

EUROPEAN
CANCER
PATIENT
COALITION

Annual Report

2014



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ECPC: A GROWING ASSOCIATION

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:

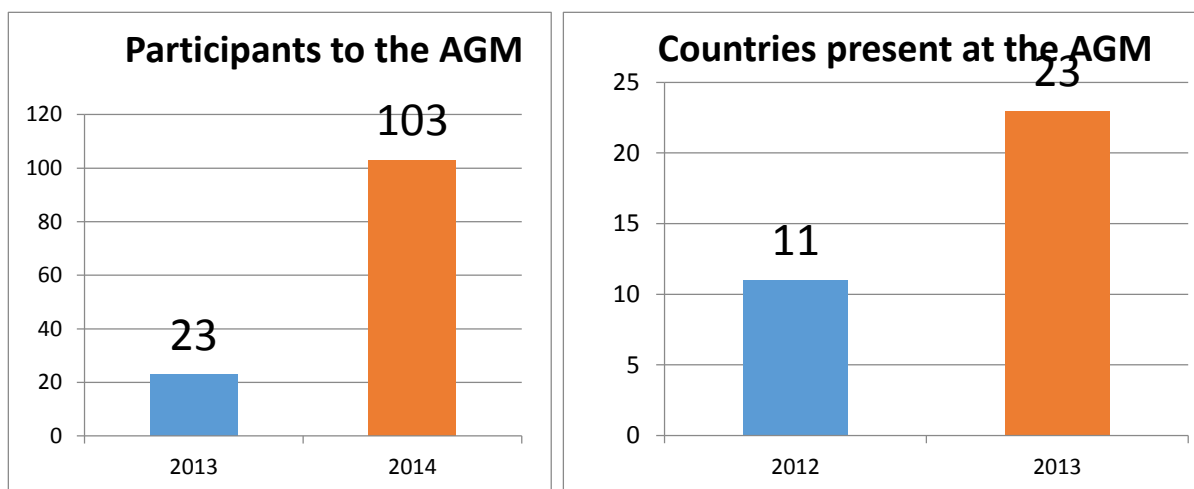
- to represent the views of cancer patients in the European healthcare debate;
- to enable and empower cancer patients by educating them about cancer and advocacy skills;
- to provide a forum for European cancer patients to exchange information and share concerns on cancer care policies in their countries 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 2014, 11 new associations joined ECPC, consolidating the Association as Europe’s largest cancer patients association.

ECPC ANNUAL GENERAL MEETING 2014

The 2014 AGM confirmed the good health and solidity of ECPC.



During the three-day AGM in Bucharest (Romania), more than 100 participants from 23 countries took part to the AGM, representing the highest number of participants ever to an ECPC AGM.

The 2014 AGM demonstrated that ECPC new deal was bearing its fruits. An increasingly challenging and professional programme, in fact, mirrored the increase in the participants. Thanks to the participation of project partners, the European Commission, the European Medicines Agency and several other guests, ECPC transformed the AGM in a true learning occasion for all ECPC members.

The AGM served also as a reflection moment for the whole organisation: the future of ECPC was discussed during the best-attended General Assembly to date. Among the most important decisions, the General Assembly confirmed its willingness to move the legal siege of ECPC from the Netherlands to Belgium, to facilitate the financial and legal management of the Association.

POLICY AND ADVOCACY

EUROPEAN BILL OF CANCER PATIENTS' RIGHTS

To coincide with World Cancer Day, February 4th, a powerful coalition of patient advocacy organizations and health care professionals developed a Bill of Rights to address the inequalities that cancer patients in Europe face every day.

The launch, hosted by the European Cancer Concord (ECC) and the European Cancer Patient Coalition (ECPC) in association with the Members of the European Parliament Against Cancer (MAC) Group, called for a commitment to tackle the cancer epidemic in Europe which will result in the death of 1 cancer patient every 10 seconds in the next 20-25 years.

The European Cancer Patient's Bill of Rights is a catalyst for change to provide every European citizen with the right to the optimum standard of care.

THE THREE PATIENT-CENTERED PRINCIPLES

- Article 1
The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.
- Article 2
The right of every European citizen to optimal and timely access to appropriate specialised care, underpinned by research and innovation.
- Article 3
The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable healthcare.

