REPORT

Patient Seminar

Prevention in Gynaecological Malignancies
September 08-09, 2016

Held during
The ESGO State of the Art Conference
September 08-10, 2016
Antalya ,Turkey

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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OPENING REMARKS

David Cibula, ESGO President

David Cibula

Key Messages

- The European Society of Gynaecological Oncology (ESGO) 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 encourages patient advocacy representatives to take an active part in the dissemination of the knowledge to gynaecological cancer patients, their caregivers, advocacy groups and the public.
- Patient advocacy representatives can play a significant role in making the new ESGO clinical guidelines for Ovarian Cancer Surgery, Vulvar Cancer Management and Cervical Cancer guidelines, understandable and accessible to patients.
- 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.

About ESGO

The European Society of Gynaecological Oncology (ESGO) is the leading European organization with more than 3400 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 post graduate 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 Chair

Murat Gultekin

Key Messages

- In the fight against cancer, scientific breakthroughs and advanced treatments are essential. But so are political decisions and the economic cost of treatment as well as the awareness and education of the public to understand and access treatment and care.
- Therefore a dialog and collaboration between ESGO, as the leading organization in Europe for gynaecological oncology and stakeholders from the government and patients advocacy groups is an essential step in the fight against cancer.
- The patient advocacy groups play an important role in the communication and promotion of the science and practice to the public and need to continuously learn and get the latest updates in the field.
- The 2-days ENGAGe patient seminar is the educational platform for patient advocacy representatives to get the updated information in the field presented by premier speakers.
- The new ENGAGe executive group will be elected as well as the network chair, who will be the voice of patients in the ESGO council.

  The elections and general assembly are part of the program in Antalya.

  Next year the patient seminar will be at the ESGO congress in Vienna.

ENGAGe 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.

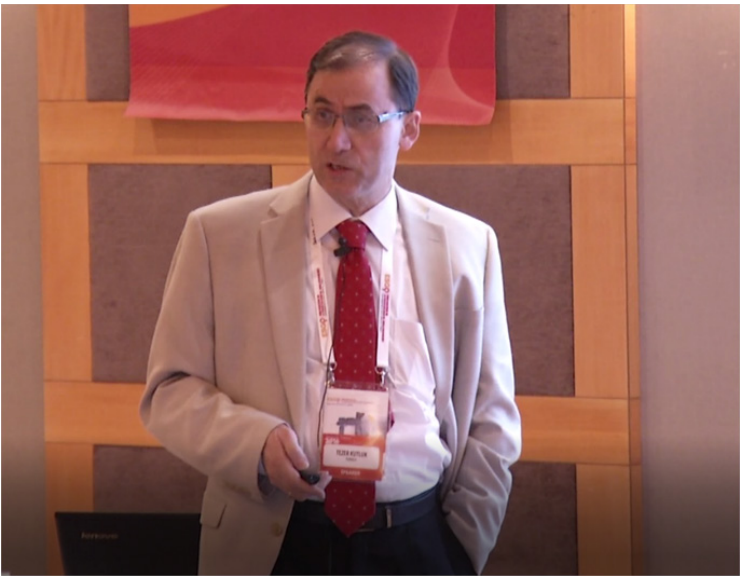
About ENGAGe

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).

SESSION 1

Gynecological Cancers: Primary and Secondary Prevention Strategies

Tezer Kutluk, Union for International Cancer Control (UICC), President



"We unite the cancer community to reduce the global cancer burden, to promote greater equity, and to integrate cancer control into the world health and development agenda."

Tezer Kutluk

Prevention Strategies in Cancer

Key Messages

- Cancer is a worldwide public health problem. 32.6 million people are living with cancer[1] and the estimated total annual economic cost of cancer globally was approximately USD 1.16 trillion in 2010.
- The big opportunity is that 30-40% of cancers are preventable.
  Breast and Cervical cancers were among the 7 most common cancers in the world in 2012[1].
- From 2006 to 2010, the death rate for all cancers combined decreased by 1.8% per year in men and by 1.4% per year in women.
- The World Cancer Declaration in 2013 calls upon Government Leaders and health policy -makers to significantly reduce the global cancer burden, promote greater equity, and integrate cancer control into the world health and development agenda.
- More work is now needed to convince governments around the world to commit to reduce the avoidable deaths from NCDs by 25% by 2025 - a target WHO believes to be achievable
- Health is recognised as a precondition for and an outcome of sustainable human development in the 2030 Agenda for Sustainable Development (SDGs),
- SDG 3 focuses on health and pledges governments to "ensure healthy lives and promote well-being for all at all ages".
- To measure progress against this goal, there are 9 targets covering a range of global health priorities including maternal and child health, communicable diseases, universal health coverage, and NCDs.

