| 13:10 - 13:30 | Mapping European Policies on Cervical Cancer Prevention | *Marina Davidashvili (EPF)* | Club H |
| ***13:30-13:35*** | ***Quick yoga*** | | Club H |
| 13:35 - 14:05 | New treatments in gyn fields-Where is our field heading?<br>How relevant?<br>How much hope can give us? | *Mansoor Raza Mirza (DK)* | Club H |
| 14:05 - 14:35 | Genetic Tests for Gyn Cancers:<br>To whom and which tests? | *Ranjit Manchanda (GB)* | Club H |
| **14:35 - 15:00** | ***Coffee break*** | | |
| **Chair: Esra Urkmez (US)** | | | |
| 15:00 - 15:40 | Personalised Health Care | *Sandro Pignata (IT)* | Club H |
| 15:40 - 16:00 | How can patients gain enough knowledge to have an influence on the design of a clinical trial? | *Birthe Lemley (DK)* | Club H |
| ***16:00-16:30*** | ***Fresh air together*** | | |
| **Chairs: Petra Adámková (CZ), Kamil Zalewski (PL)** | | | |
| 16:30 - 16:45 | How to live with ovarian cancer as a chronic disease? | *1 doctor: Jalid Sehouli*<br>*+ 1 patient: Andrea Krull (DE)* | Club H |
| 16:45 - 16:50 | TEENs in ENGAGe- new generation in HPV | *Selin Bayrakli (US)* | Club H |
| 16:50 - 17:20 | Palliative care: toward meeting the needs of patients and their families. | *Kateřina Rusinová (CZ)* | Club H |
| **17:20** | ***End of the meeting*** | | |
| ***18:30*** | ***Together Dinner for ENGAGe Members*** | | Bastion Restaurant |

| DAY 2: Saturday, October 23rd | | | |
|---|---|---|---|
| *Time* | *Lecture name* | *Speakers* | |
| **Chairs: Jalid Sehouli (DE), Maria Papageorgiou (GR)** | | | |
| 8:30 | Opening Day 2 | | Club H |
| 8:30 - 8:45 | Endometrial cancer treatment | *Nicoletta Colombo (IT)* | Club H |
| 8:45 - 9:15 | Vaginal flora | *Maria Kyrgiou (GB)* | Club H |
| 9:15 - 9:30 | What happens with the body after cc cancer- focus on triple loss functions' (defecation, urination, sex) | *1 doctor: Carien Creutzberg<br>+ 1 patient: Kim Hulscher (NL)* | Club H |
| ***9:30 - 10:00*** | ***Coffee break*** | | |
| **Chairs: Zoia Razumova (SE), Kim Hulscher (NL)** | | | |
| 10:00 - 11:00 | Sexual Health workshop | *Kathrin Kirchheiner (AT)* | Club H |
| 11:00 - 11:15 | Diagnosis curator for patients getting their cancer diagnosis | *Eva-Maria Strömsholm (FI)* | Club H |
| 11:15 - 11:45 | Who knows how to treat my rare cancer? | *Philippe Morice (FR)* | Club H |
| 11:45 - 12:15 | Fertility Art in gyn cancers | *Frederic Amant (BE)* | Club H |
| 12:15 - 12:30 | End of Life lecture | *Andrea Krull (DE)* | Club H |
| 12:30 - 13.00 | ***Happening***<br>**ORANGE MEETS PURPLE**<br>**DOCTORS AND PATIENTS TOGETHER** | | in front of the Congress hall |
| **13:00 - 13:45** | ***Lunch*** | | |
| ***14:30*** | ***Sightseeing*** | | |

| DAY 3: Sunday, October 24th | | | |
|---|---|---|---|
| *Time* | *Lecture name* | *Speakers* | |
| **Chairs: Icó Tóth (HU), Murat Gultekin (TR)** | | | |
| 8:30 - 11:00 | General Assembly and Elections | | Club H |
| ***11:00*** | ***End of the meeting*** | | |
| 11:20 - 12:00 | Meeting of the „new" and „old" EEG | | |

# About ESGO

**Founded in 1983, the European Society of Gynaecological Oncology (ESGO) is a growing not-for profit organisation and forum of more than 3,400 professionals from across Europe and all around the world, dedicated to promoting the highest quality of care for women with gynaecological cancers.**

# ESGO's mission

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

## Activities

- Publications: The International Journal of Gynecological Cancer (IJGC), the Textbook of Gynaecological Oncology, the Cancer in Pregnancy textbook, the LiFE Report (reviews of the most relevant published articles).
- Primary event in the field: ESGO Congress.
- Professional niche events: State-of-the-art conferences, masterclasses, workshops.
- ESGO eAcademy, an exclusive interactive educational online portal.
- Six established networks, including ENGAGe, and three taskforces.
- Development of formal training guidelines in gynaecological oncology and European hospital accreditation.
- Development of clinical guidelines for ovarian, vulvar, endometrial and cervical cancers.

ENGAGe
ESGO European Network of Gynaecological Cancer Advocacy Groups

# 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’s mission

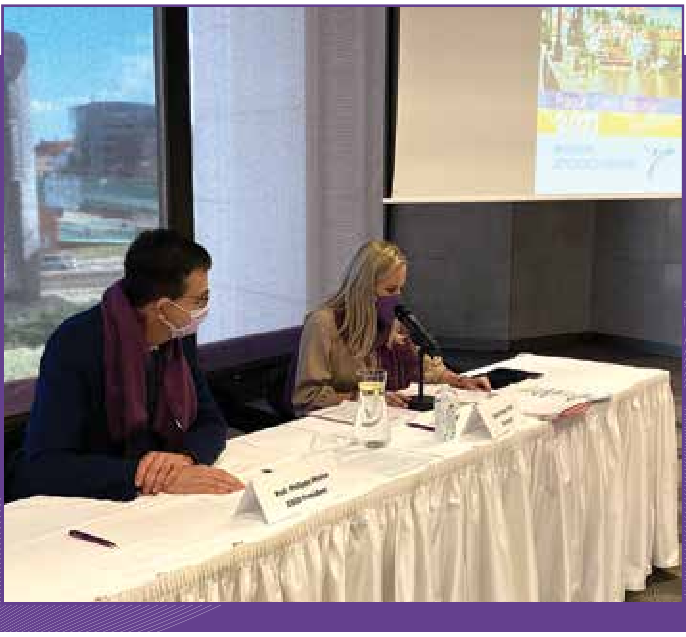
ENGAGe is committed to empowering a patient-centric approach to gynaecological cancer care, research and prevention through awareness, advocacy and education.

## 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 remarks

**ESGO President Prof. Philippe Morice (France), ENGAGe Co-Chairs Icó Tóth (Hungary) and Prof. Murat Gultekin (Turkey)**

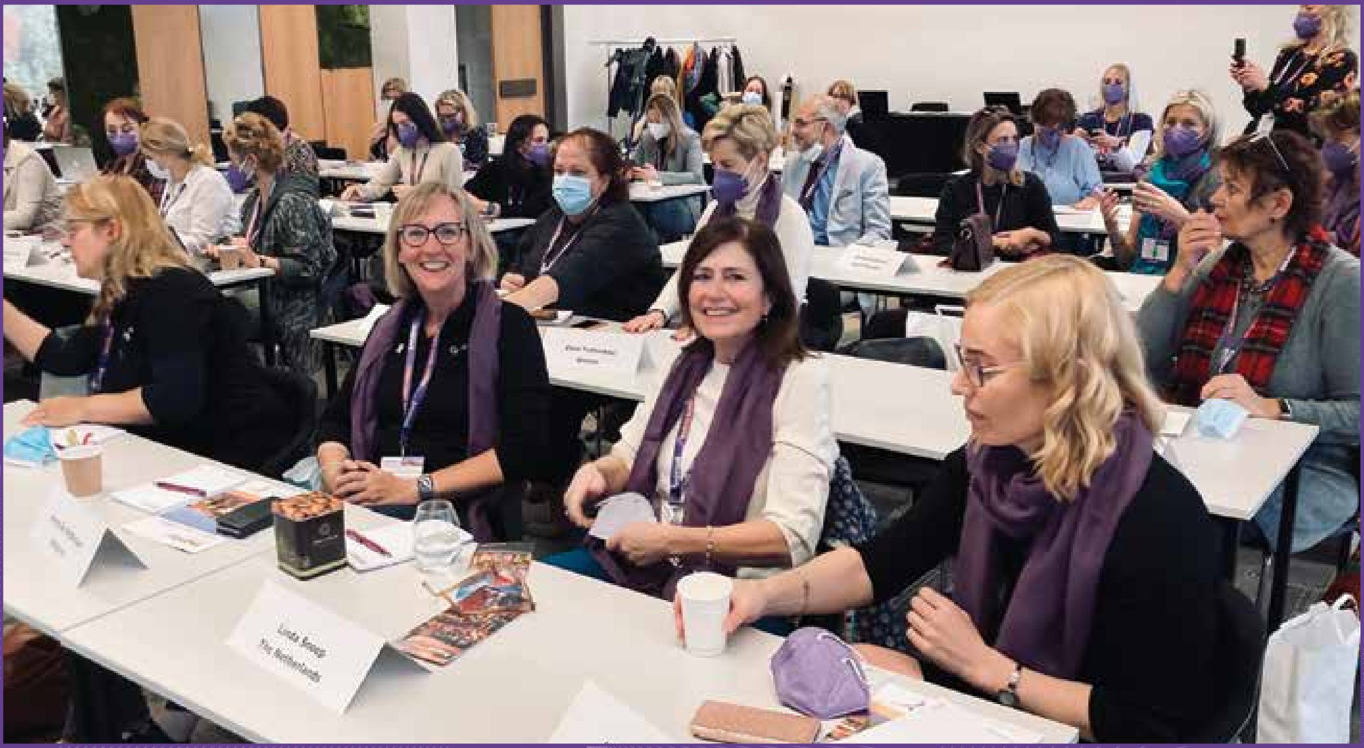


> *"The link between patients and physicians is really very important... Because we can't go in the right direction without your input. It's crucial for us."*
>
> *Philippe Morice*

## Key messages

- The ENGAGe patient advocacy network is an important part of the European Society of Gynaecological Oncology's mission to improve gynaecological cancer care for women in Europe.
- ESGO believes that the cooperation between patients and physicians is vital. The input of ENGAGe patient advocacy groups is driving better communication with and care of patients across Europe. This translates to better survival rates and quality of life.
- Over the last few years, ENGAGe has been extremely active. Thanks are especially due to the dedicated patient advocates who have been working to improve the situation not only for themselves but also for others whose health and circumstances prevent them from taking part and for future generations.
- Recent highlights for ENGAGe include new brochures and leaflets, best practice-sharing webinars, big steps in educating patients about clinical trials in collaboration with the European Network for Gynaecological Oncological Trial groups (ENGOT), the success of World GO Day and the work of the next generation of ENGAGe TEENs.
- The current Co-Chairs have taken ENGAGe from strength to strength. Although the leadership of ESGO and ENGAGe is changing, ongoing projects will continue. The cooperation will increase and become even stronger.

# Together again after COVID-19



*"This is a special patient advocacy seminar. Seeing each other, talking and being together, I think it's of much more value now after these difficult two years."*

*Icó Tóth*

- The COVID-19 pandemic situation has been very challenging for ENGAGe and its members on both a personal and professional level. But the network has adapted and even managed to grow.
- This Patient Advocacy Seminar is testament to this continued strength and resourcefulness: it brings together participants from 19 patient advocacy groups in person and 9 patient advocacy groups online from across Europe with the support of the ESGO Office.
- The programme reflects the requests of gynaecological cancer patient groups. They have come to learn from each other and the doctors and will share this valuable information through their networks.

