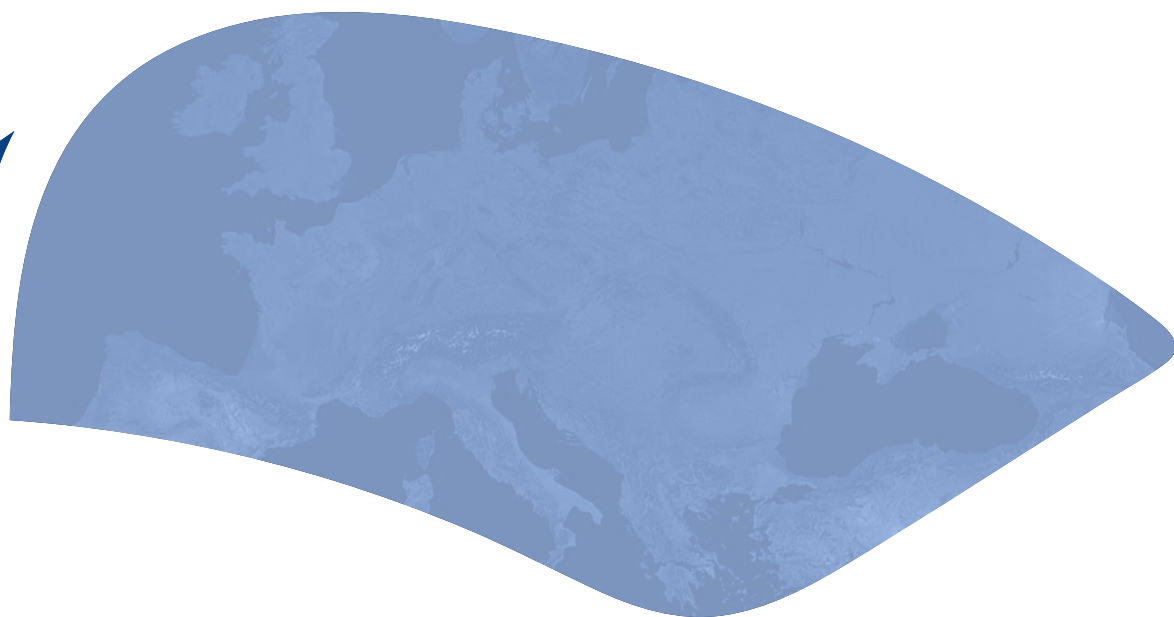




European Cancer  
Patient Coalition



# Annual Report 2018

Empowering Europeans  
affected by cancer



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# 1 • The European Cancer Patient Coalition

Established in 2003, the European Cancer Patient Coalition (ECPC) 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.

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

The motto ECPC is: **“Nothing about us, without us!”**

In 2018, 16 new organisations joined ECPC, consolidating it as Europe’s largest cancer patient association, with a total of 445 Members.  
New members who joined ECPC in 2018:

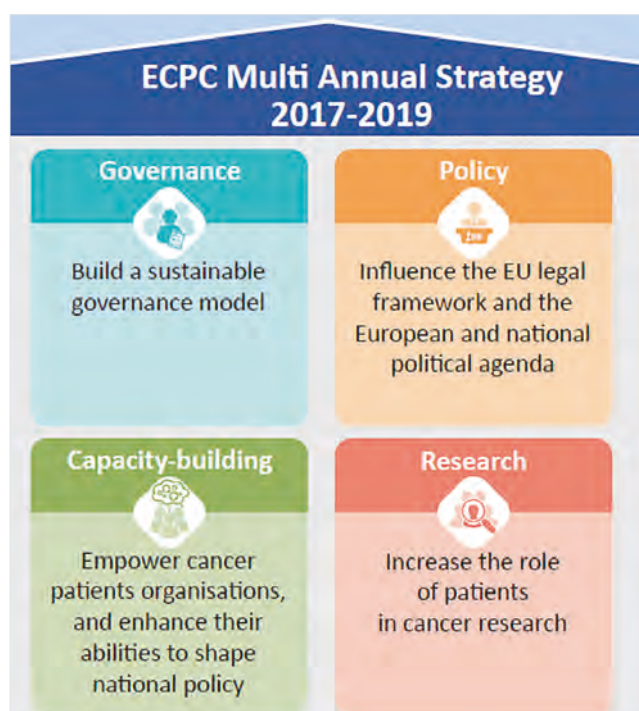
- Disabled Person Association “ILCO” Varazdin, Croatia
- EuropaColon, Poland
- HEMA, Macedonia
- HENARAN, Armenia
- HOSPICE Casa Sperantei, Romania
- Irish Society of Gynaecological Oncology Public and Patient Involvement Group, Ireland
- Mallow Flower Foundation, Hungary
- Metamazon, Turkey
- Oscar’s Angels, France
- Patients Platform Sarcoma, Netherlands
- SANO: Association for Better Health, Education and Social Care, Macedonia
- Teosofia Association, Romania
- The Cancer Collaborative (COLAB), Canada
- The Norwegian Bladder Cancer Society, Norway
- Together for Kids with Cancer Association, Romania
- Umut ve Yasam Association, Turkey

## 1.1 • Our 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.

## 1.2 • Our Strategy



The main objective of the ECPC 2018 Action Plan was to confirm ECPC's leadership as the main voice of cancer patients in Europe. ECPC 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 **ECPC 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 and Audit Committee elected in June 2016 for a duration of 3 years up to 2019. A Scientific Committee has been established in 2018 to ensure the scientific integrity of ECPC in 2018 and beyond.



## 2 • Forewords

### 2.1 • Message from the President

As I look back on the last twelve months as President of ECPC, I reflect on the great privilege that it has been to continue as President of this great organisation. In 2018 ECPC's persistent efforts to position cancer more prominently on the political agenda continued to yield results, from policy to capacity building to research.

In 2018, ECPC actively participated in public consultations, co-produced ESMO Clinical Guidelines and successfully advocated for access to health care and social-economic rights. ECPC advocacy action on the Work-Life Balance Directive for Parents and Carers achieved the formal recognition of carers and guarantees baseline support for informal caregivers across the EU. We brought a strong cancer patients' voice on the development of Health Technology Assessment regulation – for patient involvement and faster access to innovative therapies in every corner of the EU.



ECPC has become increasingly active in European health and research programmes and is now a partner in 12 multi-year projects funded by the European Commission tackling cancer research and innovation. A paper on nutritional and metabolic derangements in Mediterranean cancer patients and survivors, was accepted by the Journal of Cachexia, Sarcopenia and Muscle.

We continued our work with the European Medicine Agency (EMA) and two Joint Actions (JARC and iPAAC).

Our contribution to cancer research has been also recognised by having ECPC representatives invited to Boards of top-level cancer organisations, such as Cancer Core Europe, Pancreatic Cancer Europe, European Academy of Cancer Sciences, and Cancer Drug Development Forum.

ECPC played a crucial role at a starting point for generating and contributing ideas to the framework of the Cancer Mission Europe, joining over 60 members of the global oncology community in the Vatican in November 2018. A primary

aim of the Cancer Mission should be to achieve the long-term survival of 75% of patients with cancer by 2030 by combining innovative prevention, treatment strategies, rehabilitation and multidisciplinary follow-up.

These achievements were in no small measure due to the active engagement of our network of Members, all united in encouraging national governments to take a more proactive role in helping to improve outcomes for people with cancer. The ultimate mission of our organisation is to listen to our Members and represent them at the European level. This was once again on display at the Annual Meeting in Brussels, where over 210 delegates gathered to exchange knowledge, experience and best practices.

In 2018, 16 new organisations joined ECPC, consolidating it as Europe's largest cancer patient association. Each one of our 445 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.

## 2.2 • Message from the Directors

We are pleased to present the ECPC Annual Report 2018. This summary of ECPC objectives, challenges and achievements of the past year reflects the collective strength of the Board, the Secretariat and our Members to ensure that the voice of people with cancer is heard throughout Europe. All together we 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.

Our knowledge and our understanding come from the opinion and experience of the day-to-day challenges faced by our Members throughout Europe. We sought meaningful change together with them at national and European level to facilitate access to treatment and to improve the quality of life of cancer patients, survivors and their carers. We also provided them with high quality research and multilingual educational resources.

ECPC Board provided the strategic oversight of the organisation. We would like to particularly thank the new members of our Board who joined in 2018 for their enthusiasm, dedication, and respect. In our Brussels office, we saw the daily efforts of the dedicated and energetic staff to deliver high quality and high impact events, communication, research, projects, and policy work. We are 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 back on the past year, our activities focused on our core mission: to be the European voice of people with cancer. We achieved this by listening to our Members, providing high quality research and cancer advocacy, and producing multilingual educational resources. We delivered our objectives on cancer with



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

We see all the challenges ahead and look with excitement towards the change in the European landscape and in our organisation in 2019. We will build on the strong foundations and accomplishments of the organisation. At the end of 2018, Lydia Makaroff handed over the role of Director onto Antonella Cardone. With a modern vision of governance, empowered staff, and engaged Members, we will lead the organisation to new heights.

*Antonella Cardone and Lydia Makaroff*

## 3 • Overview of 2018

### 3.1 • Calendar of main activities in 2018

#### January

- ISMPP 2018 European Meeting: Advancing Medical Publications in a Complex Evidence Ecosystem
- The Global Promise of Cancer Immunotherapy Webinar
- All.Can Seminar Improving outcomes, driving efficiency in cancer care: How do we learn from best practice?

#### February

- Cancer Core Europe Board Meeting
- Cancer Core Europe 3rd Annual Meeting
- ESO Masterclass in Cancer Patient Advocacy 2018
- The Launch of the MEP Focus Group “Dying to Work”

#### March

- 3rd EORTC Cancer Survivorship Summit 2018
- ECPC-EORTC Course on Cancer Clinical Research for Patients
- Launch of the Transforming Breast Cancer Together Initiative: A Call for Change

#### April

- EURACAN 2nd Annual Conference
- Joint Research Centre (JRC) meeting in Ispra-ECIBC/QASDG
- Joint PCWP/HCPWP plenary meeting

#### May

- PREFER Clinical Case Studies Workshop
- The Better Policy for Metastatic Cancer Patients: Bridging the Data Gap
- iPAAC Cancer Information and Registries meeting

#### June

- Working Group on Rare Cancers (WGRC) face-to-face Meeting
- ECPC Annual Congress 2018
- The Joint Research Centre (JRC) meeting
- WIN Symposium 2018
- iPAAC Challenges in Cancer Care meeting

#### July

- European Commission Conference The way forward for HTA cooperation – the views of stakeholders

#### September

- First iPAAC Stakeholder Forum
- The first All.Can Global Summit

- ECCO European Cancer Congress
- The 2nd Gago Conference on European Science Policy
- 12th EMA stakeholder forum on the pharmacovigilance legislation
- CDDF Multi-stakeholder Workshop on Biomarkers and Patients' Access to Personalised Oncology Drugs in Europe
- Patients' and Consumers' Working Party plenary meeting
- The European Parliament event on Health Technology Assessment and Access to Innovative Oncology Drugs in Europe
- Brexit: the European Parliament's role in prioritising patients, public health and health security across Europe
- European Commission Multi-Stakeholder Workshop on Biosimilars
- EFAD Conference 2018
- CHAM 2018 - Building the European Health System
- BD4BO Do-IT Webinar "An HTA perspective on the Acceptability of Real-World Evidence and Methods to Enhance its use."

