

2022

Patient Advocacy Seminar Report



ESGO ENGAGe Patient Seminar in Gynaecological Cancers

October 28–30, 2022

Held during the European Society
of Gynaecological Oncology Congress
in Berlin, Germany.



TABLE OF CONTENTS

About ESGO	4
ESGO's mission	4
About ENGAGe	5
ENGAGe's mission	5
Objectives	5
Welcome remarks	7
Oncogynaecology in war: Stories of invincible Ukrainians	7
Workshop Part I: Aspects of healing & the rediscovery of creativity from the European Art Guild for Medicine & Culture	8
Workshop Part II: Creative writing for emotional & mental health by the German Ovarian Cancer Foundation	8
Patients involved in organisations—why is it important?	9
Outdoor against Cancer (OAC) connects us—OACCUs: EU Network for Young Cancer Survivors	10
Gynaecological cancer during pregnancy	11
Fertility preservation in cancers	12
Hormonal substitution in gynaecological cancer treatment	13
ENYGO-ENGAGe survey on sexual health after gynaecological cancer—preliminary results & workshop	14
HPV DNA Screening: An update	15
Treatments (immunotherapy, PARP inhibitors)	16
Long-term survival with gynaecological cancer	17
Clinical Trials Workshop	18
Roundtables with doctors	19
European cooking event	20
Olivia: The digital patient pathway launch	21
Posters	23
ENGAGe booth & ENGAGe Teens	24
Acknowledgements	26



About ESGO

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

ESGO's mission

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



About ENGAGe

Established by ESGO in 2012, the European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) is a network of European patient advocacy groups representing all gynaecological cancers (ovarian, endometrial, cervical, vulvar and rare cancers).

ENGAGe'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

Jalid Sehouli and Petra Adámková, ENGAGe Co-Chairs, and Nicole Concin, ESGO President, opened the meeting. ENGAGe celebrated its 10th anniversary in 2022, and so they and the group toasted the successes the network has enjoyed in the last decade.



*"We're really proud of you.
The work you do is amazing."*

Nicole Concin, ESGO President

**Save the date for the 2023
Patient Advocacy Seminar, Sept 29–Oct 1 in Istanbul!**

See you in Istanbul!



**Watch selected presentations from PAS 2022
on our YouTube Channel!**

<https://youtube.com/@engageesgonetwork4257>



Oncogynaecology in war: Stories of invincible Ukrainians

One of the ENGAGe Teens members, Margaryta Lyzogub, from Ukraine reported on the current situation for gynaecological cancer patients and doctors during the war, many of whom have had to flee to neighbouring countries to pursue their care.

The structure of care has changed drastically. She played a video titled Oncogynaecology in war: stories of invincible Ukrainians, which featured touching video testimonials from some of the people affected.



"It's much easier to realize that you're not alone in this struggle and in this fight... right now, my country is facing one of the darkest times, but in the dark, the stars shine the brightest. So thank you for supporting us all this time, and we hope that this challenge would make us stronger."

Margaryta Lyzogub, Ukraine

WORKSHOP PART I: Aspects of healing & the rediscovery of creativity

Adak Pirmorady, Germany, and Susanne Diehm, Germany



"If we want to talk about healing processes, or about good medicine, then we have to also think about the psyche."

Adak Pirmorady

WORKSHOP PART II: Creative writing for emotional & mental health by the German Ovarian Cancer Foundation from the European Art Guild for Medicine & Culture



"Creativity is released when you write. This helps to overcome the psychological effects of a bad diagnosis."

Susanne Diehm

Patients involved in organisations —why is it important?

Eva-Maria Strömsholm, Finland



"We in the Nordic countries also need good qualitative cooperation between patient organizations and doctors. And this network [NGPO] is a first step to do so."

