



EUROPEAN
CANCER
PATIENT
COALITION

**ANNUAL
REPORT**
2017

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CORRESPONDENCE

European Cancer Patient Coalition
40, rue Montoyer – 1000 Brussels – Belgium
info@ecpc.org

EUROPEAN CANCER PATIENT COALITION BOARD

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**EUROPEAN
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ANNUAL REPORT 2017

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THE EUROPEAN CANCER PATIENT COALITION

**OUR MOTTO:
"NOTHING ABOUT US,
WITHOUT US!"**

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

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



The European Cancer Patient Coalition derives its mandate to speak with "one voice" for all people with cancer from its wide membership and its democratic structure.

The motto of the European Cancer Patient Coalition is: "Nothing about us, without us!"

In 2017, 23 new organisations joined the European Cancer Patient Coalition, consolidating it as Europe's largest cancer patient association, with a total of 431 Members.

New members who joined ECPC in 2017:

- "Sabina" Association, Romania;
- Alliance of Women with Breast Cancer, Check Republic;
- Association of Cancer Patients and Friends of Cyclades, Greece;
- Cancer Association of Mykonos, Greece;
- Cancer Society of Drama, Greece;
- Cancer Support France, France;
- Chios Cancer Patients Society, Greece;
- Chronic Myeloid Leukaemia France, LMC France;
- Esperantra "Help Association for Peruvian patients", Peru;
- Evita – Support for Carriers of Genetic Mutations linked to Cancer, Portugal;
- Italian Association Melanoma Patients, Italy;
- Kilkis Cancer Patients Society, Greece;
- League of Neoplasia Patients, Friends and Families, Greece;
- Myeloproliferative Neoplasms Belgium VZW, Belgium;
- Netitaly onlus, Italy;
- NGO Karkinaki, Greece;
- Northern Ireland Rare Disease Partnership, Ireland;
- Romanian Association for Services And Communication In Oncology, Romania;
- Russian Cancer Patients Association Zdravstvyi, Russia;
- Spanish Association of Adolescents and Young Adults with Cancer (AAA), Spain;
- The Friends of Bordet Institute, Belgium;
- Thyroid Cancer Alliance, Netherlands;
- Travail & Cancer, Belgium.

MISSION

- ➔ Empower Europeans with cancer through the dissemination of information;
- ➔ Foster co-operation among cancer patients' organisations through joint activities;
- ➔ Ensure that state-of-the-art cancer care practices are shared across the European Union;
- ➔ Make cancer a priority for action in the European health policy agenda;
- ➔ Have an active role in shaping European and national healthcare policies;
- ➔ Contribute to change or create European and national laws to meet the needs of people with cancer;
- ➔ Call for the people with cancer to be included in cancer research.



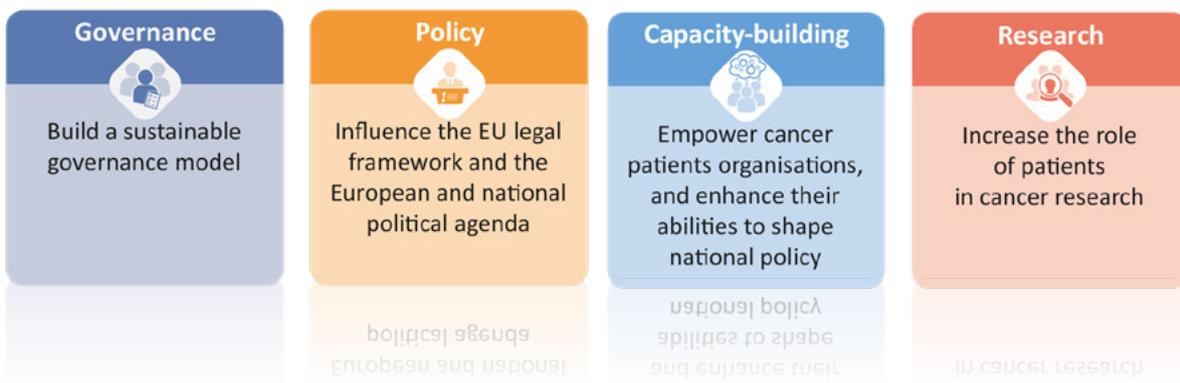
STRATEGY

The main objective of the ECPC 2017 Action Plan was to confirm ECPC's leadership as the main voice of cancer patients in Europe. The European Cancer Patient Coalition focused its activities on ensuring that patients' views play a leading role in the development of health care programs in Europe. Another main objective was to strengthen the organisation's capacity building and increase the connection between ECPC and its Membership. Moreover, the new "Multi-Annual Strategy 2016-2019" has increased media's attention and dissemination of information from the organisation. Additionally, new high-quality educational material on crucial topics like Nutrition and Survivorship were produced to provide the ECPC Members with support in their activities of advocacy and dissemination of information.

The European Cancer Patient Coalition Multi-Annual Strategy 2016–2019 increases the impact of the organisation in the cancer field throughout Europe by developing long-term aspirations. ECPC has streamlined its activities by developing and implementing, together with its Members, a coherent Multi-Annual Strategy. ECPC has consolidated and focused its activities, after a sustained period of growth over the past three years.

The Multi-Annual Strategy runs from 2016 to 2019, the same period covered by the mandate of the current ECPC Board, elected in June 2016 for a duration of 3 years.

The ECPC Multi-Annual Strategy 2016–2019





MESSAGE FROM THE PRESIDENT

As I look back on the last twelve months as President of the European Cancer Patient Coalition, I reflect on the great privilege that it has been to continue as President of this great organisation. In 2017, the European Cancer Patient Coalition's persistent efforts to position cancer more prominently on the political agenda continued to yield results, from policy to research to capacity-building.

In 2017, the European Cancer Patient Coalition organised five European Parliament events, including the launch of the "Value of Innovation in Oncology" white paper, the "Cancer Carers" white paper, the "Biomarkers in the Era of Personalised Medicine" animation, and a "Bubbles for Bladder Cancer" awareness activity. We actively participated in the European Commission public consultation on the future of Health Technology Assessment, were co-authors of the European Commission's "CanCon European Guide on Quality Improvement in Comprehensive Cancer Control", co-produced the "ECPC-ESMO Survivorship Guide", and successfully advocated for improvements to the

World Health Organisation's 2017 Cancer Resolution. We were very proud to be invited to join the European Commission's Innovative Partnership Action Against Cancer, which will be launched in 2018.

The European Cancer Patient Coalition is one of the few patient organisations directly involved in research. In 2017, we were an active member of two Innovative Medicines Initiative projects, four Horizon 2020 projects, and one Seventh Framework Programme project. The important contribution of the European Cancer Patient Coalition to cancer research has been recognised by having representatives from our organisation appointed to the Boards of the Cancer Drug Development Forum and Cancer Core Europe, as well as to the Science Policy Committee of the European Academy of Cancer Sciences and to the General Assembly of the Worldwide Innovative Networking Consortium. Our scientific paper, "Perception of Nutritional and Metabolic Derangements in Patients With Cancer and Cancer Survivors: Results

"OUR PERSISTENT EFFORTS CONTINUED TO YIELD RESULTS"

From a European Cancer Patient Coalition 2016 Survey" was finalised and submitted to a peer-reviewed journal for publication.

These results are an important achievement for all Members of the European Cancer Patient Coalition. The ultimate mission of our organisation is to listen to our Members and represent them at the European level. In 2017, we welcomed 180 participants to our Annual Meeting, and 23 new organisations joined the European Cancer Patient Coalition, consolidating it as Europe's largest cancer patient association, with a total of 431 Members. Each one of our Members are essential for the work of our organisation, and I warmly thank all of them for their tireless work to support Europeans affected by cancer.

Francesco De Lorenzo

—
"I AM INSPIRED
BY OUR
BOARD (...)"
—



MESSAGE FROM THE DIRECTOR

The Members of the European Cancer Patient Coalition are our greatest strength, that allow us to ground our European advocacy work in the realm of local experience. Our knowledge and our understanding come from the opinion, experience and suggestions coming from the day-to-day challenges faced by our Members throughout Europe.

In 2017 the Board, the Secretariat, and the Members of the European Cancer Patient Coalition produced a wide range of resources and activities to build the capacity of cancer patient organisations, advocate for better health policy, and improve patient-centricity in European research programmes.

I am inspired by our Board – cancer survivors and cancer advocates who donate their time, energy, and expertise to ensure that the strategy of the organisation is determined by people with cancer themselves. In our Brussels office, I see the daily efforts of the dedicated and

energetic staff to deliver high quality and high impact events, communication, research, projects, and policy work.

When I meet with our Members, I am encouraged by their efforts to ensure the voice of people with cancer is heard throughout Europe, and I am motivated to continue our collaborations to build tools to support European cancer awareness, education and advocacy. I am also grateful to the European Commission, the Union for International Cancer Control, and our industry partners for supporting our work and assuring the sustainability of our organisation.

As we look to 2018, our activities will focus on our core mission: to be the European voice of people with cancer. We will achieve this by listening to our Members, providing high quality research and cancer advocacy, and producing multilingual educational resources. We will deliver our objectives on cancer with a strong united voice

—
"IN 2017 THE BOARD,
THE SECRETARIAT,
AND THE MEMBERS
OF THE EUROPEAN
CANCER PATIENT
COALITION PRODUCED
A WIDE RANGE
OF RESOURCES
AND ACTIVITIES"
—

drawing on our wide membership and the support of our partners in industry and across civil society.

Together, the voice of people with cancer will be heard in environments where real and lasting change for cancer awareness, care, treatment and prevention can be obtained.

Lydia Makaroff

GENERAL EVALUATION OF THE YEAR 2017

ECPC Objectives

The main objective of the 2017 Action Plan was to consolidate the role of the European Cancer Patient Coalition as the main voice of cancer patients in Europe. In order to uphold this commitment, the organisation worked to ensure that the patient perspective had a strong role in initiatives care such as the WHO Cancer Resolution, the EU Joint Action on Rare Cancers, and the EU Joint Action on Cancer Control.

A variety of new policy issues developed at the European level, and the European Cancer Patient Coalition demonstrated that cancer patients are the most important partners in the fight against cancer and against all the cancer-related issues affecting our society. Topics like cancer carers, innovation in oncology, and survivorship were some examples of policy priorities for the European Cancer Patient Coalition in 2017.

New high-quality education materials supported the advocacy and educational efforts of the Members of the coalition on topics such as Merkel Cell Carcinoma, Cancer-Associated Thrombosis, and Immuno-Oncology. These materials were also translated into multiple languages in order to facilitate communication and understanding.

