

ECPC ANNUAL REPORT

2015

"Nothing about us without us!"

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ECPC: RISING TO NEW HEIGHTS

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 rare forms of cancer. It was set up:

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

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

In 2015, 14 new organisations joined ECPC, consolidating ECPC as Europe’s largest cancer patients’ association.

ECPC ANNUAL GENERAL MEETING 2015

The 2015 AGM took place in Brussels, Belgium from the 19th to the 21st June. The event was organised under the High Patronage of Her Royal Highness Princess Astrid of Belgium and of the European Parliament.

More than 140 participants from 26 countries took part, exceeding the numbers of last year’s AGM. ECPC had the privilege to host 52 ECPC member organisations from 24 European countries therefore succeeding to achieve a balanced participation from across Europe. We were also glad to have 12 Cancer Patient Organisations that were not ECPC members, which enriched the discussion during the sessions on Friday and Saturday. Indeed, all 6 interactive sessions provided great added value to our daily work. At the same time, ECPC took important decisions for its future.

Our sessions also showed the quality and solidity of the relationships established by ECPC with policy makers, the oncology world and other stakeholders. European Commissioner for Health and Food Safety Vytenis Andriukaitis also took the time to send us a touching video message opening the AGM. The EMA and European Commission took again the floor to discuss with patients the future of European health policy making. The research community provided us some of its finest experts. In terms of organisational management and development there was also a visible improvement and a substantial forecast of income increase for 2015.



ENHANCED COLLABORATION WITH AN INCREASED ECPC MEMBER BASE

The ECPC membership has increased drastically since 2013. However, in 2015, ECPC’s target was to involve members in different ECPC projects. Indeed, this increased collaboration with ECPC member organisations has had a great positive impact in the outcome of the projects. Some examples of this enhanced collaboration are described below.

MAKE SENSE CAMPAIGN

The **Make Sense Campaign** was launched in Brussels in 2013. Already in 2015 the campaign was rolled out in **15 countries thanks to the partnership with ECPC members**.

GUIDE FOR PATIENTS ON IMMUNO-ONCOLOGY

The Guide has been translated and disseminated in 21 countries (Bulgaria, Croatia, Czech Republic, Denmark, the Netherlands, UK, Ireland, Estonia, France, Greece, Hungary, Italy, Latvia, Lithuania, Poland, Portugal, Romania, Slovenia, Spain, Sweden and Turkey) in the course of seven months throughout the outstanding help of some of our members at national level.



NUTRITION SURVEY

More than 600 patients and patient advocates participated in the survey on the importance of nutrition in the oncology patient from March until May 2015. **GEPAC**, our member from Spain, did an exceptional work collecting 265 replies from Spain alone.

THE BRAIN TUMOUR CHARITY

The **Brain Tumour Charity (BTC)** – one of ECPC Members from the UK – requested from ECPC an analysis of the main EU policy issues that can impact BTC strategy. ECPC was happy to do the analysis and provide a schematic plan for action, providing useful and practical policy suggestions to BTC to enhance the effectiveness of its policy outreach in Europe.

LUNG CANCER EUROPE (LUCE)



Lung Cancer Europe (LuCE), Europe's most important lung cancer umbrella patient organisation, asked our help for the organisation of the event "The future of the fight against lung cancer", held in the European Parliament in November 2015.

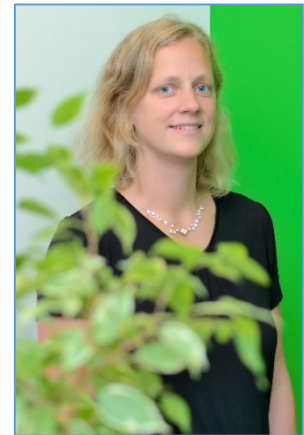
PAVEL

In April 2015, ECPC Board Member Rafal Swierzewski and Director Mihaela Militaru guided a group of young Romanian cancer survivors through a visit of the European Capital. Hosted by Romanian MEP Daciana Sarbu, these young survivors had the chance to visit the European Parliament before their return to Romania.

ECPC STAFF

FINANCIAL OFFICER

In August 2015, ECPC welcomed its new Financial Officer, Jiska Bolhuis. With more than nine years of experience in the field of communication and project management (especially in the field of public policy contracts), Jiska has a large amount of experience in managing and coordinating budgets, contracts, people and events. As a Dutch national, she speaks Dutch and English fluently and has a good knowledge of German, French as well as some basic knowledge of Spanish. Jiska is working with ECPC as a part-time freelancer.



COMMUNITY MANAGER

In fall 2015, ECPC decided to hire a dedicated professional whose primary mission would be to nurture, consolidate and enlarge the relationship between ECPC and its Members. In December 2015, after a long recruitment process, ECPC selected Anna Rek to fill the position of Community Manager.



Anna holds a Masters' degree in Contemporary European Studies and European Politics from the University of Sussex in Great Britain. She gained her professional experience and got a deep understanding of the healthcare sector while she worked for 2 worldwide pharmaceutical companies followed by a practice in a Public Relations agency, where she was responsible for developing and implementing nationwide health and disease awareness campaigns accompanied by proactive and reactive media relations. Anna has a significant experience in supporting national patient organizations, such as Polish Cancer Patient Coalition, Melanoma Academy, Amazons, The Start of Hope Foundation or the Foundation of Social Education.

LEGAL SEAT CHANGE

EXTRAORDINARY GENERAL ASSEMBLY

On the 20th February 2015 ECPC organised an Extraordinary General Assembly in The Hague, the Netherlands, in order to lay the ground for the move of the ECPC siege to Belgium. The meeting took place within the premises of the Notary Martijn van Ansem at the Barents Krans notary studio. The meeting was attended by Anemone Bogels (Director, Leven met Kanker, the Netherlands - Full Member) and Wiesława Adamiec (President, Carita foundation, Poland - Full Member). After reading the notarial deed, the notary proceeded with the Extraordinary General Assembly approval on the deed, which was approved unanimously. The notarial deed concludes the Dutch side of the process of transferring our siege to Belgium.

A NEW STATUTE

During the AGM 2015, the General Assembly approved a new version of the statute, to modernise the organisation of ECPC and to adapt it to the change of legal siege. The three main innovation to the statute are:

- A **Scientific Committee**, responsible to overview the implementation of research projects and the production of policy papers;
- The institution of the role of **Past President**, to ensure continuity among the Boards, particularly in relation to long-duration research projects;
- The **Friends of ECPC Committee**, which will collect MEPs, representatives from the institutions and VIPs who have demonstrated to support the cause of cancer patients;
- A new **Board election system**, in line with the consolidated praxis of our organisation.

SCIENTIFIC COMMITTEE

ECPC is one of the few cancer patients associations that actively works within EU funded research projects. This success was possible also thanks to our renewed partnership with medical societies and researchers. This is undoubtedly a good sign of our recognised expertise. However, with the turnover of the ECPC Boards, we fear to lose the knowledge and experience that led ECPC to win several bids for EU grants. For this reason, we have introduced a Scientific Committee, composed by ECPC Expert Members (medical societies or individual researchers), which will be responsible to overview ECPC participation in research projects and can provide ECPC with valuable scientific expertise for any other issues the Board will deem necessary.