Eva-Maria Strömsholm



Key messages

- It's important to involve patients, doctors and healthcare professionals together to develop care and find new solutions when challenges arise. Patients are the best experts in their own situation and even though professionals have professional expertise, they are not always able to put themselves in the patient's position, so sometimes there can be things left unnoticed.
- EURACAN is the European Reference Network (ERN) for Rare Adult Solid Cancer.
- ERNs are virtual networks involving healthcare providers across Europe to enable the sharing of expertise and to improve access to care for patients across the European Union, especially for complex or rare medical diseases that require highly specialised healthcare and a concentration of knowledge and resources.
- EURACAN groups together all rare adult solid cancers into ten "domains;" the EURACAN G2 domain is for Rare Gynecological Cancers.
- NGPO is the Nordic Gynaecological Patient Organisations: Suomen Gynekologiset Syöpäpotilaat ry in Finland, Nätverket mot gynekologisk cancer and Gyncancerförbundet Värmland in Sweden, KIU, Kräft i underlivet in Denmark, and Gynkräftföreningen in Norway.
- NGPO is working toward good palliative care for all, access to adequate drugs in Nordic countries, visibility for rare cancers, and for long-term side effects to be better discussed with patients.

Reference: <https://euracan.eu>

Outdoor against Cancer (OAC) connects us —OACCUs: EU Network for Young Cancer Survivors

Petra Thaller, Germany, Founder & President of Outdoor Against Cancer



"Destiny chose me as a cancer patient and during my own chemotherapy I founded Outdoor Against Cancer."

Petra Thaller



Key messages

- The four pillars of a healthy lifestyle are physical activity (including outdoor sports), balanced nutrition, sustainability and nature, and physical and mental well-being.
- Reduced sedentary behaviour is linked to lower cancer risks.
- A high proportion of cancer survivors experience potentially serious diet-related problems.
- Being in "green" and "blue" spaces help mental health and cognitive function.
- There is an association between low physical activity and risk of depression.
- Adopting a healthy lifestyle is related to substantial risk reduction in cancer morbidity.

Resources: <https://www.outdooragainstcancer.de>

Gynaecological cancer during pregnancy

Michael Halaška, Czech Republic

"Having cancer at a young age is always shocking for everybody. But moreover, it's during a period which is supposed to be like the most enjoyable period of life of woman—because she's looking forward to pregnancy.

She's looking forward to the child. And suddenly, she's shocked that she has cancer and that she has to undergo some examination and treatment and so on. And actually, unfortunately, some of the cancers are advanced stage, so that means that we try to spare the life of the patient, but also we try to spare the life of the child as well.

So at one shot, we are dealing with two lives, which makes it really complicated."

Michael Halaška

Key messages

- Pregnancy itself has no impact on the prognosis of gynaecological cancers. Surgery as well as chemotherapy should be done, preferably after the first trimester.
- Lymphadenectomy can be performed until the 22nd week of pregnancy.
- Reoperation for ovarian cancer should be considered after delivery.
- Pregnant patients should be referred to a specialized centre with a dedicated team and perinatologic unit.
- Afterward, a close follow-up should take place with the mother, fetus, and child by a skilled neurologist.
- Imaging techniques for pregnant patients vary. Ultrasound is the method of choice. MRI is widely used after the first trimester. PET scanning is not recommended.
- Treatment options for pregnant patients differ depending on the stage of the pregnancy. Radiotherapy is possible through the second trimester. Cone biopsy and surgery may be possible through the whole pregnancy. Chemotherapy may also be possible in the second and third trimester. Termination of the pregnancy is possible to allow for other treatments until the 24th week.
- Special issues concerning surgery include surgery after the first trimester, avoiding manipulation of the uterus, and other. Laparoscopy may be feasible.
- Chemotherapy during pregnancy is not contraindicated after the first trimester.
- Ovarian malignancies occur in 2–5% of pregnancies, but in 90% of the cases regresses simultaneously.
- For breast cancer patients, the complication rate and indications for surgery are similar or the same for pregnant and non-pregnant patients.

Resources: Cancerinpregnancy.org

Fertility preservation in cancers

Frédéric Amant, Belgium



Key messages

- Fertility preservation is frequently possible in early stage gynae cancers. It's important to take a referral to an onco-fertility clinic with protocol (deviation of standard treatment, motivated patient, assisted reproductive techniques...)
- Patients should take counselling, especially on the following points: the preservation of fertility is no guarantee for a successful pregnancy, and there are no randomised studies.
- Patients who undergo fertility preservation must have a strong desire to retain fertility, but age and proven fertility (or infertility) is not necessary.
- Several interventions are possible for fertility preservation: ovarian biopsy or oophorectomy, ovarian stimulation, IVM, ovarian transposition. These combine with ovarian tissue, oocyte or embryo cryopreservation.
- Ovarian transposition is a method that can be used for younger cancer patients. In it, the ovaries are moved laterally and upwards in the abdomen, outside the field of irradiation.
- The type of cancer may affect whether fertility preservation is recommended or not. In ovarian cancer, fertility sparing surgery can be offered in case of >stage 1 germ cell ovarian cancer. For endometrial cancer, the ESGO-ESMO-ESTRO Guidelines are followed.
- In addition to the pertinent ESGO network INCIP (International Network on Cancer, Infertility and Pregnancy), which includes 75 centres in 30 countries, there is an advisory board. The Advisory Board on Cancer, Infertility and Pregnancy (ABCIP) works together with INCIP and physicians on a national and international level.
- ABCIP has a form for patients to ask for advice.

