



European Cancer Patient Coalition Annual Report 2016

"Nothing about us, without us!"

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The European Cancer Patient Coalition

Established in 2003, the European Cancer Patient Coalition is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups from the most common to the rarest forms of cancer. It was set up to:

- represent the views of cancer patients in the European healthcare debate;
- enable and empower cancer patients by educating them about cancer and advocacy skills;
- provide a forum for European cancer patients to exchange information, best practice examples and share concerns on their national cancer care policies.

ECPC derives its mandate to speak with “one voice” for all cancer patients from its wide membership and its democratic structure.

ECPC motto:

“Nothing about us, without us!”

In 2016, 27 new organisations joined ECPC, consolidating ECPC as Europe’s largest cancer patients’ association, with a total of 408 members.

Message from the President

As I look back on the last twelve months as President of the European Cancer Patient Coalition, I reflect on the great privilege that it has been to continue as President of this great organisation.

2016 was a year of change and confirmation. Change because a new Board was installed after the most transparent ECPC elections on record, and also because a new Director joined us at the end of the year. Notwithstanding these important changes, there was confirmation that ECPC remains the main voice of cancer patients in Europe. Three out of seven Board Members were re-elected, ensuring continuity.

In 2016 ECPC's persistent efforts to position cancer more prominently on the political agenda continued to yield results, from policy to capacity building to research. Our calls to action were just the first step in an ECPC campaign that will build momentum over the next few years. These achievements were in no small measure due to the active engagement of ECPC's European network of Members, all united in encouraging national governments to take a more proactive role in helping to improve outcomes for people with cancer.

This unity was once again on display at the ECPC Annual Meeting in Brussels, where over 100 delegates gathered to exchange knowledge, research and best practice.

I warmly thank all the individuals – ECPC Members, Board colleagues, staff and volunteers - for all that they have done for the cause of cancer.

Prof Francesco De Lorenzo



Message from the Director

Our Members are our greatest strength to ground European advocacy in the realm of local experience: our knowledge and political power comes from the opinion, experience and suggestions coming from the day-to-day challenges faced by our Members.

I would like to thank the previous Director, Mihaela Militaru, for managing the day-to-day activities of the organisation for most of 2016. Together with Board and the rest of the Secretariat, the European Cancer Patient Coalition produced a wide range of resources and activities that built the capacity of its Members, advocated for better health policy, and ensured patient centrality in many European research programmes.

As we look to 2017, our activities will focus on our core mission: to be the European voice for cancer. We will do this through partnership: providing sustainable and strong organisational leadership at the European level; in policy: providing high quality research and policy development for cancer advocacy; and with presence: providing the best and most authoritative European source for cancer information.

We will deliver our objectives on cancer with a strong united voice drawing on our wide membership and the support of our partners in industry and across civil society.

Together, our voice will have presence and be heard in environments where real and lasting change for cancer awareness, care, treatment and prevention can be driven.

Dr Lydia Makaroff



Policy and Advocacy

Joint Action on Cancer Control



The European Guide on Quality Improvement in Comprehensive Cancer Control (CanCon) was the second Joint Action launched by the European Commission to harmonise the way European Union Member States fight cancer.

CanCon aims to contribute in different ways to reducing the cancer burden in the European Union by:

- Improving the quality of cancer care among member states;
- Improving the quality of life of cancer patients and survivors with proposals on survivorship;
- Ensuring reintegration and palliative care and a decrease in inequalities at various levels of the cancer control field.

These key elements will be combined with other relevant aspects of cancer control (integrated cancer care, community-level cancer care) to create a European Guide on Quality Improvement in Comprehensive Cancer Control.

The Joint Action represents a common effort coordinated by the European Commission (Director General Health and Food Safety) and several European Union Member States to harmonise the way cancer is fought in Europe.

The new Joint Action aims to improve overall cancer control through:

- Quality based cancer screening programmes;
- Enhancing integration of cancer care and community based cancer care approaches;
- Providing concerted efforts in all aspects of survivorship, including palliative care.

ECPC obtained formal recognition as Collaborative Partner, therefore it was necessary to contribute in several Work Packages. CanCon constituted a unique opportunity for ECPC to present the views of the European cancer community on comprehensive cancer and therefore, ECPC's participation in the various Work Packages was of key importance.

In 2016, ECPC's contribution within CanCon focused on:

- Inequalities in cancer care (Work Package 5)
- Survivorship (Work Package 8)

Joint Action on Rare Cancers



The Joint Action on Rare Cancers (JARC) and the European Reference Networks (ERN) are crucial game changers for rare cancer patients in Europe. ECPC and EURORDIS are collaborating together in representing the needs, rights and hopes of rare cancer patients within the JARC project. ECPC, in its capacity, is building on its previous work in the RARECAREnet project to help achieve the overall goal of better access of patients to highly specialized, quality and safe care in Europe.