About UICC

- Oldest and largest cancer federation in the world, established in Geneva in 1933
- More than 960 members in 160 countries: leading cancer societies, research/care centres, governmental health institutions, patient groups.
- Formal relations with UN agencies: WHO, IARC, IAEA

[1] Globocan, 2012

Samet Topuz, Istanbul Medical Faculty, Dept. of Obstetrics and Gynecology, Turkey

"Ovarian cancer has the highest rate of deaths among the gynecological cancers. Survival for ovarian cancer is related to stage, but most cases are diagnosed at advanced stages. Public education on early symptoms of ovarian cancer is highly important"

Samet Topuz

Is It Time To Implement Ovarian Cancer Screening?

Key Messages

- 70% of the cases are diagnosed at advanced stages due to lack of specific symptoms, whereas 90% of the cases are sporadic and 10% of the cases hereditary[2].
- The strongest known risk factor for ovarian cancer is a family history, which could increase the risk to 35-40%, in case of two first degree ovarian cancers relatives.
- Familial ovarian cancer syndromes (the Lynch syndrome and breast-ovarian cancer syndromes related to BRCA1 or BRCA2 mutations) occur rarely, but present much greater risk than a sporadic family history of ovarian cancer.
- Mortality from ovarian cancer has decreased only slightly in the past 30 years.
- The potential benefit of screening is its ability to identify ovarian cancer at a more localized and curable stage, leading to reduced mortality from the disease. However, a positive screening result suggestive of ovarian cancer most often is followed by surgery. Invasive procedures are associated with physical and psychological morbidity, a small risk for serious complications, and substantial financial costs.
- CA-125, the most widely studied tumor marker for ovarian cancer screening, and elevated in 50 to 90 percent of women with early ovarian cancer, but also can be elevated in numerous other conditions.
- CA-125 alone is not recommended in screening average-risk women.
- Serial measurements of CA-125, using an algorithm that incorporates age and rate of change may improve the positive predictive value of screening, but not sufficiently to incorporate into clinical practice at this time.
- Transvaginal ultrasonography (TVUS), when used alone in screening, has not been effective in identifying early-stage cancer.
- Average-risk women are not suggested to screen for ovarian cancer (Grade 2B).
- For women with a family history of ovarian cancer who do not have a confirmed ovarian cancer syndrome, we suggest management as for women at average risk (Grade 2C).
- For familial ovarian cancer patients risk reducing surgery is indicated by age 35 to 40 and when childbearing is completed.
- No North American expert groups recommend routine screening for ovarian cancer.
- For women with identified hereditary ovarian cancer syndromes SGO and the (NCCN) recommend screening every six months with CA-125 and TV-US beginning between the ages of 30 and 35 years or 5 to 10 years earlier than the earliest age of first diagnosis of ovarian cancer in the family.
- ACOG states that there is no evidence that screening improves survival in women in high-risk populations.
- The National Cancer Institute finds there is not sufficient evidence to support screening for ovarian cancer in any population, including women at increased risk.

[2] Holschneider, 2000

Cem Iyibozkurt, Istanbul Bilim University &
Istanbul Florence Nightingale Hospital,Turkey

Cem Iyibozkurt

Can Cervical Cancer Be Eradicated?

