REPORT

PATIENT SEMINAR

IN GYNAECOLOGICAL CANCERS

NOVEMBER 04-05, 2017

Held during the 20th International Meeting of the
European Society of Gynaecological Oncology (ESGO)
November 04-07, 2017 I Vienna, Austria

ENGAGe
ESGO European Network of Gynaecological Cancer Advocacy Groups

The European Voice of Gynaecological Cancers Patients

ESGO
European Society of Gynaecological Oncology

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About ESGO

The European Society of Gynaecological Oncology (ESGO) is the leading European organization with more than 1800 professionals involved in treatment, care, and research of gynaecological cancers.

ESGO's Mission:

ESGO strives to improve the health and well-being of European women with gynaecological (genital and breast) cancer through prevention, excellence in care, high-quality research, and education.

Activities:

+ Publications: International Journal of Gynaecological Cancers (co-owner), Textbook in gynae-oncology, LiFE Report – reviews of the most relevant published articles
+ Primary event in the field: ESGO Congress
+ Professional niche events: State of the Art Conference, Masterclass, Workshops
+ ESGO eAcademy: a unique comprehensive Knowledge Portal for postgraduate education
+ 6 established Networks, including ENGAGe and 3 Task Forces
+ Development of Clinical Guidelines for Ovarian, Vulvar, Endometrial and Cervical Cancers

Opening Remarks

Murat Gultekin,
Patient Seminar Co-Chair

Dina Kurdiani,
Patient Seminar Co-Chair

Denis Querleu,
ESGO President

Esra Urkmez,
ENGAGe Co-Chair

Key Messages

- The European Society of Gynaecological Oncology (ESGO) values ENGAGe and the patient seminar and is committed to engaging gynaecological cancer patient advocacy representatives in its mission to improve the quality of care for European women with gynaecological cancers.
- ESGO hopes that ENGAGe will enhance the role of patient advocacy groups and encourages patient advocacy representatives to take an active part in the dissemination of the knowledge to gynaecological cancer patients, their caregivers, other advocacy groups and the public.
- Enhancing the collaboration with patient advocacy representatives is a key step in understanding the patients' needs and improving access to treatment and care for patients.
- The 2-days ENGAGe patient seminar programme is an opportunity for patient advocacy representatives to listen to and learn from the best experts in the field and get the most updated information first hand, as well as share and exchange knowledge with peers and experts.
- Next ENGAGe Patient Seminar will be at the State of the Art Conference in Lyon, France, Oct 4-6, 2018.

About ENGAGe

Established in 2012, the European Network of Gynaecological Cancer Advocacy Groups in Europe is a network of European patient advocacy groups established by ESGO representing all gynaecological cancers particularly (ovary, endometrial, cervix, vulva, and rare cancers).

Objectives

- Facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate 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 in ESGO activities by education on current research and health policy.
- Advocate patient care policies, practices, and access to appropriate care at both national and European levels.
- Educate patient groups, health professionals, the public and health decision makers.

BLOCK SESSIONS 1

What Is a Clinical Trial?
Development of a New Drug/ New Treatment

Cristiana Sessa, Switzerland and Birthe Lemley, Denmark

"A patient accepted to a trial is asked to sign an informed consent, but can withdraw from the trial at any time."

Key Messages

- Clinical trials are usually conducted on multiple international sites, and hospitals from several countries are involved in the clinical trial.
- A pharmaceutical company or an investigator can start a clinical trial. If an investigator starts the trial and drugs are involved, there is often a collaboration with one or more pharmaceutical companies.
- A clinical trial can be blinded, and the patient does not know if the drug given is the new one being tested or is a comparison drug/placebo.
- In randomised controlled trials, patients are randomly assigned to either treatment or control arms.
- All clinical trials must be approved by an ethics committee and can't start unless the approval is given.
- Clinical trials are conducted in 3 phases, within 7 years, and involve patients with the same disease or condition:
  - Phase I involves a small group of patients, and in less than a year establishes the safety and the dosage of the drug.
  - Phase II involves already several hundred of patients, to test antitumor activity and side effects.
  - up to 3,000 patients participate in Phase III, which tests clinical advantages over standard treatment in daily life, efficacy and side effects.
- Placebo resembles an active medication or therapy, with no active therapeutic effect, so that it functions as a control. However, when there is a recognized standard treatment of proven efficacy there is no possibility of cross-over for cancer patients in the study when the tumor doesn't respond to the first therapy.
- A patient accepted to participate in a trial, is asked to sign an informed consent. However, the patient can withdraw from the trial at any time.
- An example of a clinical study was discussed during the session, DESKTOP III – surgery and chemotherapy or chemotherapy alone in case of relapse, a randomized controlled phase III study evaluating the impact of secondary cytoreductive surgery in recurrent ovarian cancer. The speakers elaborated the main issues of the study:
  - Participating patients in the study had no choice,
  - The secondary cytoreductive surgery required experienced hospital centers.
- The study results showed a relapse period of 5.6 months longer for patients undergoing surgery with chemotherapy.