# Better communication about HPV: The stigma we need to break down together

**Presenters: Prof. Murat Gultekin (Turkey) and Icó Tóth (Hungary)**

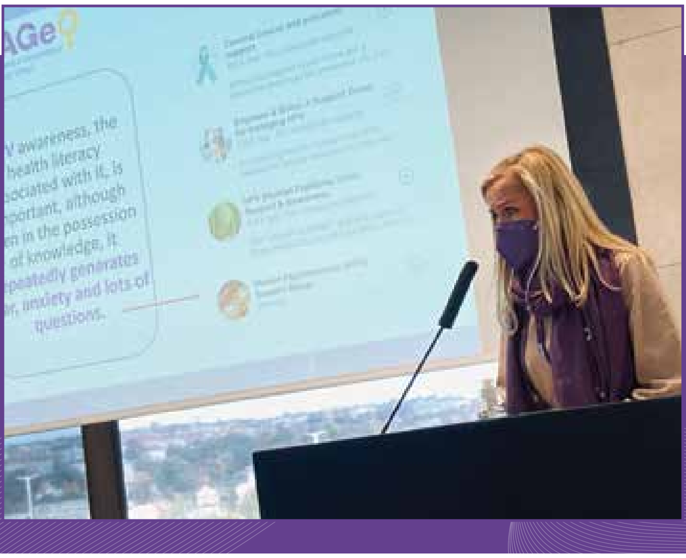
## HPV: A clinical view *(presented by Murat Gultekin)*

> *"The public's questions about HPV are growing day by day. There are many different myths, and I just want to inform you about what HPV is and give some answers to all these concerns."*
>
> *Murat Gultekin*

### Key messages

- As the World Health Organization launches its new human papillomavirus (HPV) screening and vaccination programme, public interest in HPV is rising. There are also many myths so it's important to be clear on the facts.
- HPV is a virus that can cause both cancer and non-cancerous diseases such as low-grade lesions and genital warts. It affects women and men.
- Around 9% of cancers in women are directly and primarily related to HPV. Of these, cervical cancer is the most common. However HPV can also cause anal, vaginal, penile and oropharyngeal cancers.
- Approximately 600,000 women are diagnosed with HPV-related cancers per year. Almost half of them are younger than 50.
- Of the 200+ types of HPV, HPV-16 and HPV-18 present the highest risks and are together responsible for around 70% of cervical cancers.
- HPV is highly infectious. A person's lifetime risk of HPV infection is more than 70%. In almost all cases, transmission takes place sexually; oral sex is sufficient. However there is also increasing evidence that HPV can be transmitted in non-sexual ways, including from clothing and even speculums.
- Infection normally peaks at around 20 years of age, i.e. in the first years when people become sexually active. There is a second peak between the ages of 40 and 50. This can be from a new infection or a latent one. The infection itself is asymptomatic.
- What can be done? **The HPV vaccine is effective primary prevention and screening is secondary prevention.**
- Vaccination is vital for everyone. In 97% of cases, the body will clear the HPV infection naturally. But in the other 3% of cases, people will have persistent HPV infections. We still do not know who will be in either group, but since the body does not produce natural antibodies, even those who clear the infection are at risk of a recurrence if they are not vaccinated.
- For patients, the journey to diagnosis isn't easy. It involves screenings, colposcopies and biopsies and nerve-racking waits for results. It can also put great stress on relationships.
- We can relieve much of the burden on patients simply by introducing vaccines and regular screenings. Knowledge and awareness are vital.

## HPV: Combating ignorance, doubts and fears *(presented by Icó Tóth)*



> *"We have a responsibility as NGOs to help. It's really important that we encourage women [...] to have bold conversations and know the possibilities"*
>
> *Icó Tóth*

## Key messages

- A search on social media shows that more and more people are looking for facts about HPV. Often they've heard about the virus but have inaccurate information and feel a lot of fear and anxiety.
- The public needs to know about the virus and understand its behaviour. Above all, they should know that the lesions caused by HPV infection can be prevented with the HPV vaccine and regular screening.
- Patient groups have a responsibility to help women, and many of them are working on raising awareness. This often includes translating complicated professional information.
- Basic HPV awareness can generate many questions and worries:
    - Here are some common questions we hear from women and our answers: "Should I stop having sex after an HPV diagnosis?" *(No. Most people have or have had the virus so not having sex is not the solution.)* "If I have HPV, does that mean I have cancer?" *(No. There's a big difference between a pre-cancerous lesion and cancer though the risk is there.)* "If I have HPV or my partner has HPV, can we have a baby?" *(Yes. There's no issue with pregnancy. And you can both have the vaccine.)*
    - Whether the HPV infection is high or low risk, it can put a heavy psychological burden on people and damage relationships.
    - We know that as a sexually transmitted infection, HPV carries great stigma. People concerned about the virus may experience loss of sexual desire, fear about partner infection, sexual dysfunction, and other psychological issues.
- Patient groups can help by:
    - Encouraging people to learn and ask questions about HPV
    - Highlighting risks and dispelling myths around the virus
    - Promoting the solution:

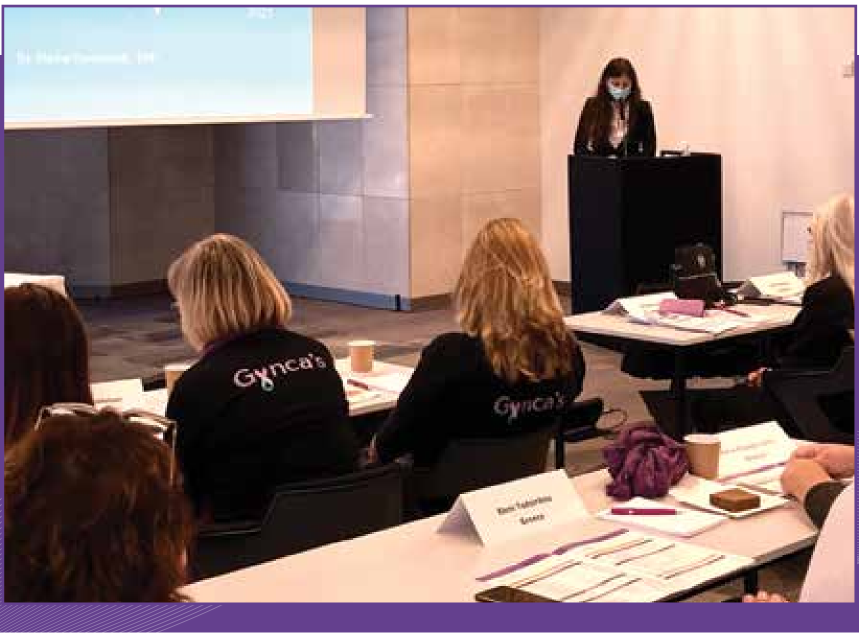
      \- HPV vaccination for children and adults of all genders even if they are HPV- infected +
      \- Regular screenings

***Resources***

*ENGAGe HPV brochure: https://engage.esgo.org/resources/hpv*
*ENGAGe HPV vaccination brochure: https://engage.esgo.org/resources/hpv-vaccination*
*ENGAGe HPV tests brochure: https://engage.esgo.org/resources/hpv-tests-brochure*

# Mapping European policies on cervical cancer prevention

**Marina Davidashvili (European Parliamentary Forum for Sexual and Reproductive Rights)**



> *"While the vaccine exists and screening is available, it's very dependent on where you live. We have a postcode lottery."*
>
> *Marina Davidashvili*

## Key messages

- European Parliamentary Forum for Sexual and Reproductive Rights (EPF) has developed a new tool to compare governments' cervical cancer policies across Europe: the Cervical Cancer Prevention Policy Atlas. EPF is a parliamentary network based in Brussels that brings together European parliamentarians who are working to improve sexual reproductive health and related rights.
- The cervical cancer prevention policy atlas rates 46 countries in Europe on their policies around preventing cervical cancer. The goal is to provide politicians and decision-makers in Europe with a simple visualisation tool to compare countries' policies. The research was completed in 2019 and will hopefully be revised in late 2021.
- The atlas scores the countries on their policies on vaccination, screening and online education about HPV and its prevention.
- The findings show a very unequal situation across Europe:
    - There is a clear divide between northern Europe, southern Europe and eastern Europe. While the vaccine exists and screening technologies are available, access is highly dependent on where you live. This leads to high incidence and mortality which could be avoided if the right policies were in place.
    - In the top-scoring countries, there is a national policy, and it is funded. The national vaccination programme is free and it covers both boys and girls. The government's online information is excellent. In the worst-performing countries, there are few funded prevention programmes and no government websites at all.
    - Good policies do not always translate to low incidence of cervical cancer. The Baltic states perform very well policy-wise but the rate there is among the highest in Europe. This is because the policies are new and their effects are not yet visible. In other cases, policies exist but are not implemented.

  - Belgium, Denmark, Ireland and the UK are the policy champions: they lead the Atlas with excellent policies on vaccination and screening and they provide high-quality evidence-based information to the public. Romania, Bulgaria, Slovakia, Belarus and Azerbaijan have the worst policies: the vaccine is not provided for free in these states, or it is only available to girls; there is no or minimal screening and no reliable online information.
- On a European and world level, good policies are in place for the elimination of cervical cancer.
  - In November 2020, the WHO launched its global strategy with the aim of reducing mortality from cervical cancer.
  - In February 2021, the European Commission launched its Beating Cancer Plan - the Plan to fight cancer.
- EPF's three basic policy recommendations are:
  - Include free and gender-neutral HPV vaccination into routine state vaccination schedules
  - Provide free population-based screening programmes, which are the only way to reach entire population
  - Provide the public with reliable evidence-based information about HPV screening and the vaccine and how both can be accessed.