To continue to represent the rare cancer patient community, ECPC counts on the expertise and collaboration of rare cancer patient organisations all over Europe.

Following the formal request of several rare cancer patient representatives during the ECPC Annual Meeting in 2016, ECPC established a Working Group on Rare Cancers (WGRC), working in parallel with the JARC, to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, will be able to contribute to ECPC's activities within the project. This is an on-going project.

www.jointactionrarecancers.eu

Challenging the Europe of Disparities in Cancer

Since the publication of "[Challenging the Europe of Disparities in Cancer](#)" in 2015, ECPC made a strong plea for a more equitable access to essential cancer care in Europe. *Challenging the Europe of Disparities in Cancer* is ECPC's long term policy strategy, and provides an evidence-based set of key recommendations to European and national policy makers.

The position paper is available to [download](#) on the ECPC website in multiple languages.

In 2016, the value of the paper was recognised by the larger oncology community. The Joint Action on Cancer Control (CanCon) used Europe of Disparities as one of the blueprints and inspiring documents to produce the CanCon Policy Paper on inequalities. The document, to be published in February 2017, sets up the key recommendations to ensure better access to essential cancer care and prevention in all EU countries.

Pancreatic Cancer Europe

Pancreatic Cancer Europe is a multi-stakeholder platform which started in 2014 from a desire to build a network of experts, patients, policy makers and industries to discuss means of tackling pancreatic cancer;

Pancreatic Cancer Europe is composed of 40 national and European experts (academics, patients, clinicians, researchers, industrials) and championed by Four Members of the European Parliament. It is committed to raising awareness of pancreatic cancer in view of improving the standard of care, diagnosis and data collection for patients suffering from this deadly cancer across Europe. The primary goal of the Platform is to ensure that pancreatic cancer is no longer a “forgotten cancer” through the creation and distribution of informative material tailored to educate the public, medical professionals and policy makers.



ECPC, a founding member, was appointed in 2016 to chair the work stream that coordinates and supports national activities as well as the dissemination of the materials produced by Pancreatic Cancer Europe. The actions at national level are designed to raise awareness and increase early diagnosis of pancreatic cancer.



17th November marked the second World Pancreatic Cancer Day. Following a few months of intense preparation, ECPC joined efforts with other dedicated organisations and stakeholders across the world to raise awareness on the day of this deadly cancer.

Pancreatic Cancer Europe held its 4th meeting at the European Parliament on 15th November to discuss European activities around World Pancreatic Cancer Day and the dissemination of materials developed by the Platform at national level. Activities at the national level included pancreatic cancer day awareness events in Greece, Spain, Italy, Poland, Romania, and UK.

www.pancreaticcancereurope.eu

Bladder Cancer

Bladder cancer remains a neglected cancer. ECPC and the European Association of Urology recognised this and joined forces to produce the first [White Paper on Bladder Cancer](#) in 2016. This collaboration was based on patient feedback and was considered an important step in the development of patient information, bringing together two major players responsible for the dissemination of accurate information to cancer patients throughout Europe.

The idea of this initiative came from the Italian ECPC Member PaLiNUro who contacted ECPC in 2015 noting that while information and patient support is far advanced in many solid tumours, it is still lacking for bladder cancer, and suggesting that a strategy aimed at joining efforts under a common platform would bring advances in the field. PaLiNUro identified the active patient groups in Europe and put us in touch with Fight Bladder Cancer, an organisation which went on to become a full member of ECPC and the coordinator of ECPC activities devoted to bladder cancer.

In line with its strategy, ECPC established an expert group made up of 14 top bladder cancer experts, urologists and representatives from patient organisations such as Action Bladder Cancer UK, Fight Bladder Cancer UK and Associazione PaLiNUro, Italy. The ECPC Expert Group on Bladder Cancer drafted the White Paper.



From the left: Prof Dr Morgan Roupret, Chirurgien des Hôpitaux, MD, PhD, Hôpital Pitié-Salpêtrière, Université Paris 6; Prof Hein van Poppel, EAU Adjunct-Secretary General; Prof Francesco De Lorenzo, ECPC President; Andrea Necchi, MD, Department of Medical Oncology, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan; Mihaela Militaru, former ECPC Director; Laurent Vogel, Senior Researcher, European Trade Union Institute; Andrew Winterbottom, Founder and Director, Fight Bladder Cancer UK and ECPC Treasurer.

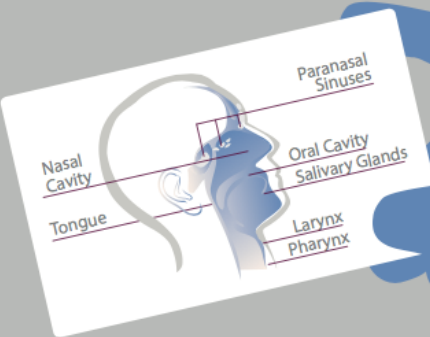
Make Sense of Head and Neck Cancer



MAKESENSECAMPAIGN

For several years ECPC has partnered with the European Head and Neck Society to deliver the Make Sense Campaign aiming to raise awareness of head and neck cancer. 2016 was the fourth consecutive year that ECPC has worked with the Make Sense Campaign Team to improve patients' outcomes and move head and neck cancer up the European healthcare agenda.