One of the main annual objectives was to strengthen the organisation and reinvigorate the connection between the European Cancer Patient Coalition and its Membership. The coalition welcomed 23 new organisations in 2017, and welcomed 141 organisations to the Annual Meeting in Brussels. The new Audit Committee and Scientific Committee have ensured that the coalition's activities are backed by sound financial management and scientific integrity. A renewed communication activity has increased the engagement with social and traditional media and improved dissemination to Members and stakeholders.

The ECPC Strategy

The ECPC Board's multi-annual strategy is based upon four pillars:

- **Governance:** to build a sustainable governance model
- **Policy:** to influence the EU legal framework and the European and national political agenda
- **Capacity building:** to empower cancer patient organisations and enhance their ability to shape national policy
- **Research:** to increase the role of people with cancer in research

The European Cancer Patient Coalition has also consolidated its relationships with other health stakeholders and also build new bridges with additional partners. At the 2017 Annual Meeting, the European Cancer Patient Coalition signed a memorandum of understanding with the European Organisation for the Research and Treatment of Cancer. The coalition also released the Patient Guide on Survivorship in collaboration with the European Society for Medical Oncology, the White Paper on Prostate Cancer in collaboration with the European Association for Urology, and co-hosted an event on Access to Innovative Oncology Drugs in Europe with the Cancer Drug Development Forum.

2017 CALENDAR OF MAIN ACTIVITIES

JANUARY

- ➔ Launch of the European Cancer Patient Coalition & Organisation for European Cancer Institutes' Joint Declaration at the European Cancer Congress in Copenhagen, Denmark
- ➔ Launch of Value of Innovation White Paper at the European Cancer Congress in Copenhagen, Denmark
- ➔ Launch of the White Paper on Prostate Cancer in Brussels, Belgium
- ➔ European Cancer Congress (ECCO) in Amsterdam, Netherlands

FEBRUARY

- ➔ World Cancer Day
- ➔ Joint Action on Cancer Control (CanCon) final event in Valletta, Malta
- ➔ IMI DO IT Big Data for Better Outcomes Kick-off Meeting in Basel, Switzerland

MARCH

- ➔ Launch of the new "Access" section on the Immuno-Oncology Portal
- ➔ European Reference Networks Conference in Vilnius, Lithuania
- ➔ FP7 eSMART Annual Consortium meeting in Vienna, Austria

APRIL

- ➔ Immuno-oncology Portal and Value of Innovation event at the European Parliament in Brussels, Belgium
- ➔ European Reference Network on Adult Solid Cancer (EURACAN) Kick-off meeting in Lyon, France

MAY

- ➔ European bladder cancer awareness month
- ➔ World Health Organisation Cancer Resolution ratified at World Health Assembly in Geneva, France

JUNE

- ➔ European Cancer Patient Coalition Annual Meeting in Brussels, Belgium
- ➔ European Cancer Patient Coalition Working Group on Rare Cancers' Meeting in Brussels, Belgium
- ➔ Worldwide Innovative Networking Symposium in Paris, France

SEPTEMBER

- ➔ Launch of the European Society for Medical Oncology & European Cancer Patient Coalition's Survivorship Guide at the European Society for Medical Oncology congress in Madrid, Spain
- ➔ Make Sense Head & Neck Cancer Awareness event in the European Parliament, Brussels, Belgium
- ➔ European Prostate Cancer Awareness Day in Brussels, Belgium

OCTOBER

- ➔ Cancer Associated Thrombosis awareness campaign
- ➔ Launch of White Paper on Cancer Carers at the European Parliament in Brussels, Belgium
- ➔ Joint Action on Rare Cancers (JARC) Annual Meeting in Milan, Italy
- ➔ IMI PREFER Patient Preferences Annual Meeting in Basel, Switzerland
- ➔ IMI DO-IT Big Data for Better Outcomes General Assembly in Berlin, Germany

NOVEMBER

- ➔ Launch event of nutrition information materials in the European Parliament in Brussels, Belgium
- ➔ Launch of updated educational and policy bladder cancer webpages
- ➔ Presentation of the Immuno-Oncology Portal and Value of Innovation at the European Alliance for Personalised Medicine congress in Belfast, Northern Ireland
- ➔ World Pancreatic Cancer Day

DECEMBER

- ➔ Cancer Biomarkers in the Era of Personalised Medicine event at European Parliament in Brussels, Belgium
- ➔ Immuno-oncology Portal available in five languages
- ➔ Launch of the survey on Bladder Cancer Patient's Experience in seven languages
- ➔ IMI DO-IT Big Data for Better Outcomes Work Package 4 Meeting in Berlin, Germany

EUROPEAN CANCER PATIENT

HEALTH POLICY

The European Cancer Patient Coalition **organised 5 events** in collaboration with 8 Members of the European Parliament and **spoke at an additional 12 events**.

The European Cancer Patient Coalition actively participated in co-creating the content of the several key European and Global policy initiatives, including:

- European Commission public consultation on the future of Health Technology Assessment
- CanCon European Guide on Quality Improvement in Comprehensive Cancer Control
- World Health Organisation 2017 Cancer Resolution

SPOKE AT
17
EVENTS



INFORMATION

The European Cancer Patient Coalition website received over **21,352 visitors over the year**. The most popular webpages were the homepage, followed by pages with information about pancreatic cancer, our members, Merkel cell carcinoma, and the EURACAN European Reference Network.

Throughout the year, the European Cancer Patient Coalition distributed:

- 250 printed copies of the "Value of Innovation in Oncology";
- 200 printed copies of the Merkel Cell Carcinoma brochure in French and English;
- 150 printed copies of the "Cancer Carers White Paper";
- 100 printed copies of the ECPC-ESMO Survivorship Guide.



AWARENESS

The European Cancer Patient Coalition participated in **18 awareness campaigns**, and led **3 awareness campaigns** highlighting bladder cancer, head and neck cancer, and cancer-associated thrombosis.



COALITION BY THE NUMBERS

EUROPEAN RESEARCH

The European Cancer Patient Coalition is **one of the few patient organisations directly involved in research.**



ECPC participated in **several European Union's Research and Innovation framework programmes**, and drew on fundamental knowledge and understanding of the patients' situation by working through its Members to truly represent patients at the EU level, while providing irreplaceable first-hand understanding of the issues revolving around cancer patients.

ECPC was an active member of **2 Innovative Medicines Initiative projects**, **4 Horizon 2020 projects**, and **1 Seventh Framework Programme project**.

This allows the European Cancer Patient Coalition to be on the forefront of scientific developments on cancer by providing the patient's perspective and driving fundamental knowledge on the science behind cancer.



= 431
ORGANISATIONS



SUPPORT AND CAPACITY BUILDING

Throughout the year, **23 new organisations** joined the European Cancer Patient Coalition, increasing the Membership to **431 organisations**. The 2017 Annual Meeting welcomed **180 participants**, representing **141 different organisations** from **42 different countries**.

MEDIA

The European Cancer Patient Coalition Twitter account rose to **3,942 followers** and the European Cancer Patient Coalition Facebook account accumulated **7,321 likes**. The European Cancer Patient Coalition was highlighted in **12 new articles**, **4 editions of POLITICO Pro Morning Health Care**, and **2 editions of Dods EU**.



7,321
LIKES

3,942
FOLLOWERS



6. Innovative eHealth and mHealth tools should be used, together with innovative care pathways, to increase patient-centricity by design and by default, and should be subject to solid, visible and transparent assessment and governance by a centralised monitoring body at the European level.

7. The performance of standardised cancer patient pathways should be carefully monitored, and national cancer plans should include strategies to ensure that the pathways are followed.

The "Value of Innovation in Oncology" White Paper was developed in collaboration with Interel Public Affairs, oncology experts, and the Members of ECPC. It includes over 30 evidence-based policy recommendations, spanning six healthcare areas – innovative medicines, diagnostics, radio-oncology, surgery, mHealth and care pathways.

The White Paper was also presented to Italian, Greek, Czech, and British national stakeholders, in collaboration with the following ECPC Members:

- Italian Federation of Cancer Patients Organisations (Italy)
- Hellenic Cancer Federation - ELL.O.K. (Greece)
- Diagonza Leukemie (Czech Republic)
- Polish Cancer Patient Coalition (Poland)
- The Brain Tumour Charity (UK)

The European Cancer Patient Coalition gratefully acknowledges the support of Bristol Myers-Squibb, Eli Lilly & Company, MSD, Novartis and Roche. The scope and the content remain the sole responsibility of the European Cancer Patient Coalition.

The *Value of Innovation in Oncology* is available in English, Italian, and Polish at:
www.ecpc.org/innovation

White Paper on Cancer Carers

The European Cancer Patient Coalition, together with Eurocarers, launched the White Paper on Informal Carers of People with Cancer at the European Parliament, during a dedicated event hosted by Heinz K. Becker MEP (European People's Party, Austria) who was also joined by his colleagues Theresa Griffin MEP (Progressive Alliance of Socialists and Democrats, UK) and Jana Zitnanska MEP (European Conservatives and Reformists, Slovakia) to urge European and national policymakers to use the full breadth of tools at their disposal to recognise, support and protect carers.

An informal carer is a person who provides unpaid care to someone who is affected by a chronic illness, disability or other long-lasting health care need, outside a professional or formal framework. The sustainability of healthcare systems depends substantially on informal carers, as they provide around 80% of care across Europe and represent an enormous cost saving to national health care systems. Yet their vital role is often unrecognised and wholly unregulated.

Public health stakeholders at the event called on European Institutions and Member States to do more to support carers, pointing to the proposed

directive on work-life balance for parents and carers in the context of the European Pillar of Social Rights. The event also highlighted best practices from Member States, including the work of the support group MammaHELP in Czech Republic and the 2014 Commitment to Carers pledge by the National Health System England.