Clinical Trials Resources

- **All Clinical trials:** www.clinicaltrials.gov
- **European trials:** engot.esgo.org

BLOCK SESSIONS 1

What Is a Clinical Trial? Development of a New Drug/ New Treatment

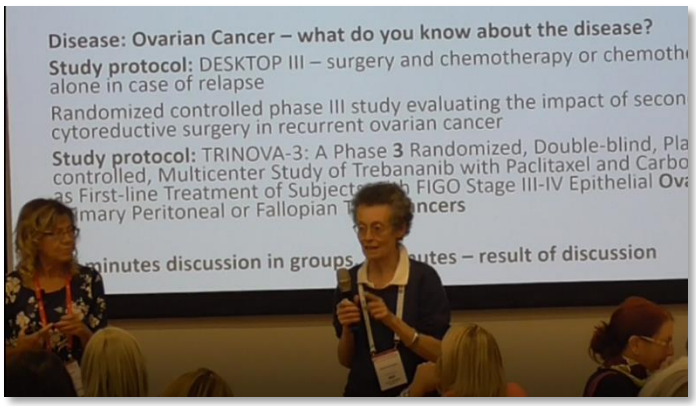
Cristiana Sessa, Switzerland and Birthe Lemley, Denmark

"The study protocol is the most important document in clinical trials."

Key Messages

- The study protocol is the most important document in clinical trials, a comprehensive plan of action that contains information concerning:
  - the reasons for conducting the research,
  - clear goals, study design and methodology,
  - patients' characteristics which might affect results,
  - safety considerations, what follow-up is provided for the safety of patients,
  - data management and statistical analysis of the clinical trial results,
  - quality assurance of the study: how patients are treated, data is collected, and samples are managed,
  - expected outcomes of the study, how the study will contribute to the advancement of knowledge, and how the results could be utilized.
- All the study results should be made available for the trial participants, the research community and the public as part of the trial registry, including the negative results, which aren't always published.
- Patient's informed consent forms should be accessible, and regularly updated with toxicity.
- An example of a clinical trial study design and protocol was discussed during the session, the TRINOVA-3: A Phase 3 Randomized, Double-blind, Placebo controlled, Multicenter Study of Trebananib with Paclitaxel and Carboplatin as First-line Treatment of Subjects with FIGO Stage III-IV Epithelial Ovarian, Primary Peritoneal or Fallopian Tube Cancers.

  The speakers elaborated the main issue of the study:
  - The placebo-controlled patients in the study got no treatment for a long period of 18 months
- In long-term studies, improvement of the quality of life with the new drug could be considered as a strong indicator and reduce the trial time as well as the burden for the placebo-controlled patients.



BLOCK SESSIONS 1

Management of Survivorship, Role of Repeated Controls and Rehabilitation

Heidi Donovan, USA

"15.5 Million US cancer survivors in Jan 2016, 20.3 million expected by 2026, 9.17 million European cancer survivors in 2012**."*