In 2016, in the absence of a parliamentary event, the ECPC team delivered a wide campaign through its community and network by sharing patient success stories on its website and developing impactful social media posts. The campaign spanned many European countries, including Belgium, Croatia, Denmark, Finland, France, Germany, Ireland, Italy, Poland, Portugal, Romania, Russia, Spain, the Netherlands, UK, Austria, Greece and Switzerland.



Head & Neck
CANCERS
are cancers that
ARISE in the
LIPs, nasal
sinuses, mouth,
salivary glands,
or voice **THROAT**
B O X

5% of ALL **cancers**
GLOBALLY are of the
Head & Neck

HEAD AND NECK CANCER:
THE SEVENTH MOST FREQUENTLY OCCURRING CANCER WORLDWIDE

www.makesense.org

European Parliament Open Day



European Parliament

On Saturday 28th May 2016, the European Parliament and other European Union institutions opened their doors to the public. The theme of the 2016 Open Day was “United in Diversity” and offered a great opportunity to discover the daily work of European Institutions and experience the real spirit of European diversity in a friendly and enjoyable environment.

In 2016, ECPC was privileged to represent its community as the only non-government organisation to have a stand. The ECPC staff welcomed visitors, shared information about the organisation and encouraged them to take a short online quiz to test their awareness of cancer, followed by a photo shoot by the "ECPC wall".

In addition, ECPC distributed pens, bracelets, balloons and positive energy to encourage everyone to join the fight against cancer.



www.europarl.europa.eu

Research

Nutrition

Nutrition is a crucial component of cancer treatment and rehabilitation as it helps people to better cope with the illness. However, given the focus on the cancer and its cure, nutrition is often neglected, leaving people with cancer and their family with doubts, questions and the need for practical guidance on how to eat better on a daily basis, especially during therapy.

In 2016 ECPC conducted its second survey on nutrition. The objectives of the survey were to:

- Measure the awareness of people with cancer about the importance of nutrition during oncologic therapy;
- Determine if, or to what extent, nutritional problems during and after oncologic therapy are perceived by people with cancer to be important by their physicians.

Over 900 responses were received, and demonstrate a perceived contrast in perspectives on nutrition between people with cancer and their health professionals. Generally, the overall preliminary data underscored the need to implement education among patients but also among healthcare professionals, in order to improve nutritional care.

People with cancer were aware that weight loss negatively impacts their therapy management, quality of life and social aspects. While unaware of cachexia and its implications, they are willing to receive more information on how to manage the issue. Additionally, responses highlighted a lack of awareness about artificial nutrition options and the potential negative impacts of vitamins and anti-oxidants on therapy.

People with cancer reported that their physicians are generally not focused on nutrition. Health professionals are not monitoring weight frequently, providing information about weight loss management or appetite improvement, nor referring patients to a nutritionist.

The study shows a serious discrepancy in need for information and practical management of cancer-related nutritional problems from people with cancer and prompts a greater focus of health professionals on these aspects of care. Most respondents suggested physicians are much less informed than patients about the relevance of nutritional issues.

These results will aid understanding of the necessary effort required from associations and health institutions to fill in any information or training deficiencies in order to meet welfare needs which are still largely submerged by indifference and misinformation in nutrition. It is ECPC's hope that this initiative is embraced by all and that it can represent the first step in constructing a pan-European course of action to increase the awareness of the importance of nutrition for people with cancer.

European Union Projects

PREFER



The Innovative Medicines Initiative (IMI) is Europe's largest public-private initiative, aiming to speed the development of better and safer medicines for patients. IMI supports this aim through collaborative research projects and building networks of industrial and academic experts to boost European pharmaceutical innovation.

In 2016 ECPC, together with other expert stakeholders, built the consortium of the IMI Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) project. The project, led by the Uppsala University in Sweden, has a main objective to strengthen patient-centric decision-making throughout the life cycle of medicinal products by developing evidence-based recommendations on how and when patient-preference studies should be performed throughout the development of new medical treatments. Patient preferences are concerned with measuring how patients value components such as treatment endpoints, route of administration, treatment duration, treatment frequency, frequency of side effects, price and quality of life. PREFER will run from 2016 to 2021.

PREFER is divided into four work packages. The methodology work package looks at the concerns stakeholders have around the use of patient-preference studies. Based on what they find, they will make recommendations about what methodologies to use in case studies that the case study work package will design and carry out. After evaluating the case studies, finally, the recommendations work package will take over and draft recommendations based on the work. The management work package will make sure this work is done on time.