The White Paper on Informal Carers was produced in collaboration with the following ECPC Members:

- Portuguese League Against Cancer (Portugal)
- MammaHELP (Czech Republic)
- Spanish Association of Cancer Patients – GEPAC (Spain)
- Italian Federation of Volunteer-based Cancer Organisations (Italy)
- Hellenic Cancer Federation- ELL.O.K. (Greece)

The European Cancer Patient Coalition gratefully acknowledges the support of Eli Lilly & Company, Merck and Pfizer. The scope and the content remain the sole responsibility of the European Cancer Patient Coalition.

www.ecpc.org/activities/policy-and-advocacy/policy-initiatives/carers

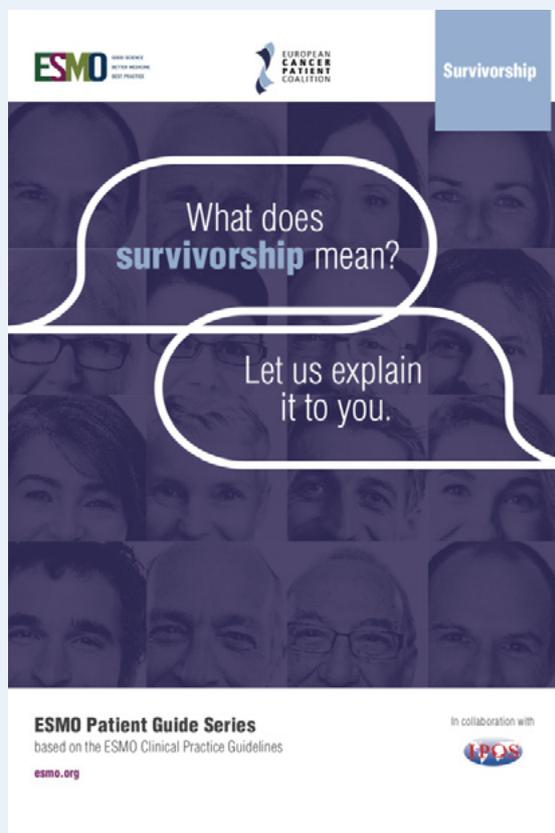


ESMO-ECPC Survivorship Guide

The European Cancer Patient Coalition and the European Society for Medical Oncology launched the Patient Guide on Survivorship at the European Society for Medical Oncology Congress.

The Patient Guide on Survivorship has been created by ESMO and ECPC, in collaboration with the International Psycho-Oncology Society, to help cancer survivors in finding new pathways to a satisfactory and normal life. It includes a checklist that cancer survivors can share with their health-care team to quickly and easily ensure an optimal survivorship care plan based on rehabilitation, late effect and second cancer prevention, as well as smooth return to work. This tool will facilitate and empower collaboration between patients and health professionals.

The Survivorship Guide focuses on health and the physical, psychological, social and economic issues affecting people after the end of the primary treatment for cancer. Post-treatment cancer survivors range from people who have finished treatment and have no disease, to people who continue to receive treatment to reduce the risk of the cancer returning, and people who have a well-controlled disease and few symptoms. Survivorship care includes issues related to follow-up care, management of late side-effects of treatment, improvement of quality of life, and psychological and emotional health. Survivorship care also includes future anti-cancer treatment, where applicable. Family members, friends and caregivers should be considered part of the survivorship experience as well.



The Survivorship Guide includes information on:

- Support in coping with the situation
- Life after initial treatment
- Preventive health
- Survivorship checklist

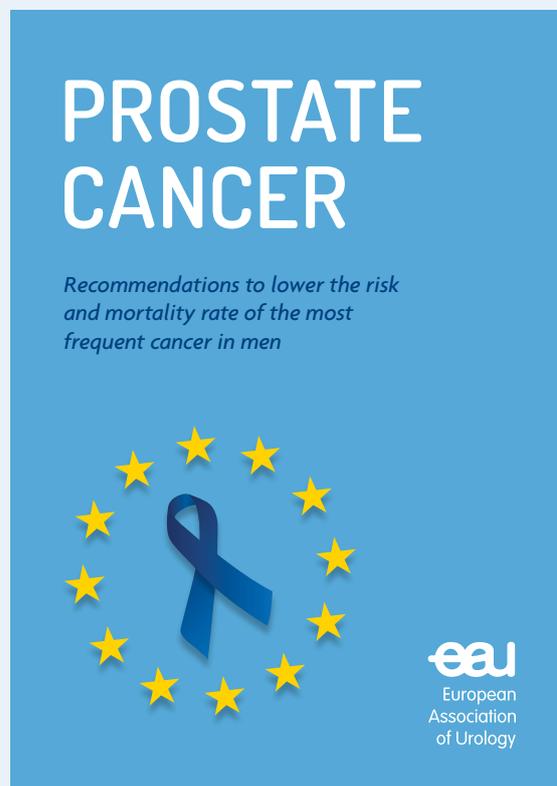
[www.ecpc.org/edu/
esmo-cancer-patient-guides](http://www.ecpc.org/edu/esmo-cancer-patient-guides)

European Prostate Cancer White Paper

As part of its contribution to cancer prevention initiatives, particularly around prostate cancer, the European Association of Urology (EAU) has initiated a White Paper to lower risk and mortality rate of prostate cancer. This White Paper was created through the collaboration of medical experts, representatives from related medical societies, the European Cancer Patient Coalition and Europa Uomo, and it addresses key topics such as risk factors and prevention, diagnosis, treatment, living with prostate cancer, the role of the EAU and the current activities initiated by the European Union (EU) regarding cancer control.

In its call for all stakeholders to consolidate their efforts and benefit from synergies, the white paper produced the following six recommendations:

- With more than 417,000 men diagnosed and more than 92,000 men recorded dying from prostate cancer, European institutions and Member States need to ensure that people with prostate cancer receive high-quality, standardised and integrated care, with a patient-centred multidisciplinary approach.
- The European Union and its Member States should ensure equitable access to novel technological tools that enable better diagnosis, treatment and research. The future is likely to encompass risk-adapted treatment programmes that require contemporary imaging and diagnostic tools.
- Access to innovative treatments and personalised medicines should be made fast and equitable for all people with prostate cancer who can benefit from them. This aligns with the Health Ministers' of the European Union's Council Conclusions as issued by the Luxembourg's and the Netherlands' European Union Presidencies.



- Prompt and consistent Health Technology Assessment should be performed on all new screening, diagnostic, therapeutic and rehabilitation technologies to provide the base for effective, efficient, targeted and optimised allocation of resources in urology and specific services related to prostate cancer.
- It is essential to sustain awareness campaigns, both at European and national level, and to help achieve the main goals set out in the White Paper.
- The European Union and its Member States should promote the implementation of cancer survivorship's plans, including specific plans to facilitate the return to a normal life for all European people with prostate cancer.

epad.uroweb.org/mission-vision/white-paper

World Health Organisation Cancer Resolution

The 70th World Health Assembly approved the resolution on "Cancer prevention and control in the context of an integrated approach" and noted the World Health Organisation report on cancer prevention and control.

This marks the first resolution dedicated to cancer by the World Health Organisation in over a decade and provides a set of recommendations aimed at controlling and preventing cancer. It complements the World Health Organisation's Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013-2020.

The "World Health Organisation 2017 Cancer Resolution" represents a firm commitment of all countries to keep cancer control as a global health priority. The resolution calls for countries to develop national plans for cancer control, to promote recommendations that support decision-making based on cost-effective use of cancer diagnostic and therapeutic services, to promote follow-up for cancer survivors, early detection of patients' needs, and to facilitate psycho-social counselling and after-care for people with cancer and their families – all topics for which the European Cancer Patient Coalition strongly advocates. It also calls for the integration of cancer efforts within the civil society, in line with the Sustainable Development Goals, and for the collaboration between non-governmental Organisations in the development of effective and affordable new cancer medicines.

During the negotiations of the new resolution, the European Cancer Patient Coalition called for the importance of patients' organisations to be recognised in the prevention, control, treatment and care of cancer.

The European Cancer Patient Coalition forwarded this recommendation to Dr Margaret Chan, outgoing WHO Director-General, and to Ms. Heidi Botero-Hernandez, First Secretary of the Permanent Mission of Colombia to the UN in Geneva and Chair of the informal consultations for the cancer resolution. Thanks to these efforts, the following clause was added to the resolution:

"The Seventieth World Health Assembly, URGES Member States [...],

(19) to continue fostering partnerships between government and civil society, building on the contribution of health-related nongovernmental Organisations and patient Organisations, to support, as appropriate, the provision of services for the prevention and control, treatment and care of cancer, including palliative care"

The European Cancer Patient Coalition was satisfied by the inclusion of this recommendation to recognise the role of patients' organisations and encourages every country to effectively involve patients in all aspects of cancer prevention and control.

European Cancer Patient Coalition Legal Network for Cancer Patients

The Legal Network for Cancer Patients brings together a solid base of legal practitioners that aim to share their legal competences to the benefit of people with cancer on a volunteer basis. The European Cancer Patient Coalition has created an online platform where lawyers across Europe can exchange information and provide legal advice.

The Legal Network for Cancer Patients supports the European Cancer Patient Coalition's policy by providing insights and understanding of key legal files related to relevant European and national issues.

This initiative was introduced by the Association of Cancer Patients from Romania (FABC), a European Cancer Patient Coalition's Member. The Legal Network for Cancer Patients aims to:

- Monitor compliance with the European Union's Legislation by the Member States;
- Defend patients' rights when the European legislation is breached by the Member States;
- Share legal best practices;
- Provide legal professional background for the European Cancer Patient Coalition's positions.

The Legal Network for Cancer Patients' team includes representatives from the following Members of the European Cancer Patient Coalition:

- Association of Cancer Patients from Romania (FABC) (Romania);
- Group of Volunteers Against Cancer (Greece);
- Italian Federation of Volunteer-based Cancer Organisations (FAVO) (Italy);
- Italian Association of Cancer Patients, their families and friends (AIMAC) (Italy);
- Pembe Hanim (Turkey);
- APDPROSTATA (Portugal);
- Firefly – Organisation for helping children and families facing malignant diseases (Croatia).

CAPACITY BUILDING

The European Cancer Patient Coalition Annual Meeting

The European Cancer Patient Coalition's Annual Meeting Event was organised under the high patronage of the European Parliament and Her Royal Highness Princess Astrid.

The Annual General Meeting took place in Brussels from the 16th to the 18th of June, when the European Cancer Patient Coalition welcomed more than 180 participants. The event has grown to become the largest gathering of patient organisations in Europe, and in 2017 hosted participants from 141 different organisations, from 42 different countries. Satellite meetings also provided opportunities for the Working Group on Rare Cancers, the Working Group on Bladder Cancer and the Legal Network for Cancer Patients to meet face-to-face.

**"THE EVENT HAS
GROWN TO BECOME
THE LARGEST
GATHERING OF PATIENT
ORGANISATIONS
IN EUROPE"**

The ECPC Annual Congress 2017 included presentations on the European Commission's Cancer Control Joint Action, an introduction to the "European guide on quality improvement", and recommendations on its application at the national level. Another central topic was nutrition –





presenting the results of the European Cancer Patient Coalition's Survey and highlighting the importance of nutritional support for people with cancer. A *Memorandum of Understanding* between the European Cancer Patient Coalition and the European Organisation for Research and Treatment of Cancer was also signed.