## October

- World Cancer Congress
- Partnering to empower people with cancer and their caregivers
- Improving cancer care - Perspectives on value & access from the cancer care community" - European Health Forum Gastein
- BD4BO Do-IT Webinar "In data we trust: Towards outcomes-based healthcare in Europe"
- Saving Lives by Increasing Awareness of Cancer-Associated Thrombosis (CAT)
- ESMO 2018 Congress
- EC/EMA workshop on electronic EU product information
- PREFER Annual Meeting

## November

- BMS Oncology Patient Advocacy Forum
- Personalised Medicine Awareness month
- KCE Trials Panel
- ISPOR Europe 2018
- 5th ONCA Conference
- Central European Cooperative Oncology Group (CECOG) Academy
- BD4BO DO-IT General Assembly
- EMA's Annual meeting with all eligible organisations
- UNIFI: Increasing Health Life Years
- 2nd PIONEER Consortium Meeting
- European Alliance for Personalised Medicine Congress
- iPAAC Genomics in Cancer Control and Care meeting
- EU Health Summit

## December

- What does the future of sustainable healthcare look like?
- European Cancer Forum – Changing the future of cancer in Europe

## 3.2 • Health Policy

ECPC plays an essential role in Europe by effectively acting as the voice of cancer patients. ECPC is committed to representing patients' interests and proposing patient-centric solutions to cancer-related problems. As such, ECPC has been a critical stakeholder in defining cancer policy in Europe. Importantly, ECPC has been raising awareness of the key issues that lead to disparities in cancer care; it has also been making practical recommendations to bridge the gap between cancer policy at EU and national levels and the cancer care practice.

ECPC has collaborated with European institutions, such as the European Commission and more closely with the European Parliament to promote key cancer policies, some of which have been successfully implemented already:

- Future EU cooperation on Health Technology Assessment – submitted amendments for systemic and meaningful patient involvement in HTA across the EU.
- Work-Life Balance Directive for Parents and Carers – submitted amendments for recognition and protection of carers across Europe, most of which have been adopted.
- Report on pathways for the reintegration of workers recovering from injury and illness into quality employment – contributed to the amendments which have been adopted.
- Jointly launched the MEP Focus Group “Dying to Work” with over 15 MEPs focused on bringing additional employment protections for terminally ill employees across Europe.
- Use of Cannabis for medicinal purposes – contributed to the discussion and advocacy towards harmonised EU legal framework for medicinal cannabis.

ECPC also organised 11 events focused on cancer policy in Brussels and across Europe and spoke at an additional 9 events.

## 3.3 • Information

The ECPC website received over 37,000 visitors over the year, achieving a 63.8% rise in comparison to 2017. The most popular webpages were the homepage, followed by pages with information about our clinical trials database, pancreatic cancer, our members and personalised medicine.

Throughout the year, ECPC disseminated various publications online and in print at a number of events in Brussels and across Europe:

- The Value of Innovation in Oncology
- The Merkel Cell Carcinoma brochures

- The White Paper on Cancer Carers
- The ECPC-ESMO Survivorship Guide.
- The 'Living Well During Cancer treatment' Nutrition Patient Guide

### 3.4 • European Health and Research programmes

ECPC is one of the few patient organisations directly involved in health and research. ECPC is actively participating in several European Union's Research and Innovation framework programmes, drawing 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.

In 2018, ECPC has been an active member of 12 projects funded by the European Union. This included Joints Actions (2) and projects under the Third Health Programme (1), the Seventh Framework Programme (2) and Horizon 2020 (7) including Innovative Training Networks (2) and projects under the Innovative Medicines Initiative (3). This allows ECPC 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.

### 3.5 • Support and Capacity Building

Throughout the year, 16 new organisations joined ECPC, increasing the Membership to 445 organisations. The 2018 Annual Meeting welcomed 210 participants, representing 156 different organisations from 35 different countries.

### 3.6 • Media

The ECPC Twitter account rose to 4,445 followers and the ECPC Facebook account accumulated 8,461 likes. ECPC was highlighted in 12 news articles, 4 editions of POLITICO Pro Morning Health Care, and 2 editions of Dods EU.

### 3.7 • Awareness

ECPC participated in 18 awareness campaigns, and led 3 awareness campaigns highlighting bladder cancer, head and neck cancer, and cancer-associated thrombosis.

## 4 • The Vatican meeting and Cancer Mission Europe

In 2018, the European Commission proposed a mission-oriented approach to research in Horizon Europe – the next European Union (EU) Research & Innovation framework programme. Fighting cancer using a mission approach is highly likely to change the lives of many families across Europe, but also beyond the borders of the EU. The increasing cancer burden is one of the leading medical and societal challenges today.

In order to rethink the strategies to combat cancer and to avoid the enormous dispersion of research funding that has not contributed to solving the problem of cancer in contrast to other diseases, about 60 participants of global oncology community, including the ECPC President, met in The Vatican in November 2018. The meeting to discuss a mission-oriented approach to cancer in Europe was organised by the European Academy of Cancer Sciences and the Pontifical Academy of Sciences. It was a key starting point for generating and contributing ideas to the framework and functioning of the Cancer Mission Europe.

A primary aim of the Cancer Mission should be to achieve the long-term survival of 75% of patients with cancer by 2030 by combining innovative prevention, treatment strategies, rehabilitation and multidisciplinary follow-up. Better handling of economic and social inequalities in countries with less-developed systems should be an essential part of the Cancer Mission.

The establishment of both Cancer Core Europe and Cancer Prevention Europe has been key to this endeavour and the active participation of ECPC in the infrastructure should act as a bridge between research and care, strengthening the social impact of translational research and integrating patients' views into research and cancer care.

ECPC as a voice of cancer patients in Europe has taken a prominent role in high-level discussions on Cancer Mission Europe and will continue to engage with the oncology community and the European Commission in 2019, and beyond, on a basis of the principle of "Science with and for Society".

Member States and the general public, including patients and patient advocates, will be involved in the Cancer Mission in a coherent and systemic way, encompassing quality assurance and accreditation. ECPC strongly supports the deployment of quality assurance schemes and the accreditation of cancer centres and therefore closely collaborates with the Organisation of European Cancer Institutes (OECI).

The European Academy of Cancer Sciences (EACS) is an academy initiated by a number of Nobel laureates with the aim of creating an organisation of prominent researchers and clinicians that can provide authoritative recommendations in the field of cancer research and cancer care to institutions and policymakers. The ECPC President represents the organisation and thus the interests of cancer patients as a Member of the Science Policy Committee of EACS.



Dissemination of information to the general public on the genomics revolution in cancer diagnosis and treatment by comprehensive cancer centres and patient organisations will facilitate this process. Patient organisations will collaborate with scientists, clinicians, politicians and industry to overcome the unacceptable disparities in cancer treatment and care, and the associated stigma by identifying important research questions concerning QoL and social issues for all cancer patients, regardless of age. ECPC can, and does, facilitate these collaborations and consequently plays a central role in the Cancer Mission. Missions should engage the society, patients and survivors, by making it clear that bold, inspirational actions at European level will develop solutions which will have an impact on people's daily life.

As many as 13 million patients will be considered long-term survivors in 2035, in need of professional and social support and demanding continuous research efforts, especially in order to facilitate full reintegration into society in all aspects. ECPC strongly advocates for considering the Cancer Mission as a mix of research challenges from cancer research through to challenges faced in Member States due to cancer, thus providing a holistic way to address challenges in cancer.

There is an urgent need to look into the research on cancer survivors in Europe. Since survivorship includes a broad range of issues, major areas of need have been outlined, with active contributions from ECPC, in anticipation of the development of a comprehensive research agenda for European cancer survivors.

It is critical to communicate that for a majority of cancer patients in Europe, cancer is not a death sentence, and the social sector should play a complementary role to the health sector in improving the reintegration of survivors to normal life and socio-economic participation in the society without discrimination.

The Cancer Core Europe considers ECPC as an indispensable partner, with President de Lorenzo as a Board Member, to expand the research continuum and ensure the longevity of the mission, making it mandatory to elicit effective social change. The successful cancer mission must benefit the advancement of cancer research, care and survivorship for all.

## 5 • Education

### 5.1 • eLearning Module on Health Technology Assessment

ECPC developed an interactive online education module on Health Technology Assessment for patients and patient advocates, with a focus on the assessment of cancer treatments. The Health Technology Assessment (HTA) is a method used to measure the value of a new medicine compared to the existing standard of treatment. It is a valuable tool which can establish the real value of medicine, taking into consideration not only clinical impact, but also Quality of Life (QoL), social and societal impact. People living with cancer and their carers best understand the need for new therapies and their impact on QoL. Their unique knowledge, perspectives and experience are crucial in determining the value of new treatments in HTA. Increasingly, cancer patient organisations are invited to contribute to the HTA of oncology treatments, although this involvement varies from country to country in Europe.



The ECPC HTA eLearning Module is an essential education tool for meaningful cancer patient organisations involvement in the HTA process. The module covers a range of topics from medicines

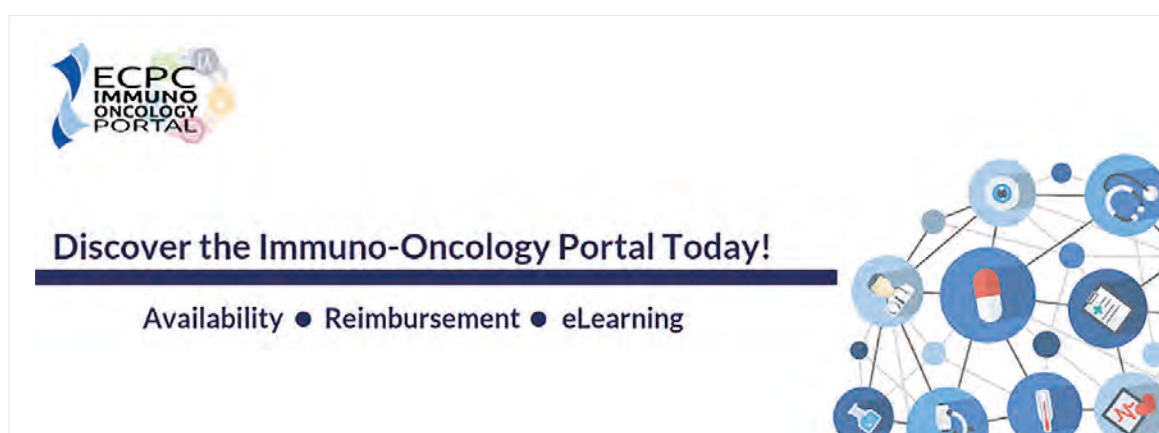
development process and their examination as part of HTA, to why cancer treatments might be reimbursed in some countries but not in others, and how cancer patient organisations can get involved in HTA.