The European Cancer Patient Coalition is one of the four patient organisations in the Patient Advisory Group of the project. The role of ECPC is to lead the Patient Advisory Group and to ensure that the methodologies identified are consistent with the specific views, experiences and preferences of patients. ECPC will also contribute to the final recommendations and to the successful dissemination of the project's deliverables.



This project is funded by the Innovative Medicines Initiative (IMI): a part of the EU Horizon 2020 Programme.

www.imi-prefer.eu



The eSMART project started in 2014, and the ongoing trial is being conducted in Greece, UK, Ireland, Norway and Austria and is on-going.

ECPC has two important roles in this project:

- To participate in Work Package 6, Dissemination and Exploitation, led by the Nursing Dept. of the University of Athens.
- Partake in all activities of the project as co-researchers including participation in the Project Technical Management Board, in the Publications Committee, the Exploitation Committee, and the Trial Committee, continually offering advice and feedback to ensure that the trial is designed and conducted in line with patients' needs and preferences. Patients involvement in the project ranges from planning, to reviewing protocol, to dissemination and exploitation.

Horizon2020MM04 – The Mesothelioma Project

The project aims to demonstrate the efficacy of dendritic cell-based immunotherapy in a clinical trial setting to address the issue of mesothelioma. This could potentially lead to a cure of asbestos-exposed workers, consumers and patients.

Malignant pleural mesothelioma is a rare but highly aggressive cancer that kills about 43,000 people worldwide every year. It is caused mainly by asbestos inhalation due to asbestos exposure and, although asbestos use is decreasing, mesothelioma incidence is expected to keep increasing for the next 20-50 years due to its long latency period. Unfortunately, there is no curative therapy for mesothelioma, making it a highly fatal disease. There is a clear demand for treatment of mesothelioma.

ECPC is involved in the work package responsible for the effective dissemination and exploitation of the results to external stakeholders. Furthermore, having ECPC as a partner will ensure the project developments are designed to better respond to the needs of the patients. This is an on-going project.



This project is funded by Horizon 2020: the EU Framework Programme for Research and Innovation.

TRANSCAN-2



ECPC was invited to participate in the Scientific Advisory Board of TRANSCAN-2 research project.

TRANSCAN-2 is the continuation of the ERA-NET on Translational Cancer Research (TRANSCAN), an initiative funded by the European Commission's ERA-NET scheme under the European Union's Framework Programme for Research and Innovation Horizon 2020 Societal Challenge: Health, Demographic Change and Wellbeing.

The objective of TRANSCAN-2 is to contribute to the building of the European Research Area through the coordination of national and regional translational cancer research funding organisations' activities, aiming at the integration of basic, clinical and epidemiological cancer research and facilitation of transnational cancer funding in Europe while avoiding the duplication of efforts and with a more efficient use of available resources.



This project is funded by Horizon 2020: the EU Framework Programme for Research and Innovation.

www.transcanfp7.eu

InSup-C



A project funded by the 7th Framework Programme, InSup-C investigated patient-centred palliative care pathways in advanced cancer and chronic diseases.

InSup-C identified best practice in integrated palliative care by examining models of care delivery across several European countries. The study focused on people with advanced cancer and on those in the later stages of chronic illness, specifically chronic heart failure and chronic obstructive pulmonary disease.

The study's goal was to find out the best way to deliver integrated palliative care to people who have advanced cancer, heart failure or lung disease. Moreover, the project delivered recommendations on best practice in integrated palliative care and on the best professional skill mix and organisational systems required to achieve optimal care.



ECPC was invited to oversee the InSup-C work, providing support across the project, ensuring that the patients' perspective is respected throughout.

This project was funded by the 7th EU Framework Programme for Research and Innovation.