## Discussion

ENGAGe members raised questions for parliamentarians and policymakers:

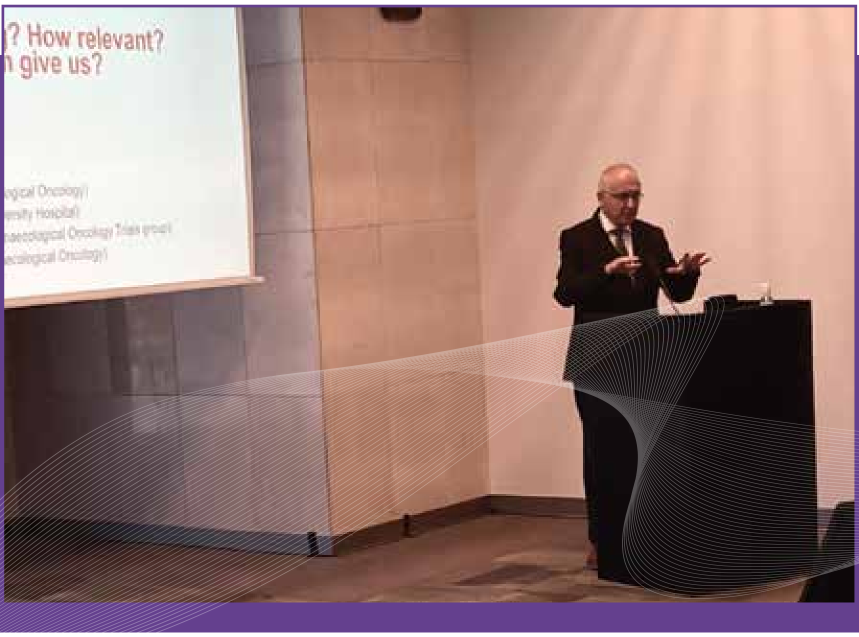
**"If HPV can affect people at different stages and even late in life, why do vaccine policies focus on children?"**

**"Even in the countries with a top report card for policies, the HPV information isn't getting through. So it's not sufficient just to have all the info. The question is, how do you make sure it actually reaches adults and young people?"**

*Resources: https://www.epfweb.org/node/552*

# New treatments in the gynaecological field: Where are we heading?

**Presenter: Prof. Mansoor Raza Mirza (Denmark)**



> *"These are the diseases that we have really needed to work hard on, and we are seeing the results of this work."*
>
> *Mansoor Raza Mirza*

## Key messages

- The biggest breakthroughs in gynaecological cancer research this year were in endometrial and cervical cancers. These breakthroughs represent the situation in the countries with the most progressive frameworks but they are not yet a reality everywhere else.
- **Endometrial cancer:**
    - For years, chemotherapy was the only option, and while it had good initial efficacy, if patients relapsed, the treatment was ineffective and the prognosis was extremely poor. This year we saw the entrance of immunotherapy into endometrial cancer treatment for these patients. The data show that 1 in 4 patients respond well to immunotherapy alone; these are the patients with "hot" tumours.
    - In the other 75% of patients with "cold" tumours, immunotherapy combined with a targeted drug (tyrosine kinase inhibitor) such as lenvatinib may be a helpful treatment. This combination produced an increase in overall survival, and some patients saw long-term benefits. This treatment is now available in Denmark and it is hoped that it will become the standard of care in the EU.
    - Immunotherapy has changed the landscape for patient management but the additional targeted drug has a lot of toxicity. So proactive care by doctors and good patient awareness of side effects are very important.
    - Clinical trials are under way across Europe to explore the efficacy of new combination treatments earlier in the disease progression, i.e. as a first-line treatment or after surgery. One trial is exploring whether immunotherapy can be used as a starting treatment on its own. We should see the results of two of these trials in 2022.

- **Cervical cancer:**
    - Ten years ago, patients with metastatic or recurrent cervical cancer were shown to benefit from adding the targeted drug bevacizumab to chemotherapy. The median overall survival of these patients improved to 17 months. More recently including immunotherapy in the treatment regime has had tremendous benefit.
    - One clinical trial showed adjunct immunotherapy was far more effective than single-agent chemotherapy for all types of patients. There were benefits in overall survival and quality of life.
    - It is early days in the research and there are many questions but the good news is that immunotherapy has a significant benefit for most cervical cancer patients. More trials are now in progress and new drugs are being approved.
    - The research is currently focused on combining immunotherapy with chemo-radiation and other standard treatments. The ultimate aim, however, is to eliminate chemotherapy as a first-line treatment.
- **Ovarian cancer:**
    - There were fewer breakthroughs in ovarian cancer research this year, but several studies delivered useful insights. Recent trials for patients with advanced ovarian cancer suggest that treatment with maintenance PARP inhibitors has most effect for patients with BRCA1, BRCA2, RAD51C and RAD51D mutations. But they can also be of exceptional benefit to other patients.
    - Phase 1 clinical trials also point to promising new treatments including a three-way combination of immunotherapy, PARP inhibitors and bevacizumab.
    - However there have not yet been any phase three trials for ovarian cancer treatments. We will probably not see the results of those trials until the end of 2022.
    - Patients with the most advanced disease are now being recruited for trials for new drugs and drug combinations in almost all countries in Europe.
    - A recent meta-study also asked whether all patients with newly diagnosed ovarian cancer should receive a PARP inhibitor as maintenance treatment. The answer was positive: maintenance PARP therapy increases progression-free survival for all these patients. Patients with BRCA mutations and HRD characteristics experienced the greatest benefit.

### *Resources*

*https://oncologypro.esmo.org/meeting-resources/esmo-congress-2021/pembrolizumab-plus-chemotherapy-versus-placebo-plus-chemotherapy-for-persistent-recurrent-or-metastatic-cervical-cancer-randomized-double-blind*

*https://www.annalsofoncology.org/article/S0923-7534(20)39891-4/fulltext*

# Genetic tests for gynaecological cancers

**Prof. Ranjit Manchanda (UK)**

> *"Apart from its treatment benefits, gene testing offers a good strategy to reduce cancer in the future."*
>
> *Ranjit Manchanda*

## Key messages

- Around 30,000 women are diagnosed with womb cancer and 44,000 are diagnosed with ovary cancer each year in Europe. Worldwide, the rates are more than 10 times higher. These numbers are slated to rise over the next 20 years, so the burden of disease will only grow. The death rate will also be proportionately greater.
- Genetic testing is a good strategy to reduce the long-term toll of cancer. These tests allow us to identify groups at high risk of cancer. These people can then be offered screenings or preventative medication and surgery.
- Previously people were often required to show a strong family history of a particular cancer to receive tests but this led to many cases being missed. Most people who carry gene alterations don't know their three-generation family histories. Now the recommendation is increasingly to offer genetic tests to everyone. The new guideline is already in place for ovarian and bowel cancer. It is being advocated for endometrial womb cancer.
- Gene testing brings benefits to different groups:
    - For cancer patients: Testing a cancer patient will reveal if they carry a faulty gene or gene mutation which is the cause of their cancer. Many of the novel treatments, particularly for ovarian and endometrial cancer, are driven by a gene-based molecular testing strategy. Genetic testing therefore improves the chances of effective treatment and survival.
    - Testing can also help prevent second cancers. Someone who has a gene that causes ovary cancer is, for example, at high risk for breast cancer. So they can undertake those screenings for secondary cancer prevention.

  - For family members: Finding out that a relative has a cancer-related genetic mutation provides an opportunity for preventative testing (sometimes called predictive testing or cascade testing). These individuals can be tested specifically for that fault. They don't need to have a full genetic screening.
  - Testing opens up options for surgical and medical prevention along with strategic lifestyle and reproductive decisions. Women at risk of ovary cancer and womb cancer may choose to take the contraceptive pill, which has been shown to reduce risk. Some patients may also decide to have hysterectomies and the removal of their tubes and ovaries. Those at risk of breast cancer may opt to have a mastectomy.
- An ENGAGe brochure is currently being compiled that will list different genes and the associated cancer risks. Today the standard guideline is that all women who have high-grade ovarian cancer should have a BRCA test. Recent research also suggests that
  - 1 in 5 ovarian cancers are caused by genetic mutations: this may involve genes such as RAD51C, RAD51D, BRIP1 or PALB2 or Lynch Syndrome genes.
  - All women with womb cancer should be tested for Lynch Syndrome genes.
- Understanding terminology is very important for patients as they read genetic reports. Germline means that a mutation is present in all the cells in the body. It is therefore inheritable. A tumour variant is a mutation found by testing tumour tissue. There may be faults in the tumour which are not inheritable
- Genetic testing can have downsides
  - Distress, effects on family relationships
  - Insurance implications in some countries
  - Stigma attached to having a gene mutation in some communities.
- All surgical prevention issues involve complex decision-making. Women making these decisions should be offered support, information and counselling.
- Traditionally genetic testing was managed through genetic counsellors. But the approach is changing as genetic testing is being mainstreamed across much of the world. Now increasingly cancer clinicians – surgeons, medical oncologists, clinical oncologists and clinical nurses – are offering patients pre-test counselling and gene testing.

***Resources***

*https://www.sgo.org/resources/genetic-testing-for-ovarian-cancer/*

*https://pubmed.ncbi.nlm.nih.gov/33004253/*

# Personalised medicine in gynaecological cancer

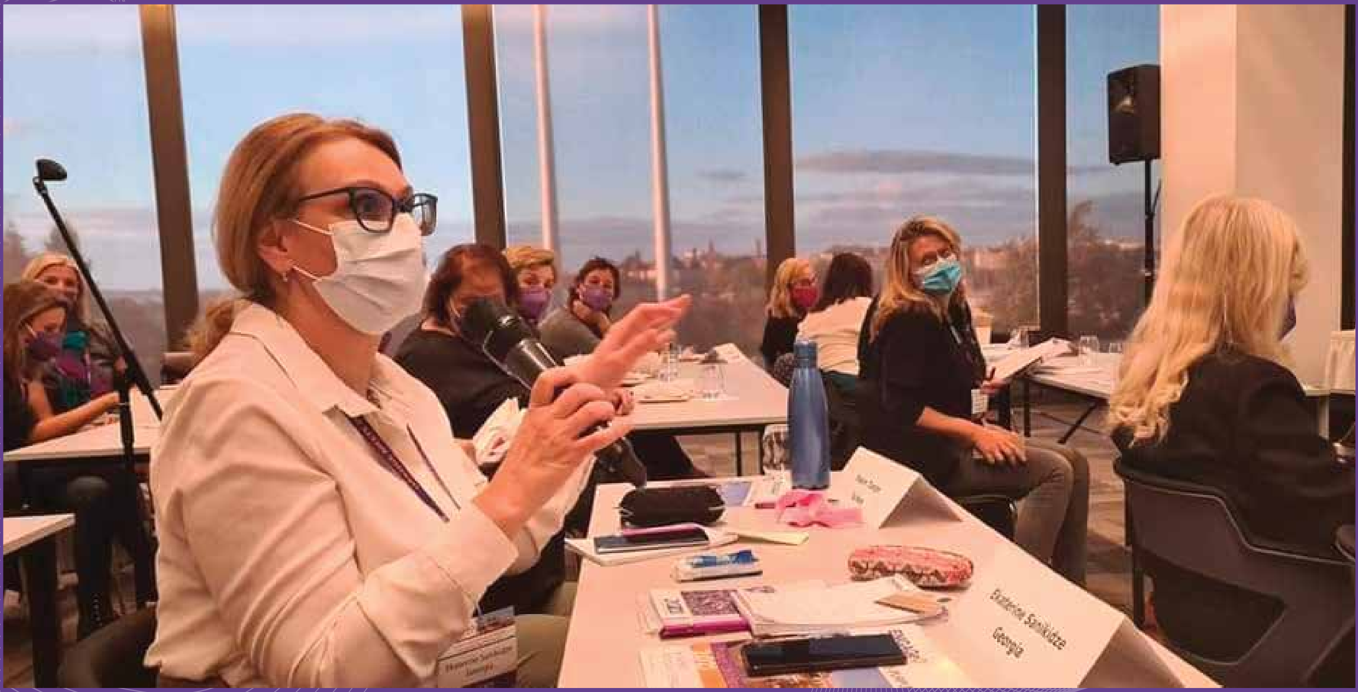
**Chair: Esra Urkmez (US). Presenter: Dr. Sandro Pignata (Italy)**

> *"We need the experience of pathologists, biologists, oncologists and gynaecologists: the skills of all these people should meet in the molecular tumour board to discuss every single case of a potentially targetable mutation. "*
>
> *Sandro Pignata*