The Bill of Rights is available for download in 11 languages on the ECPC website.

EU ELECTIONS AND ECPC CALL TO ACTION

On the 4th February 2014, during the celebration of the World Cancer Day, ECPC and its partners convened to the European Parliament in Strasbourg to launch a pan-European plea to EU policymakers to take up the fight against cancer: the Call to Action.

The Call to Action takes its rationale from the European Cancer Patient Bill of Rights and it is its first and immediate action point.

ECPC invited candidates in the European Parliament elections to publicly endorse the Call to Action, engaging themselves to fight cancer during their parliamentary mandate along with the principles set by the Call to Action.

THE CALL TO ACTION REQUESTS

- Make cancer a priority on the political agenda and to address the disparities that cancer patients and families face every single day of their lives throughout Europe;
- Address these unacceptable disparities through the establishment of an EU Cancer Plan which guarantees an improved standard of care for European cancer patients;
- Uphold the right of European citizens to receive this improved standard of cancer care wherever they may live and irrespective of their income;
- Engage proactively with the European Cancer Concord (ECC), an equal partnership involving patients, patient advocates, cancer research and healthcare leaders from across Europe;
- Adopt the principles of the European Cancer Patient's Bill of Rights, a charter for change in cancer care and research in Europe;
- Strengthen a cross party MEPs against Cancer (M.A.C) alliance so that it qualifies to become an EU Parliament Intergroup to actively represent cancer-related issues;
- Encourage the establishment of a European Cancer Survivorship Strategy, to address the needs of the more than 14 million European citizens living with cancer.

THE OUTCOME OF THE CALL TO ACTION

Through a capillary dissemination to the European Parliament, ECPC collected the support of 56 MEP Candidates, running for the May 2014 European Parliament elections.

Of the 56 initial endorsers, 28 have been elected. The list with the **Members of the European Parliament endorsing the Call to Action is to be seen on the next page.**

Andrey Kovatchev	Bulgaria	EPP
Sirpa Pietikainen	Finland	EPP
José Bové	France	Greens – EFA
Karima Delli	France	Greens – EFA
Pascal Durand	France	Greens – EFA
Eva Joly	France	Greens – EFA
Yannick Jadot	France	Greens – EFA
Michèle Rivasi	France	Greens – EFA
Nessa Childress	Ireland	Independent
Patrizia Toia	Italy	S&D
Elisabetta Gardini	Italy	EPP
Antonio Tajani	Italy	EPP
Giovanni La Via	Italy	EPP
Aldo Patriciello	Italy	EPP
David Sassoli	Italy	S&D
Silvia Costa	Italy	S&D
Marisa Matias	Portugal	GUE/NGL
Marian-Jean Marinescu	Romania	EPP
Ciprian Tananescu	Romania	S&D
Daciana Octavia Sarbu	Romania	S&D
Cristian Busoi	Romania	EPP
Adina Valean	Romania	EPP
Renate Weber	Romania	EPP
Alojz Peterle	Slovenia	EPP
Emma McClarkin	UK	ECR
Eduard Hellvig	Romania	EPP
Sean Kelly and Peter Liese	Ireland/Germany	EPP



CONCLUSION OF EPAAC

The European Partnership for Action Against Cancer (EPAAC) was launched in 2009, after the European Commission published its Communication on Action Against Cancer: European Partnership.

The specificity of the Partnership is that it brings together the efforts of different stakeholders into a joint response to prevent and control cancer. The National Institute of Public Health in Slovenia has assumed the role of leader of the EPAAC Joint Action, which encompasses 36 associated partners from across Europe and over 100 collaborating partners.

ECPC CONTRIBUTION TO EPAAC

ECPC involvement in the first Joint Action against cancer started even **before the formal creation of EPAAC**: it was also thanks to the **advocacy efforts of ECPC** that the Commission and the 2009 Slovenian Presidency of the Council of the European Union crystallized their efforts into the 3 year initiatives, concluded last March. Within **EPAAC**, ECPC provided a horizontal support to the JA, contributing to the production the first European Guidelines for the creation and management of National Cancer Plans, and in particular to:

-[Boosting Innovation and Cooperation in European Cancer Control](#), which includes a chapter from ECPC President Francesco De Lorenzo on Cancer Information System;

-**EPAAC Work Package 7 – Healthcare, Project: Psychosocial Oncology Action**. ECPC collaborated to write this chapter, under the coordination of Romanian Ministry of Health and Oncology Institute from Cluj-Napoca (IOCN).