The module equally serves as an advocacy capacity-building tool for ECPC members. Patient organisations are able to develop knowledge and importance on patient involvement in HTA, and advocate to ensure that patient input is gathered much broader on issues such as Quality of Life and legal, ethical aspects associated with the medicine, thus allowing to inform the real value of medicine at the national level. With examples and references to further patient education, the module provides the capacity to patients to know where to exert the advocacy around HTA.

With the contribution of our member patient organisations, ECPC has published a brief informative booklet on HTA & Patient Involvement: Examples from EU Member State, summarising the state of play on patient involvement in HTA processes of selected EU countries.

ECPC gratefully acknowledges the support of AbbVie, AstraZeneca, Bristol-Myers Squibb, Cancer Drug Development Forum, Eli Lilly and Company, MSD, Merck, Novartis, Roche, Takeda.

## 5.2 • Immuno-oncology portal



In 2018, ECPC continued the development of the Immuno-Oncology Portal (IOP), to respond to the needs of people with cancer to understand what cancer immunotherapies are and where they are available. The IOP now includes the latest information on cancer immunotherapies' authorisation in the European Union, the availability and reimbursement status of these therapies in 28 countries, updated twice in 2018 in March and October.

ECPC has also collaborated with the European Society for Medical Oncology (ESMO) to include more information on immuno-therapy related side-effects. The IOP now provides information on the side-effects as well as further reading provided by ESMO Patient Guides.

The Immuno-Oncology Portal is available in English, Italian, Polish, Greek, and Spanish at: [iop.ecpc.org](http://iop.ecpc.org)

ECPC gratefully acknowledges the support of Bristol-Myers Squibb, Tesaro and CDDF in maintaining the Immuno-Oncology Portal. The scope and the content of the portal are the sole responsibility of ECPC.

## 5.3 • ECPC-EORTC Course dedicated to Patients and Caregivers interested in Cancer Clinical Research

ECPC and the European Organisation for Research and Treatment of Cancer (EORTC) continued the collaboration in 2018 to jointly organise the 'Course dedicated to Patients and Caregivers interested in Cancer Clinical Research'. The bi-annual meeting organised on March 2-3, 2018 in Brussels, Belgium was designed specifically for European patients/patient representatives/caregivers. The goal of this course was to provide cancer patient advocates with a stimulating and challenging two-day training experience leading to a much greater understanding of the whole clinical trials process. ECPC provided

several travel grants for patients, patient advocates and caregivers to enable their participation in the course.

The course sessions lead to a much greater understanding of the entire clinical research process, by enabling cancer patient advocates to learn about cancer biology, personalised treatment and care, organisation of clinical research and how patient organisations can become more involved in the design and implementation of clinical trials.

ECPC gratefully acknowledges the support of Celgene and Merck for this course. The scope and the content of the portal are the sole responsibility of ECPC.

## 6 • Awareness

### 6.1 • World Cancer Day

World Cancer Day occurs on the 4th of February promoted by the Union for International Cancer Control (UICC). Its rallying cry “We can. I can” stressed how everyone has been, is or will be impacted by cancer. Therefore, the campaign aimed at engaging individuals

and communities and explaining them they all have the power to take action.



ECPC supported and amplified UICC's message by:

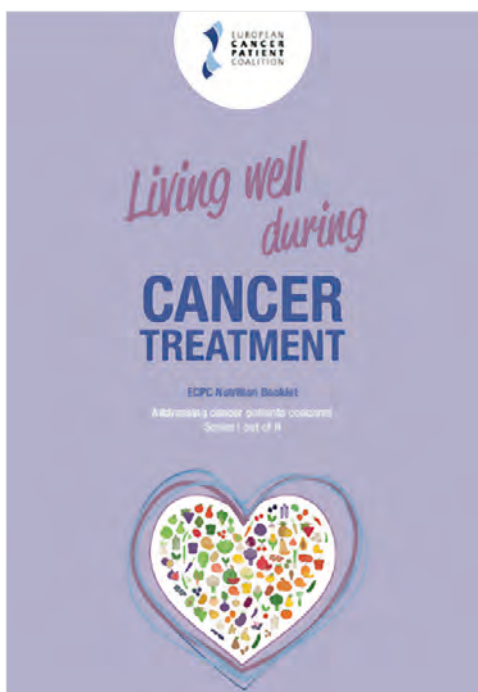
- Developing a social media calendar to schedule messages on and around World Cancer Day
- Promoting World Cancer Day messages in multiple European languages
- Joining the “Talking Hands” campaign on Twitter and Facebook
- Joining the World Cancer Day Thunderclap on Twitter
- Promoting World Cancer Day in the News section of the ECPC website.

### 6.2 • Nutrition and physical activity

Nutrition is a crucial component of cancer treatment and rehabilitation as it helps people to better cope with the illness. However, it is often neglected, leaving patients and their carers with doubts and questions on how to eat better on a daily basis, especially during therapy.

In 2018, a scientific paper reporting the results of our work in Nutrition titled ‘Nutritional and metabolic derangements in Mediterranean cancer patients and survivors: the ECPC 2016 survey’ was accepted by the Journal of Cachexia, Sarcopenia and Muscle for publication. The scientific paper provided a solid background for the development of the ECPC Nutrition booklet ‘Living Well During Cancer Treatment’.

The Living Well During Cancer Treatment Patient Booklet was endorsed by the European Society of Surgical Oncology (ESSO) and was presented again at the ESMO Congress at the European Oncology Nursing Society (EONS) Symposium 2018.



In March 2018, ECPC promoted the Nutrition and Physical Activity Awareness Month, launching a campaign toolkit for member patient organisations to jointly promote a healthy lifestyle. Our Living Well during Cancer treatment key messages were translated into Czech, Finnish, French, Hungarian, Italian, Polish, Romanian and Spanish disseminated on social media which also included a Thunderclap and Twibbon campaign.

The booklet itself highlights our “Cancer Patient’s Charter of Rights for Appropriate and Prompt Nutritional Support”. This charter is a key advocacy tool for patient organisations at national level. Furthermore, a policy webpage was developed to include information about ECPC’s Nutrition Advocacy and Physical Activity Campaign, ECPC’s Abstract on the European survey of 907 people with cancer about the

importance of nutrition *that* was published in the Annals of Oncology, and the “Charter of Rights for Nutritional Support”.

ECPC gratefully acknowledges the support of Baxter, Celgene, Eli Lilly & Co, and Helsinn. The scope and the content of the material remain the sole responsibility of ECPC.

### 6.3 • Bladder cancer campaign



ECPC has stepped up its efforts against bladder cancer with its dedicated working group to improve awareness and understanding of this common yet neglected pathology.

The second edition of the European bladder cancer awareness month was organised in May 2018. The campaign aimed at:

- Improving the co-operation between people with bladder cancer and patient organizations in Europe
- Promoting the interests of people with bladder cancer and patient organizations in Europe



- Enabling bladder cancer patient organizations to continue to develop common positions on European health policy.

### 6.3.1 • Urology Cancer Advocacy Session

ECPC co-hosted a Patient Advocacy Session at the European Association of Urology congress in Copenhagen on Sunday 18 March 2018. The objective of this meeting was to build the capacity of European prostate, kidney, and bladder patient advocacy groups to support their members and advocate for better care.

### 6.3.2 • Patient Experience Survey

ECPC presented the results of the patient experience survey at the European Association of Urology Congress in Copenhagen in March 2018, and at the Fight Bladder Cancer booth at the British Bowel Surgeons conference in June 2018. The results of the survey were also promoted in a special supplement of Fight Bladder Cancer's magazine "*Fight*", which reaches over 60,000 readers per edition.

### 6.3.3 • Awareness Campaign

The month of May is Bladder Cancer Awareness Month. Building upon its successful social media campaign, ECPC produced a Bladder Cancer Awareness Month toolkit for patient organisations in 2018. ECPC produced a toolkit that includes a Thunderclap, Twibbon, template for public event, and social media calendar. A Social Media Thunderclap allows a single message to be mass-shared, in a flash mob-style, so it rises above the noise of the social networks. By boosting the signal at the same time, Thunderclap helps organisations create action and change. On the last Sunday in May, ECPC with other bladder cancer organisations blew bubbles in public places to call for better awareness and outcomes for bladder cancer patients.

ECPC gratefully acknowledges the support of AstraZeneca, IPSEN, Roche and Bristol-Myers Squibb. The scope and the content of the material remain the sole responsibility of ECPC.

## 6.4 • Make Sense of Head and Neck campaign

In September 2018, ECPC continued to promote awareness on Head and Neck cancers in Europe as part of the Make Sense campaign, working together with the European Head and Neck Society.

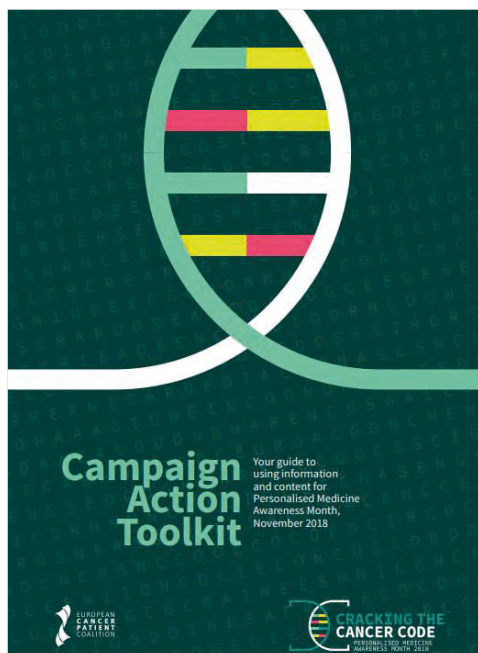


ECPC organised a roundtable policy discussion in the European Parliament, hosted by the Member of the European Parliament Lieve Wierinck (ALDE, Belgium). The event titled 'Survivorship: Life with, through and beyond Head and Neck Cancer' aimed to promote awareness of these cancers and call for prevention, standardised care, and better quality of life for people with cancer and cancer survivors.

A particular focus was placed on the importance of the multidisciplinary care and treatment for head and neck cancers to ensure optimal, patient-centred treatment decision making, highlighting the benefits for both patients and physicians, which were observed in four EU member states currently offering multidisciplinary care.

ECPC gratefully acknowledges the support Merck. The scope and the content of the material remain the sole responsibility of ECPC.

## 6.5 • Personalised Medicine Awareness Month



ECPC and our member organisations believe that people living with cancer should be informed about all available treatment options and be empowered to make the best decisions for their health, together with their healthcare team. That's why ECPC is working towards ensuring all Europeans with cancer and at risk of getting cancer have appropriate access to cancer molecular testing. This will help to promote better diagnosis, more targeted follow up and a truly personalised treatment.