www.insup-c.eu

Education

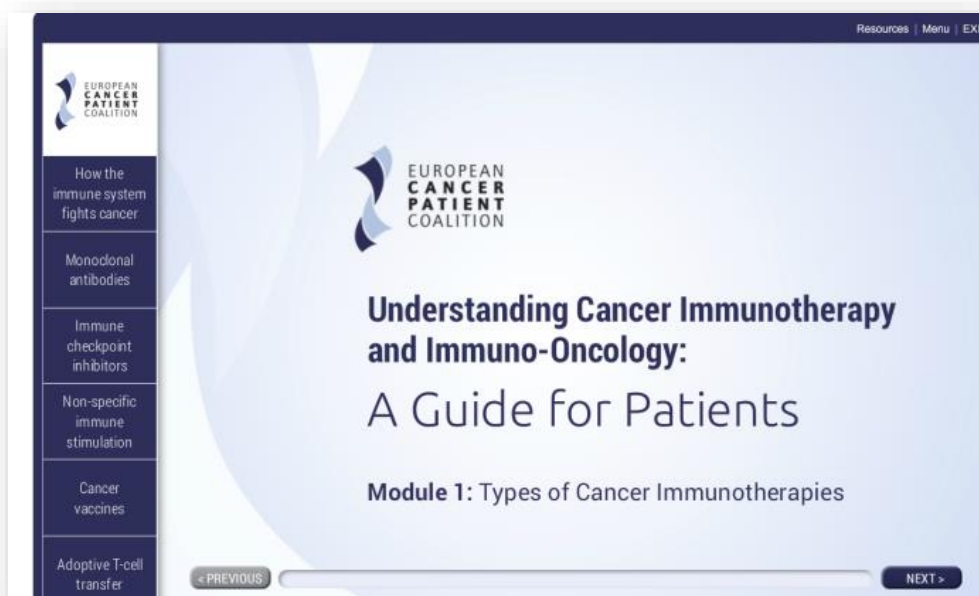
Immuno-Oncology Portal

The Immuno-Oncology Portal is an online information platform on cancer immunotherapies and immuno-oncology treatments for cancer patients across Europe.

The Immuno-Oncology Portal aims to provide patients with all forms of cancer, their caregivers and family members with up-to-date, accessible information about cancer immunotherapy – treatments with use of the immune system to fight cancer. The Portal focuses particularly on the newest type of cancer immunotherapy: immuno-oncology treatments, as these have shown very promising results for patients and are now available to treat several different cancers.

The Immuno-Oncology Portal also aims to provide general practitioners and policy makers with complex knowledge and raise awareness of the potential of immuno-oncology treatments to these audiences. It also aims to act as a pan-European Advocacy Hub by providing European cancer patient advocacy groups with advocacy tools and information on cancer immuno-oncology treatments and cancer immunotherapies more generally.

Since November 2015, the English version of Immuno-Oncology Portal has collected thousands of visits, affirming itself as one of ECPC's most viewed pages on its website. In 2016, the Immuno-Oncology Portal Module 1 & 2 was translated into Italian and Greek to better respond to the needs of patients throughout the Europe. In 2017, it will be available in Polish, Spanish, French and Dutch.



iop.ecpc.org

Patient advisory roles

European Medicines Agency



EUROPEAN MEDICINES AGENCY

SCIENCE MEDICINES HEALTH

The European Medicines Agency and patients have been actively interacting since the creation of the Agency in 1995. This cooperation was extended to include consumer groups with an interest in medicines. Both stakeholder groups bring 'real-life' experience as well as specific knowledge and expertise to scientific discussions on medicines and on the impact of regulatory decisions.

The main patients' working group functioning in European Medicines Agency is the Patients' and Consumers' Working Party established ten years ago within the Committee for Medicinal Products for Human Use. The role of Patients' and Consumers' Working Party is to advise, initiate discussions and propose solutions to all matters that are important with regards to medicines authorisation and their safety but also to develop educational materials that are clear for each patient who takes medicines. Patients' and Consumers' Working Party members also take part in discussions on improving the functioning of existing legislation (optimisation of the processes e.g. of medicines authorisation, increase in use of information technology tools) whilst progressing the development of the new legislation.

During Patients' and Consumers' Working Party meetings, ECPC's representatives speak out on current issues in the interest of cancer patients and their treatment. During the period 2013-2016, ECPC was represented by Vice President, Kathi Apostolidis and Board Member, Rafal Schwierzewsk. Ms Kathi Apostolidis, Vice President of the European Cancer Patient Coalition, has also joined the Steering Group of the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance as an observer of the European Medicines Agency Patients & Consumer Working Party, of which she is a member. Currently ECPC is involved in a multi-stakeholder discussion on a new European clinical trials database and portal, social media working group, pharmacovigilance legislation and procedures and projects that are currently under development (e.g. WEBRADR project directed to mobile technology use in adverse drug reaction reporting). In 2016, ECPC was a member of a sub-group working on the involvement of young patients (children, teenagers and young adults) in EMA's activity, co-chaired by Rafal Swierzewski, ECPC Board Member.

ESMO Patient Advocates Working Group



European Society for Medical Oncology

The ESMO Patient Advocates Working Group (PAWG) main mission is the optimisation of cancer patient care in Europe and worldwide, the continuous improvement of cancer-specific information and education, the strengthening of patient autonomy and the support of patient rights.

In 2016, the ESMO Patient Advocates Working Group had nine members and ECPC was represented by its Vice President, Kathi Apostolidis and Vice President-Treasurer, Vlad Voiculescu. Among the main tasks of the ESMO Patient Advocates Working Group was the organisation of the Patient Advocacy Track at the annual ESMO oncology conference, aiming to disseminate knowledge to advocacy groups, cancer patient associations, caregivers and the public. ECPC contributed in the program development of the Patient Advocacy Track (PAT) for 2014 and 2016, was a member of the PAT Faculty (Apostolidis, de Lorenzo, Pelouchova) responsible for preparing the 2016 and 2017 program.