The Annual Congress included presentations from the following European Cancer Patient Coalition's Members:

- Alma Zois: Defending the rights of cancer patients in Western Greece;
- Association of Cancer Patients in Finland: Defending the rights of cancer patients – the Finnish way;
- East Galway & Midlands Cancer Support UK: Defending the rights of patients with The Step Study;
- ELLOK: Adopting & transposing ECPC cancer policy at national level in Greece;
- European Lung Foundation: Lung cancer website;

- Italian Glioblastoma Multiforme Group: rare cancers in Italy;
- Karkinaki: Placing childhood cancer care on the map in Greece;
- Lung Cancer Europe: Defending the rights of Lung cancer patients;
- MOHA: How to partner with decision-makers in Hungary?
- Pembe Hanim and Metamazon: solidarity and effective advocacy in Turkey;
- Hope and Life Association: Engaging the public in cancer awareness campaigns in Turkey.

The European Cancer Patient Coalition gratefully acknowledges the support of: AbbVie, Amgen, AstraZeneca, Boehringer-Ingelheim, Bristol Myers-Squibb, Celgene, Genomic Health, Ipsen, Johnson & Johnson, Eli Lilly & Company, Novartis, Pfizer and Roche. The scope and the content remain the sole responsibility of the European Cancer Patient Coalition.

www.ecpc.org/about-us/annual-general-meetings/agm-2017

Newsletter

The European Cancer Patient Coalition's newsletter is distributed to more than 540 high-level stakeholders and European cancer patient organisations, which are included in the newsletter database. ECPC monitors and analyses what Members find more interesting, which consolidates the understanding of the Membership's needs.

ECPC also provides its stakeholders with more information on policy and advocacy in cancer at the European level. The main objective is to continue raising member organisations' understanding of the complex European public health policy panorama. This serves the double purpose of making the work and achievements in policy better understood, and, most importantly, raise Members' awareness on the impact of European health policies on their life and how they can proactively contribute to the policy work.

The European Cancer Patient Coalition's newsletter summarises the organisation's policy and project

news and initiatives. Some of the initiatives highlighted in the newsletter are carried out by ECPC and some others provide information that the ECPC's Board considers useful for all its Members and stakeholders.

Furthermore, ECPC launched the Quarterly Projects News Updates, a valuable tool for members, partners and stakeholders, providing a summary of ECPC's on-going EU-funded research projects and latest developments. The initiative also includes vital information on EU policies, strategies and funding in health research and innovation.

A strictly dedicated Policy Newsletter was also introduced as an in-depth communication of on-going policy activities and progress within the EU agenda. The European Cancer Patient Coalition gratefully acknowledges the support of Bristol-Myers Squibb and MSD for supporting the Policy Newsletter. The scope and the content remained the sole responsibility of the European Cancer Patient Coalition.

Training the survivors of tomorrow

A life saved from cancer is invaluable. The life of a child saved from cancer is possibly even more precious. For this reason, the European Cancer Patient Coalition grants scholarships to further enrich the life of cancer survivors needing help to continue their education, personal growth and a better, brighter future.

All the European Cancer Patient Coalition's Members (Full and Associate) were eligible to present one candidature. The nominated cancer survivors sent a motivation letter, explaining their

cancer journey, what they learned from their cancer experience, and their plans for the future. The motivation letter was assessed by the European Cancer Patient Coalition Board.

The European Cancer Patient Coalition gratefully acknowledges the support of Genomic Health and Inside Link for providing these scholarships.

Winners of the scholarship in 2017:

- Martin Tomik, Turkey
- Eleni Dimitra, Greece

JOINT ACTIONS

Joint Action on Cancer Control



The Joint Action on Cancer Control is a common effort between representatives from 17 European Union Member States, co-funded by the European Commission (Directorate-General for Health and Food Safety).

On the 14th and 15th of February, the new "European Guide on Quality Improvement in Comprehensive Cancer Control" was presented during the final conference of the Joint Action on Cancer Control (CanCon), in Malta. ECPC was a key partner, involved with CanCon from the beginning and contributed to the content of the guide and of the policy papers.

The European Guide on Quality Improvement in Comprehensive Cancer Control presents key recommendations to improve European countries' efforts to fight cancer. The recommendations span the whole patient journey from prevention to treatment of cancer and survivorship. The Guide explains in detail in which measure European

governments should implement to make National Cancer Control Plans more resilient and effective, focusing on the key aspects of cancer care: integrated cancer control, community-level cancer control, survivorship and rehabilitation, and screening.

Together with the Guide, CanCon produced five policy papers related to the hot topics of cancer policy with the support of high-level European experts.

ECPC was a co-author on the Chapter on "Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States", the Policy Paper on "Tackling Social Inequalities in Cancer Prevention and Control for the European Population", and the Policy Paper on "Enhancing the Value of Cancer Care Through a More Appropriate Use of Healthcare Interventions". ECPC will also be a partner in the Innovative Partnership Action Against Cancer, which will be launched in 2018.

www.cancercontrol.eu

Joint Action on Rare Cancers



The Joint Action on Rare Cancers (JARC) is a crucial game changer for rare cancer patients in Europe as it aims to advance quality of care and research on rare cancers.

The European Cancer Patient Coalition (ECPC) represents the voice of rare cancer patients within the JARC and is actively contributing across all Work Packages (WPs).

Following a request from several rare cancer patient representatives at the ECPC Annual Meeting in 2016, ECPC formally established a Working Group on Rare Cancers (WGRC) which works in parallel

with JARC to amplify and support JARC activities at the national level to lay the ground for the development of the European Reference Networks (ERNs).

The Working Group on Rare Cancers guarantees that a large number of rare-cancer patients' organisations, representing different European countries and rare cancer types, are able to contribute to the activities of the Joint Action on Rare Cancers. The key objective of the Working Group on Rare Cancers is to provide ECPC's Members and non-Members with an interest in rare cancers with the opportunity to contribute to the work of the Joint Action on Rare Cancers.

Every ECPC Member (Full and Associate) and non-Member active in rare cancers can join the Working Group on Rare Cancers. The following Members of the European Cancer Patient Coalition are part of the Working Group on Rare Cancers:

- Aivolisäke-potilasyhdistys Sella ry
- Asociación de Afectados pops Tumores Cerebrales en Espana
- Asociación de Pacientes con Tumores Raros de España
- Asociación Española de Afectados por Sarcomas
- Asociación Española de Cancer de Tiroides
- Asociația Pacienților cu Neoplazii Mieloproliferative
- Ass. Italiana Largectomees
- Associação Portuguesa Contra a Leucemia
- Association contre les maladies rares du péritoine
- Association des Patients porteurs de Tumeurs Endocrines Diverses
- Association of Cancer-Volunteers-Friends-Doctors "Smile of the Child" Athens
- Associazione Italiana GIST Onlus
- Bulgarian Association for Patients' Defense
- Bulgarsko Sdruzhenie Limfom
- CARITA 'To live with Multiple Myeloma'
- Slainte an Chlair
- Contactgroep GIST
- Društvo onkoloških bolnikov Slovenije
- Sarcoma Ireland
- El Grupo Español de Pacientes con Cáncer
- European Cancer Patient Coalition, Diagnosa Leukemie
- European Lung Foundation
- Everything for Her
- Fondazione Instituto Nazionale dei Tumori di Milano
- Glioblastome Multiforme – Cancro al Cervello
- Group of Volunteers Against Cancer
- Gynsam Sweden
- Hoved hal scancer
- International Neuroendocrine Cancer Alliance
- Italian Federation of H&N Advocacy Groups
- Lithuanian Cancer Patient Coalition
- Magnolia – Stowarzyszenie kobiet z problemami onkologiczno
- Mouth, Head and Neck Cancer
- Myeloma Euronet Romania
- Myeloma Patients Aid Association
- NET Patient Foundation
- NET-groep
- Netzwerk Neuroendokrine Tumoren e.V.
- Patientforening for Lymfekræft og Leukæmi
- Patients Aid Association for Sarcoma
- Patients with GIST Aid Association
- Pembe Hanım
- Plattform Hodenkrebs Austria
- Polish Cancer Patient Coalition
- Primind Ajutor, Viata Este Luminoasă
- Pseudomyxoma Survivor
- Romanian GIST Network – Extended to sarcoma patients
- Romanian Leukemia Association
- Community Health
- Sarcoma Ireland
- Slainte an Chlair
- Stichting Hematon
- Stichting OLIJF
- The Brain Tumour Charity
- The Cholangiocarcinoma Charity
- The Cyprus Association of Cancer Patients and Friends
- The Nationwide Association of CML Patients Aid
- Thyroid Bulgaria
- Vereniging Cerebraal
- Vivere la Speranza – Amici di Emanuele Cicio ONLUS
- VulvaKarzinom Selbsthilfegruppe e.V.

European Reference Network-EURACAN



The European Reference Networks (ERNs) are virtual networks connecting healthcare providers and centres across Europe. They aim to improve access to diagnosis, treatment and the provision of high-quality healthcare for people with complex or rare diseases that require specific knowledge and resources.

ERN-EURACAN is the European Reference Network for rare adult solid cancer gathering European centres active in the field of rare cancers. It groups rare cancers in 10 domains corresponding to the RARECARE classification and the ICD10 (International Statistical Classification of Diseases and Related Health Problems).

The European Cancer Patient Coalition is an elected European Patient Advocacy Group (ePAG) Member and is a Co-Lead in the Transversal Taskforce on Dissemination and Communication.

The first European Reference Networks (ERNs) were launched in March 2017, involving more than 900 highly specialised healthcare units from over 300 hospitals in 26 Member States. The initially established 24 ERNs work on a range of issues including bone disorders, childhood cancer and immunodeficiency.

These are not directly accessible to individual patients. However, with the patients' consent and in accordance with the rules of their national health system, the patients can be referred to the relevant European Reference Network member in their country by their healthcare provider.

The European Reference Networks (ERNs) must generally comply with the following criteria:

- apply European criteria to tackle rare diseases requiring specialised care;
- serve as research and knowledge centres treating people from other European countries;
- ensure the availability of treatment facilities where necessary.

EURACAN is one of the 24 European Reference Networks approved by the European Reference Network Board of Member States. The European Reference Networks are supported by the European Commission.



euracan.ern-net.eu

AWARENESS AND EDUCATION

Immuno-Oncology Portal



The European Cancer Patient Coalition's Immuno-Oncology platform is Europe's first information hub on cancer immuno-therapies, produced by people with cancer for people with cancer. The Immuno-Oncology Portal aims to inform and educate people with cancer on cancer immuno-therapies, explaining in detail what they are and how they work to treat cancer.