In November 2018, ECPC launched the first ever Personalised Medicine Awareness Month with a theme Cracking the Cancer Code, a pan-European campaign to bring about new conversations on diagnostic and treatment options for European citizens. The campaign was organised in partnership with the European

Alliance for Personalised Medicine (EAPM), Cancer Drug Development Forum (CDDF) and the International Quality Network for Pathology (IQN-Path).

**Throughout the Personalised Medicine Awareness Month 2018, ECPC and its member patient organisations united to call for:**

- Increased access and decreased waiting times for high-quality molecular testing to make personalised healthcare more of a reality across Europe;
- More information to educate and empower patients and caregivers around the potential and availability of molecular testing;
- A harmonised and more efficient regulatory framework across Europe which could increase access to, and potentially reduce the cost of, molecular testing.

ECPC continues working towards ensuring all Europeans with cancer and at risk of getting cancer have appropriate access to cancer molecular testing. This will help to promote better diagnosis, more targeted follow up and a truly personalised treatment.

ECPC developed a Campaign Toolkit, available in 12 languages including English, Czech, Dutch, Finnish, French, German, Greek, Italian, Lithuanian, Polish, Romanian, and Spanish to help our member patient organisations and partners to participate in the Personalised Medicine Awareness Month 2018 and make the most of the tools and materials, developed together with experts in the field. ECPC has also produced a detailed webpage and infographic on biomarkers as well as an educational video animation developed together with EurActiv. The infographic is available as a website and a downloadable leaflet.

ECPC promoted the campaign at various oncology community events including CDDF Multi-Stakeholder Workshop on Biomarkers and Patients' Access to Personalised Oncology Drugs in Europe, ESMO Annual Congress 2018 and European Congress on Personalised Medicine 2018. More than 30 partners supported the Personalised Medicine Awareness Month 2018, helping us reach over 180,000 people online across many countries in Europe and beyond.

ECPC gratefully acknowledges the support of AbbVie, AstraZeneca, Bristol-Myers Squibb, Cancer Drug Development Forum, Genomic Health, Janssen, MSD, Roche and Takeda. The scope and the content of the material remain the sole responsibility of ECPC.

## 6.6 • Pancreatic cancer awareness

ECPC continued to support the World Pancreatic Cancer Day in 2018 'Demand Better. For Patients. For Survival.' with online awareness activities throughout social media channels and the ECPC website. ECPC is a dedicated member of the World Pancreatic Cancer Coalition Steering Committee and has contributed to the development of pancreatic cancer awareness materials.

ECPC also actively participated as a Board Member of Pancreatic Cancer Europe, chairing



the work stream that coordinates and supports national activities, as well as the uptake of advocacy and awareness materials. ECPC is a member of the Steering Committee of WPCC-World Pancreatic Cancer Coalition, represented by Vice President K. Apostolidis.

ECPC gratefully acknowledges the support of Celgene for pancreatic cancer awareness activities. The scope and the content of the material remain the sole responsibility of ECPC.

## 7 • Advocacy

### 7.1 • Innovative Partnership Action against Cancer (iPAAC)

ECPC is a patient partner subcontracted under the European Commission's Joint Action on Innovative Partnership Action against Cancer (iPAAC). The Innovative Partnership for Action Against Cancer (iPAAC) Joint Action, which has been selected for funding under the Third Health Programme (2014–2020), brings together 44 partners from 24 European countries. The joint action is building on experiences from implementation of the outcomes of the European Partnership for Action Against Cancer (EPAAC), Cancer Control (CANCON), and the Joint Action on rare Cancers (JARC). The iPAAC will run from April 2018 until April 2021.



The primary target group of the iPAAC Joint Action will be policymakers at the EU level and decision makers at the national, regional and local level. The overall general objective of the iPAAC Joint Action is to develop innovative approaches to advances in cancer control on key areas of: **cancer prevention**, comprehensive approaches to the use of **genomics** in cancer control, **cancer information** and registries,

improvements and challenges in **cancer care**, mapping of **innovative cancer treatments** and **governance** of integrated cancer control, including a new analysis of national cancer control plans.

The outcomes of the work will **support Member States in implementing recommendations** from the **Action Against Cancer (EPAAC)**, Cancer Control (CANCON), and the Joint Action on rare Cancers (JARC) at national, regional, and local levels; **reinforcing of cancer prevention** through further developing current recommendations *for quality cancer screening and a sound* assessment of new potential; **providing better efficacy for dealing with neglected cancers** through development of new key indicators to assess clinical patient pathways and health care related costs of cancer and its interventions, particularly in the

case of **pancreatic cancer**; **supporting the introduction of immunotherapies into clinical practice** through a comprehensive assessment of immunotherapies and their effectiveness; **evaluating cancer care in European countries** through an assessment of quality indicators, and **supporting policymakers in the field of governance** through the development of a **Roadmap on Implementation and Sustainability of Cancer Control Actions**.

ECPC is actively within the iPAAC drawing on fundamental knowledge and understanding of the patients' situation by providing irreplaceable first-hand understanding of the issues revolving around cancer patients. ECPC will prepare and organise 2 conference meetings to address representatives for all relevant cancer patient organisations and actively support networking and mapping of contacts with patient organisations, contribute to guidelines, and advise on the selection of epidemiological indicators on cancer prevalence and survivorship and disseminate the result. Furthermore, ECPC will participate in a consensus meeting to define the definition of neglected cancers using the case for pancreatic cancer and cooperate to carry out an expert workshop, as well as, contribute to help draft practical guidance for member states successful integrating genomics in the health care system.

## 7.2 • Health Technology Assessment

In 2018, ECPC actively engaged in advocacy for a harmonised approach in the Health Technology Assessment in the European Union, for which the European Parliament has adopted its position. ECPC advocated for greater patient involvement and mandatory participation of the

Member States in EU cooperation on HTA. Following the publication of a legislative proposal for future EU cooperation on Health Technology Assessment (HTA), ECPC published a statement urging the European Parliament and the Member States to harmonise patient organisations' involvement in the HTA.

In May 2018, ECPC met with EU Commissioner for Health Vytenis Andriukaitis to present the position paper (which was updated in July 2018) on **Future Cooperation on HTA, calling for:**

- Systematic involvement of patient organisations in Health Technology Assessments;
- Formalisation of patient organisation involvement in all joint activities





completed at EU level, as well as in the assessments of non-clinical domains that are conducted at national level;

- Mandatory uptake of joint clinical assessment reports.

ECPC then worked with the ECPC Legal Network for Cancer Patients to prepare amendments to ensure that the key requests outlined in the Position Paper are represented in the legislation and the European Parliament's position. A total of 17 amendments were tabled by Members of the European Parliament Elisabetta Gardini (Italy, EPP) and Jose Inacio Faria (Portugal, EPP).

ECPC engaged with the European Commission at a meeting *The Way Forward for HTA cooperation*, attended by President de Lorenzo and Vice-President Apostolidis, as well as Head of EU Affairs Alex Filicevas. President de Lorenzo made several statements during the meeting, and a statement was published on ECPC website following the event reiterating the key messages.

Ahead of the European Parliament's ENVI Committee vote, ECPC provided voting recommendations to the rapporteur and shadow rapporteurs of each political group to ensure patients' views are represented in the legislation. The ENVI Committee has adopted a large majority of compromise amendments agreed by the European Parliament's rapporteurs and shadow rapporteurs from all parties.

In September, ECPC took the lead in driving the discussion forward ahead of the plenary vote with an event in the European Parliament "HTA & Access to Innovative Oncology Drugs in Europe" on 25 September 2018 organised in partnership with the Cancer Drug Development Forum (CDDF). ECPC's policy debate was hosted together with MEP Elisabetta Gardini (EPP, Italy) and with contributions from MEPs Cristian-Silviu Buşoi (EPP, Romania) and Lieve Wierinck (ALDE, Belgium). ECPC facilitated a well-timed discussion ahead of the European Parliament Plenary vote in Strasbourg, bringing together a panel of patients and multi-stakeholder group of experts, to exchange views with MEPs, Member States, the European Commission and the audience. With over 120 participants, representing a wide range of stakeholders from Brussels, the event reached an agreement on the need for constructive, evidence-based dialogue and patient-centeredness in the legislative process and ensuring a timely progress of the regulation.

In partnership with the European Alliance for Personalised Medicine shortly after the event in the European Parliament, ECPC released a statement, *"HTA is Filling a gap in Europe's delivery of healthcare but we need patients to be involved"* which was widely quoted in the media in Brussels.

ECPC also continued with capacity building of member organisations to empower them to advocate for patient involvement in HTA at national and future EU assessments.

ECPC gratefully acknowledges the support of AbbVie, AstraZeneca, Bristol-Myers Squibb, Cancer Drug Development Forum, Eli Lilly and Company, MSD, Novartis, Roche, Takeda, Tesaro.



## 7.3 • Work-life Balance Directive

Throughout 2018, ECPC led an EU-level campaign towards greater equality in social and employment matters related to cancer care, including a strong advocacy campaign on the Directive on Work-Life Balance for parents and carers. The objective of the proposal was to improve access to work-life balance arrangements throughout the EU. ECPC engaged with policymakers and Members of the European Parliament to bring the attention to the recommendations published in the ECPC-Eurocarers White Paper on Cancer Carers. In particular, ECPC advocated for the proposal to reinforce the formal recognition of carers and to introduce minimum standards for paid carers' leave and flexible working arrangements.

Building on these key recommendations with the ECPC Legal Network for Cancer Patients, ECPC together with several Members of the European Parliament proposed amendments to the Work-life Balance Directive. In partnership with the European Organisation for Research and Treatment of Cancer (EORTC), ECPC also launched a mapping survey to assess the existing legal frameworks and socio-economic protections for cancer patients, survivors and carers.

In September, the European Parliament, the Council of the European Union and the European Commission entered into inter-institutional negotiations, or so-called trilogue stage, aimed at reaching a compromise position in 2019. ECPC conducted outreach to the European Parliament representatives in the trilogues, asking to defend the key points concerning carers and published a statement featured in Brussels media.

The Directive on Work-Life Balance for Parents and Carers is set to be adopted in 2019.

## 7.4 • Supportive Care for People with Cancer Roundtable and Report

ECPC and the European Oncology Nursing Society (EONS) partnered to bring the attention to cancer supportive care. Cancer supportive care is the prevention and management of the symptoms and side effects of cancer and its treatment across the cancer continuum from diagnosis to the end of life.

In February 2018, a policy roundtable with patients and experts in the field was hosted in partnership with the Member of the European Parliament Lieve Wierinck (ALDE, Belgium). With treatment options for cancer patients becoming increasingly complex due to innovative health technology advancements, the multi-faceted care needs of people with cancer are growing. The Roundtable provided a timely forum to discuss these challenges and find tangible solutions for the stakeholder community to improve outcomes for people with cancer.