All ECPC Members had the chance to nominate candidates to the Scientific Committee.

PAST PRESIDENT

For the Scientific Committee to work, however, it needs leadership, coordination and a solid expertise regarding the problems of cancer patients. For this reason, we suggested the institution of the role of "Past President". The Past President is not a Board Member, but participates to the works of the Board and chairs the Scientific Committee, in order to ensure that the knowledge accumulated by the Board will be passed on. This is particularly important for EU funded projects: these projects usually last longer than the duration of the Board's mandate, therefore, it is important to demonstrate to the European Commission that ECPC is able to provide continuity.

FRIENDS OF ECPC

During the last year, we have also massively capitalised on our intense policy work. ECPC is now represented in all European Commission's tables of discussion on cancer (ECIBC/QASDG-Working Group for Quality Assurance Development Scheme of the Initiative of the European Commission for Breast Cancer, Working Group for the assessment of mHealth apps guidelines, Cancer Control Joint Action, European Medicines Agency and Expert Group on Cancer Control). On top of that, the European Parliament demonstrated to be our closest political ally: 29 MEPs signed our Call to Action (March 2014), 56 endorsed our proposal for an Intergroup on Health (Autumn 2014) and a staggering 116 MEPs supported our Declaration on the World Cancer Day (February 2015). This political capital cannot go to waste.

The solution to this problem is to create a second new committee, called "Friends of ECPC", a prestigious group of committed politicians, EU officials, VIPs that demonstrated to care about the condition of European cancer patients thorough their daily work, their charitable endeavours or their personal commitment. "Friends of ECPC" will become therefore the permanent political influence reservoir, from which future Boards will be able to draw political energy and prestige to foster ECPC policy stance.

NEW ELECTION PROCESS

The notary rightfully made us realise few inconsistencies between the way the elections were run in the past years and the text of the statute. For this reason, we have better translated the consolidated praxis used for our elections in the new statutes, fixing clearer, more transparent and democratic rules for the election of the Board, which, at the same time, are in line with ECPC tradition.

The only true novelty introduced concerns the definition of the number of Board Members: we believe it is up to the General Assembly to decide how many Board Members shall be elected. We believe that the number of Board Members shall be related to the projects and duties of the organisation, as well as taking into consideration the number of ECPC Members. For this reason, we specified that the General Assembly will decide on the number of Board Members one year before the elections of the new Board.

THE APPROVAL OF THE STATUTE

During the AGM 2015, all ECPC Members had the chance to discuss and amend the draft statute proposed by the ECPC Board. ECPC opened the consultation well in advance, asking members to check the draft and submit changes in writing.

During the AGM, each amendment proposed was discussed and voted, leading to the consolidated version adopted, and available on our website.

The final version of the statute was also used to register ECPC in Belgium.

POLICY AND ADVOCACY

LAUNCH OF THE IMMUNO-ONCOLOGY PORTAL

On the 10th November, ECPC Member Lung Cancer Europe - LuCE, organised an event at the European Parliament to **raise awareness of the innovative strategies to fight against lung cancer in Europe**. The event was jointly hosted by MEP Philippe De Backer (ALDE, Belgium) and MEP Cristian Busoi (EPP, Romania), with the collaboration of MEP Jytte Guteland (S&D, Sweden).



The event, co-organised with ECPC, also featured **the launch of the Immuno-Oncology Portal, Europe's first patient-led, scientifically validated online learning platform on cancer immunotherapy and immune-oncology.** The Portal offers European cancer patients clear information to help them understand how cancer immunotherapies work, and what role immunotherapy and immuno-oncology treatments may play in treating their cancer. One e-learning module on immune-oncology treatments is fully developed, and a second one will be available in spring 2016. The Portal, now in English, will soon be available in more European languages.



EUROPE OF DISPARITIES

One of ECPC's strongest wishes for 2015 was to raise awareness and find allies in order to set a structured agenda on the fight against cancer-related health inequalities affecting European cancer patients. This is how "Europe of Disparities" was created.

OBJECTIVES

The objectives of Europe of Disparities are to:

- Raise awareness within the European institutions about inequalities in cancer care as identified by the European cancer patient community;
- Draft and suggest a political agenda on how to tackle the pressing issue of eliminating cancer-related health inequalities in Europe;
- Reinvigorate the partnership established with 29 MEPs signatories of the ECPC Call to Action and call for more MEPs and health stakeholders to join the ECPC plea.

EUROPE OF DISPARITIES INITIATIVES

Within Europe of Disparities Projects several initiatives took place throughout 2015:

- A conference, held in the European Parliament on the 27th January 2015, to raise awareness on the cancer care inequalities and identify experts and MEPs willing to work on the topic;
- Getting the feed-back of ECPC members via a survey;
- The establishment of a **working group** for the production of the **position paper on cancer care inequalities**;
- **Launching the position paper** at the European Cancer Congress organised by the European Cancer Organisation (ECCO) in Vienna on 27 September.

EUROPE OF DISPARITIES CONFERENCE

On the 27th of January 2015, ECPC co-organised together with **MEP Elisabetta Gardini** (Head of the Italian EPP Delegation) an event at the European Parliament, in order to raise awareness on the unbearable inequalities in cancer care existing in Europe. The first part of Europe of Disparities aimed at raising some of the most important questions and unsolved dilemmas around inequalities in cancer care.

A high-level panel of speakers, representing patients, academia, industry and policy makers, launched the debate on the causes of inequalities in cancer care, providing cornerstone information for the work of the ECPC working group on inequalities in cancer care.



POSITION PAPER

In order to get our facts right and provide policy makers with a scientifically valid, brief and powerful policy document, ECPC joined forces with researchers, academics and other organisations to produce a position paper on inequalities in cancer care called "Challenging the Europe of Disparities in cancer".

The objective of the document is to point at the principal causes of inequalities in cancer care, in particular those factors that can be tackled at the European level, and to provide policy recommendations to help policy makers design effective measures to solve those inequalities, while keeping the patients at the centre.

LAUNCH OF POSITION PAPER

Europe of Disparities Paper was presented at the European Cancer Congress in Vienna, on the 27th September 2015, in the presence of the contributors of the paper, Prof Mark Lawler and Prof Richard Sullivan.



The position paper is available for download on the ECPC website and it is also available in other languages besides English (<http://ecpc.org/news-categories/policy-and-advocacy/132-ecpc-policy-initiatives-news/337-europe-of-disparities-in-cancer> and <http://ecpc.org/activities/policy-and-advocacy/policy-initiatives/306-europe-of-disparities>).

EXPERT GROUP ON CANCER CONTROL

The Expert Group was established in September 2015, having as task 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 is represented in the Expert Group by its President, Prof. Francesco de Lorenzo and its Vice President, Kathi Apostolidis, as alternative. The members of the Expert Group are representatives of the member states, oncology related scientific societies, cancer patient organizations, 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, as well as for cross-cutting themes related to cancer.

Moreover, the expert group is expected to facilitate coordination and exchange of information between EU member states and advise the Commission in the implementation of Union actions and improvement suggestions for the measures taken.