Key Messages

- Any patient with a history of cancer "from the time of its discovery and for the balance of life" is a cancer survivor.
- The number of cancer survivors is increasing dramatically in the US and is expected to grow to 20.3 million by 2026*.
- Out of 8 million female cancer survivors in the US, 3 gynaecological cancers are in top 10 prevalence of survivors: Uterine, Cervical and Ovarian cancers. 70% of survivors are over 60 years old.
- 9.17 million European cancer survivors in 2012**, due to the aging population, progress in early diagnosis and effectiveness of therapies. However, figures are lower in eastern countries vs. western and Nordic.
- Cancer "survivorship" is "Living with, through, and beyond a cancer diagnosis."
- Survivorship care is important due to the impact cancer has on the quality of life and well-being of survivors.
- Key progress in survivorship care include:
  initiation of tumor registries, development of national/multinational research cooperatives, cancer, psycho-oncology, palliative care, and survivorship associations developed as well as research, policy and action plans.
- Current guidelines for survivorship care with a focus on gynecologic cancers, according to NCCN 2017:
  - Post-treatment surveillance for the recurrent disease of Cervical and Ovarian cancers as examples.
- Cervical Cancer guidelines for survivorship care include: follow up exam (with pap) every 3-6 months for 2 years, followed by every 6-12 months for 3-5 years, imaging and labs as needed as well as patient education on symptoms of recurrence and potential long-term and late effects.
- Ovarian Cancer guidelines for survivorship care include: follow up exam (with the pelvic exam and ca-125) every 2-4 months for 2 years followed by every 3-6 months for 3 years, annually after 5 years, imaging and labs as needed, refer for genetic risk evaluation as well as patient education on long-term wellness care.
- Challenges going forward: survivorship needs must be anticipated, requires improvement of early detection of patients' needs, survivor access to rehabilitation, psychosocial and palliative care services integrated and multi-professional care.
- More research in survivorship is needed to provide data on late effects, as well as the impact and cost-effectiveness of supportive care, rehabilitation, palliative and psychosocial care intervention.

Screening for 2nd cancers resource:

- U.S. Preventive Services Task Force guidelines
  www.uspreventiveservicestaskforce.org

* *Source: Treatment & Survivorship Facts & Figures 2016-2017 ** CanCon 2017*

BLOCK SESSIONS 1

HPV Vaccination & Screening

Cervical Cancer Screening with HPV DNA: Up to Date Info from Europe

Murat Gultekin, Turkey

"HPV DNA can be used alone for primary cervical carcinoma screening."

Key Messages

- Cervical cancer is the fourth most common cancer in women. Global figures indicate 0.5 million new cancer cases per year, with a 50% mortality rate, and over 90% to 99.7% of the cases are HPV related.
- However, cervical cancer is preventable and can be eradicated.
- Primary prevention can be achieved with HPV vaccination or lifestyle choices, such as smoking cessation.
- As a secondary prevention strategy, cervical cancer can be prevented through early detection, either with a PAP smear screening test, which may be combined with a test for HPV, or alternative screening methods - VIA-VILI, or a combination of these.
- In the last 50 years, cytology-based screening programmes have reduced more than 75% of the cervical cancer incidence and mortality. However, these programmes have been successfully implemented in only 12 countries until 2016*, mortality rates are not decreasing, and population-based screening programmes are still not available in some countries. However, cervical cancer screening programmes start at the age of 30 years, every 3 years.
- Cytology-based screening issues of the Pap-Test indicate a low sensitivity for CIN2+ lesions, a high false negative rate, low reproducibility, less effective in detecting adenocarcinoma of the cervix, as well as organisational issues –a complex service to provide.
- HPV DNA screening tests are much more sensitive compared to cytology (PAP Smear tests), 96% vs. 53%, but with a lower specificity that may cause unnecessary colposcopies. However, the low specificity could be compensated with secondary tests.
- Co-testing for cervical cancer using both PAP Smear and HPV testing does not improve cancer detection to any great degree, sensitivity increased only by 2%-5%, in comparison with using HPV testing alone.
- As using HPV testing alone as a cervical cancer screening option is nearly as effective as the combination HPV and cytology co-testing, European and international guidelines changed in 2012.
- EU Guidelines for quality assurance in cervical cancer screening recommended that HPV DNA can be used alone for primary cervical carcinoma screening.
- The recommendation was supported by the FDA and followed by EFC, ASCCP, and SGO, as well as others.
- Turkey, Netherlands, Italy, Malta, Switzerland, Norway, UK, Denmark, Poland, and Germany were among the first to change the screening programme to HPV DNA.
- On the pipeline for HPV DNA Screening: HPV DNA kits and self HPV Sampling for convenience testing.
- HPV FASTER initiative, a programme aiming to reduce the number of repeated screening rounds.
- The change of system to HPV DNA programme in Turkey boosted screening tests to 1 Million in 2016.