## Key messages

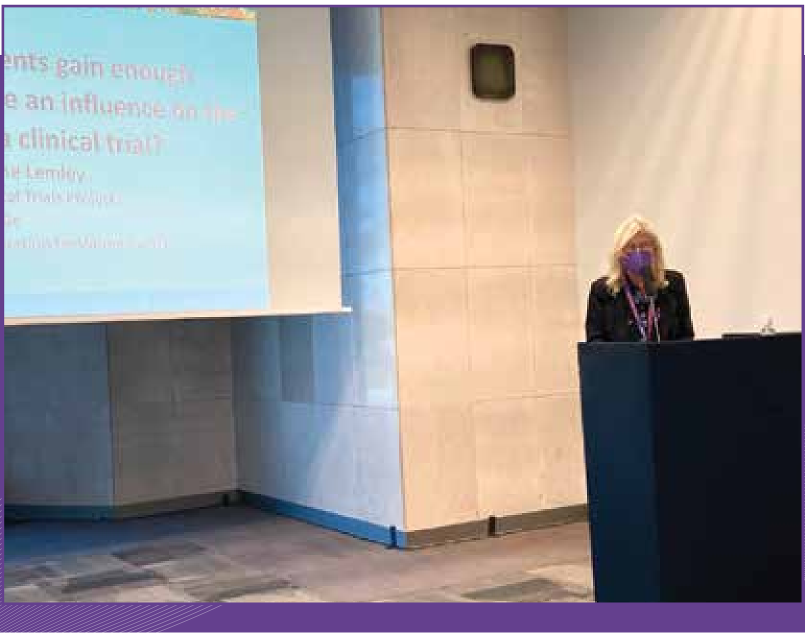
- Personalised medicine is about improving cancer therapies for patients and helping them access new therapies.
- Across Europe, this innovation is achieved through the creation of multidisciplinary teams. In Italy, these are called molecular tumour boards. These teams of different specialists discuss patient reports after genomic testing for the presence of targetable mutations.
- There are some basic financing questions for these boards: for example, who pays for testing? Not all national authorities in Europe pay for genomic tests, so these tests may not be reimbursed. There is also a similar question about who pays for the drugs to target a mutation. To get funding, experimental data is needed to demonstrate the effectiveness of the drug for a particular mutation.
- The multidisciplinary team includes pathologists, biologists, oncologists and gynaecologists, who all merge their skills and experience in the molecular tumour board. Because genetic research is expanding so fast, it's very important to have this far-reaching expertise since even a highly experienced oncologist may miss a potentially targetable mutation.
- The approach is growing in importance thanks to innovations in gene testing:
    - Low-cost next generation sequencing (NGS) is spreading. NGS is a very fast system to detect the presence of DNA mutations in tumours. It is becoming increasingly affordable and effective. NGS panels can be ordered in many hospitals in Italy.
    - Commercial panels are also available worldwide. They can test for up to 300 mutations and check for the presence of mutations both in the tumour and the blood.
- The molecular tumour board asks three questions:
    - Is there a druggable mutation?  The biologist will look at the genomic profile to pinpoint a specific mutation.
    - Is there a matched targeted agent? The board will look at drugs that have been approved for that mutation and are commercially or experimentally available.
    - How can the patient access the proposed targeted agent? One possibility is experimental trials. Across Europe, there are now many experimental trials that are molecularly driven where patients can access these drugs.

- Among the problems facing tumour boards across Europe is the great discrepancy in access to reimbursable genomic testing. The quality of the tests may also vary across countries. Every country should add a quality control programme to ensure the results of the tests are reliable. ESGO is one of the bodies lobbying for greater test access and reliability.
- In Italy, the MITO research society has set up a molecular tumour board for gynaecological cancer at national level. This is a virtual initiative, and more than 50 centres join the meetings. The platform stores patients' NGS reports and the meeting assesses the importance of any mutations, whether they are druggable and the availability of suitable clinical trials.
- This project offers patients more scope to get the best treatment and it is also helping train a new generation of physicians who can interpret molecular profile tests.



# How can patients gain enough knowledge to influence the design of a clinical trial?

**Presenter: Birthe Lemley (Denmark)**



*"We are the patients. It's our bodies in all these clinical trials. So the patient's perspective should also be there."*

*Birthe Lemley*

## Key messages

- The Clinical Trials Project was started in September 2019. Twenty patients from various European countries took part.
- Since then, six webinars have been hosted by experts from the European Network for Gynaecological Oncological Trial groups (ENGOT), ESGO's research network. Two study books and a test have been developed to enable more patients to become experts on clinical trials. ESGO is working closely with ENGOT on this project, and it is ongoing.
- The objectives of the Clinical Trials Project are:
    - To bring patient insights and perspectives into the design and implementation of local clinical trials. This may take place on a national level – for example, through the Nordic Society of Gynaecological Oncology (NSGO), the Spanish Ovarian Cancer Research Group (GEICO) or AGO-Germany or through ENGOT, ESGO, other research organisations or pharma.
    - To develop strategies to increase patient awareness of and participation in clinical trials.
    - To help gynaecological cancer patients cross borders in Europe so they can participate in clinical trials appropriate for their disease in other European countries.
    - To disseminate the results of clinical trials to individual patients and the public.
    - To use our knowledge in any other way which may support the work of ESGO, ENGOT and other affiliated organisations and ultimately benefit patients.
- Patients involved in the project should have or have had gynaecological cancer themselves and have a high level of English so they can read and understand clinical trial protocols. They can be from any European country but their organisation must be a full member of ENGAGe.

- Patient engagement in a clinical trial benefits the investigator/doctors and the pharma company, who get patient perspectives on:
  - Trial design
  - Quality of life and side effect concerns
  - Patient Reported Outcomes (PRO)
  - Informed consent
- Patients who have a good knowledge of clinical trials can also be instrumental in:
  - Spreading the word about recruitment
  - Disseminating the trial outcome
  - Organising the approval of the drug in their own countries through their national medical councils
- Concrete examples of where the knowledge gained is being used:
  - Patient perspectives in clinical trials and other studies:
    - Clinical Trial Project members have recently been appointed to the scientific board of the Personalized Clinical Management of Endometrial Cancer using Liquid Biopsy, Genomics and Artificial Intelligence project
  - Patient perspectives in the development of surveys
  - Patient input in important consensus statements
    - ESGO-ISUOG-IOTA-ESGE Consensus Statement on Pre-Operative Diagnosis of Ovarian Tumours
    - European Ovarian Cancer Consensus Guidelines
    - European consensus on BRCA/HRD testing
  - Patient input in early dialogues with the European Medicines Agency (EMA) about the introduction of new drugs.
- Patients have unique knowledge. We have had the disease and have experienced treatment regimes first hand. When we understand the clinical trial process, we can contribute important insights into what should be included. Our voices can lead to change.

***Resources***
*https://engage.esgo.org/engage-engot-clinical-trial-project*

**If you would like to participate in this project, please contact the ENGAGe office at engage@esgo.org**

***Participants in the ENGAGe Clinical Trials Project***

# ENGAGe TEENs

**Chairs: Petra Adámková (Czech Republic), Prof. Karina Dahl Steffensen (Denmark).**

**Presenter: Selin Bayrakli (USA)**

ENGAGe TEENs
ESGO | European Network of Gynaecological Cancer Advocacy Groups

> *"As teenagers, we know what other teenagers will actually listen and respond to. That's why we need a network of teenagers who can connect with and strengthen our knowledge about HPV and cervical cancers."*
>
> *Selin Bayrakli*

## Key messages

- This project empowers girls and boys from ages 13-19 to spread awareness about Human Papillomavirus/HPV, cervical cancer and the HPV vaccine to the youth of the world. The project was initiated in September 2020.
- The project´s goals are:
    - To spread awareness about the Human Papillomavirus (HPV), cervical cancer and the HPV vaccine to young people around the world.
    - To educate young people about HPV, the HPV vaccine and the prevention of cervical and other HPV-related cancers.
    - To improve communication between children and parents and remove the stigma around sexual health and sexually transmitted diseases.
- The ENGAGe TEENs project is constantly growing. Right now there are almost 40 members across nine countries: the USA, Turkey, Denmark, Hungary, Ukraine, the Czech Republic, Georgia, Italy and Canada. New members are more than welcome.
- The project is starting to have an impact. So far its activities include:
    - Organising events for World GO Day 2020 and 2021 and boosting these social media campaigns
    - Providing video clips for ENGAGe and ESGO special events
    - Speaking in webinars as more prevention campaigns recognise the importance of teenage voices
    - Completing a five-week education course about HPV
    - Translating HPV brochures

    - Launching an Instagram account
    - Designing pamphlets
    - Providing support to local patient advocacy groups
- It is also working hard on other projects:
    - Creating a crash course video on HPV and the HPV vaccine
    - Designing child-friendly educational cartoons/comics
    - Outreach in schools
    - Fundraising
- ENGAGe TEENs draws on teenagers' high level of creative, social media and design skills and their innate understanding of what will appeal to their peers.
- ENGAGe TEENs is happy to partner with and support patient advocacy groups. We can work together to connect young people with real-life patient stories or add young voices to group projects.
- **Anyone interested in joining or connecting with ENGAGe TEENs should contact the ENGAGe Office at engage@esgo.org.**

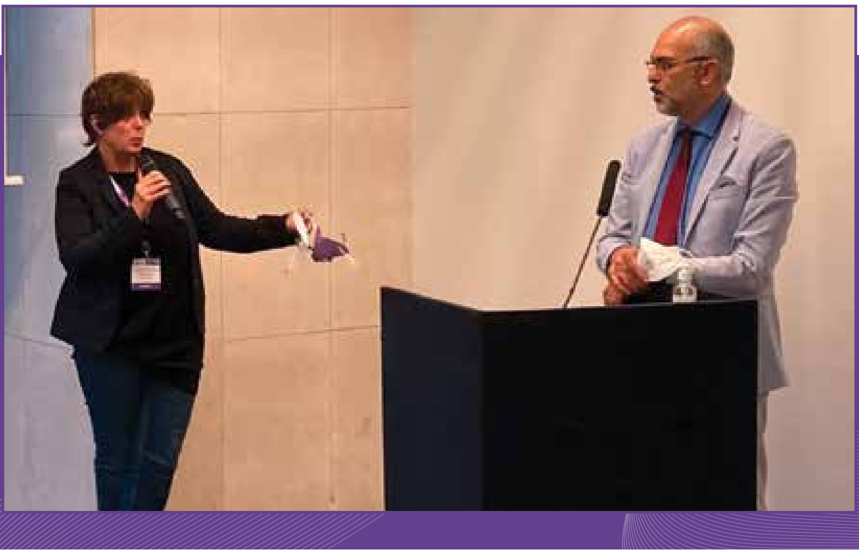
***Resources***

*https://engage.esgo.org/engage-teens-project-2/*

*https://www.instagram.com/engageteens*

# Doctor and patient perspectives: Living with ovarian cancer as a chronic disease

**Presenters: Prof. Jalid Sehouli (Germany), Andrea Krull (Germany)**



> *"As I am a longtime survivor, I still need my doctors. It's very important to me that we have good communication with enough time to share thoughts and ideas."*
> *Andrea Krull*

**Andrea Krull is an ovarian cancer survivor, and Jalid Sehouli is one of her doctors.**

**The two were asked to share their thoughts on the effects of ovarian cancer treatment on a woman's long-term quality of life. Their answers revealed important differences in their perspectives. They also considered what good care looks like when cancer is a chronic condition.**

## How does treatment for ovarian cancer change a woman's life?

- ***Jalid says:***

  "In most cases, the patient will have advanced disease at the time of diagnosis. This means that there are metastases outside the pelvic organs and perhaps bowel obstruction and abdominal discomfort. The treatment includes surgery, with the goal of the complete resection of all visible disease. There is subsequent chemotherapy and then maintenance treatment, including a PARP inhibitor regime.