EUROPEAN COMMISSION INITIATIVE ON BREAST CANCER (ECIBC)

The European Commission has approved **ECPC's participation in the European Initiative on Breast Cancer (ECIBC)**, aiming to ensure and harmonise quality of breast cancer services across European countries and to develop a voluntary European Quality Assurance Scheme for Breast Cancer Services based on EU legislation on accreditation.

The ECIBC consists of two Working Groups, the GDG - Guidelines Development Group and the QASDG - Quality Assurance Development Group. Both Groups work under the supervision of the JRC - Joint Research Centre of the European Commission. The objective of the Guidelines Development Group (GDG) is to develop evidence-based **European Guidelines for breast cancer screening and diagnosis**. The Quality Assurance Scheme Development Group (QASDG) will develop the **European Quality Assurance Scheme for Breast Cancer Services** (the European QA scheme) to set common quality and safety requirements for person-centred breast cancer services in Europe. The scheme will cover all the processes of breast cancer care (screening, diagnosis, treatment, rehabilitation & supportive care, follow-up & survivorship care and palliative care) and will be underpinned by the accreditation legal framework and evidence from guidelines.

Following a selection procedure based on specific qualification criteria, our Vice-President, **Kathi Apostolidis, was appointed to become a member** in the **Quality Assurance Scheme Development Group (QASDG)** due to her experience and knowledge in the field of breast cancer. The working group will be directly involved in the processes required for developing and piloting the '**European Quality Assurance (QA) scheme for Breast Cancer Services**'.

The working group will also:

- decide on clinical and organisational areas to be covered within the European QA Scheme;
- agree on breast cancer specific requirements making use of the evidence provided by the guidelines developed by the Guidelines Development Group (also within ECIBC);
- select and define quality indicators.

The ECIBC/QASDG working group has 29 members (clinicians in the field of breast cancer screening, diagnosis, treatment, nursing, and palliative care as well as representatives of breast cancer patients and carers) and the work is divided in sub-groups. The sub-groups undertake to prepare specific topics and documents for presentation to the QASDG plenary. ECPC is represented in the following QASDG sub-groups:

- Competence (Training, Continuous Education, etc.)
- Organisation, Scope and Modules (incl. eligibility/gate requirements)
- Indicators
- Certification (Audit, pilot run)

ECPC's participation in the ECIBC is a great opportunity to bring forward the breast cancer patient perspective and to further engage with the breast cancer community, representing a great number of our members.

CANCON

The European Guide on Quality Improvement in Comprehensive Cancer Control – CanCon is 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 EU. It will help decrease cancer mortality 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 (DG SANCO) and several EU Member States to harmonise the way we fight cancer in Europe. CanCon succeeds the first Joint Action on cancer, called European Partnership Action Against Cancer – EPAAC, in which ECPC was also represented.

The new Joint Action aims to improve the overall cancer control through quality based cancer screening programmes; to enhance integration of cancer care, community based cancer care approaches; and to provide concerted efforts in all aspects of survivorship, including palliative care. These key elements will be at the core of CANCON.

ECPC obtained a formal recognition as Collaborative Partner, therefore, we have been called to contribute into several Work Packages. CanCon constitutes a unique opportunity for ECPC to present the views of the European cancer community on comprehensive cancer and therefore, our participation in the various Work Packages is of key importance.

In 2015, ECPC's contribution within CanCon focused on:

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

INEQUALITIES IN CANCER CARE (WP5)

The Stakeholder Forum (Brussels, 12th May 2015) aimed at bringing together the CanCon partners and all other interested parties, to discuss the outcome of the project and plan future collaboration. The 2015 forum focused on enhancing equity and patient empowerment in cancer control, and was organised in partnership with the European Observatory on Health Systems and Policies.

Prof De Lorenzo set the scene for the discussion on Session 2 "Patient empowerment in cancer control", by addressing the audience with a presentation on the inequalities in cancer care existing in Europe. His presentation was inspired to ECPC position paper "Europe of Disparities in Cancer".

The CanCon partners welcomed the presentation with great interest, and it was supported vigorously by several participants and experts. Following the debate, the CANCON Project Coordinator decided to include a specific workflow within CanCon dedicated to inequalities. The work was assigned to CanCon WP5, led by the Italian Ministry of Health. The final product will be a policy paper on inequalities, supported by the CanCon partners.

SURVIVORSHIP (WP8)

During the CanCon Policy Conference (Brussels, 13th May 2015) Prof De Lorenzo was invited to express the perspective of patients on the work done by the Survivorship Work package (WP8).

WP8 is led by the French National Cancer Institute (InCa). De Lorenzo expressed appreciation for the work of WP8 but underlined that it is necessary to include more solid recommendation on the creation of a European model for National Survivorship Care Plans.

Prof De Lorenzo's recommendations were echoed by CanCon experts, in particular Prof Michel Coleman (London School of Hygiene and Tropical Medicine, CONCORD coordinator).

WORLD CANCER DAY

PRESS CONFERENCE

On the **4th of February 2015**, ECPC joined the global celebrations for the **World Cancer Day** raising awareness on the needs and expectation of cancer patients to our most important European partners.

Thanks to the support of Italian MEP, Elisabetta Gardini (EPP), we organised a **very successful press conference** within the Parliament, during which **we launched a Declaration identifying 4 priority pillars of action for the European Parliament and the Commission**, fundamental to implement the Bill of Rights:

1. The thorough implementation of the Cross Border Healthcare Directive
2. Guarantee access to cancer care
3. Ensuring access to innovative and possibly life-saving treatments
4. Following the European Commission's example through the creation of formal tables of discussion with national cancer patients' organisations, hence involving patients in the design of new national policies on cancer and research projects in the Member States.



The Declaration, a follow-up of the **European Bill of Cancer Patient Rights**, was endorsed by **160 Members of the European Parliament**.

MEETING WITH MEP GIOVANNI LA VIA

Prof. De Lorenzo and Kathi Apostolidis met on World Cancer Day with MEP Giovanni La Via, Chairman of the ENVI Committee of the European Parliament.

Prof De Lorenzo thanked President La Via for his constant support and high sensitivity to the issues faced by European cancer patients. On the occasion of the World Cancer Day, President La Via wished to discuss the **fundamental cancer issues related to the work and competences of the European Parliament**. The discussion touched upon the most important issues faced by European cancer patients, and moved to ECPC suggestions to strengthen EU and Member States capacity to act in line with the European Cancer Patient Bill of Rights.

Prof De Lorenzo and President La Via agreed on the need to **increase the efforts to implement the Cross Border Healthcare Directive**, the centre-piece granting freedom of movement to European patients. In particular President La Via agreed with Prof De Lorenzo that the **Directive is fundamental also to protect the rights of rare disease patients, in particular rare cancers**, and joined Prof De Lorenzo's high expectations for the European Reference Networks.

MEETING WITH COMMISSIONER ANDRIUKAITIS

Strong of the success of the Declaration, ECPC President, Prof. De Lorenzo and ECPC Vice President, Kathi Apostolidis also **met on World Cancer Day the European Commissioner for Health and Food Security, Vytenis Andriukaitis**. The Commissioner demonstrated a great interest in the needs and expectations of European cancer patients. “DG SANTE is open to you” said the Commissioner, welcoming the ECPC delegation.