Key Messages

- More than 99% of cervical cancer cases are caused by HPV.
- There are 34K new cervical cancer cases per year in Europe. The rates of death attributed to the cancer are still high, especially in the new member states due to lack or low implementation of organized screening programs.
- Development of cervical cancer takes 5-15 years, therefore screening programs are effective.
- PAP smear reduces mortality of cervical cancer and enables early diagnosis of pre-invasive lesions. Even a single PAP smear can reduce the cancer incidence by 45%, with 9 smears a 99% reduction is achieved.
- US Cervical Cancer Screening Protocols
  - One PAP smear every 3 years, starting at the age of 30 until 65, is the recommended frequency.
  - HPV test in addition to cytology improves the diagnosis of adenocancer and preinvesive lesions.
  - In cases that HPV test is positive, although the cytology is negative a co-test is done 12 months later. If either HPV types 16 or 16 &18 are detected a colposcopy is offered with a retest 12 months later.
- European Guidelines for Quality Assurance in Cervical Cancer Screening: Implementation of the guidelines relate to population-based screening programmes and require quality assurance at all levels.
  - Cervical cytology starts at the age of 20-30, preferably at the age of 25.
  - Screening every 3-5 years until the age of 60-65.
  - Women under the age of 30 should not be screened for HPV, due to the high rate of viral clearance.
  - If there is a positive HPV test and a high grade, low grade or equivocal cytological lesion, coloposy is offered and needs to be conducted by trained healthcare professionals.
- Recommendations according to the recent European guidelines, published in 2015:
  - HPV primary testing is more effective than cytology based screening.
  - Vaccination of girls and boys in the future for HPV types that cause 70% of cervical cancer is complementary.
- Molecular HPV Testing: new novel types of HPV have been identified, and currently there are 200 types.
- European recommendations have been updated as a result of a published study comparing primary HPV screening to cytology based screening on 94K women, and proving that primary HPV screening is more effective. Guidelines were updated as follows:
  - Primary testing for HPV in an organized population based program is acceptable for women at the age of 35+, but not under 30. Screening frequency up to 5 years if test is negative.
  - Avoid co-testing and use either HPV or cytology.
  - If HPV testing is positive cytology needs to be preformed immediately.

"Yes it can!"
Towards Cervical Cancer eradicated: HPV Vaccination and HPV-based screening of Population based programs

Joakim Dillner
Karolinska Institutet and Karolinska Hospital, Sweden

Joakim Dillner

Screening in The Nonavalent Vaccine Era: What Do We Know and What Do We Need to Know?

Key Messages

- Cervical cancer screening will remain necessary, even for vaccinated women.
- Organized screening programmes for cervical cancers are more effective than the two most used vaccinations around the world. These vaccines target two HPV types that cause roughly 70% of cervical cancers. Therefore don't stop screening, even if you get vaccinated.
- Although the new generation "nonavalent" HPV vaccine is more effective than the screening programs, still screening programs are recommended.

  The risk of invasive cervical cancer is reduced by up to 80%-90% for women who regularly participate in organized screening programmes, whereas the "nonavalent" HPV vaccine targets nine types of HPV that cause more than 90% of all cervical cancers.
- However, in a population with a high vaccination coverage less-frequent screening is required after the HPV vaccine. Women may only need cervical cancer screening 2 times in their life, instead of currently recommended 10-15 times in their life, starting at age 30, and still gain 90% protection.

  Women vaccinated with the new "nonavalent" HPV vaccine would only need one screening in their lifetime.
- Screening has side effects and isn't recommended beyond the necessary times needed in a lifetime.
- The second generation "nonavalent" HPV vaccine is currently used only in the USA, although it was already approved in Europe a year ago and is estimated to reduce cervical cancer incidence by 15%-20%.
- "The HPV- Faster Concept"[3]: One-time effort is required with combined HPV vaccination and HPV screening for rapid cervical cancer control. The concept was only published in Nature Reviews Clinical Oncology, but not implemented.

  The HPV-Faster concept: if the second generation vaccination will be given only to a population that according to HPV test results is HPV negative, thus securing a coverage of more than 90% control of the cancer, then screening programmes could be provided to less than 10% of that population that are HPV positive until cervical cancer is eradicated, approx.for 5 years instead of 50 years, as it is currently predicted.

[3] HPV-FASTER: Broadening The Scope for Prevention of HPV-related Cancer, Nature Reviews Clinical Oncology Published online on 01.09.2015: http://www.nature.com/nrclinonc/journal/v13/n2/full/nrclinonc.2015.146.html

Maria Kyrgiou, Consultant Gynaecologic Oncologist, Imperial College London, UK

"Obesity and diabetes increase the risk of womb cancer, therefore reduction of obesity and BMI through change of life style as well as increased public awareness of endometrial cancer symptoms for early detection will reduce the cancer incidence."