Since its launch in 2015, the Immuno-Oncology Portal has collected thousands of page hits, affirming itself as one of the ECPC website's most viewed pages. It provides people affected by cancer with up-to-date, accessible information about cancer immuno-oncology therapies – treatments, which use the immune system to fight cancer. These treatments represent a "break-through" in cancer therapy and they have the potential to revolutionise the way many forms of cancer are treated. In 2017, ECPC added two new sections to the Portal, one on "Authorisation" and one on "Availability" of immune-therapies for cancer in European countries. There is also the "European Cancer Patient Coalition's Guide for Patients on Immuno-Oncology", available in 21 languages.

The Immuno-Oncology Portal was presented to the European Parliament in Brussels, as well as to national stakeholders, in collaboration with the following ECPC Members:

- Italian Federation of Cancer Patients Organisations (Italy);
- Hellenic Cancer Federation- ELL.O.K. (Greece);
- Diagnóza Leukemie (Czech Republic);
- Polish Cancer Patient Coalition (Poland);
- The Brain Tumour Charity (UK).

The Immuno-Oncology Portal is available in English, Italian, Polish, Greek, and Spanish at: iop.ecpc.org

The European Cancer Patient Coalition gratefully acknowledges the support of AstraZeneca, Bristol-Myers Squibb, MSD, Merck, Pfizer, Roche, and CDDF in producing the Immuno-Oncology Portal. The scope and the content of the portal are the sole responsibility of the European Cancer Patient Coalition.

CARE IS PARTICIPATION

12 April 2018 - LUISS University, Rome, Italy

- Presentation of the ECPC report "Value of Innovation" and the Immuno-Oncology Portal
- Session: What Do We Mean by Patient-Centricity?
- Session: Digital-Enabled, Patient-Centered Innovation: Overview and Dynamics

ECPC members represented: © F.A.V.O., © AIMAC and © AILAR. This event was supported by BMS, Merck and Pfizer.

ECPC IMMUNO-ONCOLOGY PORTAL GOOGLE ANALYTICS DATA

Language	Total Page Hits
English	32,335
Polish	4,441
Spanish	2,104
Italian	12,825
Greek	5,503

National events, where the Immuno-Oncology Portal was presented in collaboration with ECPC Members

EUROPEAN ALLIANCE FOR PERSONALISED MEDICINE (EAPM) CONGRESS SESSION: IMMUNE-ONCOLOGY AND THE VALUE OF INNOVATION FROM THE CANCER PATIENT PERSPECTIVE

30 November 2017
Belfast, UK

The Value of Innovation from the Cancer Patient Perspective

➔ European Cancer Patient Coalition, Belgium

Access to Immuno-Oncology and other Innovations for People with Cancer in the United Kingdom

➔ Brain Tumour Charity, UK

Current and Developing Innovation in Colorectal Cancer

➔ University of Surrey, UK

Addressing the Europe of Disparities in Cancer

➔ Queen's University Belfast, UK

The Cancer Innovation Challenge

➔ The Data Lab, UK

Panel Discussion with key stakeholders

This event was supported by BMS, Merck, and Pfizer.

PREVENTION – INNOVATION – LIFE ONCOLOGY 2018 PRESS EVENT

21 November 2017
Warsaw, Poland

Presentation of the ECPC report “Value of Innovation” and Introduction of the Immuno-Oncology Portal and its development

The role of primary and secondary prevention in oncology – Research saves lives – Early detection is life

From prevention to treatment – Key aspects of improving the quality of oncological care in Poland

ORGANISATIONS REPRESENTED:

- ➔ European Cancer Patient Coalition
- ➔ Polish Society for Research on Breast Cancer
- ➔ International Senological Society
- ➔ Polish Cancer Patient Coalition

This event was supported by BMS, Merck, and Pfizer.

Merkel Cell Carcinoma

Merkel cell carcinoma is an aggressive form of skin cancer and its incidence rate has tripled from 1986 to 2001. Merkel cell carcinomas may be curable when detected and treated at an early stage with either surgery or radiotherapy, but since they are usually aggressive and advance quickly with high chances of local and distant recurrence, early detection and removal are crucial.

The European Cancer Patient Coalition dedicated a section of its website to Merkel Cell Carcinoma, to provide informational and educational material on this form of cancer, on the available treatments and on the great importance of early diagnosis. For this purpose, ECPC adapted information which was originally produced by The Skin Cancer Foundation.

ECPC also had all the informational material on Merkel Cell Carcinoma translated in several European languages, to make the informative webpages available in English, Dutch, Spanish, French, Swedish, Italian, German and Danish.



The educational section of the ECPC website on Merkel Cell Carcinoma also includes a printable educational leaflet, which is available in all above-mentioned languages. Additionally, the leaflet in English and French language was printed and disseminated at the ECPC Annual Meeting 2017 and at the other main events organised and attended by ECPC.

The European Cancer Patient Coalition gratefully acknowledges the support of Merck and Pfizer in producing the informational material on Merkel Cell Carcinoma. The scope and the content of the portal are the sole responsibility of the European Cancer Patient Coalition.

www.ecpc.org/mcc

GOOGLE ANALYTICS DATA ON MERKEL CELL CARCINOMA

Language	Total Page Hits	Avg. Time on Page
English	5,876	19:15 minutes
Dutch	548	11:46 minutes
Spanish	455	21:17 minutes
French	747	29:23 minutes
Swedish	903	19:22 minutes
Italian	1,548	28:44 minutes
German	519	44:12 minutes
Danish	705	16:04 minutes

Bladder Cancer

SURVEY ON BLADDER CANCER PATIENTS' EXPERIENCE

The European Cancer Patient Coalition continued to focus on bladder cancer in 2017, as it still is a neglected cancer. The ECPC Bladder Cancer Working Group conducted a Pan-European patient-experience survey. The survey was trans-

lated into Dutch, Finnish, French, Greek, Italian, Norwegian, Polish, and Spanish, and gathered over one thousand responses from people affected by bladder cancer and from people who assist them.

BLADDER CANCER AWARENESS MONTH

The month of May is the "Bladder Cancer Awareness Month". ECPC shared facts, statistics, risk factors and symptoms on social media. A Bladder Cancer Awareness Month Toolkit was also created to help Members coordinate activities and maximise the power of social media. The Bladder Cancer social media Thunderclap was released with a social reach of 336,262 people. On the last Sunday of May, ECPC also supported "Bubbles for Bladder Cancer", an initiative started by Fight Bladder Cancer.

The Bladder Cancer Awareness Campaign was supported and amplified by the following ECPC Members:

- Italian Federation of Cancer Patients Organisations (Italy);
- Bladder Cancer Italy – PaLiNuRo (Italy);
- Hellenic Cancer Federation – ELL.O.K. (Greece);
- Cancer Survivors Organisation (Romania);
- Living with Bladder or Kidney Cancer (Netherlands);
- Bladder Cancer Canada (Canada);
- Association of Cancer Patients in Finland (Finland);
- Spanish Association of Cancer Patients – GEPAC (Spain);
- Bladder Cancer Norway (Norway);
- Polish Cancer Patient Coalition (Poland);
- The Brain Tumour Charity (UK);
- Cancer Survivors Association (Turkey).



ECPC gratefully acknowledges the support of AstraZeneca, Ipsen and Roche. The scope and the content are the sole responsibility of the European Cancer Patient Coalition.

Educational material on bladder cancer is available in English at:

www.ecpc.org/edu/bladder

The White Paper on Bladder Cancer is available in English, Italian and Turkish at:

ecpc.org/activities/policy-and-advocacy/policy-initiatives/bladder-cancer

World Cancer Day

World Cancer Day occurs on the 4th of February, it is promoted by The Union for International Cancer Control (UICC) and takes place under the tag-line "We can. I can.", exploring how everyone can do their part to reduce the global burden of cancer.

ECPC promoted the World Cancer Day's messages in multiple European languages and joined the "Talking Hands" campaign on Twitter and Facebook. ECPC also joined the World Cancer Day Thunderclap initiative on Twitter and promoted World Cancer Day in the News section of the ECPC website.



Make Sense of Head and Neck Cancer

The European Cancer Patient Coalition continued its partnership with the European Head and Neck Society to deliver the Make Sense Campaign, to place head and neck cancers higher up on the agenda of European healthcare.

The Make Sense Campaign took place from the 18th to the 22nd of September, the theme was "Supporting Survivorship", and its activities focused on improving the lives of head & neck cancer survivors. ECPC organised a lunch event at the European Parliament, hosted by Lieve Wierinck MEP (Alliance of Liberals and Democrats for Europe, Belgium) to promote better quality of life for people with cancer and cancer-survivors. During the event, top experts in the field of public health and patient advocates noted that survivorship requires a collaborative approach from people with cancer and healthcare professionals.

The campaign was supported and amplified by the following ECPC Members:

- Diagnoza Leukemie (Czech Republic);
- Hellenic Cancer Federation – ELL.O.K. (Greece);
- Plymouth Head and Neck (United Kingdom);
- Travail & Cancer (Belgium).

ECPC gratefully acknowledges the support of Merck. The scope and responsibility remain the sole responsibility of the European Cancer Patient Coalition.

makesensecampaign.eu



European Prostate Cancer Awareness Day



European Prostate Awareness Day takes place on the 27th of September. In 2017, ECPC collaborated with the International Society of Urology, the European Association of Urology and Europa Uomo (the European Prostate Cancer Coalition) to promote the "European Prostate Cancer Awareness Day". At the European Prostate Cancer Awareness Day event, policy makers, scientific experts, European associations working in the

urological field and representatives of European patient groups with an interest in prostate disease gathered together at the European Parliament, in Brussels.

This event aimed at raised awareness, understanding and knowledge on the management of prostate cancer and called on the European Commission and other European institutions to raise awareness about this form of cancer and about what can be done at the European level to support positive change.

epad.uroweb.org

Cancer Associated Thrombosis



World Thrombosis Day is on the 13th of October and focuses attention on the condition of thrombosis. World Thrombosis Day seeks to increase global awareness on thrombosis, including its causes, risk factors, signs and symptoms.

Cancer-Associated Thrombosis is linked with poor prognosis, and it is the second leading cause of death among people with cancer. People diagnosed with cancer should be aware that minor lifestyle changes can make a difference in decreasing the risk of Cancer-Associated Thrombosis. They can increase their levels of physical activity, quit smoking, and stay hydrated. Cancer-Associated Thrombosis needs to be made a priority issue for health professionals and policy-makers. Investing in prevention, early diagnosis and timely treatment of Cancer-Associated Thrombosis has the potential to save many lives and healthcare resources.