Mr. Andriukaitis stated his willingness to follow the path set by his predecessor regarding the inclusion of patients’ perspective within the work of the European Commission. In particular, **he focused on the important role that organisations, like ECPC, have in disseminating key health-related information to patients**. Prof. De Lorenzo and Commissioner Andriukaitis exchanged views on the **unbearable inequalities that some of the 10 million European citizens affected by cancer have to face every day**, and agreed on **the need to quickly and swiftly implement the Cross Boarder Healthcare Directive**.

WRITTEN DECLARATION ON THE RIGHTS OF CANCER PATIENTS

Together with MEP Elisabetta Gardini (EPP, Italy) and other 18 MEPs, ECPC devised a strategy to raise the European Parliament's awareness on the rights of European cancer patients. Strong of the political support of committed MEPs, we agreed that the first step would be to launch a **Written Declaration** to secure the support of the European Parliament on this issue.

The Written Declaration finds its origin in MEP Gardini's 4th February Declaration, delivered during a press conference in celebration of the World Cancer Day 2015. The success of that informal statement stirred the momentum in favour of European cancer patients, creating the perfect circumstances for further political successes.

The Written Declaration asked the European Commission to:

- Create one single European system to evaluate the benefits of new drugs, therefore reducing the delays in access to new, life-saving medicines.
- Act immediately to understand why many essential cancer drugs are missing from the market and submit proposals for the solutions of this problem;

What is a Written Declaration?

Written Declarations are strong political instruments in the hands of MEPs, by which they can show the support of the Parliament for a specific topic, problem or request. Even if Written Declarations are not considered acts of the Parliament representing its position, they still have to be signed and supported by at least 50% +1 of all MEPs (376 MEPs) to be approved, therefore confirming their strong political value.

Through the tremendous lobbying of ECPC and its Members, the Written Declaration gathered the **support of 257 MEPs** and has therefore not been adopted as an official position of the European Parliament. However, we consider it was a great success and opportunity to raise awareness on topics of utmost importance such as HTA and shortages of medicines.

PARTICIPATION TO INTERNATIONAL CONFERENCES

MEPS AGAINST CANCER 10 YEAR ANNIVERSARY

Brussels (Belgium) 9 December 2015; De Lorenzo

Prof De Lorenzo was invited to speak at the 10th Anniversary of MEPs against cancer (MAC) on behalf of ECPC. The anniversary took place at the European Parliament. He talked about the role of cancer patients on cancer policy. European Commissioner for Health and Food Safety, Mr. Andriukaitis, was also speaking at the event.

INTERNATIONAL SOCIETY FOR PHARMACOECONOMICS AND OUTCOMES RESEARCH (ISPOR)

Milan (Italy) 9-10 November, 2015; Apostolidis

The **International Society for Pharmacoeconomics and Outcomes Research (ISPOR)** is active in the policy, science, and practice of pharmacoeconomics (health economics) and outcomes research (the scientific discipline that evaluates the effect of health care interventions on patient well-being including clinical, economic, and patient-centered outcomes). **The Fourth Patient Representatives Roundtable** held during the ISPOR 18th European Congress, in Milan, Italy, discussed how to ensure the voice of the patient is heard in every facet of health care decision making.

The 60 participants of the Roundtable were representatives of European patient umbrella organisations, healthcare and HTA organisations and the industry, who convened to discuss patient participation in HTA and participate to a workshop on “Optimizing Patient Involvement In Payer Health Care Decisions To Access New Therapies”. The workshop explored how all stakeholders including patients, HTA, payers, and the industry can work together to optimize patient involvement in decisions, based on work conducted by the ISPOR European Patient Representatives Roundtable.

ECPC was represented at the 4th Patient Representatives Roundtable and the workshop by Vice President, Kathi Apostolidis, who presented on what is needed to make patients’ participation in HTA agencies possible, stating that currently there is more tokenism than real patient involvement in HTA, since patient involvement is limited mostly to surveys and toolkits and not in patients’ facilitation and education, evaluation of types of involvement and in measuring impact of patient involvement in decision making, among other.

ECONOMIST'S "WAR ON CANCER"

London (UK) 20 October 2015; De Lorenzo

The British Journal “**The Economist**” invited ECPC President, Prof De Lorenzo to speak at the **War on Cancer Summit**, that took place in London (UK) on the 20th October 2015. War on Cancer brought together the most influential healthcare leaders from Europe to explore and shape the dialogue on cancer. Prof De Lorenzo President spoke on “**The empowered patient - making the individual part of the solution**”. He focused his speech on the importance of ensuring access to lifesaving innovative drugs, while ensuring also the sustainability of healthcare systems. In particular, he reiterated the fact that cancer patients live today the paradox that safe and efficient new treatments exist, but a large portion of EU cancer patients don’t have access to them, or do not access them in a timely fashion. He went on promoting the idea of harmonising the process of Health Technology Assessment in Europe (HTA), to strengthen the relationship between EMA and HTAs, in order to find faster, more efficient and cost-effective ways to ensure reimbursement of truly effective drugs.

2ND CONFERENCE ON EUROPEAN REFERENCE NETWORKS

Lisbon (Portugal) 8-9 October 2015; De Lorenzo

Prof De Lorenzo attended the **2nd Conference on European Reference Networks, organised by DG SANTE**, in October 2015 in Lisbon. The conference brought together highly specialised healthcare providers, patient and professional associations, clinical experts, national authorities and healthcare assessment or accreditation organisations. The conference focused on the **implementation of European Reference Networks** and facilitated the exchange of information and expertise on **establishing and evaluating such Networks** whilst looking into the next steps of the deployment process. The event built on the success of the 1st conference on European Reference Networks which took place in Brussels in June 2014.



18TH ECCO - 40TH ESMO EUROPEAN CANCER CONGRESS

Vienna (Austria) 25-29 September 2015; De Lorenzo, Apostolidis, Pelouchova, Voiculescu, Swierzewski, Militaru, Florindi, Christoforidis.

During the European Cancer Congress (ECC), ECPC had a booth in the Patient Advocacy Square, perfectly located in the middle of the Exhibition hall of the venue. The Square was designed to give European patient organisations an opportunity to display their resources and services to the professional oncology community and where healthcare professionals and other stakeholders were able to meet, interact, and exchange information with patient advocates on the vital issues and challenges faced by cancer patients.

ECPC was present to raise the voice of cancer patients and attended several meeting and discussions. Most importantly, we came to the ECC to present the final version of "Europe of Disparities in Cancer", the ECPC policy strategy to fight inequalities in cancer care. **The paper was launched on Sunday 27th September 2015, during a press conference attended by more than 50 participants.**



ECPC was also invited to present at the ECCO-CDDF Special Session on "European Regulation and Health Technology Assessments in Immunotherapy". The purpose of the session was to debate on the challenges that immunotherapy in cancer care represent for regulators given the very different nature of the efficacy and side effect profile, compared to traditional medicines.

ECPC Vice President, Kathi Apostolidis, presented on "How Effective is the Public in Influencing HTA Decisions?" stating that HTA cannot be a solely technical evaluation and that HTA should be a bridge between the world of research and the world of decision making. She presented ECPC's position for a stronger EUnetHTA, the need to further harmonise HTAs in Europe to reach EU-wide HTA reference evaluation, to institutionalize the patients' role in HTA bodies and to consider the importance of survivorship in HTA evaluation.