* *Source: International Agency for Research on Cancer Report, 2016*

BLOCK SESSIONS 1

HPV Vaccination & Screening

HPV Vaccination and Future of Cervical Cancer in Europe

Xavier Bosch, Spain

"HPV vaccination has a significant impact on disease prevention."

Key Messages

- EU HPV-Related Disease Burden annual estimation figures are 52,000 Cancers and close to 6M precancerous lesions.
- Despite screening proposals, the burden of HPV infections and disease in Europe remains important notably in Eastern countries.
- HPV screening is the technology of choice for secondary prevention.
- Achievements of 10 years of HPV vaccination include efficacy in Phase III and worldwide coverage.
- Countries with a well-organised screening programme and high levels of participation in screening have observed a substantial decrease in cervical cancer incidence.

- Current strategies for preventing cervical cancer include primary prevention via HPV vaccination and secondary prevention using cytology tests or HPV detection methods to screen for cervical cancer precursors.
- HPV vaccination programmes mainly target girls aged 9–14 years, with some countries extending the coverage up to age 18 or 26. Until 2015, 23 EU countries have introduced HPV vaccines.

- HPV vaccination has a significant impact on disease prevention. Broad spectrum vaccines and gender-neutral vaccination are the alternatives choices in the most advanced countries.

- **HPV FASTER concept.**
  Women in middle age groups, found HPV negative and receiving a broad-spectrum HPV vaccine, have an extremely low subsequent risk of cervical cancer. Under these risk estimates, the requirements for further screening are likely to be minimal, one or two for a lifetime, and necessarily HPV based.

- In Europe HPV cancer prevention will include intelligent combinations of HPV vaccination and HPV based screening.

- New protocols are being conceived and tested as we learn more on the potential of these technologies, including:
  - Extension of vaccination to women in screening ages
  - Systematic vaccination of high risk groups
  - Less frequent screening, diagnostics and treatment events using HPV tests
  - Self-sampling in screening programmes

BLOCK SESSIONS 1

HPV Vaccination & Screening

Why we can? Why we cannot? ENGAGe Perspective

Maude Anderssen, Sweden

"Each year over 3,000 women are diagnosed with gynae-cancers in Sweden, and approx. 1,500 women die."

Key Messages

- Cervical cancer is the most spread cancer worldwide today.
- 20 years ago, this disease was most common in the western countries, but today it is mainly in the former Eastern European countries, Asia, and Africa, due to economic and other reasons.
- Each year over 3,000 women are diagnosed with gynaecological cancers in Sweden, 560 women are diagnosed with cervical cancer, and approx. 1,500 women die.
- Cervical cancer is the second most common form of cancer among women under the age of 45.

Why can we?

- HPV-vaccination of girls is included in the national vaccination programme in all Swedish schools, from the ages 10-12 years and for girls born in 1993 until1998.
- Some counties in Sweden have free vaccinations up to the age of 26 years.
- The screening will be free of charge starting from January 1st, 2018.
- HPV-vaccination with screening equals a good prognosis to avoid cancer later in life.
- Information is disseminated by the gynaecological cancer organisations, professionals, and the government.
- Cooperation with GYNSAM sister organisations in the Nordic countries and translation of information on screening and vaccination to our immigrant women.

Why We Cannot?

- An improved follow-up of the women neglecting the screening tests.
- We cannot treat rare cancer patients.
- No decision has yet been taken whether to give boys HPV-vaccine in Sweden, although the efforts made.
- Rumors that HPV-vaccine can cause side effects.
- Drugs are not available or are too expensive.
- We don't reach women with a psychological disease.

ENGAGE Perspective?

- We need to gather all gynaecological organisations to collaborate under the ENGAGE umbrella– to become a powerful force.
- Promote ideas on the social media channels.
- Patient representatives should listen to the experts at the ESGO congress, the speakers would be instructive for us.

GYNSAM – The Gynaecological Cancer Patients National Coalition in Sweden

Gynsam is a nonprofit organisation with approx. 1,000 members in Sweden and 13-member organisations from the north to the south of Sweden.

Gynsam aims to influence stakeholders to establish a common care plan and guidelines throughout Sweden.

BLOCK SESSIONS 2

How Can the Patient Evaluate Quality of Care? ENGAGE Perspective

Denis Querleu, France and Birthe Lemley, Denmark

"ESGO/ENGAGe should foster patients' involvement by translating the ESGO guidelines into "lay" language."