ECPC shared social media messages and collaborated with EurActiv to publish an article on thrombosis. Educational material on Cancer-Associated Thrombosis (CAT) for people with cancer was also produced and disseminated in different languages, including English, French, German, Greek, Portuguese and Spanish.

The work of ECPC on Cancer Associated Thrombosis (CAT) was supported by the following ECPC Members:

- Spanish Association of Cancer Patients – GEPAC (Spain);
- Society of Cancer Patients of Athens – KEFI (Greece);
- Hellenic Cancer Federation- ELL.O.K. (Greece).

The European Cancer Patient Coalition gratefully acknowledges the support of LEO Pharma. The scope and the content remain the sole responsibility of the European Cancer Patient Coalition.

www.ecpc.org/edu/thrombosis

Pancreatic Cancer

WORLD PANCREATIC CANCER DAY



The 16th of November is dedicated to pancreatic cancer. ECPC is a member of the World Pancreatic Cancer Coalition, which coordinates the World Pancreatic Cancer Day: "a Day of action, a world of

difference". On this day people come together to bring attention to pancreatic cancer and highlight the need for greater awareness, funding and research, to reach better outcomes for patients affected by this form of cancer.

ECPC developed a social media calendar with proactive messages on and around the World Pancreatic Cancer Day, shared material on the "news" section of the ECPC website, joined the global Thunderclap organised on Twitter and published the *World Pancreatic Cancer Report*.

PANCREATIC CANCER EUROPE

Pancreatic Cancer Europe (PCE) is a multi-stakeholder platform which includes experts, cancer patients, policy makers and industry.

It is composed by 40 national and European stakeholders and championed by three Members of the European Parliament: Françoise Grossetête (European People's Party France), Philippe Juvin (European People's Party, France) and Daciana Octavia Sârbu (Progressive Alliance of Socialists and Democrats, Romania).

The goal of the Platform is to ensure that pancreatic cancer is no longer a neglected cancer, through the creation and distribution of information material targeted at the public, medical professionals and policy makers.

ECPC Members involved in Pancreatic Cancer Europe:

- Europa Colon (Europe);
- Hellenic Cancer Federation- ELL.O.K. (Greece);
- Irish Cancer Society (Ireland);
- Italian Federation of Volunteer-based cancer organisations (FAVO);
- Lithuanian Cancer Patient Coalition (Lithuania);
- Pancreatic Cancer Action (UK);
- Polish Cancer Patient Coalition (Poland);
- Society of Cancer Patients of Athens – KEFI (Greece);
- Spanish Association of Cancer Patients – GEPAC (Spain).

The European Cancer Patient Coalition gratefully acknowledges Celgene's support for the activities related to pancreatic cancer. The scope and the content remain the sole responsibility of the European Cancer Patient Coalition.

www.ecpc.org/edu/pancreas

Cancer Biomarkers in the Era of Personalised Medicines

Cancer biomarkers are proteins, or other biological substances or processes, that provide information about the presence and activity of cancer in the body. They are usually detected in blood or urine, and are used to diagnose early-stage cancers, to improve the accuracy of prognosis and to predict how well a person will respond to treatment. Cancer biomarkers can also be used to select those cancer patients who are most likely to derive therapeutic benefit from chemotherapy, immuno-oncology therapy, surgery, or radiotherapy. In fact, biomarkers are essential to identify the "Achilles' heel" of the tumour, which doctors can target with specific drugs. In short, biomarkers help to identify those patients who may benefit from different types of cancer treatment, ensure sustainable healthcare systems and avoid treatment-related toxicity.

Marlene Mizzi MEP (Progressive Alliance of Socialists and Democrats, Malta) hosted an event in the European Parliament on the important topic

of Cancer Biomarkers in the Era of Personalised Medicines. At the event, ECPC encouraged action for increased access to biomarkers, while raising awareness on the topic and increasing patients' understanding of where they need to go to access molecular testing and other types of biomarkers. During the event, ECPC Member Europa Donna Malta, highlighted the vital role that cancer biomarkers play in improving cancer care throughout Europe. ECPC also launched a video animation on cancer biomarkers in Europe, which is available on the ECPC website.

The European Cancer Patient Coalition gratefully acknowledges the support of AstraZeneca, Merck and MSD. The scope and the content remain the sole responsibility of the European Cancer Patient Coalition.



RESEARCH

Nutrition in cancer care



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

The European Society of Medical Oncology (ESMO) 2017 Congress was hosted in Madrid and attracted nearly 24,000 participants from 131 countries where ECPC presented Poster #1450P. This European survey of 907 people with cancer about the importance of nutrition was also published as a supplement to the "Annals of Oncology" as Abstract #3714, and was summarised in a manuscript that was submitted to a peer-reviewed journal for publication. The study findings demonstrated a substantial need for more information and practical management of cancer-related nutritional problems for cancer patients.

In November 2017, Daciana Octavia Sârbu MEP (Progressive Alliance of Socialists and Democrats, Romania) hosted an event at the European Parliament on "the Role of Nutrition in Cancer Care". The discussion focused on the results of a study conducted by ECPC, Sapienza University of Rome and Healthware International, which analysed the importance of nutrition for people with cancer.

The event at the European Parliament also witnessed the launch of a Nutrition Consultation Document, which will be adapted to the Living Well During Cancer Treatment booklet. This booklet includes the results from the survey on the crucial role of nutrition in cancer care, together with questions that patients' can ask to their oncologists, and a Cancer Patient's Charter of Rights for Appropriate and Prompt Nutritional Support.

ECPC Members involved in developing the survey and booklet on cancer and nutrition include:

- Diagnoza Leukemie (Czech Republic);
- Hellenic Cancer Federation- ELL.O.K. (Greece);
- HungerNdThirst Foundation (Netherlands);
- Italian Federation of Volunteer-based Cancer Organisations (FAVO) (Italy);
- Les Amis de l'Institut Bordet (Belgium);
- Sláinte an Chláir, Clare Cancer Support (Ireland).

The European Cancer Patient Coalition gratefully acknowledges the support of Helsinn and Baxter. The scope and the content remain the sole responsibility of the European Cancer Patient Coalition.

www.ecpc.org/edu/nutrition

Innovative Medicines Initiative (IMI)

PREFER PATIENT PREFERENCES



Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) is a five-year project funded by the European Commission's Innovative Medicines Initiative (IMI) 2 programme to evaluate different ways of assessing clinical patients' preferences. The project aims to establish recommendations to support the development of guidelines for industry, regulatory authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products. The research project runs from October 2016 to September 2021.

Over this period, patient preferences will be studied both from the academia and industry's points of view. This project will provide a better understanding of recommended best-practice approaches to patient-preference studies.

The project will also show how patient preference studies can give valuable information to support decision-making for regulators and HTA bodies.

PREFER is divided into four work packages. The "Methodology Work Package" focuses on stakeholders' concerns around the use of patient-preference studies. Based on what they find, they make recommendations about what methodologies to use in case studies that the

"Case Study Work Package" will design and implement. After evaluating the case studies, the "Recommendations Work Package" takes over to draft recommendations based on the work. Finally, the "Management Work Package" then ensures that the work is completed in a timely manner.

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

Uppsala University and Novartis lead "Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER)" under the Innovative Medicines Initiative 2 Joint Undertaking. IMI is a partnership between the European Union's Horizon 2020 programme and the European pharmaceutical industry (represented by EFPIA, the European Federation of Pharmaceutical Industries and Associations).

The PREFER project is funded by the Innovative Medicines Initiative (IMI): a part of the European Union Horizon 2020 Programme, Grant Agreement No.115966.

www.imi-prefer.eu



DO-IT BIG DATA FOR BETTER OUTCOMES (BD4BO)



Big Data for Better Outcomes is a programme funded by the European Commission's Innovative Medicines Initiative (IMI) 2 programme, launched to facilitate the transition towards outcomes-focused healthcare systems across Europe.

From 2017 to 2019, the Big Data for Better Outcomes, Policy Innovation, and Healthcare Systems Transformation (BD4BO-DO>IT) consortium will coordinate the IMI 2 Big Data for Better Outcomes (BD4BO) programme, identifying and addressing opportunities for data-driven healthcare system transformation based on input from healthcare systems stakeholders and on knowledge developed in the BD4BO disease specific projects: Alzheimer's Disease, hematologic malignancies, cardiovascular diseases and prostate cancer.

To fully benefit from the transformative potential of big data in healthcare, the detailed personal and biological information available in existing databases needs to be considered from the point of view of care-delivery, from the development of innovative medicines and treatments to market access, adoption and use within healthcare systems.

DO-IT will act as a Coordination and Support Action for the BD4BO programme, realising synergies across disease specific projects and maximising

impact on European healthcare systems. The project will in particular: aggregate learnings and disseminate findings from the Big Data for Better Outcomes projects on methods of selecting and measuring outcomes in real world settings, develop minimum data privacy standards for the collection, use, storage and transfer of clinical and biological data, engage with key stakeholders to understand value and limitations of outcomes based approaches, recommend areas for future collaborative research to address gaps in standards, methodologies and tools, among others.

The European Cancer Patient Coalition is collaborating with European expert patient groups to develop informed consent forms, minimum data privacy standards, and supporting materials for the BD4BO overarching projects. ECPC is participating in compiling concise and comprehensive educational material which will provide European patients with the basic knowledge to understand the importance and power of clinical trials, bio banking, and exploratory research. ECPC is also contributing to the overall internal and external communication and dissemination the project's deliverables.

BD4BO-DO>IT is funded by the Innovative Medicines Initiative (IMI): a part of the European Union Horizon 2020 Programme, Grant Agreement No. 116055.

www.bd4bo.eu



Horizon 2020

TRANSCAN-2



Aligning national/regional and translational cancer research programmes and activities (TRANSCAN-2) is the continuation of the previous ERA-NET programme on translational cancer research TRANSCAN. TRANSCAN-2 is a collaborative network of ministries, funding agencies and research councils with programmes in translational cancer research. The network is composed of 28 partners from 19 countries and runs during the period 2015-2019.

The project links translational cancer research funding programmes among the partners, most of which also took part in the previous TRANSCAN

project. This model allows an efficient use of the dedicated national resources and the coordination of the financial management of multinational research projects aiming to harmonising administrative procedures as much as possible.

The European Cancer Patient Coalition is represented in the Scientific Advisory Board, which serves as a source of input and feedback about the work of TRANSCAN-2 and collaborates closely with the Network Steering Committee and the Network Coordination Unit.