30 YEARS OF EU ACTION AGAINST CANCER

Luxembourg (Luxembourg) 15 September 2015; De Lorenzo, Apostolidis

Prof. De Lorenzo participated as a speaker in the high level event "30 years of EU action against Cancer" on the 15th of September 2015 in Luxembourg, marking the 30th anniversary of the Council conclusions of 1985 which paved the way for the first action at European level on cancer. The event was organized jointly by the Commission and the Luxembourg Presidency of the Council

This conference offered the possibility for a reflection and discussion based on impact and on future action in the field of cancer. The participants included the 60 members of the Expert Group on cancer control, including ECPC President Prof Francesco De Lorenzo and Vice President Kathi Apostolidis, and around 60 invited participants (MEPs against cancer, patient groups, health professionals, and high level personalities).

In his contribution, Prof De Lorenzo praised the commitment of the European Union and of the Commission in particular in the fight against cancer. European Partnership for Action Against Cancer - EPAAC and the successive initiatives of the Commission clearly created added value of European cancer patients, but great inequalities in cancer care still exist. In his conclusions, Prof De Lorenzo' underlined **the demonstrated capacity of the**

Commission to play an important role in cancer control, and suggested two major lines of action for the future: **ensure the implementation of EPAAC and CanCon policy recommendations and enlarge the competences of the Commission in public health through the amendment of the European Union treaties.**

OEI ONCOLOGY DAYS

Porto (Portugal) 22-24 June 2015; De Lorenzo, Presti

ECPC President Francesco De Lorenzo and ECPC Audit Committee Member Dr. Pietro Presti took part to the Oncology Days organised by the **Organisation of European Cancer Institutes (OEI)** in June 2015 in Porto, Portugal. Prof. De Lorenzo spoke during the session on the "Role and organisation of a European Cancer Network: debating comprehensiveness", providing a presentation covering the "The expectation of patient's association about CCNetwork". Dr. Presti described his experience within the BenchCan project, within which he represents ECPC and ensures that patients' perspective is taken into due consideration.

AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO) ANNUAL MEETING 2015

Chicago (USA) 30 May 2015; De Lorenzo, Florindi

ECPC was present at the American Society of Clinical Oncology (ASCO) 2015 Annual meeting represented by President Prof De Lorenzo and Francesco Florindi.

ECPC was awarded scholarships to participate to the event in Chicago, the global largest cancer scientific conference.

ATHENS BREAST CONFERENCE – THE TRIPPLE ALLIANCE: THE PATIENT – THE DOCTOR – THE GOVERNMENT

Athens (Greece) 22-23 May, 2015; Apostolidis

The **Hellenic College of Mastology** in collaboration with **IEO Istituto Europeo di Oncologia** and the **European Academy of Senology** organised the conference to honour Prof Umberto Veronesi, the renowned scientist aiming to present how breast cancer care has to collaborate with its main three stakeholders.

ECPC Vice President, Kathi Apostolidis was invited to present the European Bill of Cancer Patient Rights and its impact on the triple alliance. Inequalities in access to breast cancer screening, diagnosis and care are not conducive to patient empowerment. If patients cannot have access to a minimum of health care, then we cannot talk about patient-centricity of the health care system.

CANCON POLICY CONFERENCE - CANCER SURVIVORSHIP: A POLICY DIALOGUE

Brussels (Belgium) 13 May 2015; De Lorenzo

Prof De Lorenzo was invited as a panellist for the CanCon Policy Conference, held within the Committee of the Regions, in Brussels, on the 13th May. The Policy Conference aimed at discussing with a wide audience on the topics faced by CanCon. In particular, the conference tackled the issues related to survivorship.

BUCHAREST FORUM HEALTHCARE

Bucharest (Romania) 27 March 2015; De Lorenzo

ECPC President Francesco De Lorenzo was invited to participate as a panelist to the Bucharest Forum Healthcare organised by the Romanian chapter of the Aspen Institute.

The Aspen Institute Romania and Link Resource, under the auspices of the Romanian Government and with special support of Romanian Ministry of Healthcare, National Health Insurance House and National Agency for Medicines and Medical Devices, are developing a long term dialogue platform designed for decision-makers in the healthcare sector. Focusing on public policies and best practices in healthcare the series (comprised of public and closed door meetings), the event was part of the Aspen Institute Romania's Healthcare and Quality of Life Program. Building on a body of European and regional expertise, they aim to deepen the conversation on managed entry agreements for pharmaceuticals, EMA guidelines for patients' associations, medical research and social health insurance vs private health insurance. The organisers aimed for lively, non-partisan and inclusive debates with a view of supporting, streamlining and assisting efficient policy making in the field.

EAHP CONGRESS 2015

Hamburg (Germany) 24-27 March 2015; De Lorenzo

ECPC President Francesco De Lorenzo has been invited as a speaker to the 20th Annual Congress of the European Association of Hospital Pharmacists - EAHP. Prof De Lorenzo met EAHP President Dr. Frontini to discuss a range of issues, including addressing inequalities in healthcare provision across Europe. On the 26th March, Prof De Lorenzo delivered a speech on the patients' perspective during the "Stakeholder discussion on responding to the information challenge posed by medicines shortages".

PRESENCE IN THE MEDIA

In 2015, the initiatives of ECPC received media coverage in Euractiv and POLITICO as well as various magazines and newspapers in several member states.

PARNTERSHIPS CONCLUDED IN 2015

CANCER DRUG DEVELOPMENT FORUM (CDDF)

CDDF' mission is to provide a unique platform to facilitate interactions between all stakeholders (academia, regulatory authorities, policymakers, the pharmaceutical industry and patient advocates) in order to improve the efficiency of cancer drug development. CDDF greatly contributed to the development of one of ECPC's most important projects, the Immuno-Oncology Portal, by providing key funding and via the expert opinion of CDDF Chairmain Prof Heinz Zwierzina.

ECPC was invited to present at the ECCO-CDDF Special Session on "European Regulation and Health Technology Assessments in Immunotherapy" that took place at the 2015 ECCO-ESMO Congress. Prof De Lorenzo was also invited to take part to the CDDF 8th Alpine Meeting.

ECPC AND OEI SIGN MEMORANDUM OF UNDERSTANDING

During ECCO-ESMO 2015, the Presidents of the Organisation of European Cancer Institutes (Prof de Valeriola) and of the European Cancer Patients Coalition (Prof De Lorenzo), signed the agreement establishing the terms of collaboration for the coming years.

ECPC and OEI are two major complementary actors in the fight against cancer and against all the cancer-related issues in Europe, combining similar objectives about quality of care, respect of patients' wishes, research and innovation.

The agreement is a milestone in the European challenge to ensure timely and affordable access to the best treatment and care available to all European cancer patients, throughout their life. The topic is often argument of discussion at national and European level and the two signing Organisations are now engaged to move from theory to practice, giving concrete and measurable results to the expectations of the patients and their families.



To increase the empowerment of European cancer patients, the agreement will work on a better dissemination of information, to ensure that state-of-the-art cancer care practices are shared across the EU and to support the concept that cancer is a priority for actions on the European health policy agenda.