Key Messages

- Most important source are the guidelines in each country that are prepared by specialists for each type of gynaecological cancer, and patients should ask their doctors how to find these guidelines.
- PROM – Patient Reported Outcome Measure, is a questionnaire for patients where they can report side effects, late effects of the treatment and symptoms which might be a sign of relapse. This can also be used to report psychological side effects, so that help may be offered.
- News from ASCO in June 2017: overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment
- The PROMova, a collaboration between KIU – a patient organisation for women with gynaecological cancer and the PhD. working on the PROM. is now used in several Danish hospitals to detect the side effects, late effects, sexual issues, psychological effects and symptoms of relapse of the disease.
- There are advantages and disadvantages of measuring CA125 to detect relapse of ovarian cancer.
  A tool is being developed for the woman to make the right decision and is used at one Danish hospital.
- Patients should be also aware of the ESGO certification for surgeons in Europe.
- What is considered low quality of care? Sheer ignorance, inability to master the technique, unavailability of equipment or drug, overloaded with work, no time to learn, train or speak.
- The patient can impact the quality of care by asking questions about:
  - The benefits or risks of the procedures or treatments, as survival, disease-free survival and quality of life.
  - Standards and guidelines and if there is or not an alternative option.
  - The case or experience

  As an alternative, a patient can take a second, independent, expert opinion or check the names on PubMed before the treatment.
- The patient should be aware of forums and personal network, rather than rely on independent doctors.
- The role of ESGO/ENGAGe is to elaborate all the necessary documentation on the state of the art, recommendations, guidelines, and associated quality indicators, and foster patients' involvement by translating these into "lay" language, first in English and then translate these documents to local languages.

BLOCK SESSIONS 2

New Treatment Options in Ovarian Cancer

Mansoor Mirza, Denmark

"Clinical Progress in Novel Therapies includes: Anti-angiogenic therapy, PARP inhibition, and Immunotherapy."

Key Messages

- The need for Level 1 evidence is a key factor, and best tested in a randomized clinical trial. For example, the Phase II Trial in Ovarian Cancer with Gemcitabine got a negative outcome only when it was tested in phase III as a randomized trial.
- Clinical Progress in Novel Therapies include: Anti-angiogenic therapy, PARP inhibition, and immunotherapy.
- So far, only Bevacizumab is approved for ovarian cancer. Bevacizumab is only allowed once during the disease. The benefit of adding bevacizumab is given in primary, early and late relapse.
- Every ovarian cancer patient should receive bevacizumab during disease.
- Niraparib, as a selective PARP1/2 inhibitor, will provide a clinical benefit to all patients who have platinum-sensitive recurrent ovarian cancer, and who are in response to platinum, regardless of gBRCA mutation status.
- PARP significantly improved PFS in patients with platinum-sensitive recurrent ovarian cancer. Efficacy is highest in BRCAmut population.
- Beyond BRCA, platinum-sensitivity remains the best "biomarker" for response to PARP inhibitors.

BLOCK SESSIONS 3

Late Effects of Treatment Including Lymphedema Radiotherapy

Alina Sturdza, Austria

"Radiation treatment of gynaecological cancer can cause long-term side effects, impacting on the quality of life of patients."

Key Messages

- Late side effects can occur at any time after the completion of treatment, are more frequent in locally advanced cancers treated with curative intent, i.e cervical cancer. In severe cases may require treatment or intervention.
- Many could be prevented through appropriate supportive care.
- Lymphedema is a collection of fluid that causes swelling in the arms and legs

  Without normal lymph drainage, fluid can build up in the affected arm or leg, and lymphedema can develop.
- Medication such as Tamoxifen, radiation therapy, surgery, and injury to the lymph nodes can also cause lymphedema.
- Severe and moderate lymphedema occurs very rarely (5%), and is significantly increased by preexisting comorbidities, higher body mass index, invasive lymph node staging, previous abdominal or inguinal surgery and extended radiation fields.
- Radiation treatment of gynaecological cancer can cause long-term side effects impacting to some degree on the quality of life of patients.
- While 1/3 to ½ of patients may develop some kind of long-term toxicity, severe toxicity is very rare.
- In some gynecological malignancies, the benefit of radiation treatment may outweigh the limited toxicity, i.e Cervical cancer.
- Future research is aiming to improve the outcome while decreasing the toxicity profile.