Maria Kyrgiou

Obesity and Endometrial Cancer

Key Messages

- Obesity rates are rising worldwide. In 2008, 1.5 billion under the age of 20 were obese and in the UK, 50% of women are predicted to be obese by 2050. In the USA, approx. one-third of adults are obese.
- If post 2000 trends continue, by 2025, global obesity prevalence will reach 18% in men and surpass 21% in women; severe obesity will surpass 6% in men and 9% in women. Nonetheless, underweight remains prevalent in the world's poorest regions, especially in south Asia.
- According to WHO, overweight and obesity are the most important known avoidable cause of cancer after smoking. Current studies predict only an increase of obesity in the future.
- Endometrial and ovarian cancers incidence frequency are the highest in the countries where obesity rates are high, as these cancers have been correlated with obesity.
- In the UK, there has been a 40% increase in Endometrial cancer since the 90s mostly in post and menopause women, according to Cancer Research UK.
- Endometrial and Ovarian cancers are currently part of the 8 cancers that are linked with obesity / being overweight, according to the World Cancer Research Fund.
- In Aug 2016, The International Agency of Research in Cancer (IARC) have raised awareness in the New England Journal of Medicine on the role of obesity and cancer stating that the female malignancies have the highest association with obesity than any other cancer.
- The Imperial College London conducted an umbrella review to verify the correlation between obesity and different women cancers, which showed that the risk of developing or dying from cancer was the highest with obesity.
- The clinical challenges for physicians that manage obese patients are significant. Endometrial cancer which is prevalent in obese patients is managed with techniques as laparoscopic and robotic surgery, which are safe, less morbid, with a better recovery for patients.
- Risk factors that increase endometrial cancer are obesity and diabetes, but with caffeine and smoking it significantly reduced the cancer incidence.
- The mechanism which obesity and diabetes lead to womb cancer, has been correlated with estrogen, diabetes and insulin, chronic inflammation and infection, on top of genetic variation lead to cancer.
- The Women's Health Initiative trial study in the US, found that diabetes was one of the major factors that increased the risk for womb cancer. As for metabolic unhealthy women that had normal weight, the study found that diabetes was promoting breast cancer.
- Obese cancer survivors have a high risk of developing recurrent endometrial cancer.
- How can we help? We need to understand better the mechanism that increases womb risk from obesity and etiology in order to identify the markers that can predict women at high risk for which we can target interventions and prognostic tools.
- There are no suitable screening for endometrial cancer, but raising public awareness of early symptoms is important.
- Change of life style, physical activity, low calorie diet, bariatric surgery, vegetable and fruit consumption have a major impact on reducing the risk of the cancer incidence.

SESSION 2
Special Issues for Patient Advocacy Groups

Eka Sanikidze, Georgian Patient's Union, Tbilisi Cancer Center, Georgia

Eka Sanikidze

Barriers On Grant Receiving and The Ways To Solve Them

Key Messages

- One of the goals of the NGO in the fight against cancer is to improve the methods of timely detection and effective cure of cancer by increasing awareness and advocate for implementation of cancer screening and prevention programs, which require funding.
- Government funds are allocated for cancer programs, but there is a need for allocation of funds for training of non specialists to rise alertness.
- The greatest challenge an NGO faces is to find funding opportunities, as there is a lack of grants for cancer prevention and diagnosis purposes.

  The need of knowledge and experience to write a winning proposal is another challenge that an NGO needs to confront.

  In addition, grant regulations and restrictions could be a barrier for newly established organizations as well as the need of resources to find the opportunities and manage the process.
- Main ways to solve these barriers include:
  - Technical assistance from an experienced organization, an affordable service that could sometimes be offered at no cost.
  - Initial funds for staff education and development are usually feasible as well, and build the skills required for writing the proposals and managing the process.
  - Creation of regional networks empowers the NGO as well as establishment of representations of famous organizations in various countries.

Esra Urkmez

Fundraising: Don't Reinvent The Wheel and Think Outside of The Box

Key Messages

- Fund raising is the process of gathering voluntary contributions of money or other resources, by requesting donations, from individuals, businesses, charitable foundations and government agencies.
- Fundraising isn't always about money, service contributions are often provided more easily, if you just reach out with the right approach and simply ask.
- There is no need to re-invent the wheel! Good ideas for fundraising activities are out there.
- Money contributions can be collected for specific projects as awareness sport events or fundraising nights/events by engaging patients, cancer survivors, caregivers, healthcare professionals, media and the public in the fight against cancer.
- International grants, as the ones offered by Rotary and UICC, support large scale awareness activities and are important opportunities to consider, but require you to present a strong project plan together with the grant application.
- Voluntary contributions of resources and services are another effective fundraising way to consider.
- These include sponsored brochure printing, stands, website programming, webinar platforms, PR support and more.