The two Organisations shall coordinate and cooperate in carrying out activities of common interest included in their annual work program, with the purpose of avoiding duplication of efforts, reducing in the same time the costs. The collaborating activities will be undertaken by the organisation of seminars and round tables, collaboration on joint projects, training courses and joint publications. The joint initiatives will include, but are not limited, to the following topics: patient safety, biobanking, palliative care, patients' participation in clinical trials, patients' empowerment, standards of care.

ECPC - UICC



Promotion of the universal values enshrined in the World Cancer Declaration constitutes the objective of the collaboration between ECPC and the Union for International Cancer Control - UICC. Crystallised after the meeting of the Presidents (ECPC - Prof De Lorenzo, UICC - Dr.Kutluk) in Geneva (in May 2015), the collaboration is being finalised into a Memorandum of Understanding between the two organisations. The Memorandum will cover the design and implementation of joint advocacy events in Europe.

ECPC - EUROPEAN ASSOCIATION OF UROLOGY

The European Association of Urology (EAU) represents the leading authority within Europe on urological practice, research and education. Its mission is to raise the level of urological care and to facilitate the continued development of urology in Europe and beyond. In 2012, the EAU Patient Information was established with the

aim to provide reliable patient information - on a variety of urological diseases - based on the latest scientific evidence, expert recommendations and patient's needs.

The ECPC and the EAU embarked upon the EAU Patient Information project on Bladder Cancer in 2015. This collaboration is based on patient feedback and is 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. EAU also had a major role in the drafting of ECPC Paper on Bladder Cancer.

CAMPAIGNS

PANCREATIC CANCER ACTIVITIES

PANCREATIC CANCER EUROPE

Pancreatic Cancer Europe (PCE) is a platform that started in 2014 from a desire to build a platform of experts, patients, policy makers and industries to discuss means of tackling pancreatic cancer;

PCE is composed of **40 national and EU experts** (academics, patients, clinicians, researchers, industrials), and **championed by 4 Members of the European Parliament** and is committed to raising awareness around pancreatic cancer in view of improving standard of care, diagnosis and data collection for patients suffering from this deadly cancer across Europe. The major consensus 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.



Since its foundation, PCE has made significant advances: "**10 key facts**" and "**10 warning signs of PC**" are documents that inform the public about the basics of pancreatic cancer and the low lying symptoms to watch out for. "**Think PC**" is directed at healthcare professionals and in particular, GPs to watch out for combinations of symptoms that could indicate pancreatic cancer. The "**PC Declaration**" signed by Members of the European Parliament acts as a commitment to put pancreatic cancer on the political agenda, to create policies specific to the challenges posed by pancreatic cancer and to take concrete steps on the road to better care for patients.

The work has now begun on disseminating this material throughout the Member States and reaching people at national level through national allies/organisations and through the [PCE website](#) which acts a portal for those seeking more information on pancreatic cancer.

ECPC ACTIVITIES WITH THE PCE

ECPC, a founding member, was appointed in 2015 to chair the work stream that coordinates and supports national activities as well as the uptake of the materials produced by Pancreatic Cancer Europe. With coordinated actions at national level designed to raise awareness and increase early diagnosis we want to ensure that pancreatic cancer is "forgotten no more".

The European pancreatic campaign was transposed to the national level in Greece by ECPC member K.E.F.I. – Association of Cancer Patients, Volunteers, Doctors and Friends. The PCE informative documents were translated in Greek while the "**PC Declaration**" was adapted to the needs of Greek pancreatic cancer patients and presented to the Greek health care authorities. ECPC Vice President, Kathi Apostolidis (also K.E.F.I. Board Member) and Ali Stunt, Founder and CEO of Pancreatic Cancer Action (UK) presented the ECPC and Pancreatic Cancer Europe

activities and the importance of the Declaration at both European and national level at a conference organised in Athens on November 13, 2015.

WORLD PANCREATIC CANCER DAY 2015

November 13th 2015 marked the second World Pancreatic Cancer Day (WPCD). ECPC together with other dedicated organisations and stakeholders across the world joined efforts to raise awareness on this deadly cancer during that day following a few months of intense preparation. Some of the WPCD related activities included:

- The launch of new World Pancreatic Cancer Day (WPCD) website in October 2015
- The launch of the Pancreatic Cancer Europe website
- The promotion and dissemination of materials on pancreatic cancer using social media both from the WPCD Steering Committee and the Pancreatic Cancer Europe.
- Pancreatic Cancer Europe held its 3rd meeting at the European Parliament on November 10th in order to discuss about the pan EU activities around WPCD and about the dissemination of the materials developed by the Platform at national level.

MAKE SENSE CAMPAIGN



For several years ECPC has partnered with the European Head and Neck Society (EHNS) to deliver the Make Sense Campaign aiming to raise awareness of head & neck cancer. The campaign currently spans many European countries, including Belgium, Croatia, Denmark, Finland, France, Germany, Ireland, Italy, Poland, Portugal, Romania, Russia, Spain, the Netherlands, UK with potential to expand in 2016 to Austria, Greece and Switzerland.

UNITING VOICES

In 2015, our activities were tied to the theme of [#UnitingVoices](#). 'Uniting Voices' was the 2015 social media campaign which sparked a much needed conversation about head and neck cancer.

Through this theme we:

- Encouraged head and neck patients to have a voice, and speak up for improved care across Europe;
- Gave patients a sense of community, to show them they are not suffering alone;
- Highlighted the benefits of multidisciplinary care and how by uniting all aspects of patient care, patient outcomes can be improved.

The amazing number of **368,400 handlers used the hashtag of the campaign** during the 3 days of the campaign run in September 2015.

Furthermore, **782 media articles in a large number of national outlets were generated.**

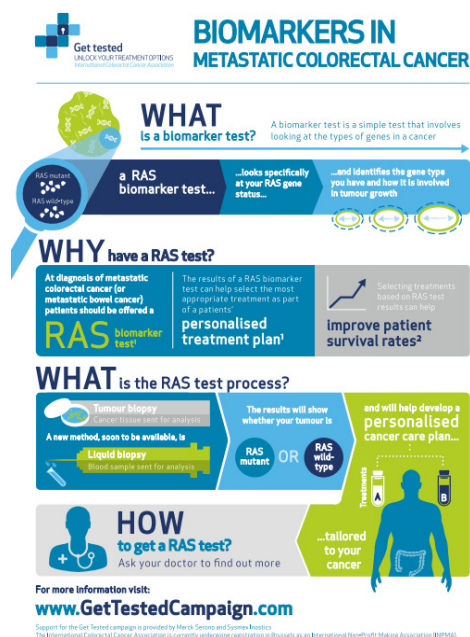
Most importantly, **over 12,000 patients were screened for head and neck cancers, in one day, in the 15 countries involved in the campaign.**

ECPC is very proud to be a part of this successful and impactful campaign.

ENVI COMMITTEE DEBATE

In 2015 our champion MEP on head and neck cancers, Daciana Sarbu (Romania, S&D), triggered a debate in the ENVI Committee on rare cancers and head and neck cancers in particular.

GET TESTED CAMPAIGN



ECPC is pleased to have been involved on the 24th of March 2015 in the launch of a new awareness campaign '**Get Tested**'. The Get Tested campaign aims to raise awareness and understanding of the importance of RAS biomarker testing in patients who are newly diagnosed with metastatic colorectal cancer (mCRC), and to encourage them to discuss testing with their doctor.