BLOCK SESSIONS 3

Late Effects of Treatment Including Lymphedema Surgery

Jalid Sehouli, Germany

"Be critical for adjuvant therapies."

Key Messages

- Worldwide, every year more than 14 million will be primarily diagnosed with cancer. More than 65% of the cancer patients will survive more than 5 years.
- Surgery will never cause late toxicities; adjuvant therapy only causes it.
- Quality of life and sexuality of patients after treatment for gynaecological malignancies: results of a prospective study in 55 patients. 78% of the patients suffered from sexual dysfunction.
  The main reasons include: the feeling of losing her attractivity, dryness of the vagina, dyspareunia.
- Patients with arm lymphedema: diagnosis of secondary arm lymphedema, in 86% of the patients within 12 months. Patients with leg lymphedema average time to diagnosis 0.5 +/- 1.8 years.
- Cancer patients increased psychological stress and needs for professional support. Cancer patients with lymphedema have a significantly higher risk for depression and psychological disbalances, as quality of life and body imaging concept are inferior.
- Critical indication for any surgical procedures for every individual patient.
- Best surgical techniques for preserving health tissues and compartments, including Nerve-sparing approach.
- Be critical for adjuvant therapies, what therapy for and for what goal.
- Systematic evaluation of acute and late toxicities.
- Create a systematic interprofessional and interdisciplinary network for best supportive care.
- Conduction of prospective trials focussing on lymphedema, bladder and stool function, sexuality and quality of life.

BLOCK SESSIONS 3

Late Effects of Treatment Including Lymphedema Chemotherapy

Elisabeth Aval-Lundqvist, Sweden

"Patients need to be educated about the long-term and the late side-effects."

Key Messages

- Each year 1.6 million females are diagnosed with cancer in Europe, of these, 682 657 are diagnosed with gynecological cancers, including breast cancer.
- In 2012, out of 4.6 million European women diagnosed with a history of cancer in the previous 5 years, over 2.5 million were gynecological cancer survivors. Many received chemotherapy and millions of women in Europe are living with consequences of cancer and cancer treatment.
- The frequency of various long-term and late side-effects of chemotherapy is difficult to quantify.
  - Few longitudinal longterm studies
  - Many patients receive a combination of different treatment modalities e.g. surgery and chemotherapy
  - Estimations that at least 50% of cancer survivors experience long-term or late side-effects
- The objectives of follow-up after cancer treatment are not only early detection of recurrent disease, but also assess side-effects; by physicians and patients.
- Patients should be educated about symptoms of potential recurrence and potential long-term and late effects of treatment, and should also be counseled on sexual health, lifestyle adaptation, nutrition, exercise, obesity, and cessation of smoking.
- Follow-up schemes may be individualized taking prognostic factors, treatment modality and estimated risk and/or occurrence of side-effects into account.
- Millions of women in Europe have survived cancer and/or are living with gynecologic cancer.
- Many of them suffer from long-term and/or late side-effects after cancer and its treatment, such as chemotherapy.
  Patients need to be educated about long-term and late side-effects.
- Multidisciplinary networks of dedicated specialists are needed, and the care needs to be coordinated.
- Cancer rehabilitation start from diagnosis and a rehabilitation plan should be created and provided to all cancer patients.
- Predictive markers needed to identify those with the highest chance of benefit and those with the highest risk of side-effects, so that treatment is tailored to the individual patient.
- Knowledge of the mechanism behind side-effects has led to advances in treatment techniques and needs to be continued.

BLOCK SESSIONS 3

Late Effects of Treatment Including Lymphedema
ENGAGE Perspectives

, Maria Papageorgiou, Greece

"Together we can make a change, to live as long as we have, and in the best possible way."