  Social services available for NGOs that you need to apply for include:

  - A grant of 10,000USD of in-kind advertising per month on Google search.
  - Access to donated/discounted products and services from Microsoft, Adobe, Cisco, Intuit, and Symantec for nonprofits and libraries qualified with TechSou.

SOCIAL MEDIA AND HOW TO?

Sertac Doganay, Turkey

Sertac Doganay

How to Reach Millions for Free

Key Messages

- Internet is used intensively all around the world and therefore is considered an important channel.

  More than 3 hours per day are spent on the internet, mainly on social media, according to a recent worldwide survey[4].

  In relation to the usage of internet for health related purposes, for example in Turkey, searches are conducted at least once a month and up to 3 times a week or more. Research on disease, symptoms and medications are mostly done online, according to a survey[5].

- There are 100 billion searches are on Google per month all around the world. In Europe, statistics[6] indicate at least 90 monthly searches per user.

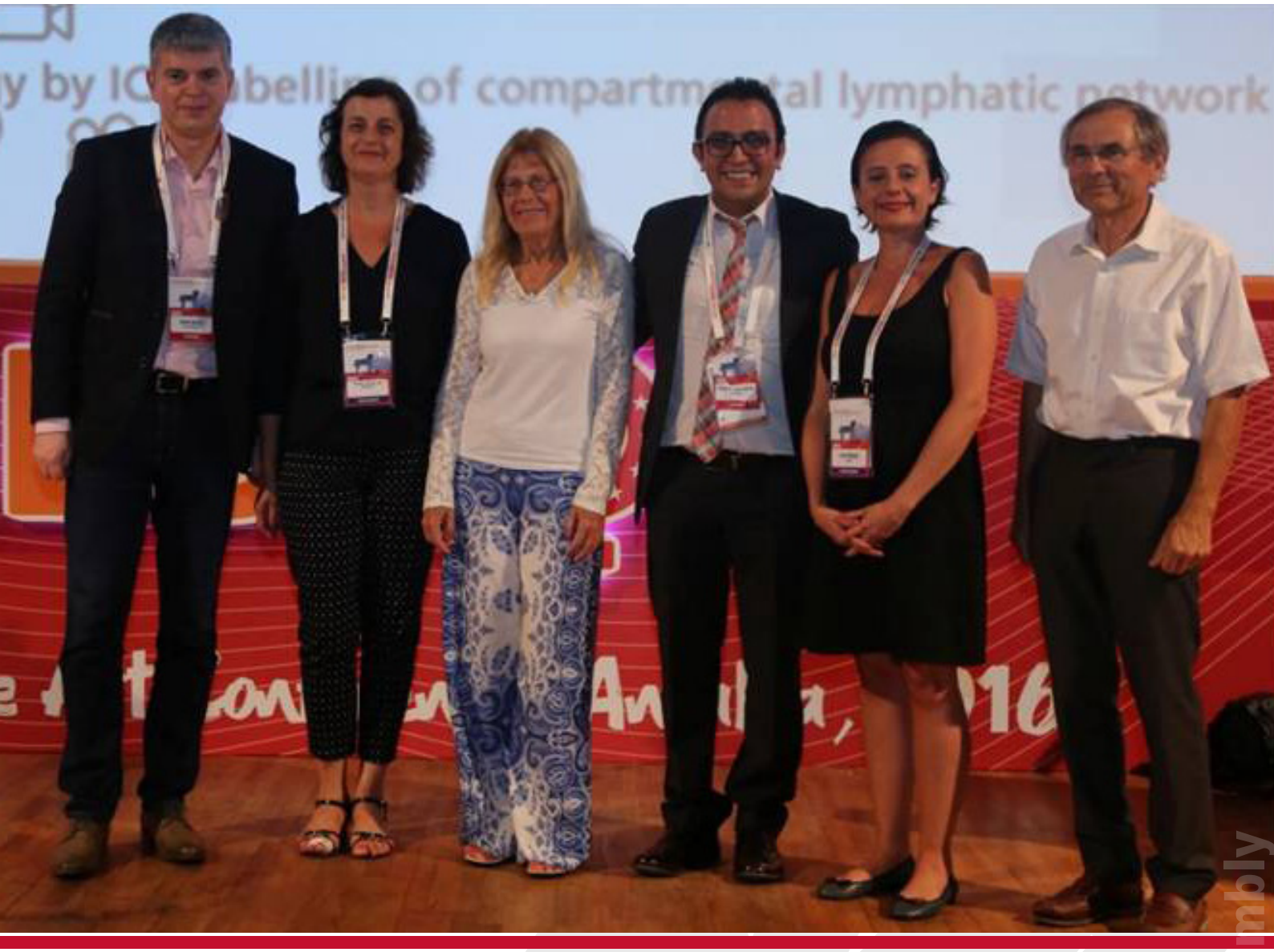
- Nowadays big data plays an important role in healthcare predictions, as in the case of the algorithm of helpmap.org that spotted the Ebola outbreak 9 days before WHO announced it. Another example is Wikipedia that can use the page views data to predict disease outbreaks prior to official health advices[6].