The Roundtable succeeded in promoting the importance of supportive care for people affected by cancer and cancer nurses in Europe and raised further awareness about cancer-associated thrombosis and chemotherapy induced nausea and vomiting, which were summarised in the report published on the occasion of the European Cancer Nursing Day on 18 May 2018. To launch the report, ECPC collaborated with MEP Lieve Wierinck to publish an opinion-editorial in EurActiv.

ECPC greatly acknowledges the support of Helsinn and LEO Pharma A/S.

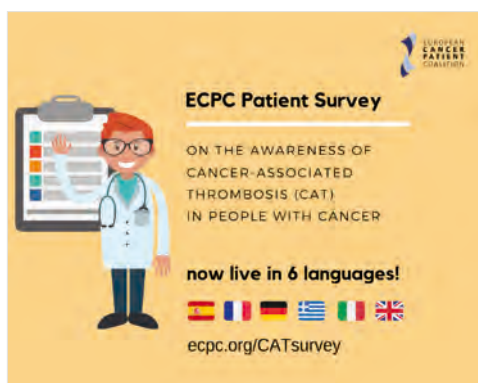
## 7.5 • Cancer-associated Thrombosis Awareness Amongst Patients

On the occasion of the World Thrombosis Day – 13 October 2018, ECPC has launched the report on the Cancer-Associated Thrombosis Awareness Survey results which measures the current levels of patient awareness of cancer-associated thrombosis in 5 European Countries.

The survey revealed very low awareness about cancer associated thrombosis among cancer patients in Europe. A vast majority of respondents said that, before taking part in the survey, they were unaware that people with cancer have a higher than normal risk of developing thrombosis.

ECPC is using the results of this survey to identify where more education and information is needed, and advocate for more action on this issue. This survey is also a tool to demonstrate towards policymakers and health professionals where more needs to be done to raise awareness about cancer-associated thrombosis and supportive care among cancer patients.

ECPC officially presented the findings of the report and recommendations for action at an event in the European Parliament. The event titled Saving Lives by Increasing Awareness of Cancer-Associated Thrombosis (CAT) was organised in collaboration with the European Thrombosis and Haemostasis Alliance and World Thrombosis Day Initiative, and kindly hosted by Members of the European Parliament Deirdre Clune (EPP, Ireland) and Nessa Childers (S&D, Ireland).



ECPC greatly acknowledges the support of LEO Pharma A/S.

## 7.6 • Joint Action on Rare Cancers

The Joint Action on Rare Cancers (JARC) aims to integrate and maximize efforts of the European Commission and EU Member States to advance quality of care and research on rare cancers. The public health challenge posed by rare cancers combines both the typical problems of rare diseases and cancers where the need of timely diagnosis and access to quality treatment is vital. JARC is producing recommendations aimed at optimising the developments of the European References Networks (ERNs) in the area of rare cancer through synergies with Member State policies on rare cancers.

Accordingly, the JARC is shaping its efforts around the ERNs specifically devoted to rare cancers (ERN for rare adult solid cancers (EURACAN), ERN for adult rare hematological cancers (EuroBloodNet) and ERN for pediatric cancers (ERN PaedCan). These ERNs have been conceived by the European Commission as a means to provide “highly specialised healthcare for rare or low-prevalence complex diseases”.

The formal activation of ERNs is a cornerstone in the EU cooperation on rare cancers, and the JARC is instrumental to help them evolve by optimizing the creation of ERNs through the provision of operational support and professional guidance in the areas of quality of care, epidemiology, research and innovation, education and state of the art on prevention, diagnosis and treatment of rare cancers.

We believe that harmonized application of the guidelines at national level is vital in delivering on the objectives of the Cross-Border Healthcare Directive. ECPC is building on experience gained during its 3 years collaboration in the RARECAREnet project. In order to better represent the rare cancer patient community, ECPC counts on the expertise and collaboration of rare cancer patient organisations all over Europe. Following the formal request of several rare cancer patient representatives during the ECPC Annual Congress 2016, ECPC has established a Working Group on Rare Cancers, working in parallel with the Joint Action on Rare Cancers, to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, will be able to contribute to the activities of the JARC. ECPC has a horizontal role representing the voice of the rare cancer patients across all the projects.

In 2018, ECPC mapped patient educational material and performed a patient survey to identify gaps in availability of educational material, which will be the basis to develop ad hoc information material in the following year. ECPC is advocating to ensure that treatments issued by ERN linked centres of expertise are accepted for reimbursement in all Member States.

## 7.7 • Legal Network for Cancer Patients

The ECPC Legal Network for Cancer Patients, established in 2017, held a working meeting at the ECPC Annual Congress 2018. Members discussed the legislative

progress at the EU level and set out the work plan for 2018. The ECPC Legal Network for Cancer Patients played a significant role in developing amendments to the legislative proposal on Work-Life Balance Directive for Parents and Carers and the Regulation for future EU cooperation on Health Technology Assessment, which were submitted by partner Members of the European Parliament. For the first time, the Work-Life Balance Directive for Parents and Carers reinforces the formal recognition of carers and introduces minimum standards for paid carers' leave and flexible working arrangements.

The ECPC Legal Network for Cancer Patients worked with the European Organisation for Research and Treatment of Cancer (EORTC) to conduct a survey of its member organisations to map legal provisions in social and employment law affecting people with cancer. The survey identified the challenges faced by people with cancer in different EU Member States: those undergoing acute treatment, the survivors and carers. The findings will be used to develop a White Paper on Social Disparities in Europe in 2019.

## 7.8 • European Commission Initiative on Breast Cancer



ECIBC is a person-centred initiative to improve breast cancer care. The JRC-Joint Research Center of the European Commission, with ECIBC, is developing the most up-to-date evidence-based recommendations on screening and diagnosis, with a platform of trustworthy guidelines for the whole care pathway.

There two working groups active on ECIBC, the Guidelines Development

Group (GDG) and the Quality Assurance Scheme Development group (QASDG). They are composed by experts selected through public open calls. The working groups' members discuss and draft documents either from "remote"- within virtual working environments - either face to face in meetings organised, generally, every three months.

They represent a very wide range of expertise with the aim to be as inclusive as possible. ECPC is represented in the QASDG by Vice President K. Apostolidis.

The **European QA scheme** is a collection of requirements and indicators. Its implementation guarantees that compliant breast cancer services can offer to users (women, patients and carers) top quality and most updated procedures for breast cancer screening and care. The requirements focus on the person's needs and are based on the most updated evidence-based guidelines. The scheme applies to Breast Cancer Services (BCSs), defined as all healthcare services covering, in continuum, the full extent of breast cancer

management, from screening to follow-up, and in some cases until the end-of-life care.

The objective of the **Guidelines Development Group** (GDG) is to develop evidence-based European Guidelines for breast cancer screening and diagnosis (the European Breast Guidelines) for screening and diagnosis. The GDG followed the GRADE approach in defining the healthcare question of interest (population of interest, interventions to be compared and patient-relevant outcomes- PICO), synthesizing the evidence and developing the recommendations for the Guidelines. It was carried out within virtual working environments and in meetings organised every three months.



The ECIBC is developing recommendations for breast cancer screening and diagnosis. Supplemental recommendations will be developed and updated as new evidence and priorities emerge. You can consult the published cancer screening and diagnosis recommendations on the ECIBC website.

<https://ecibc.jrc.ec.europa.eu>

## 8 • Capacity-building activities

### 8.1 • ECPC Annual Congress 2018

The ECPC Annual Congress continues to be the Europe's largest gathering dedicated to people with cancer hosting more than 210 stakeholders from 156 organisations and 35 countries in 2018.

Representatives from the European Commission, the European Medicines Agency (EMA) and the European Parliament have featured as speakers in 2018 together with key opinion leaders and experts from the world of oncology. The topics covered in 2018 ranged from Health Technology Assessment, Immunotherapies and Molecular Testing to much broader challenges faced by cancer carers and survivors.

The ECPC Annual Congress also presented an opportunity for industry partners to better understand the status of cancer patients' advocacy in Europe and hear the voice of expert patients and patients' advocates from different countries. The ECPC 2018 Annual Congress is also where the annual working group meetings took place, offering more in-depth debates on specific areas such as social disparities, rare cancers and bladder cancer.





Members of ECPC were also selected to share their best practices, successes, and challenges.

*"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." said Francesco de Lorenzo, President of the European Cancer Patient Coalition. "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."*

This event was held under the high patronage of the Her Royal Highness Princess Astrid of Belgium, the European Parliament, and the European Commission. In a video message from the European Commissioner of Health & Food Safety, Vytenis Andriukaitis stated *"Cancer patients across Europe regrettably face disparities and delays in accessing innovative technologies that work, therefore*



*I think that the focus on Health Technology Assessment for this Annual Conference is excellent. This is a very important and very relevant issue. I believe that EU cooperation has clear potential to facilitate innovative technologies across Europe that truly provide patients with the best treatment available for their*



*specific conditions. The European Parliament and Council are currently discussing the Commission's proposal on HTA. This is the moment that the constructive input of the European Cancer Patient Coalition and all patient organisations is of crucial importance. I would like to thank you for your continued engagement and strong support on our HTA proposal."*

## 8.2 • ECPC newsletter

A newsletter regularly informs ECPC Members and stakeholders of all the initiatives of the organisation. More than 700 email addresses of national and European cancer patients' organisations and other stakeholders are included in the database. It is an instrument to increase ECPC Members' participation in the activities of the association. ECPC can monitor and analyse what ECPC's Members find more interesting, which consolidates our understanding of the Members' needs.

In 2018 ECPC continued to provide its Members and stakeholders with information on policy and advocacy in cancer. The objective is threefold: to raise understanding of the complex EU public health policy panorama, to explain the impact of EU health policies on their life, and to engage them to proactively contribute to ECPC's policy work. This newsletter also included relevant information on any new cancer treatments that have been authorised by the European Medicines Agency (EMA).

ECPC published a Project Newsletter addressed to stakeholders and Members with updates in the projects in which ECPC is partnering in. The organisation also sent newsletters to invite its Members to events, to disseminate a survey on social and employment matters and promote several awareness campaigns.

## 9 • EU Health and research programmes

### 9.1 • European Reference Network for Rare Adult Solid Cancer (EURACAN)

European Reference Networks (ERNs) are virtual networks involving healthcare providers and other stakeholders across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. ERNs will reinforce their capacities to benefit thousands of Europeans diagnosed with a rare or complex condition from 2017 to 2021.

The EURACAN European Reference Network gathers all rare adult solid cancers which are grouped in 10 domains corresponding to the RARECARE and RARECARENet classification, in addition to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). EURACAN is coordinated by the Centre Leon Bernard.

ECPC is one of the patient organisations representing the needs, rights and hopes of adults with rare solid cancers as a European Patient Advisory Group Representative coordinated by EURORDIS. Furthermore, ECPC is co-chairing the Transversal Taskforce under Communication and Dissemination. In 2018, ECPC oversaw the translation of the website into 10 additional languages and maintained the EURACAN website and social media accounts, established in 2017. ECPC also published the first two EURACAN quarterly newsletters.