Key Messages

- Maria Papageorgiou was diagnosed with stage-3 endometrial cancer in 2011, and since then leads ERIFILI, the patient advocacy group for women with gynaecological cancers in Greece.
- From a patient advocate perspective, Maria indicated that the interactive discussions with medical practitioners at the ENGAGe patient seminar reflect a change - the voice of patients is heard.
- According to Maria's experience, late side effects impact the cancer survivor's quality of life and make it quite challenging.
- Maria was diagnosed with cancer at the age of 45, and revealed that she underwent surgery, followed by chemotherapy and radiotherapy. The unexpected severe side effects Maria experienced because of the treatment, led her to initiate a survey for women with gynaecological cancers.
- 73 women responded to the survey, most between the ages 41-65 and diagnosed with endometrial cancer. 80% of the women indicated that there was no collaboration between health practitioners regarding the late side effects of the treatment.
- The survey responders listed some of the late side effects of the treatment they have endured, including: insomnia, brain fog, decreased concertation, lack of attention, memory loss, fatigue, tiredness, swollen ankles or legs, problems with the intestinal, incontinence, sensitivity, diarrhea, constipation, fistulas, bowel adhesions, bladder problems, incontinence, poor bladder control, urinary discomfort, as well as pain.
- Maria emphasized that patients don't expect their doctors to know everything, but do expect them to listen, especially when they speak about pain and discomfort, as well as to be up-to-date on the latest practice and consult their peers if needed.
- The lack of collaboration and knowledge sharing among doctors leads to poor post-treatment care for cancer patients.
- The quality of life after treatment is highly important for cancer patients, who want to live well for whatever time is left, which is sometimes a challenge.
- The cancer patients' experiences could have an important impact on treatment and care, if doctors choose to listen and consider these insights to advance the quality of care, as well as the quality of life. Together we can make a change, to live as long as we have, and in the best possible way.
- Maria states in her closing remarks a take-home message for doctors on behalf of the cancer patients: "We are here for you whenever and however you need us!"

SPECIAL SESSION

Collaboration between Patient Advocacy Groups and ESGO

Power of being visible: Media, NGOs and Awareness Activities

Murat Gultekin, Turkey

"ENGAGe as the voice of gynaecological cancer survivors needs to raise awareness and get the support of governments."

Key Messages

- ESGO's mission is to improve the health and well-being of European women with gynaecological cancers through prevention, treatment, research, and education.
- ESGO is an umbrella society that advances science, with specialized networks in gynaecological cancers: ENGOT – the network of clinical trial studies, ENYGO – the network of young professionals, ENPIGO – the network of prevention, ENTRIGO – the network of translational research and ENGAGe network of patient advocacy groups.
- ESGO has converted the outcomes of the scientific knowledge and research studies to practical guidelines, ready to be used by professionals and available in different formats: eBooks on the web, App for mobile devices and printed pocket size guidelines.
- The policy set, the ESGO guidelines, require the acceptance by governments, which play an essential role in raising standards of treatment and care.
- To reach this goal, ENGAGe as the voice of gynaecological cancer survivors needs to raise awareness, and get the support of governments.
- Breast cancer NGOs for example, have successfully managed to gain the support of governments and policymakers by establishing a strong voice and raise awareness for women with breast cancers.
  An example of leadership that ENGAGe should learn from and follow.
- ENGAGe advocacy representatives need to fight the myths, establish collaborations on both a national and international, level, work hand in hand with all stakeholders in raising awareness, especially promotion through exceptional events, covered by the media to reach a wide audience.
- Being visible takes planning and thought. Together we can fight to reduce the incidence of women with gynaecological cancers and save lives.

SPECIAL SESSION

Collaboration between Patient Advocacy Groups and ESGO

The other side of the coin: What the patients want to tell their doctors – Result from a survey

, Esra Urkmez, USA

"Together we need to raise public awareness and improve the care of patients."