- Dance with Cancer Association published its Facebook page 4 years ago and reaches today 2.5 million people per month. The association managed to establish a group of volunteers, including prominent doctors and earned its credibility in the market.

- Non-profit associations can apply for a 10,000 USD grant for Google ads and increase their online presence.

[4] Global Web Index Survey, Jan 2016
[5] Survey in 2013, published on socialtouch.com.tr
[6] Statistics from 2012 Published on Statista.com
[7] Announced in the BBC news health on Nov 14 2014

ENGAGe GENERAL ASSEMBLY



The 1st ENGAGe General Assembly of members was held as part of the Patient Seminar program in Antalya, to establish the formal structure of the ENGAGe Executive Group, Bylaws, voting rules and reporting method to members, including elections of the 1st ENGAGe leadership and representation in the ESGO Council.

ENGAGe Executive Group (EEG) Elections

The structure of the EEG, consisting members of the ESGO Council and elected representative of ENGAGe group members, was formally finalized with the elections of the 3 representatives of group members at the general assembly:

- Esra Urkmez,
  Kanserle Dans, Turkey
- Birthe Lemley,
  Danish Gynae Cancer Patient Society, Denmark
- Mihaela-Simona Ene,
  HomeCare Association, Romania

In addition, Esra Urkmez was elected as the first ENGAGe co-Chair and ESGO Council member (with no voting rights) representing the voice of patients.

The elected representatives were presented during the ENGAGe session at the State of the Art conference.

PATIENT SEMINAR REPORT

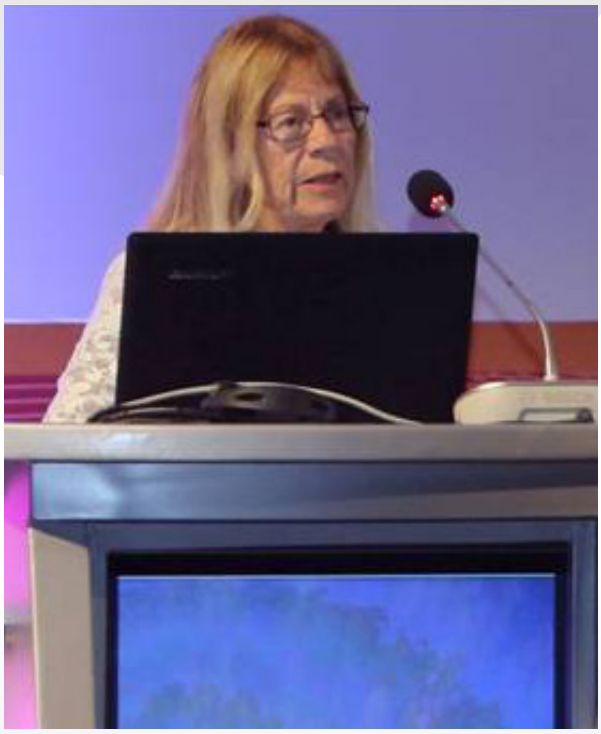
The New ENGAGe EEG Presentation at The State of The Art Conference