### 9.2 • IMI BD4BO DO-IT

The overall goal of the Big Data for Better Outcomes (BD4BO) programme is to facilitate the use of 'big data' to promote the development of value-based, outcomes-focused healthcare systems in Europe. Big data has become a common theme in global policy and clinical arenas. The growing focus on its use in health has come as policy makers and clinical leaders recognise the potential value in leveraging data to optimise the quality of care, improve patient outcomes, and increase efficiency in healthcare.

Within the BD4BO programme, the Big Data for Better Outcomes, Policy Innovation and Healthcare System Transformation (DO-IT) was established in 2017 and will run until 2019. DO-IT aims to:

- Define a programme strategy that ensures quality, consistency and sustainability of health outcomes related activities across individual BD4BO projects.
- Integrate, synthesise, and manage knowledge from all BD4BO projects, making it easily accessible via a single knowledge exchange platform.

- Act as pivotal point of collaboration, stakeholder engagement and communication for all BD4BO projects.
- Provide transparency and enable the use of patient health data and human biological samples for research purposes by developing minimum data privacy standards for Informed Consent Forms and supporting materials.

In 2018, ECPC hosted two Patient Focus Groups, delivering 38 recommendations on the DO-IT Clinical, Non-Clinical, and Biobanking Informed Consent Forms (ICFs), as well as the patient educational materials. In June 2018, DO-IT launched a practical toolkit for the identification, selection, and measurement of outcomes including in real-world settings, as well as two webinars: “An HTA perspective on Acceptability of Real-World Evidence and Methods to Enhance its use” and the “In data we trust: Towards outcomes-based healthcare in Europe”.

ECPC and BD4BO Do-IT researchers have been disseminating, presenting, and discussing project results up to date at various conferences and workshops.

### 9.3 • IMI BD4BO PIONEER

PIONEER is one of the 4 BD4BO disease-specific projects launched with the objective of harnessing the opportunities of big data to promote patient-centred outcomes. The project serves as the European Network of Excellence for Big Data in Prostate Cancer. It is funded by the Innovative Medicines Initiative 2 (IMI2) and runs from January 2018 to January 2023.

By applying advanced data analytics and developing a data-driven platform of unparalleled scale, quality and diversity, PIONEER will empower meaningful improvement in clinical practice, prostate cancer disease-related outcomes, and health-economic outcomes across the European healthcare landscape. PIONEER assembles, standardises, harmonises and analyses high-quality big data from diverse populations of prostate cancer patients across different stages of the disease to provide evidence-based data for improving decision-making by key stakeholders.

ECPC is part of the work package on dissemination and communication of the project's aims, objectives and results. It runs in parallel with all other work packages and for the entire lifecycle of the project. ECPC and other patient organisations ensure that the project outcomes are effectively communicated to patients in a language they can understand. The participation of ECPC ensures that patients engage in their disease management, thus leading to better treatment adherence and improved Quality of Life (QoL).

ECPC also ensures that the visual identity of PIONEER is aligned with the branding of the BD4BO DO-IT project.

In 2018, PIONEER has identified, through a comprehensive prioritisation

exercise, the top 5 research questions for prostate cancer which all the relevant stakeholders (healthcare professionals, pharmaceutical companies, and patients) agree that they need to be, and can be, answered through the use of Big Data and Big Data analytics. These research questions overarch each work package contributing to their investigation and, as such, are used to validate PIONEER's framework and provide valuable insights into the diagnostic and treatment pathways of the different stages of prostate cancer.

## 9.4 • IMI PREFER Patient Preferences

PREFER, funded by the Innovative Medicines Initiative (IMI), is a 5 year project with the main objective to strengthen patient-centric decision making throughout the life cycle of medicinal products (a term which, in the context of the proposal, also includes medical devices) by developing evidence-based recommendations to guide industry, Regulatory Authorities, HTA bodies, reimbursement agencies, academia, and health care professionals on how and when patient-preference studies should be performed and the results used to support and inform decision making. The project runs from 2016 to 2020.

ECPC leads the Patient Advisory Group which involves a total of 4 patient organisations including Muscular Dystrophy UK (MDUK), European Patients' Forum (EPF) and International Alliance of Patients' Organizations (IAPO). Up to 2018, we helped put support systems in place for data management, a project website, plans for how to communicate about the project and connect with the stakeholders we will be writing our recommendations for, and a Glossary of Terms. Moreover, the project successfully completed a comprehensive assessment of methods used in health preference studies, as well as, interviewed 143 different stakeholders to find out what they desire, and expect, from preference studies.

The survey and focus groups addressed stakeholders' concerns, needs, and methods the studies should meet and if and when we could use patient preferences to make decisions on drugs and medical products. PREFER also completed a review of "psychological constructs" that could influence a person's preferences and decision-making. The scientific team progressed to develop guidelines for selecting which of these psychological constructs we will include in the upcoming PREFER preference studies.

ECPC participates equally with other researchers in the Project Management Board and Steering Committee offering advice and feedback to ensure that the trials are designed and conducted in line with patients' needs and preferences. In 2018, PREFER initiated the design of 4 preference studies that include information collected from various stakeholders, and other completed work. ECPC and PREFER researchers have been disseminating, presenting, and discussing project results up to date at various conferences and workshops.

## 9.5 • H2020 ImmunoSABR metastatic lung cancer

ImmunoSABR is geared towards opening up a new paradigm in treating metastatic cancer by obtaining clinical proof of concept for a novel bi-modal curative treatment strategy. High precision stereotactic ablative radiotherapy (SABR) is combined with immunotherapy to form a powerful synergistic anti-tumour strategy. ImmunoSABR will run from 2016 to 2022.

The ImmunoSABR clinical trial is trying to find a better way to treat metastatic cancer. In this randomised open label phase II clinical trial, stereotactic ablative radiotherapy (SABR) will be combined with L19-IL2 immuno-oncology therapy in people with limited metastatic non-small cell lung cancer (clinicaltrials.gov no. NCT02735850). ImmunoSABR will also use cancer biomarkers to develop a way to predict which people will most benefit from this novel treatment strategy.

ECPC is part of the consortium to represent the voice of the cancer patients, organising a patient consultation session to discuss ImmunoSABR and disseminating information about the trial. In 2018, ECPC gave input into the development of the informed consent forms and the patient information brochure. In addition, ECPC has been conveying information about the ImmunoSABR trial to its own network, other relevant European patient organisations, and the general public. At the conclusion of the project, ECPC will organise a final event within the European Parliament.

## 9.6 • H2020MM04 DENIM mesothelioma

Malignant pleural mesothelioma is a rare but highly aggressive cancer that annually kills about 43,000 people worldwide. It is mainly caused by asbestos inhalation due to asbestos exposure and, although asbestos use is decreasing, mesothelioma incidence is expected to keep increasing for the next 20-50 years due to its long latency period. Unfortunately, there is no curative therapy for mesothelioma, making it a highly fatal disease. There is thus a clear unmet medical need for the treatment of mesothelioma. The main objective of the project is to demonstrate the efficacy of dendritic cell-based immunotherapy in a randomised Phase 2/3 clinical trial in order to address this urgent need. The project will run from 2016 to 2019.

Due to several delays in the country approvals for the clinical studies, the starting date of the study has been postponed to June 2018 with a completion date in January 2021. An amendment has been initiated. The project is in its initial phase.

## 9.7 • H2020 Transcan-2 European Research Area

The ERA-NET: Aligning national/regional translational cancer research programmes and activities - TRANSCAN-2 is a five-year project funded by the

European Commission under the EU framework programme Horizon2020 and runs from 2015 to 2019.

The objective of TRANSCAN-2 is to contribute to the building of the European Research Area through the coordination of activities of national and regional translational cancer research funding organisations, aiming at the integration of basic, clinical and epidemiological cancer research and facilitation of transnational cancer funding in Europe with the ultimate aim to streamline EU-wide cancer screening, early diagnosis, prognosis, treatment and care.

TRANSCAN-2 has the goal of coordinating national and regional funding programmes for research in the area of translational cancer research. The specific challenge is to promote a transnational collaborative approach between scientific teams in demanding areas of translational cancer research while avoiding the duplication of efforts and ensuring a more efficient use of available resources, to produce significant results of higher quality and impact, and share data and infrastructures.

The Italian Ministry of Health and the National Institute of Health act as Joint Call Secretariat. ECPC is represented in the Scientific Advisory Board, one of the three main governing bodies of the network. The Scientific Advisory Board serves as a source of input and feedback about the work of TRANSCAN and is in close collaboration with the other two bodies: The Network Steering Committee, as the strategic decision-making body and the Network Coordination Unit, as the body responsible for the day-to-day management and the external TRANSCAN consortium representation.

## 9.8 • FP7 eSMART mHealth symptom management

eSMART (e-Symptom Management using Advanced Symptom Management System Remote Technology) is a research project financed under the Seventh Framework Programme, coordinated by the University of Surrey. The clinical trial aims to evaluate the impact of a mobile phone-based, remote monitoring, symptom management intervention (the Advanced Symptom Management System, ASyMS) on the delivery of care to people diagnosed with non-metastatic breast, colorectal or haematological cancer during chemotherapy and for one year after the end of treatment. eSMART involves 10 world-renowned European and one American partner. The project runs from 2014 to 2019.

eSMART aims to demonstrate how technology can be instrumental in the delivery of patient focused, anticipatory care that improves the outcomes and quality of life of people with cancer. It will demonstrate the effects of a real-time, mobile phone based, remote patient monitoring and care. The interventions will address key cancer patient symptoms and cancer care results and the delivery of care during and after chemotherapy. The remote patient monitoring system via ASyMS will help people with cancer reduce the



symptom burden experienced during chemotherapy and improve their quality of life during acute treatment and survivorship. Most important, the project results will facilitate changes in clinical practice thus, leading to improved delivery of cancer care.

Patients have a prominent co-researcher role in eSMART and participate in all project activities from project concept to implementation. ECPC participates equally with other researchers in the eSMART project in the Project Technical Management Board, in the Publications Committee, and in the Exploitation Committee, offering advice and feedback to ensure that the trial was designed and conducted in line with patients' needs and preferences.

ECPC and eSMART researchers have been disseminating, presenting, and discussing project results up to date at various conferences and workshops.

## 9.9 • Innovative Training Networks

ECPC takes part in two Innovative Training Networks (ITNs) as a partner organisation. We contribute to the training courses by offering expertise in patient involvement, as well as advocating the role of patients/co-researchers as the best partnership model between researchers and patients, since it allows patients to contribute with their unique experience to key decisions regarding research projects.

ECPC is participating in the Project Advisory Board to monitor the project progress and provide input on the design and direction and using its communication channels to share information about the project and its results. ECPC delivers a presentation on the role that people with cancer play in research during the planned training activities. ECPC also advises on the communication of complex research results to a wide audience, bringing the patient perspective and recommendations for scientific writing.