TRANSCAN-2 is funded by Horizon 2020: the European Union Framework for Programme for Research and Innovation, Grant Agreement No.643638.

www.transcanfp7.eu

DENIM H2020MM⁰⁴ (MESOTHELIOMA)



DENIM is an abbreviation of "Dendritic cell Immunotherapy for Mesothelioma". Malignant pleural mesothelioma is a rare but highly aggressive cancer that kills about 43,000 people worldwide every year. Unfortunately, there is no therapy for mesothelioma, which makes it a highly fatal disease. Thus, there is a clear unmet medical need on the treatment of mesothelioma. The main objective of the project is to demonstrate the efficacy of dendritic cell-based immunotherapy in a randomised phase II/III clinical trial, to address this urgent need. This could potentially lead to a cure of asbestos-exposed workers, consumers and people with cancer. The project runs during the period 2016 -2019.

The European Cancer Patient Coalition (ECPC) ensures the project's compliance with the needs of the people with cancer and is involved in the work package responsible for the effective dissemination of the project news and results among external stakeholders.

ECPC also shares news and results related to the project to all its Members through the monthly newsletter, the website and social media platforms.



This project received funding from the European Union's Horizon 2020 research and innovation programme, grant agreement No.668769

www.denimstudy.eu

IMMUNISA

Cervical cancer is caused by high risk subtypes of the human papillomavirus. Once infected, prophylactic vaccines no longer prevent the development of cervical cancer, which can only be treated with surgery, chemotherapy or radiotherapy. The need for an effective therapy to treat recurrent and metastatic cervical cancer is extremely high. Targeted immunotherapy is an effective approach to induce a tumour directed immune response. This response can be induced with a vaccine that mediates expression of immunogenic antigens by dendritic cells, which in turn cause a strong T-cell mediated immune response directed towards diseased cells with similar antigens.

IMMUNISA proposes the use immunotherapeutic platform of Synthetic Long Peptides to mediate dendritic cell antigen expression, resulting in robust T-cell responses against the cancer. In a

multi-centre randomised Phase II clinical trial, IMMUNISA will investigate if a vaccine in combination with chemotherapy can prolong the progression free survival rate of people with cervical cancer. The project will run from 2017 to 2021.

The European Cancer Patient Coalition (ECPC) is ensuring the project's compliance with the needs of the people with cancer and is involved in project management and dissemination. ECPC also promotes project findings to all its Members through its newsletter, the website and social media platform.



IMMUNISA is funded by Horizon 2020: the European Union Framework Programme for Research and Innovation.

IMMUNOSABR



ImmunoSABR is a phase II clinical trial which aims to test if the combination of Stereotactic Body Radiation Therapy and L19-IL2 immuno-oncology therapy improves the progression-free survival rate in people with limited metastatic non-small cell lung cancer. The research project runs from 2017 to 2022.

The ImmunoSABR clinical trial's goal is to find better approaches to the treatment of metastatic cancer. In this randomised and open label phase II clinical trial, stereotactic ablative radiotherapy is combined with L19-IL2 immuno-oncology therapy in people with limited metastatic non-small cell lung cancer. ImmunoSABR also uses cancer biomarkers to develop a way to predict which people will benefit the most.

ECPC, as part of the consortium to represent the voice of the European cancer patients, organised a patient consultation session to discuss the ImmunoSABR trial, providing a platform for panel discussions with patients regarding clinical trial design. ECPC will also give input into the development of the informed consent forms and the patient information brochure. In addition, ECPC will convey information about the ImmunoSABR trial to its own network, all other relevant European patient organisations, and the general public. Finally, ECPC will ensure the dissemination of project results by coordinating an end-of project transnational meeting to be hosted at the European Parliament.



ImmunoSABR is funded by Horizon 2020: the European Union Framework for Programme for research and Innovation, Project No. 733008.

www.immunosabr.info

7th Framework Programme

ESMART



The e-Symptom Management using Advanced Symptom Management System Remote Technology (eSMART) is funded by the European Commission's Seventh Framework Programme. The clinical trial evaluates the impact of a mobile phone-based, remote monitoring, symptom management intervention (Advanced Symptom Management System, ASyMS) on Patient Reported Outcomes and the delivery of care to people diagnosed with non-metastatic breast, colorectal or hematological cancer receiving first line chemotherapy and for one year after treatment.

eSMART is coordinated by the University of Strathclyde and involves 10 world-renowned European and one American partners, among them seven Universities, University medical centres and a technology companies. This research project runs from 2014 to 2019.

The eSMART project demonstrates how technology can be useful in developing tools to deliver patient-focused and anticipatory care which improves the outcomes and quality of life for people with cancer. Furthermore, this research

project demonstrates the effects of a real-time, mobile phone based, remote patient monitoring and care. The interventions address key cancer patient symptoms and cancer care results, but also the delivery of care during and after chemotherapy. The remote patient-monitoring system via mobile phone, called Advanced Symptom Management System (ASyMS), helps people with cancer in reducing the burden of symptoms experienced during chemotherapy and improve their quality of life during acute treatment and survivorship. Most important, the project's results will facilitate improvements in clinical practice and lead to improved delivery in cancer care.

People with cancer have a prominent co-researcher role in eSMART and participate in all the project's activities, from concept to implementation. ECPC, in its patient representative role, participates equally with other researches within the eSMART Project Technical Management Board, the Publications Committee and the Exploitation Committee, offering advice and feedback to ensure that the trial is designed and conducted in compliance with patients' needs and preferences.



eSMART is funded by the **Seventh Framework Program (FP7)**: the European Union's Research and Innovation for 2007-2013, Project No.602289.

esmart.cis.strath.ac.uk

PATIENT ADVISORY ROLES

European Medicines Agency



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

The European Medicines Agency is responsible for the scientific evaluation of medicines developed by pharmaceutical companies which are to be used in the European Union.

The Patients and Consumers' Working Party is the main patients' working group within the European Medicines Agency and the Committee for Medicinal Products for Human Use. The role of the Patients and Consumers' Working Party is to advise, initiate discussion and propose solutions to all important matters related to medicines' authorisation and safety, but also to educate patients about the medicines which they use.

ECPC, as accredited member of the Patients' and Consumers' Working Party, expresses the views of people with cancer. The Patients and Consumers' Working Party meetings focused on the European Medicines Agency's Annual Report, its interactions

with patients, consumers, healthcare professionals and their organisations, its work plans for the future and the outcome of the European Antibiotic Awareness Day. The meetings also provided updates on topics such as biosimilars, the 10-year report on conditional marketing authorisations, regulators' and health technology assessment bodies' related activities and feedback from the scientific committees.

Representatives from ECPC work with the EMA to improve pharmacovigilance and implement European regulations on clinical trials. The EMA has also asked ECPC to be a co-author on the EMA paper on "The increasing importance of the patients' voice in the development of innovative medicines", which will be published in 2018.

European Society for Medical Oncology (ESMO) – Patient Advocates Working Group



The European Society for Medical Oncology (ESMO) is one of the leading European professional organisation for medical oncology. ECPC and ESMO have a long-standing history of collaboration.

ECPC is represented within the ESMO Patient Advocates Working Group, which is responsible for the optimisation of 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 Patient Advocates Working Group's main activities and responsibilities are:

- Providing adequate information about cancer, its diagnosis, treatment, palliative care and aftercare;
- Organising meetings, where patients' organisations and individuals can express their wishes, concerns and requests;

- Interacting with patients to share concerns, experiences, and developing action plans for strengthening the role of patients in the oncology community;
- Helping physicians and other healthcare providers to understand the specific needs of individual patients, to enhance the quality of the communications and personal interactions;
- Building strong coalitions between patients' representative groups, physicians working in the field of cancer and other healthcare providers, in order to improve the quality of cancer care;
- Assisting physicians in reaching out to specialists for advice when it comes to rare and/or complex cancer cases.
- ESMO and ECPC co-authored two joint statements on the General Data Protection Regulation: "Data protection and health research in the EU: a major step forward, now urgently to reassert" and "Joint ESMO-ECPC Reply to the Article 29 Working Party Consultation on the Guidelines on Consent Under Regulation 2016/679".

ECCO Patient Advocate Committee



The European Cancer Patient Coalition is a member of the European Cancer Organisation's Patient Advisory Committee, which was established to contribute to the European Cancer Congress by

providing patients' perspectives, helping healthcare professionals and all delegates to better understand the "desires" of patients, rather than just their perceived "needs". The Patient Advisory Committee was also in charge of developing the programme of the "Patient Advocacy Track" at the 2017 edition of the European Cancer Congress.

www.ecco-org.eu

Expert Group on Cancer Control

The Expert Group on Cancer Control was established in 2016 and its members include representatives of member states, oncology related scientific societies, cancer patient organisations and civil society representatives.

The Expert Group was established to meet the need for improved coordination among European states on the topic of cancer control. The Expert Group has an advisory role and assists the Commission in the preparation of legal and policy documents, guidelines and recommendations on cancer control and guidelines on cancer data, including epidemiology, cancer screening, quality assurance and information on cancer prevention, clinical cancer research and cross-cutting themes related to cancer.



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

ECPC is a member of the Expert Group on Cancer Control and represents the interests of European with cancer.

Collaboration for Oncology Data in Europe (CODE)



Representatives from ECPC attended stakeholder meetings organised by the Collaboration for Oncology Data in Europe (CODE) on several different occasions in 2017. CODE is supporting the creation of a large-scale Oncology Data Network that will collate comprehensive, up-to-date data

to describe how anti-cancer medicines are used in clinical practice. The technology platform is designed to be able to aggregate data on anti-cancer medicine usage for all forms of cancer, in all patients, and for all treatment centres across Europe who wish to join.

Representatives from ECPC are members of the CODE stakeholder group, and emphasise the importance of improving real-time monitoring of clinical practice while protecting patient privacy.

www.code-cancer.com

All.Can multi-stakeholder initiative



All.Can is an international multi-stakeholder initiative set up to optimise the efficiency of cancer care by focusing on improving outcomes for cancer patients. It was established to create political and public engagement around efficiency improvements in cancer care, and ECPC is one of the founding members of the initiative. The International Brain Tumour Alliance, a Member of ECPC, is also a member of All.Can.

All.Can was launched at the European Parliament in 2016 and over one year it has grown to become an expanding movement with diverse membership.

The All.Can initiative currently has 20 members representing patient organisations, policymakers, healthcare professionals, research and industry. This initiative envisions a world where people with cancer are always at the heart of sustainable care. All.Can includes an extensive research programme, and implements policy engagement activities, in order to facilitate the initiative's mission and vision.