ECCO Patient Advocates Committee



The European CanCer Organisation's Patient Advisory Committee (ECCO-PAC) was established in 2009 to contribute to the European Cancer Congresses by providing the patient perspective, helping healthcare professionals and all delegates to better understand the 'desires' of patients rather than just their perceived 'needs'. The Patient Advisory Committee was also in charge of developing the programme of the 'patient advocacy' track at the 2017 congress.

The 2016 European CanCer Organisation's Patient Advisory Committee had 15 members and ECPC was represented in it for a second mandate by its Board Member and Secretary, Jana Pelouchova.

Expert group on cancer control



The Expert Group was established in September 2016 to assist the Commission in the preparation of legislative proposals and policy initiatives concerning cancer. The members of the Expert Group include representatives of the member states. ECPC was represented in the Expert Group by its President, Prof Francesco de Lorenzo and its Vice President, Kathi Apostolidis. The members of the Expert Group are representatives of the member states, oncology related scientific societies, cancer patient organizations and civil society representatives.

The Expert Group was established to respond to the need for improved coordination among member states on cancer control. The Expert Group will have an advisory role and will assist the Commission with the preparation of legal and policy documents, guidelines and recommendations on cancer control, guidelines on cancer data including epidemiology, cancer screening, quality assurance and information on cancer prevention, clinical cancer research and cross-cutting themes related to cancer.

Moreover, the expert group was expected to facilitate the coordination and exchange of information between Member States of the European Union and advise the European Commission on the implementation of Union actions and suggest improvements on the measures taken.

Capacity building

ECPC Annual Meeting

The 2016 Annual Meeting took place in Brussels, Belgium from the 3rd to the 5th June. The event was organised under the Patronage of the European Commissioner for Health and Food Safety, Vytenis Andriukaitis. The 2016 Annual Meeting was organised around the theme of cancer survivorship. On the 5th of June ECPC celebrated World Cancer Survivors Day by dedicating proceedings entirely to survivorship.

The Annual Meeting 2016 confirmed itself as the largest cancer patients' gathering in Europe with 144 participants from 27 European and non-European countries. The biggest privilege, however, was to welcome over 90 ECPC full and associate Members, actively participating, sharing best practices and contributing to the discussions.

ECPC was also pleased to host eight cancer patient organisations that were not ECPC members, numerous stakeholders, industry representatives and outstanding speakers. There were six interactive sessions covering several key topics related to the issues of survivorship in cancer and recent developments in cancer policy at European level, each one received great engagement from the participants.

During the meeting, ECPC made important decisions for its future by electing the Board and Audit Committee for the 2016-2019 triennium. This made the 2016 Annual Meeting an even more appealing event for ECPC stakeholders, as it provided a unique opportunity to meet the new Board in its entirety.

The 2016 Annual Meeting offered the ECPC community yet another great opportunity to raise important questions, address the most alarming issues and share many wonderful and promising ideas and initiatives. The energy and inspiration derived from this gathering resulted in ECPC growing stronger and even more motivated and inspired to continue its mission.



From left: Nicolas Philippou, Pietro Presti, Natacha Bolanos, Dan Cimpoeru, Kathi Apostolidis, Francesco De Lorenzo, Jana Pelouchova, Andrew Winterbottom

ECPC-EORTC seminar on clinical trials

ECPC co-organised a seminar on clinical trials in collaboration with the European Organisation for the Treatment and Research of Cancer (EORTC) in March 2016. The programme covered the fundamentals of clinical trials, ranging from basic cancer biology to innovative cancer treatments. On the second day, participants discussed case studies with the faculty, applying the newly acquired knowledge from the interactive sessions. Twenty-eight patients and patient advocates from across Europe took part in the seminar. ECPC and EORTC promoted the seminar on their websites and social media and selected participants following a registration process. Reimbursement of travel and accommodation expenses were provided for all participants.

ECPC and EORTC created a [website](#) dedicated to sharing course material, including presentations and a video recording of the session, via the password protected EORTC website. The evaluation survey resulted in positive feedback, with the clear majority of participants stating they would recommend the course to others and found it useful, complete and understandable.

The course also provided a great networking opportunity during the breaks and throughout dinner. ECPC provided a keynote presentation on the Immuno-Oncology Portal, as an example of the catalysing role patients can have in disseminating scientifically complex information to fellow patients.

Cancer Advocacy Academy

The role of Information and Communications Technology is fundamental to ensuring cancer patients can access and understand vital information about their disease as well as enabling them to raise their voice and utilise the potential of existing media channels. This project enabled access to online, specialised, scientifically accurate information for patients from European countries with limited access to the internet.

The project was financed by the Waldesian Church. ECPC used the grant to provide eight of its Members with computers, printers, scanners, headphones and other useful equipment intended to improve the quality of their daily activities and facilitate their engagement with the fast-paced 21st century. The ECPC members which received equipment represent the following countries: Romania, Greece, Bulgaria, Poland, Slovenia, Macedonia and Spain.