### 9.9.1 • European Liquid Biopsies Academy

Liquid biopsies have been heralded as a game changer in cancer management, with blood tests offering a minimally invasive, safe, and sensitive alternative or complimentary approach for tissue biopsies. The European Liquid Biopsies Academy (ELBA) is an ITN that educates 15 Early Stage Researchers (ESRs) with the skills to circumvent the obstacles currently hampering effective development and commercialisation of liquid biopsy approaches. It makes scientific advances towards widespread implementation of blood-based diagnostics tests, create a sustainable network to foster long-term multidisciplinary relationships to accelerate clinical translation of blood-based diagnostics tests and publish a roadmap to liquid biopsy test development. The project runs from 2018 to 2021. The project is in its initial phases.

### 9.9.2 • PREDICT

Tumour cells can differ greatly both between patients (inter-tumour heterogeneity) and within patients (intra-tumour heterogeneity). These differences affect how patients respond to cancer therapy and hampers wide deployment of personalised medicine for cancer treatment. PREDICT is an ITN that will educate 15 ESRs in the fields of radiomics and personalised medicine. These researchers are trained to use big data analytics on large amounts of radiographic images to determine tumour heterogeneity and predict how patients will respond to treatment. This project runs from October 2017 until September 2021. The project is in its initial phases.

## 10 • Collaborations & Partnerships

### 10.1 • European Medicines Agency

The European Medicines Agency (EMA) is a decentralised agency of the EU responsible for clinical efficacy assessment of medicines, ensuring that all medicines available on the EU market are safe, effective and of high quality.



Through ECPC Vice President Apostolidis and Associate Consultant Rafal Swierzewski, ECPC expresses the views of people with cancer as an accredited member of the Patients' and Consumers' Working Party (PCWP), the main patients' working group within the EMA 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.

In 2018, ECPC participated as the Agency's stakeholder in tasks described in the Business Continuity Plan (BCP) elaborated by EMA due to Brexit and its possible consequences on the process of oncologic medicines authorisation, evaluation and availability in EU-27 countries after Brexit. This included ECPC representation and active participation in the process of European Clinical trials portal and database development (Clinical Trial Information System), Digital Health in EMA, PCWP face to face and virtual meetings and review of new oncologic medicines documentation.

ECPC has also continued its representation in Technical Anonymization Group (TAG), created by EMA on the regulatory needs connected to medical, clinical and research data transparency. Additionally, ECPC involved several patient representatives in Scientific Advisory Groups and other scientific advice procedures of the European Medicines Agency. These patient representatives shared their real-life perspective and experience in relation to medicines in their disease area.

Lastly, ECPC participated in the workshops titled "EMA/EMA workshop on availability of authorised medicines", "EMA Regulatory Science to 2025 workshop" and "Big Data Workshop: Regulatory Solutions for Big Data Challenges".

### 10.2 • ESMO

In 2018, ECPC and the European Society for Medical Oncology (ESMO) continued the long-established partnership and implemented the actions and commitments agreed in the Memorandum of Understanding. By enhancing the existing cooperation and increasing the efforts to achieve their common goals

and objectives in the field of cancer to satisfy new needs and new rights of people with cancer across Europe.

### 10.2.1 • ESMO Guidelines

ECPC is directly involved in drafting of updates of the new ESMO Clinical Practice Guidelines. Updated regularly by the ESMO Guidelines Committee, the Guidelines are the standard for best practice of a vast variety of cancers, and represent the most reliable, evidence-based resource to help oncologists in taking practical decisions that affect patients' lives. ECPC and ESMO decided to partner so to include more patient-friendly and solid information in the guidelines. To do so ECPC invited some of its Members to assess the information material to make sure it was understandable for patients. In the last years, each updated ESMO Guideline contained a reviewed, patient-oriented survivorship chapter. Simultaneously, ECPC published on its website all ESMO Guides for Patients, an invaluable source of information, which is often overlooked by those that could benefit the most.

### 10.2.2 • Response on the guidelines on consent under GDPR

Jointly with ESMO, ECPC submitted a response to the Article 29 Working Party consultation on the guidelines on consent, in relation to the General Data Protection Regulation (GDPR). As the processing of 'special categories of data' regulated under the GDPR is of fundamental importance to the future of medical breakthroughs and bringing better outcomes for patients, both organisations proposed further clarifications within the guidelines to avoid any discrepancies in the implementation of the regulation.

### 10.2.3 • Survivorship Guide

The ECPC-ESMO Survivorship Guide, a useful tool for patients and physicians offering concise but comprehensive summary of patient diagnosis and treatment in addition to follow-up care, was translated into several additional languages. In 2018, the Survivorship Guide was made available in English, German, Greek, Spanish, French, Croatian and Italian and is available on the ECPC and ESMO websites as well as in print, and was distributed at key events throughout the year.

### 10.2.4 • 2018 ESMO Congress in Munich

As every year, ECPC was present at the ESMO Annual Congress 2018, the biggest European gathering for oncology community, which took place between 19-23 October in Munich, Germany. The event was the opportunity for hundreds of patient advocates for networking and gave the possibility to discuss vital issues and challenges faced by cancer patients.

The ESMO Annual Congress 2018 was held under the tagline “*Securing access to optimal cancer care*” and also featured a dedicated nursing track through a collaboration with the European Oncology Nursing Society (EONS).

ECPC, as a Member of the ESMO Patient Advocates Working Group (PAWG), actively participated in the process of making sure that patients were in the centre of the ongoing discussions. The ESMO PAWG main mission is 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.

As each year, ECPC had a strong representation at the ESMO Annual Congress. ECPC President de Lorenzo, Vice-President Apostolidis together with other ECPC Board Members, Maude Andersson and Matti Jarvinen, as well as the secretariat closely followed the sessions focused on patient advocacy, as well as attended fruitful meetings with our partners, discussing joint activities and the ECPC Action Plan for 2019.

ECPC Board Member Matti Järvinen presented twice at the EONS11 Symposium. His presentations included sharing the patient perspective on “Carers’ role in patients’ cancer journey” and “The essential elements of safety standards for systematic cancer therapies”. ECPC Board Member Maude Andersson also presented on “The impact of contact nurses from a patient’s perspective” during EONS11 Symposium session on: Nursing roles: “Aiming for Better Recognition of Cancer Nursing Across Europe to improve Patient Outcomes.”

### 10.3 • ECCO Patient Advocate Committee

ECPC is a member of the European Cancer Organisation (ECCO) Patient Advisory Committee, which was established to contribute to the European Cancer Congress by providing patients’ perspectives and helping healthcare professionals and all delegates to better understand the “desires” of patients, rather than just their perceived “needs”.



[www.ecco-org.eu](http://www.ecco-org.eu)

### 10.4 • All.Can

ECPC is one of the founding members of All.Can, 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's improvement in cancer care. ECPC is represented in the Steering Committee of All.Can and actively participates in its governance and various working groups.



In 2018, ECPC actively supported the dissemination of All.Can Patient Survey to patient organisations across Europe. The survey collected views from a number of countries in Europe and globally, on what needs to improve or change in the delivery of care for cancer patients throughout the care pathway. The findings will help identify the greatest opportunities to improve efficiency in cancer care in a way which is most meaningful to patients and will be published in 2019.

All.Can also organised a seminar in the European Parliament in January 2018, in partnership with ECPC and several other leading organisations in oncology and the MEPs Against Cancer group.

ECPC supported the organisation and participated at the first ever All.Can Global Summit which took place in Vienna in September 2018, bringing together more than 50 attendees from 15 countries.

Over the course of 2018, the All.Can community has doubled its outreach to over 150 experts with a number of new national initiatives launched globally.

[www.all-can.org](http://www.all-can.org)

## 10.5 • Union for International Cancer Control (UICC)



ECPC organised a session at the World Cancer Congress 2018 which took place in Kuala Lumpur, Malaysia in October, organised by the Union for International Cancer Control (UICC) of which ECPC is a member. The session under the conference track called "Maximising quality of life and death. Empowering patients and caregivers" was organised to strengthen participants' understanding of the benefits of building partnerships to support people with cancer and their families and deliver

practical insights and lessons. The ECPC Audit Committee member Pietro Presti presented the intervention "Patients partnering with policymakers to advocate for better support for informal carers in Europe" to highlight the



achievements of ECPC at EU level to recognise and protect carers across Europe.

[www.uicc.org](http://www.uicc.org)

## 10.6 • Organisation for European Cancer Institutes (OECI)

ECPC and the Organisation of European Cancer Institute (OECI) continued its collaboration for the third year. Since the signing of the Memorandum of Understanding in 2015, this incredibly powerful partnership effectively represents all those involved in the race to win the fight against cancer using the best tools at ECPC's disposal.



In 2018, ECPC President de Lorenzo presented the role of meaningful patient involvement in the future cancer research in the EU at the 1<sup>st</sup> Meeting OECI European Cancer Mission. The meeting gathered key experts and stakeholders of the oncology community committed to work together. ECPC was acknowledged as a strong partner in science and an essential partner for defining future cancer research and collaboration with patients.

[www.oeci.eu](http://www.oeci.eu)

## 10.7 • European Organisation for Research and Treatment of Cancer (EORTC)

ECPC continued the ongoing partnership with the European Organisation for the Research and Treatment of Cancer (EORTC), one of the most important academic research institutions in the field of cancer in Europe. The EORTC aims to improve the standards of cancer treatment by testing more effective therapeutic strategies based on drugs, surgery and/or radiotherapy.



ECPC and EORTC have signed a Memorandum of Understanding in 2017 to formalise and strengthen their partnership. Collaborating activities include the organisation of seminars, meetings, roundtables, joint projects, training and joint publications.

In light of this MoU in 2018, ECPC and the EORTC have organised the bi-annual Course dedicated to Patients and Caregivers interested in Cancer Clinical Research in Brussels, Belgium. The course aimed to provide cancer patient advocates with a stimulating and challenging two-day training experience leading to a much greater understanding of the whole clinical trials process.

The ECPC Legal Network for Cancer Patients worked with EORTC to develop and disseminate the survey of its member organisations to map legal provisions in social and employment law affecting people with cancer and carers.

ECPC closely collaborates also with EORTC/QoL group that conducts research to better understand the effects of cancer and its treatment on the health-related quality of life of diverse populations of patients with cancer, across different cultures. ECPC is an invited presenter at the EORTC/QoL Group Conference.

[www.eortc.org](http://www.eortc.org)

## 10.8 • 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.

In 2018, ECPC and EAU have signed a Memorandum of Understanding (MoU) to formalise the partnership which has been ongoing since 2015. It enables collaboration between both organisations and facilitated the implementation of joint projects. ECPC has supported the development of the EAU Scientific and Policy Briefing paper on Kidney Cancer, which was launched during a policy roundtable in October 2018.

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](http://www.uroweb.org)

## 10.9 • European Alliance for Personalised Medicine (EAPM)

ECPC is one of the founding members of the European Alliance for Personalised Medicine (EAPM), which 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.