Murat Gultekin, Patient Seminar Chair
ENGAGe Co-Chair

Esra Urkmez, Dance With Cancer, Turkey
ENGAGe Co-Chair

Mihaela-Simona Ene, HomeCare
Association, Romania, ENGAGe EEG

Birthe Lemley, Danish Gynae Cancer Patient
Society, Denmark, ENGAGe EEG

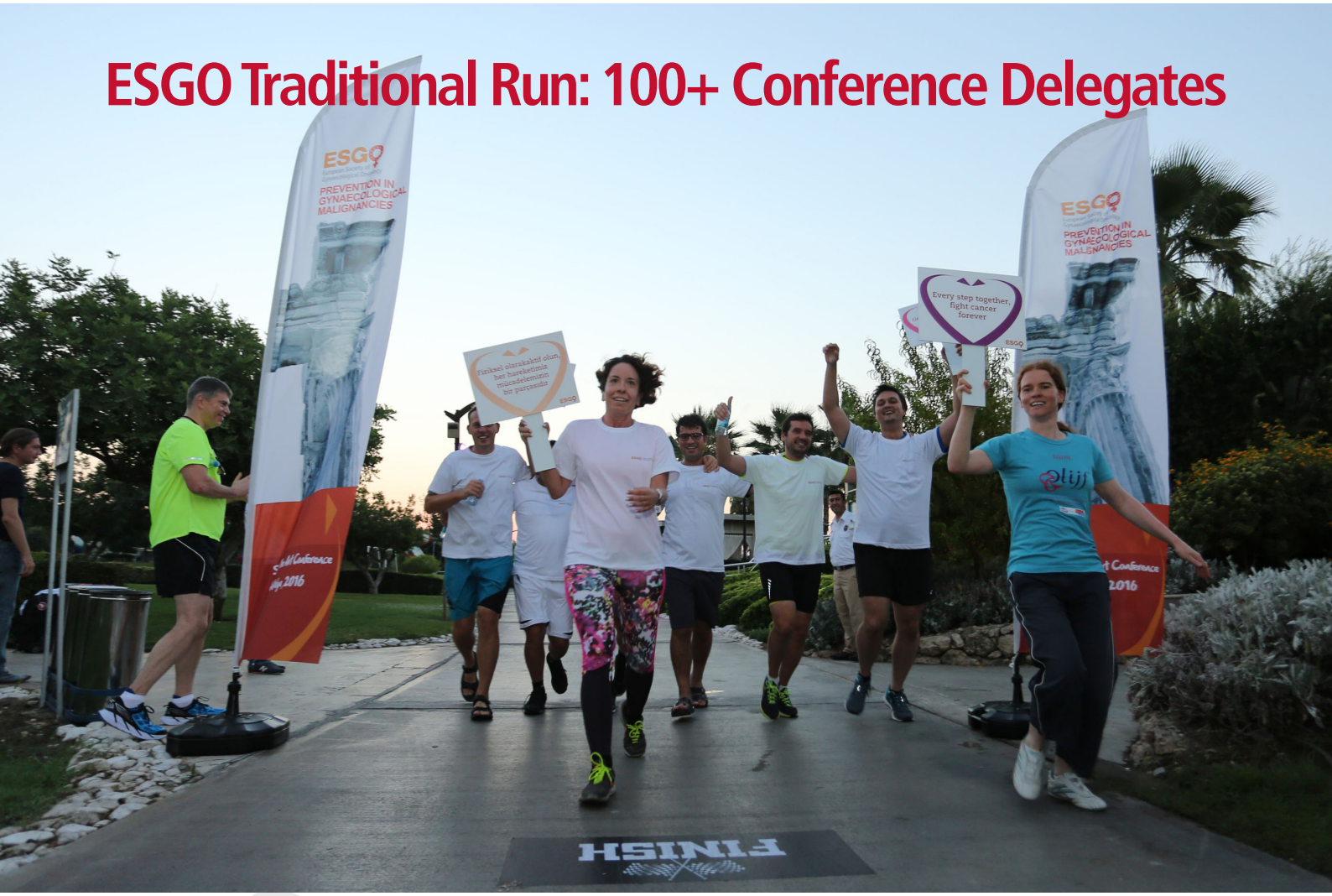


Watch the presentations at: engage.esgo.org/en/eeg

AWARENESS EVENTS

Cancer patient advocacy representatives together with the State of the Art conference delegates attended the awareness activities, including the ESGO run, spinning and yoga. The aim of these activities was to raise attention to the importance of a physical activity in the prevention of cancer.