ECPC has been actively involved in All.Can activities throughout the year 2017, including the development and launch of the policy report "Towards sustainable cancer care: Reducing inefficiencies, improving outcomes." The goal of the report is to improve efficiency in cancer care, as a mean to secure better outcomes for people with cancer and to make better use of all available resources as a result. ECPC contributed to the development of the "Patient Survey UK pilot", which will be conducted over 2018 to shed light on patients' experience in their cancer treatments.

www.all-can.org

PARTNERSHIPS

European Society for Medical Oncology

In 2016 the European Cancer Patient Coalition and the European Society for Medical Oncology (ESMO) signed a "Memorandum of Understanding", aiming at enhancing the existing cooperation between the two organisations, increasing the efforts to achieve their common goals and objectives in the field of cancer, and meeting the new needs and new rights of people with cancer across Europe. ECPC and ESMO have collaborated on a large range of key policy issues related to cancer, including the updated version of the ESMO Clinical Practice Guidelines and of the ESMO Handbook on Cancer Survivorship.

ECPC was directly involved in drafting the updates of the new ESMO Clinical Practice Guidelines. The Guidelines are updated regularly by the ESMO



Guidelines Committee and set the standard for best practice in a vast variety of cancers, while representing the most reliable, evidence-based resource to help oncologists in taking practical decisions that affect patients' lives. At the same time, ECPC published on its website the ESMO Guide for Patients, an invaluable source of information, which is often overlooked by those that could benefit the most from it.

www.esmo.org

Union for International Cancer Control (UICC)



The Union for International Cancer Control (UICC) is a membership organisation that exists to help the global health community to accelerate the fight against cancer.

Founded in 1933 and based in Geneva, UICC's growing membership includes more than 900 organisations across 155 countries and collab-

orates with the world's major cancer societies, with ministries of health, research institutes and patient groups.

Together with its Members, key partners, the World Health Organisation, the World Economic Forum and others, UICC is tackling the growing cancer thread on a global scale.

Since 2015 ECPC is a Full Member of UICC and kept close ties with its leadership to identify future areas of collaboration between ECPC and UICC, in Europe and beyond.

www.uicc.org

Organisation for European Cancer Institutes (OECI)



The European Cancer Patient Coalition collaborates with the Organisation for European Cancer Institutes since 2013. In 2015 ECPC and OECI signed an official "Memorandum of Understanding" to seize a long-standing collaboration which marked a milestone in cancer advocacy: Europe's largest cancer patient's association formally joined forces with the organisation which includes the best oncology centres in Europe.

The *Memorandum of Understanding* first foresaw the creation, launch and implementation of a Joint Declaration on Good Relational Practices in Cancer

Care and Research. The Joint Declaration outlined the vision that ECPC and OECI share regarding how patients and cancer centres shall interact to enhance patients' quality of life.

Hospital testimonies, ethical frameworks, patients' charters and policy recommendations never fail to mention the central role of patients. However, in practice, there is little guidance on how to better include patients in the decision-making process which takes place within the hospitals' structure. In 2017, ECPC and OECI launched calls for expression of interest regarding this specific issue.

The implementation of each pilot project is managed by a local Member of ECPC and OECI, under the supervision of both organisations.

www.oeci.eu

European Organisation for Research and Treatment of Cancer (EORTC)



The European Organisation for the Research and Treatment of Cancer (EORTC) is one of the most important academic research institutions in the field of cancer in Europe.

EORTC aims to improve the standards of cancer treatment by testing more effective therapeutic strategies based on drugs, surgery and/or radiotherapy that are already in use.

ECPC and EORTC collaborate on several topics of common interest, ranging from cancer-related policy issues to patients' awareness and empowerment. Every two years, ECPC and EORTC jointly organise the Cancer Clinical research methodology Course for Patient Advocates.

www.eortc.org

European Association of Urology (EAU)



The European Association of Urology (EAU) is the leading authority within Europe on urological practice, research and education. Its mission is to raise the standard level of urological care and to facilitate the continuous development and improvement of urology in Europe and beyond.

The European Association of Urology Patient Information was established in 2012, with the aim to provide patients with reliable information on a

variety of urological diseases based on the latest scientific evidences, expert recommendations and patient's needs.

In 2015, ECPC and EAU started collaborating on the European Association of Urology Patient Information project on Bladder Cancer. This collaboration is based on patients' feedback and is considered an important step forward in the development of patients' information, involving two major players who are responsible for the dissemination of accurate information to people with cancer throughout Europe.

www.uroweb.org

European Alliance for Personalised Medicine (EAPM)



The European Alliance for Personalised Medicine (EAPM) brings together professionals and patient advocacy groups with extensive scientific, clinical, caring and training expertise in Personalised Medicine and diagnostics, as well as leading academic institutions, industry and other expert stakeholders.

The alliance is co-chaired by the former Member of the European Parliament John Bowis and the former European Union Health's Commissioner David Byrne. ECPC is a founding member of the Alliance and a key partner in the its initiatives.

ECPC was responsible for the session on "Value of Innovation from the Cancer Patient Perspective" at the EAPM 2017 congress in Belfast, and is leading the patient track at the EAPM 2018 congress in Milan.

www.euapm.eu

Cancer Drug Development Forum



The Cancer Drug Development Forum's mission is to provide a unique platform to facilitate interactions between all stakeholders (academia, regulatory authorities, policymakers, the pharmaceutical industry and patient advocates) and to ultimately increase efficiency in the development of cancer drugs.

CDDF contributed greatly to the development of one of ECPC's most important projects, the Immuno-Oncology Portal, by providing key funding and expertise.

A representative of the European Cancer Patient Coalition sits in the Board of the Cancer Development Forum.

www.cddf.org

European Society of Surgical Oncology



The European Society of Surgical Oncology, ESSO, was established in 1981 to support its members in advancing the science and practice of surgical oncology for the benefit of cancer patients. ESSO achieves its goals through a range of activities related to education, research and leadership in multidisciplinary care.

According to its vision, ESSO represents the most established cancer treatments and develops standards for the care for cancer patients through its core values as well as its activities in the field of education, homogenisation of skills, quality health-care and, ultimately, qualification.

ESSO contributed to the ECPC document "Living Well with Cancer", and ECPC nominated patient advocates to join the ESSO Patients' Advisory Committee.

www.essoweb.org

Biobanking and BioMolecular resources Research infrastructure



The Biobanking and BioMolecular resources Research infrastructure – European Research Infrastructure Consortium establishes, operates and develops a pan-European distributed research infrastructure of biobanks and biomolecular resources, aiming at facilitating the access to resources as well as facilities, and to support high quality biomolecular and medical research.

The activities of the Biobanking and BioMolecular resources Research infrastructure – European Research Infrastructure Consortium are guided by the following core-values: pan-European in scope, combined with scientific excellence, transparency, openness, responsiveness, ethical awareness, legal compliance and human values.

ECPC is a member of the BBMRI-ERIC Stakeholder Forum. The two organisations are collaborating to translate Italian guidelines for biobanking informed consent to the European level.

Worldwide Innovative Networking Consortium



The Worldwide Innovative Networking (WIN) Consortium in personalised cancer medicine's members include 43 leading organisations representing all stakeholders in the personalised cancer medicine field, covering 20 countries and 4 continents. The shared vision of the Worldwide Innovative Networking Consortium aims to deliver effective and personalised cancer medicine to patients worldwide. The WIN Symposia, held

annually in Paris, gathers leaders representing a breadth of stakeholders from all around the world to learn, share and collaborate. The WIN 2017 Symposium focused on the theme 'Expediting Global Innovation in Precision Cancer Medicine' and was held in Paris, France, from the 26th to the 27th June. The overarching goal of the Symposium was to share information to promote and accelerate cutting-edge investigations and the use of personalised, targeted cancer therapy.

Two representatives from the European Cancer Patient Coalition sit in the General Assembly of the Worldwide Innovative Networking Consortium.



INDUSTRY PARTNERS

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

The European Cancer Patient Coalition is grateful to the following partners that helped to support its advocacy, education and capacity-building activities:

PUBLIC ENTITIES AND NON-PROFIT ORGANISATIONS:



INDUSTRY PARTNERS:



EUROPEAN CANCER PATIENT COALITION INCOME STATEMENT

For the years ending (Dec 31, 2015; Dec 31, 2016; Dec 31, 2017)

Revenue (€)	2015	2016	2017
Grants received			
<i>Industry partners</i>	513.385	492.500	664.100
<i>Non-industry</i>	148.629	100.452	94.510
Other revenue	20.898	14.000	8.400
☛ Total revenues	682.912	606.952	767.010
Expenses (€)			
Payroll/human resources	189.661	212.787	276.934
• Employer contributions	60.692	95.342	127.493
• Net salaries	104.314	117.445	149.446
Running costs	69.809	69.111	71.099
• Office rent and maintenance	40.127	37.041	42.169
• Energy consumption	1.524	1.333	1.384
• Office supplies	2.351	2.535	2.414
• IT maintenance and costs	4.908	3.364	4.202
• Telephone and internet	3.062	5.983	4.851
• Website costs	2.003	1.300	in projects
• Fee subscriptions	2.504	1.934	2.379
• Other office costs (printing, coffee machine, postage, etc.)	3.645	1.053	2.678
• Exceptional costs made in order to transfer ECPC from NL to BE	9.685	5.179	
• Legal / Notary costs			3.400
• IT investment		9.390	6.691
• Bank costs			429
• Insurance costs			501
Board	28.037	25.648	24.790
• Board travel	10.066	20.449	18.895
• Board travel advocacy	11.740	5.199	5.895
Awareness	62.663	89.398	12.012
EORTC		21.372	12.012
Waldesian Church Project		27.941	
Advocacy	41.862	36.961	89.210
• Advocacy	31.445	30.445	6.000
• Staff travels advocacy	6.897	6.516	in projects
• EU lobby for policy	3.520		n/a
Immuno-Oncology		40.085	13.239
Bladder Cancer			6.622
Biomarker Campaign			6.911
Value of Innovation in Oncology			7.180
Merkel Cell			8.021
World Cancer Day			2.180
Nutrition			10.973
Pancreatic Cancer			2.320
HTA Policy			7.584
Policy, other			18.180
Capacity building	80.325	97.615	107.569
ECPC Annual Meeting 2017	80.325	97.315	107.445
ECPC Newsletter			124
EU funded projects	32.816	30.054	32.889
• Project travel	13.094	12.811	19.857
• Project publications	2.948	2.292	3.154
• Project conferences and catering	3.662	2.331	2.455
• Other project expenses	13.112	12.620	7.423
☛ Total expenses	505.173	561.574	614.503
• Deficit/Surplus	163.831	45.378	152.507



EUROPEAN
CANCER
PATIENT
COALITION

40, rue Montoyer
1000 Brussels
Belgium
info@ecpc.org
www.ecpc.org