The Campaign also presented a **White Paper**, co-authored by ECPC, to Members of the European Parliament and European Commission representatives **calling for improved access to testing for patients newly diagnosed with metastatic colorectal cancer (mCRC) and for the routine use of RAS biomarker testing in establishing a personalized cancer care plan.**

In parallel to the launch event in Brussels, a co-ordinated global media campaign was implemented across 35 countries. A website to support the campaign, www.GetTestedCampaign.com, was also launched, containing patient friendly downloadable resources such as infographics, patient case studies, and biomarker videos.

NUTRITION IN THE ONCOLOGY PATIENT

During 2015 ECPC developed a **survey on Nutrition in the Oncology Patient** aimed at investigating the perception of nutritional and metabolic issues during cancer by patients, caregivers, and people working in patient organisations. The background of this survey was based on the concept that adequate nutrition in the oncology patient can:

- Prevent weight loss and help in weight gain;
- Improve adherence to therapy and minimize side effects;
- Improve the efficacy of anticancer therapies;
- Improve physical status, strength and quality of life;
- Prevent the development of serious conditions such as cachexia during treatment.

The survey was initially developed in Italian by experts Prof Muscaritoli and Prof Molino from the Sapienza Università of Rome, Mr. Ravot and Mr. Scala from Healthware International and ECPC President, Prof De Lorenzo. It was then translated in 10 additional languages.

PRELIMINARY RESULTS

A total of 658 replies were collected and preliminary data was presented at the ECPC AGM 2015 in Brussels during a dedicated session. One relevant aspect that most of the answers highlighted is that **physicians are much less informed than patients about the relevance of nutritional issues**. In addition, the preliminary data obtained from the present survey suggested that discrepancies still exist between the patients' expectations/demands, and the answers they may get from physicians about the metabolic and nutritional issues in cancer. In particular, this underscores the **need to implement education among healthcare professionals in order to improve nutritional care**.

In 2016, ECPC will launch a second round of the survey to consolidate the results and obtain information from additional countries.

PROJECTS

EU PROJECTS

RARECAREnet

CREATION OF INFORMATION MATERIALS

Following the establishment of an online library with information on rare cancers on the RARECAREnet website, ECPC contacted the **European Lung Foundation (ELF)** to help us in the creation of missing materials on rare subtypes of rare cancers in order to complete our library. The ELF produced a factsheet on adenosquamous carcinoma, large cell neuroendocrine carcinoma, salivary gland-type lung carcinoma, granular cell lung tumours and typical/atypical carcinoids following guidance from ECPC.

ORGANISATION OF NATIONAL CONFERENCES

In 2015, ECPC achieved important deliverables for the purposes of the RARECAREnet project, aiming at building an information network in order to provide comprehensive information on rare cancers.

Starting in May 2015, ECPC organized 4 national conferences as part of the RARECAREnet project in Belgium, Bulgaria, Slovenia and Ireland. The objectives of the meetings were to present the RARECAREnet high resolution studies and volume analysis results in each selected country and to open a discussion on the quality of care for rare cancers and which is the best model to ensure it. National stakeholders, including Ministry of Health representatives, cancer registry representatives, patients and expert oncologists were present in each of these conferences. By the end of these events, ECPC had acquired a full picture of the situation in four different countries. All meeting reports will be available by July 2016.



ESMART

eSMART reached in December 2015 almost two years of operation, during which the trial was being prepared. The trial will start in 2016 in all project locations (Greece, UK, Ireland, Norway and Austria).

The project foresees two roles for ECPC:

- As partners in WP6 Dissemination and Exploitation together with the Nursing Dept. of the University of Athens
- As co-researchers having a substantial role in all activities of the project including participation in the Project Technical Management Board, in the Publications Committee, the Exploitation Committee, and the Trial Committee, always 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 project activities planning, to protocol reviewing, to project dissemination and exploitation.

EUROCANPLATFORM

The EurocanPlatform project organised in 2015 its 3rd Summer School for translational cancer research on 12-16 October 2015 in Porto Bay, Algarve, Portugal. The Summer School was organised in collaboration with the German Cancer Consortium and the European Association for Cancer Research, and consisted of a five-day programme of lectures and group discussions which covered all aspects of the translational research continuum from basic/pre-clinical research to clinical and outcomes research. There was a focus on the development of personalised (precision) cancer medicine. The course provided to the participants the opportunity to interact with an expert international faculty of speakers and patient organisation representatives.

ECPC President, Prof De Lorenzo, was invited to deliver a lecture on "The role of patient organisations". This marked the second participation of our president to the Summer School who also had a teaching role in 2014.

HORIZON2020 – THE MESOTHELIOMA PROJECT

In August 2015, the first Horizon2020 project of which ECPC is a partner, got approved by the European Commission. The project aims to demonstrate the efficacy of DC-based immunotherapy in a clinical trial setting in order 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 annually kills about 43,000 people worldwide. It is mainly caused 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 thus a clear unmet medical need for the treatment of mesothelioma.

ECPC will be involved in the WP responsible for the effective dissemination and exploitation of the results to external stakeholders. Furthermore, having ECPC as a partner will ensure that the developments of the project are designed and adapted to respond better to the needs of the patients.

TRANSCAN-2

ECPC has been invited to participate in the **Scientific Advisory Board (SAB) of TRANSCAN-2** research EU funded project, where it is represented by its Vice-President, Kathi Apostolidis.

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 EU 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. The SAB has a crucial role in this ambitious project as it provides advice on strategic issues, on needs and priorities concerning the type of research projects to be funded by the joint transnational calls, including training, mobility and capacity building.

The 15 experts of the SAB meet once a year, to discuss the scientific priorities for the planned joint transnational calls and collaborate on line during the year. The works of the SAB are governed by confidentiality.

INNOVATIVE MEDICINES INITIATIVE

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 in order to boost European pharmaceutical innovation.

In 2015 ECPC, together with other expert stakeholders built the consortium of the IMI PREFER project. The project, led by the Uppsala University in Sweden has as main objective to strengthen patient-centric decision making throughout the life cycle of medicinal products by developing evidence-based recommendations to guide industry, Regulatory Authorities, HTA bodies, reimbursement agencies, academia, and health care professionals on how and when patient-preference studies should be performed and the results used to support and inform decision making.

In December 2015, the PREFER project successfully passed the first evaluation stage. The results of the second and final evaluation are expected in summer 2016.

CANCER ADVOCACY ACADEMY

In November 2015, ECPC received a Waldensian Otto per Mille grant from the Waldesian Church in Italy for a project called "Cancer Advocacy Academy". The aim of the project is to enhance the access to specialised, scientifically correct online information for European patients from those European countries with proven insufficient records of access to internet.

ECPC used the grant in order to provide 8 of its members with computers, printers, scanners, headphones.

The ECPC members that already received the equipment represent the following countries: Romania, Greece, Bulgaria, Poland, Slovenia, FYROM and Spain.

The second part of the project, to be developed in the second semester of 2016 will provide two dedicated online trainings:

1. ECPC will deliver an individualised audit of the presence of the 8 selected ECPC members across the social media channels where they are present: Facebook, Twitter and YouTube with the aim to build a clear, comprehensive Communication Strategy.
2. The second training will focus on advocacy skills and government affairs.