Resources:

<https://guidelines.esgo.org/about/guidelines-in-development/endometrial-cancer/fertility-sparing-treatment-guidelines/>

www.ab-cip.org

Hormonal substitution in gynaecological cancer treatment

Desislava Dimitrova, Germany

"The individual risk of the patient should be evaluated before starting of the therapy... and we need to regularly reassess if the hormone replacement therapy should be continued if the symptoms are still there."

Desislava Dimitrova, Germany



Key messages

- Hormone replacement therapy is necessary when there are menopausal symptoms, there is an ovarian insufficiency due to surgical removal of the ovaries or due to chemotherapy or radiotherapy, or there is primary ovarian insufficiency.
- Menopause is defined as the absence of a period for one year. The menopausal transition has three stages: Pre-Menopausal Transition, Early MT, and Late MT.
- Oestrogen affects many places in the body; more than just the reproductive organs. It increases body temperature and mood, regulates collagens in the skin, lowers cholesterol, and affects the cardiovascular system.
- Hot flashes are a common symptom of menopause. They are transient sensations of heat, sweating, flushing, anxiety, and chills lasting for 1–5 min. They affect 85% of all postmenopausal women, usually for 5–10 years.
- Vulvovaginal atrophy (VVA) causes dryness, burning, itching, vaginal discomfort, pain and burning when urinating, dyspareunia, and spotting during intercourse. It affects up to 50%–60% of postmenopausal women.
- Lack of oestrogen during menopause is also associated with bone loss and osteoporosis.
- Hormone replacement therapy can be oestrogen alone or a combination of oestrogen and progestogens. It is applied orally, vaginally or transdermally. This therapy can alleviate menopausal symptoms, reduce risk of osteoporosis and improve the quality of life. It is not a contraceptive.
- Contraindications for HRT include: Current, past or suspected breast cancer; oestrogen-sensitive malignant tumour; undiagnosed genital bleeding; untreated endometrial hyperplasia; previous idiopathic or current venous thromboembolism; active or recent arterial thromboembolic disease (angina, myocardial infarction); untreated hypertension; active liver disease; porphyria cutanea tarda.
- Taking types of HRT can increase risk for certain other diseases, including stroke and breast cancer (estradiol + progesterone) and endometrial cancer. Micronized progesterone is considered safer. In addition, taking oral oestrogen is linked to increased risk of venous thromboembolism, though transdermal application is not.
- HRT should be avoided in granulosa cell tumours and uterine sarcoma.
- Phytoestrogens are a class of compounds, non-steroidal, either of plant origin or metabolically derived from plant precursors.
- Periodic assessment of the need for ongoing use of hormone therapy should be individualized on the basis of a woman's menopause symptoms, general health and underlying medical conditions, risks, treatment goals, and personal preferences.

ENYGO-ENGAGe survey on sexual health after gynaecological cancer—preliminary results & workshop

Zoia Razumova, Sweden, and Kathrin Kirchheiner, Austria

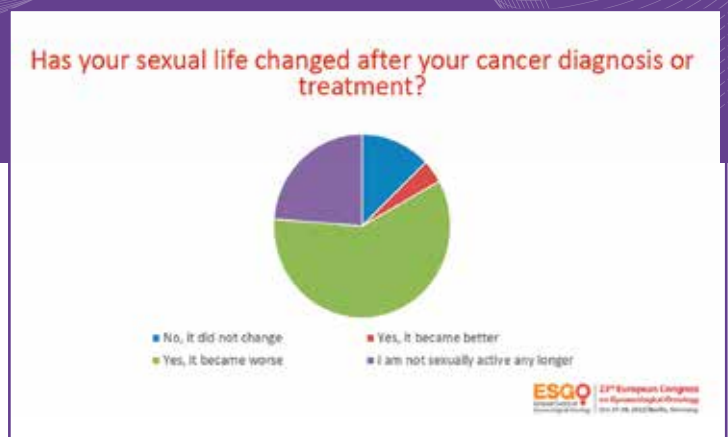


Sex is much more than talking about intercourse or having intercourse, sexual health is as a topic, it's so much broader, it affects so many areas of your life."