CANCON: THE NEW JOINT ACTION ON CANCER

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 to create a European Guide on Quality Improvement in Comprehensive Cancer Control.

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.

- **WP2-Dissemination**

High level of engagement of internal and external communications to set cancer control on the European agenda and foster networking across different fields of science. A website will be used as key tool to disseminate the European Guide, activities of the JA and public documents prepared by other WPs

ECPC Representative: Francesco Florindi

- **WP4-Methodology**

It will deliver the final document of the European Guide on Quality Improvement in Comprehensive Cancer Control. It will ascertain the methodology for the preparation of the Guide and assure the quality and coherence between the chapters.

ECPC Representative: Francesco De Lorenzo

- **WP5 Member States Platform**

WP5 is the specific Work-package designed to share among Members States (MS) the different challenges they face and those national/local experiences in cancer control which could be a valuable lesson for others.

ECPC Representative: Francesco De Lorenzo

- **WP6 Integrated Cancer Control**

This work package gives recommendations for the organisation of comprehensive cancer services and best care for the population in any given area

ECPC Representatives: Kathi Apostolidis

- **WP7-Community Level Cancer Control**

Will examine aspects of community cancer care and its interactions with other dimensions in the course of comprehensive cancer care such as continuity of cancer care after discharge from initial treatment, reintegration and rehabilitation of survivors and management of their long-term follow up, early diagnosis.

ECPC Representative: Kathi Apostolidis

- **WP8-Survivorship and Rehabilitation**

Develop a European organizational framework with a list of recommendations for addressing survivorship and rehabilitation and proposed tools. All phases across the cancer care continuum will be taken into consideration as well as the patient's status.

ECPC Representative: Francesco de Lorenzo

- **WP9-Cancer Screening**

Create principles for organizing and evaluating population based cancer screening programmes as part of the national cancer control plan in each EU MS.

ECPC Representative: Pietro Presti

ECPC – PART OF THE EUROPEAN COMMISSION'S EXPERT GROUP ON CANCER CONTROL

In June 2014, the European Commission adopted a Decision, which establishes an Expert Group on Cancer Control. 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.

The members of the expert group are representatives of the member states, representatives of three patient organisations, two European cancer prevention organisations, two European professional/scientific organisations, one industry, and one IARC representative.

The official launch and first meeting of the Expert Group took place in Milan on the 23rd and 24th September 2014, and coincided with the Informal Meeting of the Health Ministers under the Italian EU Presidency.

F. de Lorenzo and K. Apostolidis represent ECPC within the Expert Group. In 2014, the Expert Group has been called to work on opinions related to: rare cancers and palliative care.

GENERAL DATA PROTECTION REGULATION

After having supported ESMO Position Paper on the Regulation, ECPC lobbied the Council of the European Union during the Italian Presidency for the introduction of amendments that would ensure the survival of cancer registries, pivotal for the creation of historical and perspective epidemiological studies on cancer.

ECPC URGES ELIMINATION OF DISPARITIES IN CANCER CARE IN EUROPE

On the 18th of February 2014, within the European Parliament, ECPC and OEI organised together the Conference '**How uniform is cancer care in Europe**'.

The conference was organised with the support of Members of the European Parliament Patrizia Toia, Alojz Peterle and Nessa Childers and brought together experts in oncology, patients, decision-makers and physicians to advance responses to cancer care disparities across Europe.

One of the solutions suggested at the conference was to reduce the fragmentation of high quality cancer services and instead concentrate clinical cancer care within hospital setting and non-hospital settings.



CALL ON THE EUROPEAN COMMISSION TO SUPPORT EARLY DIAGNOSIS STRATEGY FOR HEAD AND NECK CANCERS

On 23 September 2014, together with the European Head and Neck Society (EHNS), ECPC reconvened in the European Parliament to call for the implementation of a Europe-wide head and neck cancer early diagnosis awareness programme.