The second part of the project consisted of two specialised online trainings:

1. ECPC delivered a tailored social media audit to identify the key issues faced by organisations communicating their activities, with the aim to build a clear, comprehensive communication strategy, and increase the capacity of cancer patients' organisations to use social media channels. The organisations were asked to report the key issues they faced. Based on the audit outcomes and organisations' feedback, ECPC produced a toolkit with practical information and recommendations which was then shared with the participating organisations.
2. The second training focused on advocacy skills, government affairs and on how to use ECPC campaigns to advocate for the rights of cancer patients at local level. The training, called "From European to National Level" aimed at improving the collaboration of ECPC and its members and understanding their advocacy support needs. Based on the feedback received and in order to address these issues, ECPC put together a step-by-step advocacy guide to help its Members achieve their national objectives.

Partnerships

European Society for Medical Oncology

The European Cancer Patient Coalition (ECPC) and the European Society for Medical Oncology (ESMO) have signed a Memorandum of Understanding with the aim of enhancing the existing cooperation and increasing the efforts to achieve common goals and objectives in the field of cancer to satisfy the new needs and rights of cancer patients across Europe.

The Memorandum establishes a legal framework for current and future collaborations, leaving complete freedom and discretion to the partners. In this respect, the Memorandum works alongside existing ECPC and ESMO agreements with third parties, avoiding duplication and enriching existing initiatives.

The first topic ECPC and ESMO started collaborating on was survivorship care. ECPC is directly involved in the drafting of the Survivorship chapters of the new [ESMO Clinical Practice Guidelines](#). Updated regularly by the [ESMO Guidelines Committee](#), the Guidelines are the standard for best practice of a vast variety of cancers, and represent the most reliable, evidence based resource to help oncologists in taking practical decisions that affect patients' lives. ECPC and ESMO decided to include more patient-friendly and solid survivorship care provisions in the guidelines, reflecting cancer patients' growing need for a structured follow up after the acute treatment phase.

In the coming years, each updated ESMO Guideline will contain a reviewed, patient-oriented survivorship chapter. ECPC and ESMO will also ensure that the Guides for Patients will include updated provision on survivorship care, in line with the Clinical Guidelines.



www.esmo.org

Union for International Cancer Control

ECPC has been a full member of Union of International Cancer Control since late 2015. The Union of International Cancer Control immediately recognised the value and importance of having ECPC as one of its members and gave it a key role within the World Cancer Congress 2016 in Paris.

ECPC participated in several sessions:

- **UICC Regional Meeting - Europe: Life beyond cancer, challenges and opportunities for patients and society**. During this meeting, presented by Dr Claudia Ferrari from the Institut National du Cancer (France), all UICC European Members were introduced to the preliminary recommendations of the Joint Action on Cancer Control (CanCon) related to survivorship. ECPC also presented 2 best practices on survivorship: the ECPC-ESMO Memorandum of Understanding (presented by Dr Fatima Cardoso) and the work of ECPC Members FAVO-AIMaC in relation to the return to work (presented by Elisabetta Iannelli);
- **The promise and challenges of immuno-oncology for the cancer community**: ECPC took an active part in the session by presenting the Immuno-Oncology Portal in this meeting chaired by the UICC President Dr Sanchia Aranda;
- **Practice, Policy and Advocacy reports**: ECPC presented the paper “Challenging the Europe of Disparities in Cancer Care”, the backbone of ECPC policy strategy;
- **Cancer at the grassroots - Community Development Strategies**: ECPC Board Member Dan Cimpoeu presented the ECPC Legal Network for Cancer Patients (LNCP), ECPC’s very own group of lawyers committed to protect cancer patients’ rights;
- **Experiences of cancer survivorship**: Prof De Lorenzo spoke to a committed group of patients’ advocates regarding the ECPC’s best practices in survivorship and follow up care;
- **Collaborating on solutions to ensure sustainable access to new oncology medicines for patients and governments - A case study from Europe**: ECPC Board Member Dan Cimpoeu spoke about his experience defending the rights of Romanian cancer patients to access innovative and essential cancer treatments;
- **Strengthening health systems for Cancer and NCD co-morbidities: successful approaches for integrated care**: ECPC Director Lydia Makaroff spoke about the importance of reorienting health systems for chronic conditions, and to integrate care packages across cancer and other non-communicable diseases.

ECPC provided scholarships to 8 ECPC Members to participate in the World Cancer Congress, which covered costs of travel and accommodation.



Industry Partners

ECPC seeks to partner with responsible corporations and foundations to advance its mission to promote cancer care, prevention and treatment throughout Europe and guarantee the sustainability and impact of the coalition. ECPC strongly believes in mutually beneficial strategic alliances to elevate cancer to the top of the public agenda.

ECPC is grateful to the following partners that helped further its advocacy, education and capacity-building activities in 2016.