  All these elements have a big influence on quality of life. So, from the time of diagnosis, it's important to focus on pain management, anaemia and electrolyte disturbances. We need to look at preserving muscle activity through pre-habilitation - an active training programme before surgery. The same applies to the period before chemotherapy and again before continuing with the maintenance approach.

  Quality of life has social and cognitive as well as physical meanings. Doctors can help patients to communicate their needs. This might mean connecting them with psycho-oncological and creative therapies or supporting their communication with partners and relatives."

- ***Andrea says:***

  "Every aspect of your life is disturbed and feels confusing after ovarian cancer treatment. Your body and your sexual life are disturbed; your family life is disturbed. Your financial situation is also changed since it takes some time to get back to work. You see that life is limited and that you will need permanent and very regular check-ups with your doctors. Your anxiety level is different, and you focus more on your own perceptions, and on what you want to achieve in the rest of your life."

## What does it mean to live with a “chronic disease”?

- ***Jalid says:***

  “First of all, although most patients have advanced disease, ovarian cancer is curable, so cure is one of the most relevant treatment goals. Even after a relapse, long-term survival is possible. We now have improved surgery, chemotherapy and maintenance treatments. And this targeted therapy approach aims to turn this disease with acute symptoms into more of a chronic condition. Patients may go even 10 years with no relapses.”

- ***Andrea says:***

  “I see a chronic condition as one which needs permanent observation and reflection. It means living with an illness which might be stronger than myself. And I therefore need a good team and a good network of different helpers, such as doctors, support groups, family and others who are at my side. They can support me to achieve the best quality of life. But dealing with a chronic condition is very demanding, not only for my body but also for my soul and for those around me -- my family, friends and doctors as well.”

## What are the challenges around preserving quality of life after cancer treatment?

- ***Jalid says:***

  ”At the end of the day, patients want to achieve their goals: to interact with their family, to do their daily work and also live their private life. And that‘s why we have to individualise the targets: to know what a person‘s resilience factors are and what they find personally important, and to bring this into the goal of any treatment decision.”

- ***Andrea says:***

  “The most challenging issue in my life is not overreacting or trying to control my condition too much. It’s important for me to handle my anxieties well, so that I can relax and lead a more or less normal life. That’s not always easy; it’s very challenging sometimes.

  Quality of life means having quite a normal life, enjoying life with my family and friends and animals in the countryside. But it also means having trust again in myself, in my body, in my psyche and in my doctors, who still play a very important role in my life. Quality of life means having no treatment for as long as possible.”

## How can doctors help patients improve their quality of life?

- ***Jalid says:***

  “As a doctor, you’re trained to cure patients. That’s good but it’s not enough. Quality of life issues are very important for patients. But to know the patient‘s perspective, you have to talk with them and ask their history, their stories, their expectations and preferences. You can’t define quality of life for your patients, but you can address quality-of-life issues in the treatment decision-making process. You have to ask your patients and listen to them.”

- ***Andrea says:***

  “The doctors can be on my side when I need them. They can give me important information to help me handle my illness, and they can accompany me through difficult situations. They can show that there’s time to ask questions and discuss hard issues. If I feel trust and can contact my doctor whenever I have an urgent need, I have a very high level of quality of life.

  But it’s also important that my doctors are trained in communication. And that they research ovarian cancer. If I have a doctor like that on my side, I’m impressed. And I can feel relaxed.”

***Resources***

*https://youtu.be/6X-X8gUmX-c*

# Palliative care: Meeting the needs of patients and their families

**Dr. Kateřina Rusinová (Czech Republic)**

> *"Our principle is 'live every day as best you can'"*
> *Kateřina Rusinová*

## Key messages

- Palliative care has historically often been reduced to terminal (end-of-life) and hospice care. But today the team at Prague's General University Hospital focuses on patients' experiences from the time of diagnosis and throughout treatment. This is early palliative care.
- This model is about providing care based on people's needs and not their prognosis.
- The palliative unit has its own out-patient clinic at the hospital. It took several years to set up, and it was important to make the space comfortable and inviting for patients so they would find it easier to communicate there.
- The team is multi-disciplinary and includes psychologists, social workers, nurses and doctors. During the COVID-19 pandemic, meetings have been taking place via Zoom.
- The team began in the anaesthesiology department with one afternoon each week allocated to palliative care:
    - Since 2017, it has evolved, and in January 2021, an official Department of Palliative Care opened at the hospital.
    - The team provides early palliative care and support to more than 500 patients a year. The unit is modelled on a palliative care department in Munich, Germany and it bases its work on best practices internationally.
    - Both the hospital and the local university medical faculty are supporting this initiative to develop clinical palliative care. The work includes research and the education of future physicians.
    - Fundraising is an ongoing issue as hospitals tend to prioritise high-tech intensive care over palliative medicine.
- The team is the subject of a new documentary **Intensive Life Unit** *(Jednotka intenzivního života)* (2021) directed by Adéla Komrzý.
    - The film responds to the lack of public conversations about end-of-life care and the negative experiences some people have had of this area of medicine.
    - It captures the intimate contact and communication between doctors and patients as they try to make decisions that are good for the patient.

    - It has been selected for screening at international film festivals.
- The team is also involved in changing Czech medical student education. It has introduced a course in the basics of communication and palliative care. Previously this course was optional but now it is compulsory for third-year medical students, who receive six hours training in communication:
    - The focus of the course is on the appropriateness of care. This means care that is good for patients, matches their goals and is medically realistic.
    - Another key issue is responding to difficult questions from patients. This is about giving students basic structures to support good communication.
    - The course also teaches doctors to learn from patients about their information needs, values and preferences. This includes asking questions like, Is there a next of kin or other person you would like to hear the information with you? If I have difficult news for you, how would you like me to communicate? What do you know about your disease? And what is important to you besides the treatment? What should I know about you to take good care of you?
- Team members provide training to colleagues from across the Czech Republic, who shadow them in their daily clinical work.
- The team has now founded an official journal of palliative medicine. This quarterly journal highlights topics such as the importance of patient-focused care, good communication, early palliative support and matching treatment with patient values and preferences.

## Discussion

**Participants had questions and comments about early palliative care:**

*“I think one of the biggest problems is that most patients are referred to palliative care when they’re at the end of life. And before that, maybe they have years where they need palliative care. And so we’re starting to talk about early palliative care. But when I refer my patients to early palliative care, they think they’re dying. So how do we change how we talk about palliative care and get more patients referred to early palliative care?”*

*“We’re also here from patients’ groups. We can spread the word about palliative care being available for people in need.”*

*“Some of the women in the palliative phase in our group - they just change the word. They call it chronic cancer care. I know it’s just a word but I think it can make a big difference. It can give it another feeling, another emotion.”*

*“[Our group] has been making videos and we explain to patients what [palliative care] really means. We explain it isn’t about dying but about what happens when you face difficulties and having support to make the best decision possible.”*

*Resources: https://www.kviff.com/en/programme/film/57/34742-intensive-life-unit*

# Endometrial cancer treatment

**Chairs: Jalid Sehouli (Germany), Maria Papageorgiou (Greece).**

**Presenter: Prof. Nicoletta Colombo (Italy)**

> *"Immunotherapy has changed the face of many cancers over the past decade and finally this is also happening for endometrial cancers!"*
>
> *Nicoletta Colombo*

## Key messages

- Endometrial cancer is still the most common gynaecological cancer in the developed world. It is the only gynaecological cancer with rising incidence and mortality.
- It remains primarily a disease of post-menopausal women:
    - There has been a 25% increase in cases over the past decade.
    - 80% of women present with stage 1 disease with an excellent prognosis.
    - There are limited treatment options for women with advanced or recurrent disease
- In stage 1 disease, surgery is still the mainstay of treatment. Typically it is minimally invasive (laparoscopic or robotic surgery).
- An important step in recent years has been the identification of four different subtypes of endometrial cancer: POLE, MMrd, NSMP and P53abn. These subtypes:
    - Can be identified using widely available methods (there is no need for complex genetic panels).
    - Tell us about the prognosis and the likely efficacy of treatment.
- These molecular subgroups should be used to decide on adjuvant treatment based on recent guidelines:
    - All POLE-mutated tumours are low risk, irrespective of their stage and grade.
        - No adjuvant treatment is needed.
    - All P53abn tumours are high risk, irrespective of their stage and grade.
        - More aggressive treatment is needed. This may be External Beam Radiation Therapy (EBRT) with chemotherapy; sequential chemotherapy and radiotherapy; or chemotherapy alone.
- We have also seen some positive developments in systemic treatment. At present:
    - For low-grade (grade 1 or 2) non-rapidly growing tumours:
        - The recommended therapy is hormone therapy

    - In more advanced or recurrent disease:
        - 6 cycles of carboplatin and paclitaxel are given every 3 weeks
        - Currently no standard second-line treatments are available
        - However, a recent small phase-2 study suggests that the combination of palbociclib with letrozole may offer a beneficial hormonal treatment.
- On the immunotherapy front, new data divides tumours into two groups based on their biomarkers:
    - Hot tumours (MSI-H/dMMR tumours)
    - Cold tumours
- The hot tumours may respond well to single-agent immunotherapy even as a second-line or third-line treatment.
    - In Europe, the drug dostarlimab has been conditionally approved for patients with MSI-H/dMMR-type endometrial tumours. For other patients, it is not effective.
- However a recent phase-3 study points to the benefits of combining immunotherapy with anti-VEGF (anti–vascular endothelial growth factor) therapy for patients with cold tumours. These patients with advanced or recurrent endometrial cancer were treated with lenvatinib plus pembrolizumab.
- Current trials that combine chemotherapy with immunotherapy also promise to deliver positive results.

## Discussion

### Can we finally talk about immunotherapy as a treatment for gynaecological cancers?

**An ENGAGe member raised this question:**

*"So in the recent past, we heard that we shouldn't talk about immunotherapy in gynaecological cancer because it was giving too much hope. But now things seem to be changing. So my question is, can we as patient groups talk about immunotherapy?"*

**Dr. Colombo's answer:**

*"Yes, I think you should because I'm talking about endometrial cancer. And a month ago, I also presented very important data on cervical cancer. And we don't know about ovarian cancer so well, but [immunotherapy] is working much more in endometrial cancer and cervical cancer. So I think if you focus on cervical cancer and endometrial cancer, we do have very important and solid data on the efficacy of immunotherapy in these diseases, and this will change dramatically in the future."*

*Resources:*

*https://pubmed.ncbi.nlm.nih.gov/31682550*

*Makker, V.  New England Journal of Medicine (in press)*

# Vaginal flora

**Prof. Maria Kyrgiou (UK)**

> *"And I think a lot of you must have heard about this microbiome and the flora in our bodies …There are so many preparations that you can buy in the pharmacy at the moment but a lot of the things that are available haven't necessarily been assessed."*
>
> *Maria Kyrgiou*

## Key messages

- The human body is heavily colonised by bacteria: for every 1 trillion human cells in our bodies, there are about 10 trillion bacterial cells.
- These bacteria are a significant factor in health and disease, and this may include the development of gynaecological cancers. Growing efforts to understand the microbiome (oncobiome) aim to help patients and prevent these cancers in the future.
- Research into the microbiome has especially addressed the gut and the bowel and the links with metabolism, immunity and other aspects of health.
- In gynaecology, the focus is on the vagina. In the past, some meta-analyses suggested a potential link between a condition called bacterial vaginosis (BV) and cervical pre-cancer and the presence of human papillomavirus (HPV). Population studies also pointed to an increased risk of endometrial and ovarian cancer in women with pelvic inflammatory disease.
- However these were only hypotheses that could not be proven. Next generation sequencing techniques are providing a fuller picture.
- The vaginal microbiome is affected by a woman's ethnic background. Other key factors include hormones, smoking, menopause, pregnancy and changes during the menstrual cycle.
- Cervical disease and HPV are the focus of studies which ask why some women clear the virus while others do not. This is where the microbiome becomes relevant. Researchers look at the biology of the whole system:
    - The host – the woman with her own genetics and immune system.
    - The virus with its oncogenic potential.
    - Bacteria that interact with the host and the virus.