The meeting took place during the second annual Make Sense Campaign Head and Neck Cancer Awareness Week, and was attended by MEPs, representatives of the European Commission and a panel of European head and neck cancer experts. The aim of the event was to harness the support of the European Commission for an early diagnosis strategy in head and neck cancer, devised by the EHNS and ECPC.

Still in 2014 ECPC successfully established agreement from European 10 head and neck patient groups to form a Make Sense Campaign European PAG Network, which aims to assist all patients with head and neck cancer across Europe to receive the best possible care.

FIRST WORLD PANCREATIC DAY, 13TH NOVEMBER 2014, BRUSSELS

ECPC joined pancreatic cancer patient organizations across the world to organise and celebrate on November the 13th **the first World Pancreatic Cancer Day**. After more than 6 months of preparation, a series of events and initiatives within the European Parliament marked the WPCD2014, including:

- An awareness campaign inside the Parliament, ran by ECPC;
- The drafting of the political Call-to Action led by Members of the European Parliament Dr Philippe Juvin (EPP, France), Philippe De Backer (ALDE, Belgium), Françoise Grossetête (EPP, France) and Daciana Sârbu (S&D, Romania);
- The launch of the European Platform on Pancreatic Cancer, which gathers leading experts, involved in pancreatic cancer, in the field of academia, research, patient organizations, policy-makers and industry.

Our Romanian member organisation „Sfânta Ana”, chaired by Mrs. Bogdana Costoiu joined our awareness efforts and did all the necessary formalities in order to lit up in purple, the colour of pancreatic cancer, the famous Romanian monument Gate of Kiss in Targu-Jiu.

IMMUNO-ONCOLOGY POLICY ACTION FRAMEWORK, 19TH NOVEMBER 2014, BRUSSELS

On the 19th November 2014, the European Cancer Patient Coalition (ECPC), together with Philippe de Backer, ALDE MEP and Cristian Silviu Busoi, EPP MEP, launched two important new documents at the European Parliament (**Immuno-oncology: a policy action framework** and **What is immuno-oncology: a guide for patients**). These documents are designed to improve the understanding of policymakers and patients of immuno-oncology therapies and the role that they may play in the future care of cancer



patients. **The Guide for Patients was translated by ECPC in 23 languages and disseminated in 16 countries with the support of ECPC member organisations.** Other six language versions are in the process of dissemination.

PARTICIPATION TO INTERNATIONAL MEETINGS

EUROPEAN SOCIETY OF MEDICAL ONCOLOGY CONGRESS

Madrid (Spain) 26-29 September 2014; De Lorenzo, Apostolidis, Pelouchova, Militaru.

The Patient Advocacy Track provided European patient organisations, oncologists and bodies involved in patient care with an excellent networking opportunity – giving participants the possibility to discuss vital issues and challenges faced by cancer patients. ECPC, as a Member of the ESMO Patient Working Group, actively participated into the definition of the ESMO2014 Patient Track, which took place on the 27th and 28th September 2014.

During the ESMO congress, ECPC also started discussions with ESMO on the unfortunate situation related to the incapacity of non-prescribers, including patients and patients' advocates, to participate to all the sections of the congress.

EUROPEAN HEALTH FORUM GASTEIN

Gastein (Austria), 1-3 October 201, Florindi.

The EHFG is the most important high-level public health forum in Europe, bringing together experts from across Europe to discuss the future of health, including cancer. Francesco Florindi was awarded with a scholarship to attend the meeting.

FUTURE OF HEALTHCARE

Brussels (Belgium), 18th November 2014; De Lorenzo

De Lorenzo has been invited to co-chair a roundtable discussion on "Next generation in health accreditation" organised within the Roundtable on the Future of Healthcare, hosted by MEP Christel Schaldemose and supported by Sustania and DNV-GL. The meeting aimed at inspiring smarter, safer and more sustainable healthcare systems that put the person in the centre of care.

EU CLINICAL TRIALS PORTAL AND UNION DATABASE

London (UK), 9th December 2014; Apostolidis, Swierzewski.

ECPC Representatives to the EMA Kathi Apostolidis and Rafal Swierzewski will take part to the stakeholders meeting organised by the Agency on the new EU clinical trials portal. According to the recently approved Clinical Trials Regulation, the portal has to be created as a centralised hub for the registration of all European clinical trials. This represents a legal requirement of the new Regulation. K. Christoforidi attended the annual training offered by EMA to members of the PCWP, in order to increase our in-house knowledge and understanding of the activities of the EMA and PCWP.