Not-for-Profit Organisations and Public Entities



WALDENSIAN CHURCH
UNION OF METHODIST AND WALDENSIAN CHURCHES



Top five industry partners

MERCK



Other industry partners

abbvie

AMGEN®



Boehringer
Ingelheim

Baxter



Genomic Health
LIFE. CHANGING.

HELSINN
Building quality cancer care together

IPSEN
Innovation for patient care

Johnson & Johnson

Lilly

NOVARTIS



2016 Finances

Expenses	2015	2016	Difference	%
Payroll/human resources¹	€ 189,661	€ 212,787	€ 23,126	+12 %
• Employer Contributions	€ 60,692	€ 95,342		
• Gross salaries	€ 128,969	€ 117,445		
○ Employee Contributions	€ 24,656	€ 20,419		
○ Net salaries	€ 104,314	€ 98,771		
Running costs	€ 69,809	€ 69,111	- € 698	-1 %
• Office rent & maintenance	€ 40,127	€ 37,041		
• Energy consumption	€ 1,524	€ 1,333		
• Office supplies	€ 2,351	€ 2,535		
• IT maintenance & costs	€ 4,908	€ 3,364		
• Telephone & internet	€ 3,062	€ 5,983		
• Website costs	€ 2,003	€ 1,300		
• Fee subscriptions	€ 2,504	€ 1,934		
• Other office costs (printing, postage)	€ 3,645	€ 1,053		
• Cleaning costs office	€ 0	€ 5,179		
• Transfer ECPC from NL to BE	€ 9,685	€ 0		
• IT investment 2016	€ 0	€ 9,390		
Board	€ 28,037	€ 25,648	- € 2,389	-8.5 %
• Board travel ²	€ 21,806	€ 20,449		
• Other (communication, catering)	€ 6,231	€ 5,199		
Awareness	€ 62,663	€ 89,398	+ € 26.735	+43 %
• Immuno-Oncology Portal		€ 40,085		
• EORTC Clinical Trials Seminar		€ 21,372		
• Waldesian Church Project		€ 27,941		
Advocacy	€ 122,187	€ 134,576	+ € 12.389	+ 10 %
• Annual Meeting	€ 80,325	€ 97,615		
• Advocacy ³	€ 31,445	€ 30,445		
• Staff travels advocacy ⁴	€ 6,897	€ 6,516		
• EU lobby for policy	€ 3,520			
EU funded Projects	€ 32,816	€ 30,054	- € 2.762	- 8.4 %
• Project travel	€ 13,094	€ 12,811		
• Project publications	€ 2,948	€ 2,292		
• Project conferences & catering	€ 3,662	€ 2,331		
• Other project expenses	€ 13,112	€ 12,620		
• TOTAL EXPENSES	€ 505,173	€ 561,574	+ € 56.401	+ 11%
• Deficit/Surplus	€ 163,831	€ 45,378		

¹ Belgium has one of the highest rates of taxation for average salaries out of all EU and OECD countries.

² According to the statutes of ECPC, the Board meets at least four times per year.

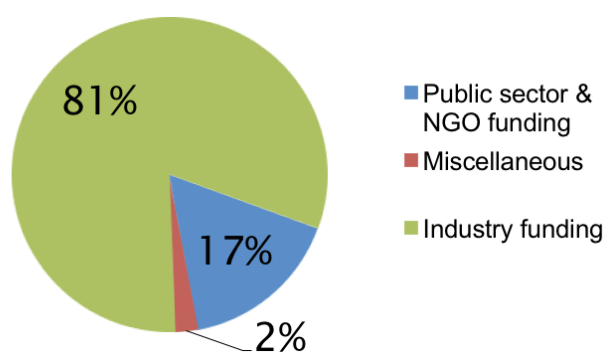
³ Membership fee UICC, contract with EurActiv, costs for stand in the EP, etc.

⁴ In general, staff travel is reimbursed by the organisers. ECPC may offer support if deemed useful by the Board.

For the financial year 2016, the revenue from different sources amounted to a total of **€ 606,952**.

Running costs, human resources, operational costs and implementation of projects during the previous year came to a total of **€ 561,574**, leaving a positive balance of **€ 45,378**.

2016 Revenue by origin



For further details, please see the full 2016 ECPC Financial Report at www.ecpc.org

Calendar of main activities for 2017

- **January 2017**

- Launch of Value of Innovation at the European Cancer Congress
- Launch of the ECPC-OECI Joint Declaration at the European Cancer Congress
- Launch of the White Paper on Prostate Cancer

- **February 2017**

- World Cancer Day
- Joint Action on Cancer Control (CanCon) final event in Malta

- **April 2017**

- CanCon and Value of Innovation event at the European Parliament

- **May 2017**

- Bladder cancer awareness campaign

- **June 2017**

- ECPC Annual Meeting

- **September 2017**

- Make Sense of Head & Neck Cancer Campaign

- **October 2017**

- White Paper on the Condition of Cancer Patients' Carers

- **November 2017**

- World Pancreatic Cancer Day