- Different studies have started to detect associations:
    - Studies of monozygotic twins found that the bacteria in the vaginal microbiome differed when one had the HPV infection.
    - Research into the different stages of pre-invasive disease and invasive cancer found that the more depleted lactobacillus levels were, the more severe lesions became.
    - The endometrial cavity, which was once thought to be sterile, is now also understood to host bacteria.
- However all this research requires caution because of the risk of confusing the microbiome with environmental and other contaminants.
- New research is taking off in exciting directions:
    - Some scientists are asking whether the microbiome in the bowel could be used to activate an immune response against tumours elsewhere in the body.
    - Others are investigating the issue of causality, i.e. whether the microbiome can be shown to cause cancer:
        - A study of women with CIN2, a moderate-risk precancerous cervical lesion, found that those with lactobacillus depletion had significantly less chance of clearing the lesion,
        - Another study of women patients found that after the removal of the disease, their microbiome was unchanged. This suggests they may have an intrinsic susceptibility to inflammation that puts them at higher risk of a recurrence.
- Concerning treatments and prevention:
    - Probiotics are now widely available in pharmacies and supermarkets. They have received much media coverage, and it is claimed that they restore health, but there is little data to support this. Like supplements, these products are not subjected to the same trials as drugs.
    - In Israel, researchers are treating women with intractable BV with vaginal transplants. This approach is based on the same principle as faecal transplant therapies.
- Bacteria dominate our bodies and inevitably play a role in what happens to it. We are continually learning more about the bacteria-cancer link. Based on current technologies, we will understand much more about the oncobiome in the next 10 years.

***Resources***

*https://pubmed.ncbi.nlm.nih.gov/27802830*
*https://pubmed.ncbi.nlm.nih.gov/23717441/*
*https://pubmed.ncbi.nlm.nih.gov/26574055/*

# Doctor and patient perspectives: What happens to the body after cervical cancer treatment?

**Presenters: Prof. Carien Creutzberg (Netherlands) and Kim Hulscher (Netherlands)**

> *"My advice to a woman who's having cervical cancer treatment right now would be to talk with her doctor, to ask about the long-term effects on her quality of life. That way you can communicate and decide together so you have the best quality of life possible in the long term."*
>
> *Kim Hulscher*

**Kim Hulscher is a cervical cancer survivor and Carien Creutzberg is a doctor. They were invited to share their thoughts on how cervical cancer treatment affects a woman's long-term quality of life.**

**The focus of their conversation was on parts of life that are often not spoken about because they're considered taboo: urination, defecation and sexuality. Carien says: "This used to be very hidden because no one wanted to talk about sex and other problems. But we're now focusing much more on talking about it and trying to find ways to improve quality of life."**

## What changes in a woman's life after cervical cancer treatment?

- ***Carien says:***

  "Everything changes after you have cancer in an area where you have your bladder, your bowel, your sexuality. Treatment is often associated with anxiety, fatigue and symptoms and it's difficult to pick up your old life afterwards."

- ***Kim says:***

  "When a woman is diagnosed with cervical cancer, there will be several changes: She will lose faith in her body. She'll also be afraid that she might die and that she won't be there for her family anymore. She will suffer great fatigue and have less energy than she had before. And most cervical cancer treatment will also mean that a woman won't be able to have children anymore. She'll have early menopause. So cervical cancer treatments have an overall effect on a patient's womanhood."

## How does cervical cancer treatment affect bladder function?

- ***Carien says:***

  "Cervical cancer treatment [either primary radiotherapy with chemo or surgery and radiotherapy] will lead to an increase in urinary frequency and often a reduced bladder reserve. In the long term, it can also lead to minor incontinence. Pelvic floor exercises are recommended to try and prevent these problems."

- ***Kim says:***

  "Women can have several problems with their bladder after cervical cancer treatment. One problem can be having no feeling at all in your bladder so you don't feel any sensation, which means you have to set your alarm every two hours to make sure you go to the bathroom to empty your bladder. Another problem can be an overactive bladder. It means you may have very little in your bladder but still feel like you've been in a car for six hours and really have to go to the bathroom. Other women have trouble getting all the urine out of their bladder, which can cause regular bladder infections."

## How does cervical cancer treatment affect the intestines?

- ***Carien says:***

  "After having radiotherapy, women will experience more frequent bowel movements. There can also be more bowel urgency, but with modern treatment techniques, [the impact] is reduced. Some women can have long--lasting symptoms though for most it will resolve in a few months."

- ***Kim says:***

  "Cancer treatment also causes a lot of problems in the intestines. A woman can suffer from diarrhoea, which, of course, causes a lot of problems, and you need to make sure there's a bathroom close all the time. Or it can also cause an obstruction, which is something I suffer from and I'm always looking to balance what I can and can't eat. The worst thing that can happen after cervical cancer treatment is a bowel obstruction due to intestinal adhesion. Eventually that can even cause death."

## How does cervical cancer treatment affect a woman's sexuality?

- ***Carien says:***

  "The impact on sexuality will be major.  It is cancer diagnosed in the area where you normally have your sexuality. There will be changes either through surgery or through therapy with shortening of the vagina. The joy and ease of having sex are also reduced. So it's really recommended that every woman who undergoes treatment has counselling and rehabilitation support."

- ***Kim says:***

  "Cervical cancer treatments has a really, really big effect on sexuality. A lot of women experience pain during intercourse. Some women won't be able to have intercourse anymore. A lot of women experience bleeding and infections and therefore also fear having any sexual contact at all. Women who have a partner may be afraid that the partner will want to leave them if they can't have regular sex. And women who don't have a partner may be afraid that no one will be interested in them if they can't have sex on a regular basis because it hurts or it takes a while for the body to recover after sexual contact."

## How does cervical cancer treatment impact the lymphatic system?

- ***Carien says:***

  "After surgery, there's the risk of having lymphoedema with swelling of the legs. Massage and lymphoedema physiotherapy are recommended."

- ***Kim says:***

  "When a woman has her lymph nodes removed during cervical cancer treatments, she can have problems with the lymphatic system. If she also has radiation, there's an even a bigger chance that she'll develop lymphoedema. When you have lymphoedema, either one or both your legs are swollen or it's even higher up in your belly and, of course, it's very uncomfortable. The other thing is that it's not really flattering. I know a lot of women who wear long skirts, dresses or pants all the time so that nobody will see their compression garments. When it's warm, I usually do wear shorter things, and I do get a lot of stares and that is really not comfortable. So it's not just a health problem. It's also a social and a psychological problem."

## What’s your advice to a woman undergoing cervical cancer treatment when it comes to long-term quality of life?

- ***Carien says:***

  “I would really recommend that every woman seek rehabilitation support. It can be either be counselling or rehabilitation exercises and physical therapy. Because it takes time to get the symptoms resolved and also to get a grip on your life again.”

- ***Kim says:***

  “My advice would be to talk with her doctor, to ask about the long-term effects on her quality of life. Usually, the doctor won‘t talk about that with you. But you should be informed so you know how to make the right decisions. Ask your doctor for all the information: What does this treatment do to your body in the long-term? What does it do to your quality of life? That way you can communicate together and decide together so you will have the best quality of life possible in the long term.”

***Resources***

*https://youtu.be/mSHFTe99ZgI*

# Sexual health workshop

**Chairs: Dr. Zoia Razumova (Slovenia), Kim Hulscher (Netherlands).**

**Presenter: Assoc. prof. Kathrin Kirchheiner (Austria)**

> *"After a cancer diagnosis and treatment, life changes in so many ways and, of course, sexual life might also change, but this is not so much about grieving what was lost and was normal before. It's more how to create a new normal [...] What feels good now, that's the new normal."*
>
> *Kathrin Kirchheiner*

## Key messages

- In 2018, the American Society of Clinical Oncology published the following recommendations for sexual health interventions for all people with cancer:
    - It is important to discuss the sexual health/dysfunction that results from cancer or treatment with patients
    - The discussion should:
        - be initiated by a member of the healthcare team at the time of diagnosis.
        - continue throughout follow-up.
        - include the patient's partner only if the patient wishes.
    - The patient should be given access to self-help resources and referral information
- Nevertheless there is an overall reluctance among clinicians and patients to talk about cancer- and treatment--related sexual difficulties.
- Patients are reluctant to raise the subject because they feel concerned about making the doctor uncomfortable or they are embarrassed and believe it is the clinician's responsibility to raise it. Sometimes they think that their sexual health concerns are invalid or that sexual issues are an expected and untreatable complication.
- Clinicians are concerned about making patients uncomfortable or they lack time and privacy to deal with these topics, are not aware of effective interventions or feel inadequately skilled or trained.
- Meanwhile studies of cervical cancer survivors show that their sexual life is dramatically worse compared to that of a healthy age-matched reference population. Even four years after treatment, patients reported:
    - Vaginal atrophy and dryness
    - Vaginal bleeding

    - Vaginal adhesions
    - Vaginal stenosis
    - Pain during intercourse
    - Loss of libido
- Strategies for dealing with vaginal atrophy and dryness include
    - Using vaginal moisturiser
    - Using a water-based lubricant that is pH neutral with no irritating ingredients for all penetrative sexual activities
    - Using a local oestrogen cream to promote epithelial regeneration (for non-hormonal sensitive tumours)
        - One study suggests hormonal replacement therapy has a positive impact on sexual health leading to less vaginal dryness, less pain during intercourse and more sexual enjoyment.
- Vaginal bleeding during or after intercourse is most often caused by small, easily ruptured blood vessels (telangiectasia)
    - This is harmless if the blood loss is minor.
    - Vaginal moisturiser or a local oestrogen cream may help.
- Vaginal adhesion (the sticking together of the vaginal walls) is more concerning
    - In the early stages, adhesions look like small folds and can easily be resolved manually.
    - In more advanced stages, adhesions in the lower third of the vagina may lead to pain and bleeding and ultimately this can cause vaginal occlusion, which is not surgically correctible.
    - To prevent vaginal adhesions:
        - Separate the vaginal walls regularly.
        - Dilate the vagina with a finger or a dilator (available for free from most hospitals). If using a dilator, insert the dilator up to the very end and turn it clockwise for several minutes.
- Vaginal stenosis causes fibrotic changes that make the vaginal tissue more rigid. This leads to pain during intercourse.
    - Dilation is the standard treatment strategy:
        - It should start early after treatment (~4-6 weeks, when there is no more inflammation).
        - It should be done regularly (daily or at least 3 times a week).
        - It should be continued for many years.
- There is low patient compliance with dilation and other preventative measures. The reasons why patients do not want to focus on sexual health include:
    - The survivorship effect ("I just survived cancer, this is the last thing on my mind")
    - The impact of other side effects on daily life (bladder, bowel problems, fatigue etc.)
    - A lack of libido
    - Trauma from disease and treatment (needing more time to heal not only physically but also mentally)
- Medical referrals may be another obstacle. Some doctors assume women don't need assistance with sexual rehabilitation based on their age, sexuality, relationship status or religion.
- To make vaginal dilation more comfortable, there are different options:

  - Use a tampon with vaginal cream and leave it in the vagina overnight to prevent occlusion.
  - Use a vibrator made from medical silicone.
- To deal with pain during intercourse
  - Use protective bumper products designed to reduce the depth of penetration.
  - Explore sexual positions that reduce pain.
  - Focus on extended foreplay. Orgasm has the added benefit of improving vaginal health.
- Pelvic floor exercises may also be useful but it is important to identify what is wrong with your pelvic floor. Exercises will vary depending on the pelvic floor issue.
  - A tense pelvic floor is very common.
  - In more complex cases, biofeedback tools or consultation with a pelvic pain physical therapist may help.
- Rediscovering the libido often takes some time. The brain is the largest organ involved in women's sexual life, and after cancer diagnosis and treatment, it is common and normal to lose interest in sex. This is because:
  - Survivors need to regain a sense of their genitals as a private zone and to rediscover them as a source of pleasure and not of pain and threat. Invasive treatments like brachytherapy can be particularly traumatising.
  - Time is needed to observe and cope with changes.
  - Time, gentleness and understanding are needed for sexual thoughts and fantasies to return along with the rediscovery of pleasurable sensations.
- Basic practical advice:
  - It may be helpful to think of the return of sexual desire as a sign of vitality, vibrancy and getting back into life (the "defeat of cancer").
  - Try to reintegrate sensuality and intimacy into daily life.
  - Sometimes sexual desire needs a jump-start (experimenting with erotic material, sex toys etc.)
  - Self-care can be a good starting place.
  - Talking to a sex therapist or psycho-oncologist can be helpful.
- **Patience and compassion are key.** After cancer diagnosis and treatment, there are massive changes, including to sexual life. This is not about grieving what was lost or was normal before. It's more about how to create a new normal with a lot of understanding for your own body. It's about understanding that your body is vulnerable now and is different to how it was before. It's physically different and it's also emotionally different.
- **ENGAGe will soon release a self-help booklet about sexuality after cancer.**

# Diagnosis curator for patients getting a cancer diagnosis

**(presented by Eva-Maria Strömsholm, Gynecological Cancerpatients in Finland)**

> *"A diagnosis curator could be a kind of mental first aid for a patient who has just been diagnosed with cancer."*
>
> *Eva-Maria Strömsholm*

## Key messages

- The idea of the diagnosis curator is that within 1 to 3 days after getting a cancer diagnosis, every cancer patient should be offered support – from a diagnosis curator.
- This is because a cancer diagnosis can be a shock for a patient. They may feel lost and overwhelmed by all the information and feelings that a diagnosis brings.
- A diagnosis curator is a healthcare professional who can give patients the big picture about their situation and help them through the worst part of the crisis phase so they have more strength to recover from cancer treatment.
- How would this work?
    - The patient receives the cancer diagnosis.
    - Their doctor or nurse contacts the diagnosis curator about the new patient.
    - The diagnosis curator meets the patient within 0-3 days at the hospital.
    - The diagnosis curator listens to the patient's worries and repeats the information from the doctor about the diagnosis and possible treatments.
    - The patient can better cope with the acute crisis immediately after a cancer diagnosis and they are not left alone.
- The benefits of this system would include:
    - Promoting the mental well-being of the patient
    - Helping the patient understand their illness and also their own strengths and resources.
    - Promoting the patient's mental recovery – a crucial part of rehabilitation.
    - Investing in psychological supports from the very start.

- After 1 to 3 appointments, the diagnosis curator will refer the patient to additional supports if they are needed.
- The European Reference Network on Rare Adult Solid Cancers (EURACAN) has surveyed gynaecological cancer centres about the diagnosis curator idea. The results showed that:
    - 50% of centres had a coordinating nurse but only for medical care.
    - 79% had a worker who looked after patients' psychological needs – this was usually a psychologist.
    - These systems were set up locally but national-level programmes were not common.
    - 100% of centres supported having a diagnosis curator for gynaecological cancer patients at the hospital.
- Patients themselves say they would like their care to include:
    - Discussion of long-term side effects and help with managing them so they are not left alone with the problems.
    - Discussion of fertility issues and alternatives before undergoing surgery and chemo treatment.
    - Access to psychosocial support and peer support groups.
    - An individual rehabilitation plan from the start of the cancer journey.
    - Help with getting back to school or work after treatment.
- About Gynecological Cancerpatients in Finland:
    - Founded in February 2020 by gynaecological cancer patients.
    - A nationwide and bilingual (Finnish, Swedish) patient association.
    - Emphasises the prevention and early detection of gynaecological cancers.
    - Aims to improve the quality of life of gynaecological cancer patients and to advance their rehabilitation.
    - Coordinates four patient networks via Facebook.
    - Runs a peer support group via Teams.
    - For more information, contact: info@gysy.fi

***Resources***

*https://gysy.fi/en/information-about-the-association*

# Who knows how to treat my rare cancer?

**Presenter: Prof. Philippe Morice (France)**

> *"Patients [with rare cancers] do not have to be so isolated. We have a connection, a bridge to [treat] them in the best way."*
>
> *Philippe Morice*

## Key messages

- Until two decades ago, rare cancers were considered fatal because of the lack of knowledge about how to cure them.
- According to the scientific definition, a rare disease is one with an incidence of 6 cases per 100,000 people.
    - In gynaecological oncology, this mainly refers to ovarian diseases although some uterine and cervical diseases are also included.
- Rare gynaecological cancers are mainly seen in young patients and so the treatment often has a secondary aim: to preserve fertility options, i.e. the uterus and at least one ovary.
- **EURACAN** is a very important network that works on rare cancers across Europe. It covers non-gynaecological cancers as well.
    - The network connects a wide range of experts (medical oncologists, surgeons, radiation oncologists, etc.) across the continent. Pathologists are crucial contributors since they characterise the histological or molecular characteristics of a disease.
    - The goal is to work together to find the best possible treatment for the patient with the rare cancer.
- France also has an organisation at national level: the French National Network dedicated to Rare Ovarian Malignant Tumours:
    - Founded around a decade ago, the network includes 3 national + 22 regional expert centres
    - Its aims are:
        - To increase the number of patients with rare ovarian diseases whose treatment strategy is decided through dedicated regional multidisciplinary tumour boards (MDTBs).

  - To ensure the most accurate possible diagnosis including systematic second review by an expert pathologist.
  - To disseminate the latest knowledge to the medical community through education programmes and clinical practice guidelines

- A doctor can submit the rare cancer patient's case and access the best practice standards on every aspect of treatment– indications for chemo, what kind of chemo, what kind of staging surgery, etc. The patient stays anonymous.
- As the science on rare gynaecological cancers is moving extremely fast, clinical practice standards are updated each year.
- The network now responds to almost 1500 cases a year as the incidence of ovarian and other gynaecological cancers continues to rise. So rare cancers are actually relatively frequent.
- The diagnostic review process leads to a change in the medical strategy in nearly 10% of cases. This may mean life-preserving surgery that would not have happened if the patient hadn't been referred to a centralised hub.
- The final area of the network's work is clinical trials. Although organising trials for a rare disease is very difficult, it is possible. There are two ways this can be done:
  - The trial can be run across different countries.
  - It can be a basket trial. This clinical trial is not limited to a single cancer site but may include tumours at different sites with the same molecular alterations.
- ESGO has been involved in developing several apps that provide a similar multidisciplinary dedicated rare cancer network at European level.
- The network model is very important because these cases are highly complex. This means they require a robust pathological review along with input from experts fluent in the latest research.

## Discussion

### An ENGAGe member asked: "Is there anything patient advocacy groups can tell women with rare cancers who are looking for treatment centres?"

**Prof. Morice's response:**

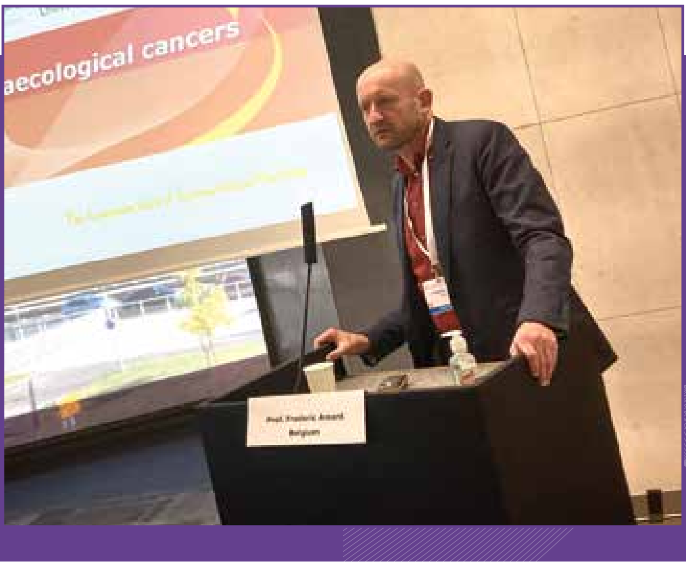
*"I've mentioned what exists in France, but fortunately, it's not the sole country in Europe with this kind of robust network. If a patient is asking how to manage this, they can go to the EURACAN website, and there are some specific fields they can fill in there. There's mapping that exists in different countries. So patients are not so isolated. We have a connection, a bridge to [treat] them in the best way."*

*Resources:*

*https://euracan.eu/expert-centres-referral-pathways/experts/*

# Fertility preservation in gynaecological cancers

**Presenter: Prof. Frédéric Amant (Belgium)**



> *"[After a cancer diagnosis], many young women are faced with problems around their fertility. And the message I want you to take home is that although fertility is endangered, there is the potential to preserve it in some cases."*
>
> *Prof. Frédéric Amant*

## Key messages

- Fertility preservation is often possible in the early stages of gynaecological cancers.
- However this means deviating from the standard (most effective) treatment protocol so the patients involved must be highly motivated.
- The fertility team becomes involved if a patient has a cancer diagnosis and wants to preserve her fertility. The team assesses whether the patient is a good candidate for fertility preservation treatment. This means looking at internal factors:
    - Overall health
    - Ability to give informed consent
    - Age
    - Ovarian reserve – capacity to become pregnant later on
- The team also considers external factors:
    - The type of cancer treatment (drugs, radiotherapy, etc.) and its toxicity to the ovaries and the uterus
    - The time available and the urgency of the cancer treatment; some emergency treatments do not allow enough time for fertility preservation procedures
    - The availability of local expertise and resources
- Lastly there are unknown risks:
    - Smoking
    - High body mass index
    - BRCA mutations
    - Particular cancer types
    - Impact of targeted agents on fertility
- If the patient qualifies for reproductive assistance, there are options:
    - An embryo can be frozen for later use (in vitro fertilisation) in the woman or a surrogate mother if this is legally allowed.