PROJECTS

RARECARENET

In 2014, 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. **ECPC has created an online library with information on rare cancers. The information provides details on the different types of cancer, the treatment options and treatment follow-up.**

BENCHCAN

Within its effort to reduce inequalities in cancer care, European Cancer Patient Coalition (ECPC) found in the Organisation of European Cancer Institutes (OECI) a precious ally. In 2013 a cooperation initiative was established, aiming at identifying possible solutions to the unacceptable inequalities in cancer care among Member States and at cooperating in EU research projects. As part of Bench-Can Project, the ECPC accepted to take an active role participating to the Pilot Sites' visits and the cooperation between the two Organisations become dynamic and effective. The goal of the Bench-Can Project is not to rank cancer centres, but to benchmark best practices and identify examples of excellence that will contribute to reduce inequalities in cancer care in EU.

The Bench-Can partners discussed and drafted the tools, including processes and outcomes indicators, to be employed in the Pilot Sites. The draft version has been then validated enabling the benchmarking group to effectively compare the Pilot Sites, in order to peer review the benchmarking exercise and to identify areas for improvement in quality of care and patients' outcomes. The Comprehensive Cancer Centres participating to the piloting phase involve patients and carers in the benchmarking process, providing information and assessing performances based on their experience. In this framework, ECPC Audit Committee Member, Dr. Pietro Presti, collaborates to guarantee that the voice of patients is heard and to ensure that they have timely and affordable access to the best treatments and care.

Thanks to the ECPC collaboration, the Bench-Can Project has the needed expert support to guide the centeredness of the patients across all pilot sites.

PROJECT PROPOSALS

Through the year, ECPC received several offers to participate to EU funded research projects under the new EU Framework Programme for Research, called Horizon 2020. Below a sum up of the proposals submitted.

- **BreCaReMo** - addressing the development of a mHealth supported point-of-care device for monitoring therapy and early detection of recurrence and metastasis in breast cancer patients, after surgery, chemo and radiation therapy.
- **DUAL4CANCER** – aiming to reduce Head and Neck Cancer by gathering clinical evidence for a tri-modal curative treatment strategy for patients with CA IX positive HNSCC.



- **HIRESLED** – having as main objective to understand the reasons for poor outcome, in elderly cancer patients (> 65 years) in Europe, and identify actions to reduce inequalities in this population.
- **IMMUNOLIGO** – a pioneering consortium geared towards opening up a paradigm in treating metastatic cancer by gathering clinical evidence for a bi-modal curative treatment strategy for patients with oligometastatic disease, for who at present palliative treatment is the current standard of care.
- **MOCAN** – meant to empower patients with cancer to use integrated, intelligent and motivating ICT that supports self-management (“Integrated Cancer Care Pathway”).
- **PRIMULA** - aimed to advance the optimal management of patients with metastatic cancers, by defining new personalized therapeutic strategies.
- **RoutingCancer** – aiming to investigate and evaluate evidence on outcomes and resource requirements of the personalisation of lung cancer clinical pathway in the Belgium, Germany, the Netherlands, Spain and the United Kingdom towards informing policies of health and care systems in Europe.

TEAMECPC

In 2014, ECPC continued its efforts to promote healthy lifestyles through the participation of ECPC staff to sports events. TeamECPC grew bigger and diversified the runs in order to get more people motivated and involved. On the 18th of May 2014, four members of the TeamECPC run the Brussels 20 Km to raise awareness on Pancreatic Cancer and mark ECPC’s renewed engagement towards pancreatic cancer patients. Then, in September 2014, an even larger team, took part in the Colour Run. **Mr. Giorgos Kapetanakis from the Society of Cancer Patients of Katerini in Greece (Member of ECPC) joined TeamECPC for the run to help us raise awareness on cancer and send a message of strength and optimism to all people affected by cancer.**

LAUNCH OF A NEW WEBSITE

In 2014 ECPC also launched a new website designed with a fresh look and user-friendly navigation also featuring on its home page a database of clinical trials that is so far the most accessed section of the website.