ESGO Traditional Run: 100+ Conference Delegates

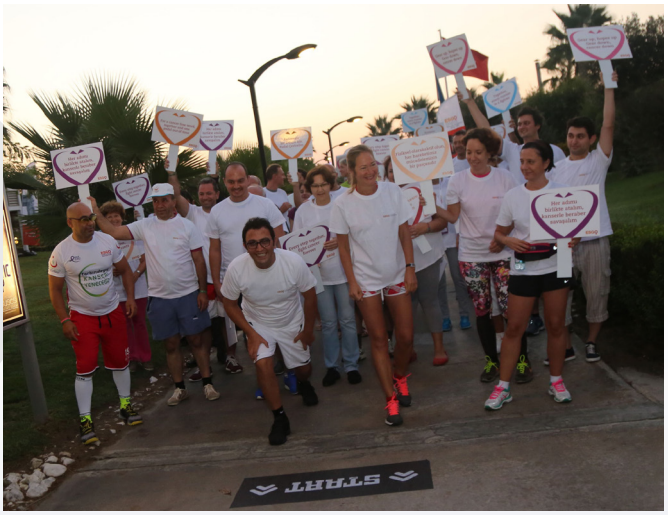


Let's Be Active, Everyday Counts

Raise Awareness Against Cancer

Early morning prior to the start of the second day of the conference, over 100 conference delegates together with cancer patient advocacy representatives joined the ESGO run to raise awareness.

At the end of the run balloons in the colors of the gynaecological cancers were set free, symbolizing that the fight against cancer is an everlasting contest. The run was followed by fitness and Yoga activities on the beach.



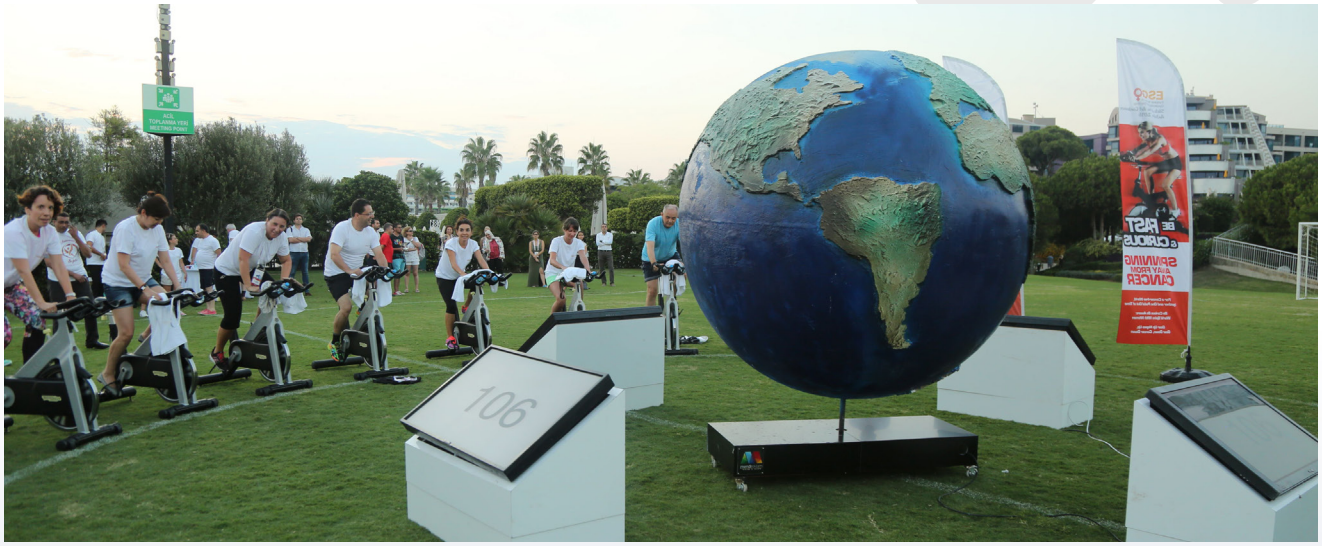
Spinning Away From Cancer

Be Curious, Be Aware

The World Spins With Women

At the end of the first day of the conference, 20 international cancer patient advocacy group representatives together with experts and health professionals attended an outdoor spinning activity.

The spinning devices were connected with a cable to a world globe, and attendees were challenged to reach the highest spinning speed level. The joint spinning efforts lightened the World globe.



ACKNOWLEDGEMENTS

Many people have been responsible for the success of this patient seminar

In particular, ESGO would like to thank:

- All the speakers, chairs and participants
- Individuals who contributed to the organisation of the seminar:
  Murat Gultekin, Patient Seminar Chair
  Ezgi Hacikamiloglu, Patient Seminar Coordinator
  David Cibula, ESGO
  Elisabeth Avall Lundqvist, ESGO
  Denis Querleu, ESGO
  Rene Laky, ENYGO

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The European Voice of Gynaecological Cancers Patients

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