ECPC PATIENT ADVISORY ROLES

EUROPEAN MEDICINES AGENCY

Year 2015 is exceptional in the history of the European Medicines Agency (EMA). This year marks the 20th anniversary of the creation of the Agency as an institution responsible for medicines authorisation for the entire European Union. The European Medicines Agency (EMA) 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 of these stakeholder groups bring a '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 EMA is the "Patients' and Consumers' Working Party" (PCWP) established 10 years ago within CHMP. The role of PCWP 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 fully recognised and clear for each patient who takes medicines. PCWP members take part also in discussions about improving the functioning of the existing legislation (optimisation of the processes e.g. of medicines authorisation, and increase in use of IT tools) whilst progressing the development of the new legislation.

During PCWP meetings ECPC's representatives speak out on current issues, lying in the interests of cancer patients and their treatment. ECPC is an active member of the Patients and Consumers Working Party (PCWG) at the EMA and during the period 2013-2016, it is represented by Vice President, Kathi Apostolidis and Board Member, Rafal Schwierzewski, PhD.

Currently ECPC is involved in a multi-stakeholder discussion on a new European clinical trials database and portal, social media topic working group, pharmacovigilance legislation and procedures, projects that are currently under development e.g. WEBRADR project directed to mobile technology use in adverse drug reaction reporting. From this year, ECPC is a member of a sub-group working on 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 (PAWG)

The ESMO Patient Advocates Working Group (PAWG) has as main mission 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.

The ESMO/PAWG has nine members and ECPC is represented in it by its Vice President, Kathi Apostolidis and Vice President-Treasurer, Vlad Voiculescu. Among the main tasks of the ESMO/PAWG is 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 has contributed in the program development of the Patient Advocacy Track(PAT) for 2014 and 2015, and was also a member of the PAT Faculty (Apostolidis, de Lorenzo, Pelouchova) and prepared the program for 2016 and 2017.

ECCO - PATIENT ADVOCATES COMMITTEE (PAC)



The ECCO 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 PAC, besides other, is also in charge of developing the programme of the 'patient advocacy' track at the congress.

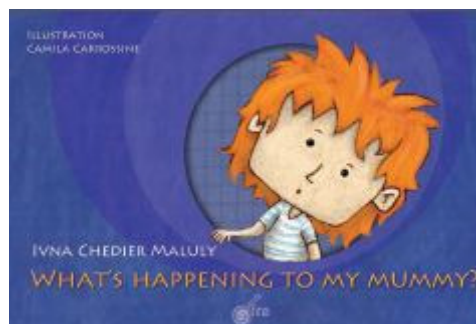
The ECCO-PAC has 15 members and ECPC is represented in it for a second mandate by its Board Member and Secretary, Jana Pelouchova. In 2015 the PAC undergone a renewal and extension of the membership with the objective to reflect the breadth of predominantly European cancer patient advocacy groups. The ECCO-PAC developed the agenda of the patient advocacy track of ECC2015 congress in Vienna. J. Pelouchova was involved in the “Rehabilitation” session focused mainly on issues related to cancer at work. More than 25 patient advocates spoke at ECC2015 and more than 130 attended as delegates.

OTHER ECPC ACHIEVEMENTS

WHAT’S HAPPENING TO MY MUMMY

ECPC supported the translation and printing of a book for children – “What’s happening to my mummy?” by Ivna Maluly.

Ivna Maluly is 40 years old and is a breast cancer survivor. For a few years now she has lived in Brussels but she used to be a journalist in Brazil. She contacted ECPC in 2014, presenting her script for a book for children written in Portuguese and we agreed right away to help her with the translation and printing of the book in English and French. Her book tells the story of a mother (true story of Ivna) who loses her breast and has to explain what is happening to her son Elias, three and a half years old. The reader will discover a gripping tale accompanied by amazing graphics, a true example of overcoming a great challenge and the touching love between mother and child. We believe these stories to be so important. Beyond the science and statistics about cancer lie such true stories of mums that need to reassure their children with lots of love, calm and normalcy and having the courage to be honest and pronounce the word cancer.



The book was launched during ECPC General Assembly 2015 and 5000 copies have been distributed over the year, including during important events such as the European Cancer Congress 2015 in Vienna and the European Parliament Open Days 2015.

DIAGNOSIS BREAST CANCER - A GUIDE FOR PATIENTS AND SURVIVORS

ECPC supported the English translation as well as the publication of the **Diagnosis Breast Cancer, A Guide for Patients and Survivors** drafted by our members from Zebra organisation. Diagnosis of breast cancer is a shock for women and brings fear, sadness sometimes anger and often feelings of powerlessness replacing security and confidence. In these circumstances women have to make decisions that have an impact on their lives and their survival. The brochure drafted by ZEBRA and translated with the help of ECPC can help in making the right decisions.

The Guide for Patients and Survivors lists information about the possibilities for early detection, current therapies as well as stories of strong survivors such as Shirley Bianca.



EUROPEAN PARLIAMENT OPEN DAYS



In May 2015 the European institutions in Strasbourg, Luxembourg and Brussels held Open Days and celebrated Europe Day. For the occasion, ECPC was granted a stand at the European Parliament (EP) of Brussels. The ECPC staff was present to welcome visitors to the stand and share with them information about our organisation as well as raise awareness on cancer. **This was a great achievement for ECPC as it was the only NGO to have a stand within the EP.**

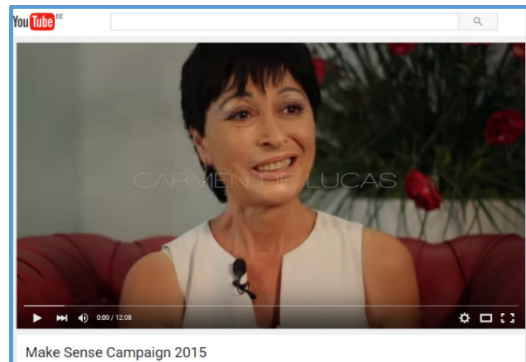
TEAM ECPC

CANCER RESEARCH UK LONDON WINTER RUN

On the 1st of February 2015, **TeamECPC took part in the Cancer Research UK London Winter 10km Run**. Cancer Research UK is a cancer research and awareness charity which aims to reduce the number of deaths related to cancer. Five volunteer brave runners represented ECPC and conquered the winter cold in order to **“freeze cancer and its tracks”** and support this great initiative.

ECPC RUNS THE 20KM BRUSSELS

With a team of more than 30 runners, ECPC took on Brussels' most famous run. **TeamECPC run the 20km of Brussels on the 31st of May 2015.** Our team has never been so large! Thanks to the growing number of runners and their great help, ECPC managed to fundraise the money to produce together with our member from Spain, GEPAC, a testimonial clip of a former Spanish mezzosoprano singer, Carmen de Lucas, that lost her voice to tongue cancer. The clip was a major tool of the online dissemination of the Make Sense Campaign.



ECPC RUNS THE COLOR RUN 2015

Two TeamECPC members run in 2015 the 5km Color run in September 6th to raise awareness of head and neck cancer.