Key Messages

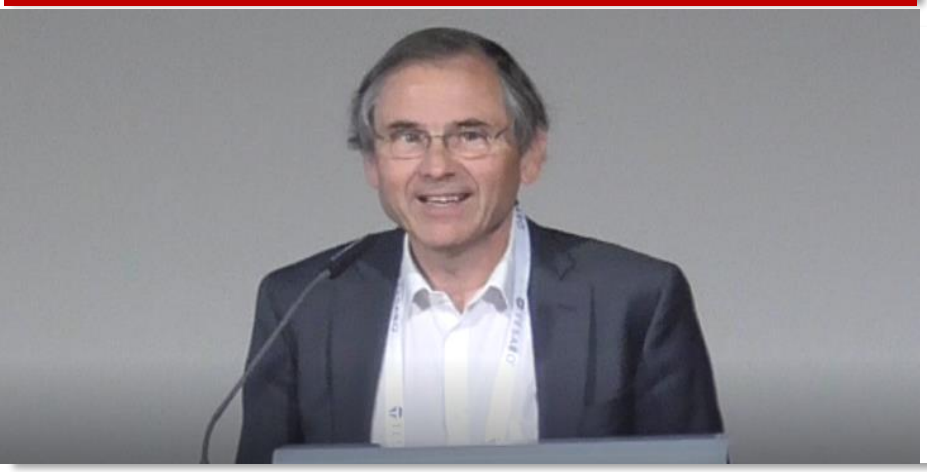
- ENGAGe initiated a survey in Europe in 2017, addressing the question - What patients want to tell their doctors?
- The objective of the survey was to have patients tell their doctors and health care providers: What is being done well by their Health Care Team, what is missing in patient care and what areas need improvements?
- The survey was conducted in 10 European countries, for 3 weeks, 1436 gynecologic cancer patients responded to the survey. More than half of the responders were between 41-65 years old and diagnosed in the last 4 years, most with one of the following cancers: ovarian (39%), breast (26%), uterine (15%) or cervical (13%).
- The patients responded to 35 questions, including topics such as awareness, prevention, diagnosis, treatment and clinical trial.
- The survey outcomes revealed that:
  - Many patients did not know about HPV vaccinations, PAP Smear Test, or BRCA Tests for Ovarian Carcinoma. However, these patients claimed that they would want to know. Patients' education level had an impact on knowledge.
  - Even if patients knew about the HPV vaccinations or tests, many of them had no access to them, or any finances to get them done or did not find them relevant. In these cases, patients stressed the need to have the access.
  - In both cases, patients emphasized the need to be educated.
- One of the survey's conclusion is that we need to find a way to improve the prevention in these countries, together we need to raise public awareness.
- As for the diagnosis and treatment stage the survey revealed that in the first conversations with doctors:
  - Many of the patients did not get printed informative material from their doctor during first visits and they were too shocked to understand what the doctor was telling them.
  - The patients want printed materials to take home, so when we get over the shock they can educate themselves and their caregivers.
  - Patient organizations should be working with doctors to provide the informative brochures, and with sponsors as well.
- As the treatment starts, the survey showed that the patients mostly don't know: what to expect, what to eat, how to cope and how to live with it.
- Numbers and studies are meaningless unless we do something with them together. Take an active part in the vision of ENGAGEe to improve the care of women with gynaecological cancers.

SPECIAL SESSION

Collaboration between Patient Advocacy Groups and ESGO

How can the patients evaluate the quality of care?

Denis Querleu, France



"Do I do well? or Can I do better? The essence of quality of care."

Key Messages

- ESGO has initiated a complete set of guidelines for gynaecological cancers, to set standards of treatment and care across Europe.
- These guidelines include endometrial, ovarian, vulvar and cervical cancers as well as rare cancers and adolescent tumors planned for 2018.
- Doctors that follow these recommended guidelines meet the quality of care measures set on a European level.
- The guidelines will be updated regularly and available for professionals even on smartphones to enable easy access anytime, anywhere.
- However, these guidelines are not only for doctors, they will be made accessible to patients as well, with the collaboration of the ENGAGe advocacy groups.
- These guidelines will be translated to "lay" language, first in English and then translated to local European languages, as well as other languages, to extend the reach and advance the knowledge among patients.
- Quality assurance of cancer treatment was set for advanced ovarian cancer surgery, with a specially designed quality indicators guide.
- Gynaecological oncology hospital centers that meet the ESGO standards are certified and receive a special certification.
- Regarding quality, the question that should be asked is "do I do well? Or "Can I do better?"

Roundtable Discussions

- What is New in Gynaecological Cancer?
- Let the Expert NGOs Speak

Experts shared the latest insights and listened to the patient advocates' perspective and experiences.

Day 1: What is New in Gynaecological Cancer?

Table 1: Ovarian Cancer
Jonathan Ledermann, UK

Table 2: Cervical Cancer
Francesco Raspagliesi, Italy

Table 3: Vulvar & Vaginal Cancer
Sven Mahner, Germany

Table 4: Uterine Cancer
Carien Creutzberg,The Netherlands

Day 2: Let the Expert NGOs Speak

Table 1: Policy Advocacy
Simona Ene, Romania

Table 2: How to get Doctors involved with NGOs
Sevil Benli, Turkey

Table 3: Working with ESGO
Denis Querleu, France
Cristiana Sessa, Switzerland

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