  - Ovarian tissue or cells (oocytes) can be stored until the woman has recovered from the cancer.
  - The ovaries can be transposed (moved out of the field of radiation) or drugs can be given so they are less sensitive to chemotherapy.
- Storage involves freezing embryos or ovarian cells at -180 degrees Celsius (cryopreservation).
- In vitro fertilisation is the most efficient method for preserving fertility.
  - The success rate is about 1 in 3 for women younger than 35 years old; when women reach 41 or 42, the rate drops to around 20%.
  - The protocol takes 4-6 weeks and delays cancer treatment.
  - A source of donor sperm is required.
- The freezing of ovarian cells is a method for women who cannot freeze an embryo.
  - The cell is frozen and then thawed for subsequent fertilisation.
  - Subsequent live births have been reported, but the data is limited to small case studies.
  - The success rate varies from 5 to 15% depending on the treatment centre. Many cells die in the thawing process.
- An ovariectomy is the removal of the whole ovary.
  - The ovary or some of its tissue is then frozen so that it can later be used or implanted into the patient after recovery from cancer.
  - In many cases the ovary becomes active again. However there is a risk that restoring the ovary could implant cancer cells into the patient.
  - For this reason, this procedure is becoming less popular.
- Other gynaecological techniques aim to reduce the damage that anti-cancer treatments can do to fertility:
  - Transposing the ovaries, i.e. moving them as high as possible, can take them out of the radiation field. They can later be repositioned to allow for conception.

    - The success rate for this procedure ranges from 33% to almost 92% depending on the clinic where it takes place.

    - There is a risk of damage to the ovaries due to insufficient blood supply.

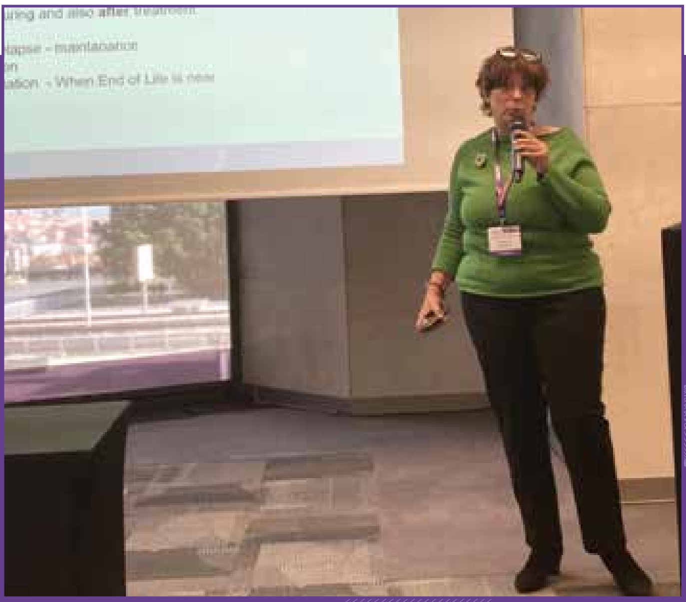
    - The procedure is limited to young women who are only receiving radiotherapy.
- The cancer type and severity also determine whether preserving fertility is an option:
  - Cervical cancer: For small tumours, conisation (removal of a cone-shaped piece of abnormal tissue) is the standard. For larger tumours, some centres have used radical surgery that damages the uterus. Recent studies support using neoadjuvant chemotherapy to shrink the tumour before less radical surgery.
  - Ovarian cancer: Fertility-sparing surgery can be safely offered to all stage IA and IC1 low-grade ovarian carcinomas. For stage IC2, IC3 and grade 3 disease, recurrence is more likely and this risk must be discussed with the patient. There are no fertility preservation options for higher grade cancers.
  - Endometrial cancer: Options are only available for grade 1 non-aggressive cancers that do not invade the uterus. Treatment includes taking high-dose hormones for six months.
- The International Network of Cancer, Infertility and Pregnancy has established a virtual advisory board where physicians can submit the cases of infertile patients or patients who want to preserve their fertility. Doctors receive input from a panel of experts in the field. The advisory board hopes to work together with national tumour boards.

***Resources***

*https://www.esgo.org/network/incip*

# End-of-life lecture

**Presenter: Andrea Krull (Germany)**



> *"We need the option to choose. We need somebody who explains this is one option, this is another option and please think about what is best for you. […] We need it during treatment, after treatment and especially if we are dying."*
>
> *Andrea Krull*

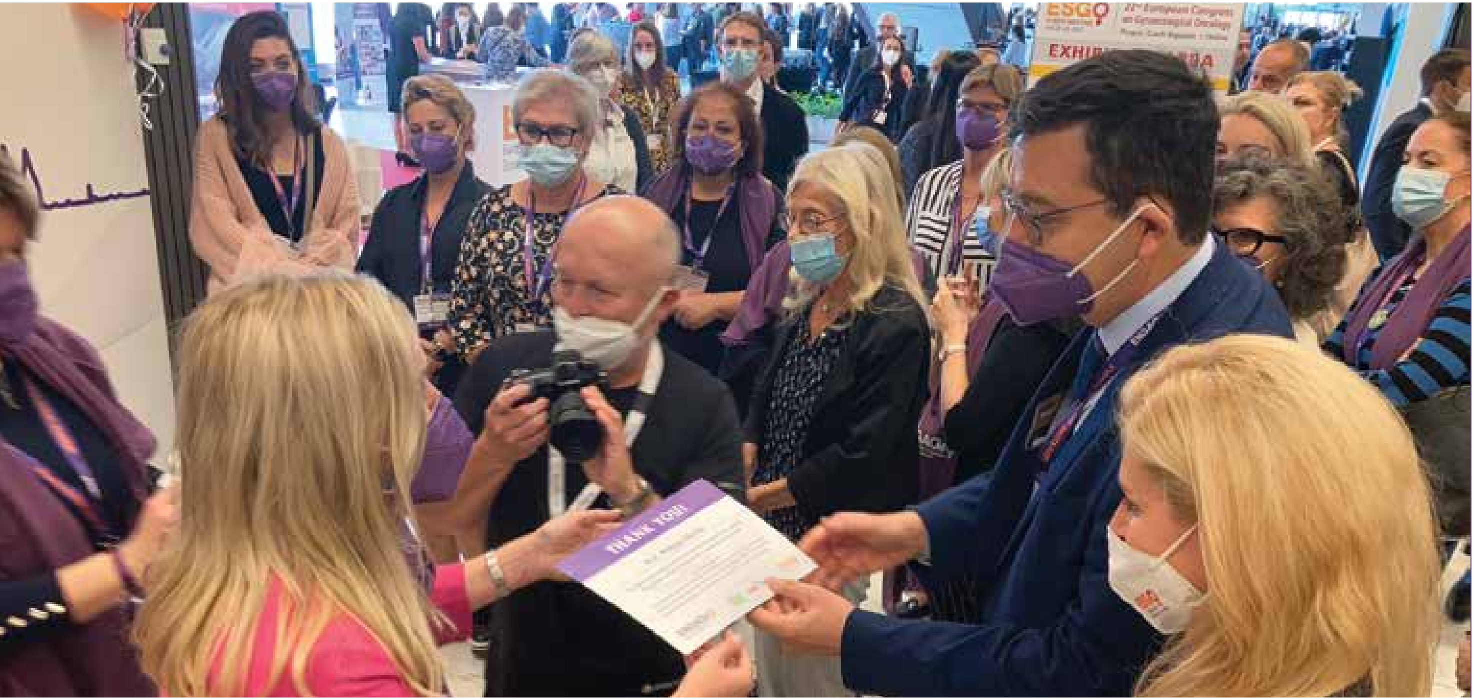
## Key messages

- Andrea was diagnosed with stage 4 ovarian cancer in 2013. She is the chairwoman of the German Association of Ovarian Cancer.
- The association supports women across Germany. It runs an information hotline, hosts online meetings and workshops with experts, educates and trains medical staff and creates brochures and public awareness campaigns about ovarian cancer.
- After they receive a gynaecological cancer diagnosis, women often feel alone and confused and have trouble talking about their situation. Many assume the diagnosis means they will die soon. Few feel that they have enough help or are fully informed and know what to do.
- When asked about their wishes for the end of their lives, these women said they wanted:
    - All facts and concerns to be openly addressed, discussed, clarified and taken care of by their clinic or doctors.
    - To live for as long as possible with a good quality of life.
    - To be supported with empathy and care.
    - To have the same medical contact/supporting doctor throughout their care.
    - To experience little or no pain and to have close contact with a doctor/nurse.
    - To be relieved of anxiety.
    - To experience as good a death as possible.
    - To receive early referrals to appropriate nursing staff.

- Doctors are placed in a difficult position when they have to tell someone they're at the end of their life. They may be seen as potential saviours and preventers of doom. In this tough position, doctors should:
    - Take the patient's concerns very seriously.
    - Be aware of the great existential importance of the conversation.
    - Accept the patient's view as decisive.
    - Communicate in a way that instils trust and confidence: make eye contact, listen well, ask questions and give additional and targeted information.
- However these needs are sometimes forgotten in the daily stress of clinics and practices.
- This is why Andrea's mission is to help doctors and patients understand one another's perspectives. She wants to break the taboo around talking about dying. She is also working to reduce patients' anxieties so they can feel more peace.
- This work led her to write a booklet about dying. It has also inspired other projects:
    - Running workshops about end-of-life issues for nurses, doctors and patients.
    - In the shoebox project, patients are invited to fill a shoebox with photos, letters, memories and other keepsakes for their loved ones. Preparing these boxes is a deeply meaningful and emotional experience for these women. The boxes are a chance to have important conversations with the family and say goodbye.

# Happening: ORANGE MEETS PURPLE

## *Doctors and Patients TOGETHER*

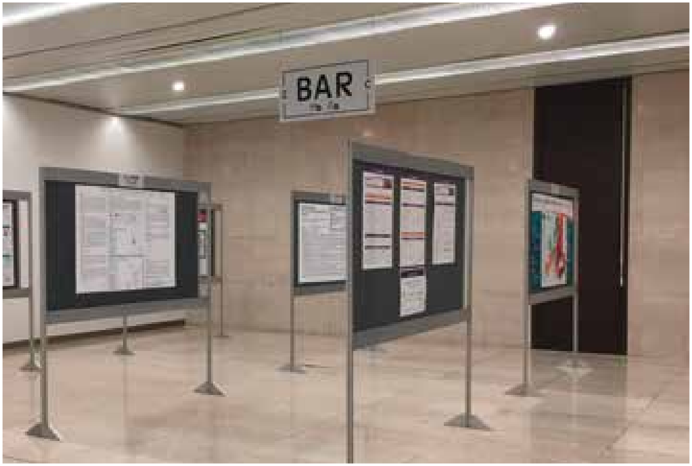


*ESGO doctors and ENGAGe patient advocates came together for a special ceremony at a unique photo wall at Prague Congress Centre on October 23, 2021. This wall in the colours of the two networks was inspired by their common work to improve the communication about gynaecological cancers at both a European and local level. "On behalf of ENGAGe, I want to thank you for all your support and help, " outgoing Co-Chair Icó Tóth told Philippe Morice, Past President of ESGO. "We need your input, we need your ideas, we need your activity," Morice said.*

## ENGAGe Information Booth

*ENGAGe had its own information booth at the European Society of Gynaecological Oncology Congress from October 22 to 24 in Prague. Selin Bayrakl and Anika Adámková from ENGAGe Teens shared information about ENGAGe's mission and projects and copies of its latest patient publications.*

# ENGAGe Poster Presentations



*Eleven poster presentations about the innovative work of patient advocacy groups across Europe were on display at Prague Congress Centre from October 22 to 24, 2021. These posters showcased national and local efforts to help prevent and detect gynaecological cancers and support patients. They were viewed by ESGO and ENGAGe delegates at two separate locations.*

# Mid-Session Yoga Break

*Participants took a yoga break between sessions at the Patient Advocacy Seminar on October 22, 2021.*

# ACKNOWLEDGEMENTS

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

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

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

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# Notes

# Notes

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