Kathrin Kirchheiner

Key messages

- The ESGO-ENYGO-ENGAGe Survey on Sexual Health after Gynaecological Cancer launched in October 2021. It had patient-driven questions and was developed with the help of a psycho-oncologist and clinical psychologist. Questions were translated in 10 languages.
- In total 609 responses were collected from countries in Europe, North and South America, and New Zealand.
- By a large margin, most respondents answered NO to the questions if their health care team addressed their sexual health issues and if they were offered sexual consultations after cancer diagnosis and treatment.
- If they were offered sexual counseling, 60% of the patients accepted it.
- The majority of respondents said that their sexual life changed for the worse after receiving a cancer diagnosis or treatment. Commonly cited symptoms included difficulty reaching orgasm, vaginal dryness, and a lack of sexual desire.
- Common sexual health problems and examples include in the physical realm (vaginal dryness, bleeding, pain), psychological (decreased interest, distress during intercourse, body image problems), and interpersonal (lack of intimacy, impact on relationships).



HPV DNA Screening: An update

Murat Gultekin, Türkiye, ESGO Prevention Committee Chair



“Don’t forget HPV is a virus that we can all—be it in either lower- or higher- or middle-income countries—we can come together and we can fight it, prevent it, and even eliminate it.”

Murat Gultekin

Key messages

- ESGO needs patient voices and patient advocates need ESGO.
- The Prevention Committee’s strategic goals are, briefly, to develop visibility, create advocacy programmes, collaborate with relevant stakeholders (WHO Cervical Cancer Elimination, EU Beating Cancer Plan), contribute to elimination activities, raise awareness of GO Cancers and their prevention to the lay public.
- The WHO, as part of their vision of a world without cervical cancer, has set a “90-70-90” target. By 2023, the WHO aims to make sure that 90% of girls are vaccinated with the HPV vaccine by age 15, that 70% of women are screened with a high-precision test at ages 35 and 45, and that 90% of women identified with cervical disease receive treatment and care, worldwide.
- There is a worldwide trend to high-performance (e.g., HPV DNA) tests, with Pap smears being phased out after 2030. For lower-resource areas, HPV standard tests are available, but triage to genotyping is preferable.
- Some methods for self-sampling HPV assays are now as reliable as clinician-administered tests. Urine, blood, and swab samples are possible, though each has some drawbacks.
- The WHO recommends women follow a screen & treat/screen, triage, treat approach using HPV DNA detection from age 30 with a regular screening interval every 5 to 10 years.
- DNA and mRNA tests are producing similar results, though more testing is underway.
- A recently published ESGO Prevention Committee paper lists the officially recommended primary tests for cervical cancer screening in Europe.

Resources: List of validated assays

<https://bit.ly/ESGOlistofHPVtests>

Treatments (immunotherapy, PARP inhibitors)

Mansoor Mirza, Denmark, Vice President of ESGO, Past Chairman ENGOT

Key messages

Advanced ovarian cancer

- Great advances in treatment have been made for ovarian cancer. Long-term survival is now more easily achieved. PARP inhibitors are a step toward curing the disease, and recent study results are extremely positive.
- The PRIME and ATHENA-mono studies have confirmed the benefit from PARPi-mono in HRp, as observed in PRIMA.
- The data indicates that PARP inhibitors may be suitable for first-line treatment, but it will need to be approved by regulators first.

"In 10 years we have completely changed the magnitude of disease for ovarian cancer."

Mansoor Mirza

Role of immunotherapy in endometrial cancer

- Immunotherapy has shown good results in trials with endometrial cancer patients.
- Updated molecular classifications of EC predict biological behaviour. More trials are needed, though it's not easy to get approval to do a trial since there are such small groups of patients.

Immunotherapy in cervical cancer

- Concurrent chemoradiation for the treatment of locally advanced cervical cancer has resulted in a significant improvement in overall survival.
- The first two phase III trials of immune therapy in cervical cancer are imminent.

Selected further reading

DRUG	TRIAL	REFERENCE
Olaparib	SOLO1	Moore K et al. NEJM 2018
Olaparib + bavacizumab	ENGOT-OV25 PAOLA1	Ray-Coquard I, et al. NEJM 2019
Niraparib	ENGOT-OV26 PRIMA	Gonzales-Martin A...Mirza MR, et al. NEJM 2019
Rucaparib	ENGOT-OV45 ATHENA	Monk et al. J Clin Oncol 2022
Pembrolizumab	KEYNOTE-158	O'Malley D, et al. Presented at European Society for Medical Oncology Congress 2019
Dostarlimab	GARNET	1. Oaknin A, et al. Ann Oncol. 2020;31(suppl_4):S1142-S1215 2. Berton D, et al. J Clin Oncol. 2021;39(suppl_15):2564
Lenvatinib + pembrolizumab	KEYNOTE 775	Makker V, et al. Presented at Society for Gynecologic Oncology Virtual Annual Meeting 2021

Long-term survival with gynaecological cancer

Hannah Woopen, Germany



"All together, the quality of life and the general health status of our long-term survivors in the world is pretty good."

Hannah Woopen

Key messages

- Cancer is a chronic disease. Worldwide, there are 14 million new cancer diagnoses per year.
- "Long-term" survival is defined as longer than five years after the initial diagnosis. More than 65% of cancer patients survive longer than five years in the western world.
- The quality of life of these survivors increases with time. Long-term survivors without recurrent disease rate their quality of life higher than those who have it.
- Over half of long-term survivors report symptoms after five to ten years, as do 40% after ten years. The most commonly cited side effects are fatigue, concentration difficulties, polyneuropathy, and gastrointestinal problems.
- Some 39% of patients with gynaecological cancer develop lymphoedema.
- In studies on long-term survivors and secondary cancers, breast cancer and smoking-related cancers were the most frequent secondary cancer. Cancer patients also have a higher cardiovascular risk than the general population. Changes in lifestyle (exercise, nutrition) can lower these risks.
- The first German Survivorship Clinic for gynaecological cancer patients has been established. The main goals are to improve quality of life, establish early recognition and treatment of long-term side effects, promote physical and psychological health and be an information platform for lifestyle and long-term side effects specific for long-term survival.

Resources:

Survivorship care plan template

Survivorship-clinic.de

Carolinmeetshanna.com

GCIG-Consensus Guideline for Long-term survivorship in Gynecologic Cancer: a position paper from the Gynecologic Cancer Intergroup (GCIG) symptom benefit committee

<https://bit.ly/GCIGConsensusLongTerm>

Clinical Trials Workshop

Ancillary to the PAS, a meeting of the Clinical Trials group was held in Berlin. This project is a collaboration with ENGOT that aims to educate a group of gynaecological cancer patients to a level where they will be able to give the patient perspective in the design and development of clinical trials. The knowledge of this group of patients may also be used in surveys, consensus statements, as co-authors in articles in medical journals, as patient reviews for foundations, etc.



Highlights of the meeting included a lecture on how to write a study protocol, by Ane Appelt from the University of Leeds and Leeds Cancer Centre, UK; a presentation of NOGGO and a preview of study development in gynae cancer, by Jolijn Boer, Germany; and a discussion of clinical trial timelines with ENGAGE Co-Chair Jalid Sehoul, Germany



Roundtables with doctors

Julia Klews, Germany, Prehabilitation. Kristina Lindemann, Norway, Palliative Care. Daniela Fischerová, Czech Republic, Cancer Care.

Roundtable discussions with medical professionals are a popular tradition at the Patient Advocacy Seminar. These small group sessions give the patient advocates a unique chance to ask questions and learn about specific topics.



European cooking event

Jalid Sehouli, Germany; Max Stiegl, Austria; Omar Saad, Germany; Teresa Zukic, Germany; Volker Osieka, Germany; Susanne Fechner and Lisa Sinettermann, Deutsche Stiftung Eierstockkrebs (German ovarian cancer foundation)



*Together we cook
against women's
cancer!*



The Forum Gynäkologische Onkologie invited the ENGAGE PAS delegates to a fantastic, interactive European Cooking event with chefs Max Stiegl, Omar Saad and Volker Osieka and special guest Teresa Zukic. Participants were invited to cook alongside the chefs. ENGAGE Co-Chair Jalid Sehouli prepared a soup and served the group tea.



Olivia: The digital patient pathway launch

ENGAGE is delighted to present Olivia, a digital pathway that contains tailored information to help address the individual needs of ovarian cancer patients and their families and caregivers. Launched on the main stage of the ESGO 2022 Congress by ESGO President Nicole Concini and then at the Patient Advocacy Seminar, Olivia aims to support patients through every step of their ovarian cancer experience.

Discover Olivia: <https://ovarian.gynecancer.org/>

Resources:

Watch an Instagram livestream of our launch at the PAS with ENGAGE Co-Chairs Jalid Sehouli and Petra Adámková, Past Co-Chair Icó Tóth, and ESGO President Nicole Concini.

<https://bit.ly/OliviaLaunchatPAS>



Watch Icó Tóth introduce us to Olivia on an Instagram livestream

<https://bit.ly/IcoIntroducesOlivia>



Watch Andrea Krull tell her story in an Instagram reel

<https://bit.ly/AndreasOliviaStory>



Posters



Once again, ENGAGe members displayed posters of their projects in the main hall of the ESGO Congress.

Watch presentations of the posters on our YouTube Channel:

<https://youtube.com/@engageesgonetwork4257>



ENGAGe journey since 2012

Patient Advocacy Seminars



ENGAGe leadership



Clinical trials project



**INFORMATION
IS POWER
BUT COMMUNICATION
IS THE SOLUTION**

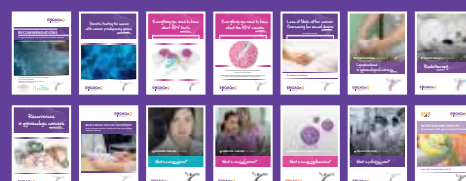
World GO Day

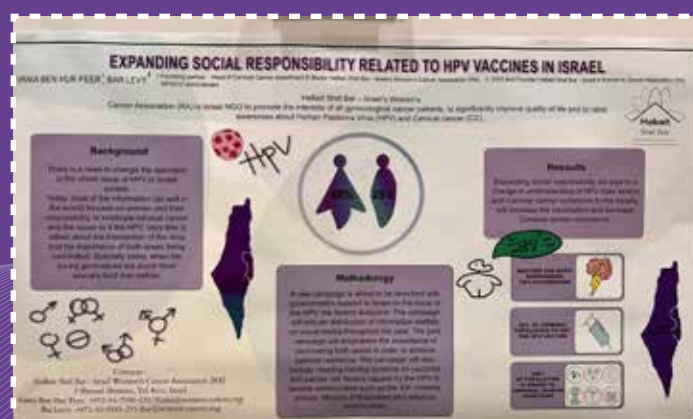
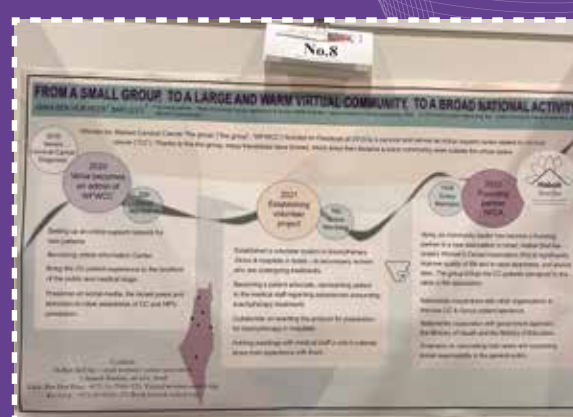


ENGAGe TEENs project



Brochures





ENGAGE Booth & ENGAGE Teens

The ENGAGE Booth in the main hall of the ESGO Congress was a big hit! We were glad to introduce our network and highlight our projects to delegates from around the world. And big thanks to the ENGAGE Teens for pitching in at the booth! Their comic on HPV was well-received.

The ENGAGE Teens is a branch of ENGAGE who are raising awareness about HPV, cervical cancer and the HPV vaccine, particularly among youth! We were pleased to welcome new project leader Francesco Di Fino, from Italy. He is taking over from Selin Bayrakli, from the USA.

Follow ENGAGE Teens on Instagram: <https://instagram.com/engageteens>





ACKNOWLEDGEMENTS

ENGAGe would like to thank 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.

AstraZeneca 

GSK

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THERAPEUTICS

 MSD

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