European Alliance for  
Personalised Medicine

In 2018, ECPC collaborated with the EAPM to launch the first ever Personalised Medicine Awareness Month in November. At the Annual European Congress on Personalised Medicine 2018, which took place in Milan, Italy, ECPC led a Patient Track covering the biggest challenges for patients in the field of personalised medicine.

[www.euapm.eu](http://www.euapm.eu)

## 10.10 • Cancer Drug Development Forum

The Cancer Drug Development Forum (CDDF) aims 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.



ECPC President de Lorenzo represents the organisation in the Board of CDDF and actively contributes to committees of various events organised by CDDF. CDDF also contributed to the launch of the first Personalised Medicine Awareness Month in November 2018.

In 2018, ECPC and CDDF organised a multi-stakeholder Workshop on Biomarkers and Patients' Access to Personalised Oncology Drugs in Europe, which took place in Brussels, Belgium. The event brought together over 150 experts from the oncology community and concluded with a session on Health Technology Assessment which took place in the European Parliament.

## 10.11 • European Society of Surgical Oncology



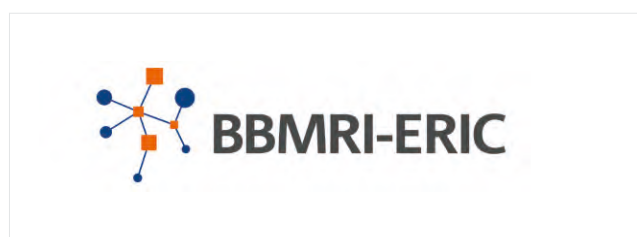
The European Society of Surgical Oncology (ESSO) aims to advance the science and practice of surgical oncology for the benefit of cancer patients. The organisation has established a Patient Advisory Group (PAG) within its structure to incorporate the perspective of patients.

ECPC is represented in the PAG by Vice President K. Apostolidis and has contributed to its work, supporting the pursuit of surgical specialisation in oncology. ESSO leads 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 of cancer patients through its core values as well as its activities in the field of education, homogenisation of skills, quality healthcare and, ultimately, qualification.

[www.essoweb.org](http://www.essoweb.org)

## 10.12 • 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 has steadily supported BBMRI-ERIC since its first Stakeholders Forum in 2010, attended by its then Director and ECPC members. In 2018, ECPC joined

the BBMRO-ERIC Stakeholder forum, which is the main interface for European patients' organisations, civil society, industry and academia to interact with the biobanking universe. The role of stakeholders is enshrined in the BBMRI-ERIC statutes: as one of the advisory boards, the Stakeholder Forum contributes to the decision-making process of BBMRI-ERIC, together with the Scientific and Ethical Advisory Board (SEAB). ECPC representation ensures we are on the forefront of biobanking developments necessary for biomedical research.

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 21 countries and 4 continents. The shared vision of the Worldwide Innovative Networking Consortium aims to deliver effective and personalised cancer medicine to patients worldwide. Two ECPC representatives sit in the General Assembly of the WIN Consortium.

The WIN Symposia, held annually in Paris, gathers leaders representing a breadth of stakeholders from all around the world to learn, share and collaborate. In 2018, the 10<sup>th</sup> year Anniversary edition of the WIN

Symposium was titled "Global Implementation of Precision Oncology: WINning the War against Cancer" and was held from 25 to 26 June. During the WIN 2018 Symposium, ECPC President de Lorenzo presented about Patients' access to Precision Oncology.

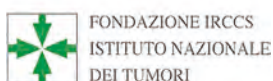


## 11 • Industry Partners

ECPC seeks to partner with responsible corporations and foundations to advance its mission to promote cancer prevention, treatment and survivorship 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.

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

### 11.1 • Public Entities and Non-Profit Organisations



### 11.2 • Top five industry partners





### 11.3 • Other industry partners

abbvie

AMGEN

**Baxter**

 **Boehringer  
Ingelheim**

janssen 

 **Celgene**

 **Genomic Health**  
LIFE. CHANGING.

 **HELINN**  
Building quality cancer care together

 **IPSEN**  
Innovation for patient care

 **TESARO**

 **Takeda**

*Johnson & Johnson*

*Lilly*

  
NOVARTIS

 **Pfizer**

## 12 • European Cancer Patient Coalition Income statement

### 2018 Income sources

| Source of Revenue in 2018                 | Amount (€) | Percentage |
|---|------------|------------|
| <b>EU-funded Projects</b>                 | € 71.752   | 7%         |
| • JARC                                    | € 20.000   |            |
| • EURACAN                                 | € 2.045    |            |
| • PREFER                                  | € 27.005   |            |
| • PIONEER                                 | € 21.596   |            |
| • DENIM mesothelioma                      | € 1.105    |            |
| <b>Donations</b>                          | €9.953     | 1%         |
| <b>Miscellaneous revenue</b>              | € 15.542   | 1,5%       |
| • Reimbursements                          | € 10.542   |            |
| • other                                   | € 5.000    |            |
| Total non-industry revenue                | € 97.247   |            |
| Grants from pharmaceutical companies for: |            | 90,5%      |
| • Annual Congress 2018                    | € 108.995  |            |
| • Carers work-life balance                | € 20.000   |            |
| • Clinical Trials                         | € 20.000   |            |
| • HTA                                     | € 205.000  |            |
| • Personalised Medicine Month             | € 195.000  |            |
| • Immuno-Oncology                         | € 40.000   |            |
| • White Paper Cancer Patients' Carers     | € 10.000   |            |
| • Make Sense                              | € 25.000   |            |
| • Nutrition and Physical Activity         | € 50.000   |            |
| • Bladder Cancer                          | € 65.500   |            |
| • Supportive Care Roundtable              | € 14.254   |            |
| • Supportive Care Survey                  | € 80.000   |            |
| • Merkel Cell Carcinoma                   | € 29.386   |            |
| • Survivorship                            | € 48.750   |            |
| • Pancreatic Cancer                       | € 15.000   |            |
| Total Industry revenue                    | € 926.885  |            |

**Total revenue €1.024.132**

## 2018 Expenses breakdown

| Expenses   | 2017      | 2018      | Difference  | %    |
|--|-----------|-----------|-------------|------|
| <b>Staff Costs<sup>1</sup></b>                                 | € 276.934 | € 417.820 | + € 140.886 | +50% |
| • Employer Contributions                                       | € 127.493 | € 162.448 |             |      |
| • Gross salaries   | € 149.446 | € 254.086 |             |      |
| • Employee Contributions                                       | € 19.428  | € 38.113  |             |      |
| • Net salaries   | € 130.018 | € 215.973 |             |      |
| • Other costs (training, team building)                        |           | € 1.573   |             |      |
| <b>Management and Running Costs</b>                            | € 71.099  | € 88.429  | + € 17.330  | +24% |
| • Office rent & maintenance                                    | € 42.169  | € 54.579  |             |      |
| • Energy consumption   | € 1.384   | € 1.556   |             |      |
| • Office supplies  | € 2.414   | € 4.471   |             |      |
| • IT maintenance & costs                                       | € 4.202   | € 8.412   |             |      |
| • Telephone & internet   | € 4.851   | € 8.308   |             |      |
| • Fee subscriptions  | € 2.379   | € 2.154   |             |      |
| • Other office costs (printing, coffee machine, postage, etc.) | € 2.678   | € 4.852   |             |      |
| • Legal / Notary costs   | € 3.400   | € 2.845   |             |      |
| • IT investment  | € 6.691   |           |             |      |
| • Bank costs   | € 429     | € 326     |             |      |
| • Insurance costs  | € 501     | € 926     |             |      |
| <b>Board</b>   | € 24.790  | € 28.142  | + € 3.352   | +13% |
| • Board Institutional travel <sup>2</sup>                      | € 18.895  | € 18.545  |             |      |
| • Board advocacy travel <sup>3</sup>                           | € 5.895   | € 9.597   |             |      |
| <b>Annual Congress</b>   | € 107.569 | € 138.997 | + € 31.552  | +29% |
| <b>Advocacy &amp; Awareness</b>                                | € 12.012  | € 14.752  |             |      |
| • Staff advocacy travel <sup>3</sup>                           |           |           |             |      |
| <b>Projects</b>  | € 76.030  | € 334.419 |             |      |
| • Biomarkers   | € 6.911   | € 44.124  |             |      |
| • HTA  | € 7.584   | € 72.600  |             |      |
| • Immuno-Oncology  | € 13.239  | € 40.800  |             |      |
| • World Cancer Day   | € 2.180   | € 13.559  |             |      |
| • Make Sense   | € 10.973  | € 31.009  |             |      |
| • Nutrition and Physical Activity                              | € 6.622   | € 65.040  |             |      |
| • Bladder Cancer   |           | € 4.502   |             |      |
| • Supportive Care Roundtable                                   |           | € 41.808  |             |      |
| • Supportive Care Survey                                       | € 8.021   | € 16.521  |             |      |
| • Merkel Cell Carcinoma  |           | € 4.456   |             |      |
| • Survivorship   | € 2.320   |           |             |      |
| • EORTC Patient Days   | € 18.180  |           |             |      |

|                                  |                  |                    |                  |             |
|----------------------------------|------------------|--------------------|------------------|-------------|
| <b>EU Projects</b>               | € 32.889         | € 3.768            |                  |             |
| • Project travel                 | € 19.857         | €3.768             |                  |             |
| • Project publications           | € 3.154          |                    |                  |             |
| • Project conferences & catering | € 2.455          |                    |                  |             |
| • Other project expenses         | € 7.423          |                    |                  |             |
| <b>TOTAL EXPENSES</b>            | <b>€ 614.503</b> | <b>€ 1.026.327</b> | <b>€ 411.824</b> | <b>+67%</b> |
| <b>RESULT</b>                    | <b>€ 152.507</b> | <b>-€ 2.196</b>    |                  |             |

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

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

3 As common practice, travels of the Board and staff are reimbursed by the conference organisers or specifically allocated to projects' budgets. ECPC intervenes with further financial support only if the organizer does not cover the full costs. This is decided on a case by case basis.





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# FINANCIAL REPORT 2018

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European Cancer Patient Coalition



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***“Nothing about us, without us!”***

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# Revenue and results for 2018

For the financial year 2018, the revenue from different sources amounted to a total of **€ 1 024 132**. Running costs, HR, operational costs and implementation of projects during the previous year came to a total of **€ 1 026 327**, leaving a negative balance of **€ 2 196**.

## ECPC funding comes from:

- Industry funding;
- European Commission – for several multi-year projects;
- NGOs and Foundations;
- Other sources: donations.

When budgeting for the different projects and activities of the association, several estimates were made in relation to income expected before 31 December 2018. For industry funding, contracts are signed with the financial supporting company and it is relatively easy to estimate the expected income. For European Commission funded projects however, since they are multi-year projects, their costs and incomes are allocated across more than one year and an accurate yearly estimate is more difficult to make. We have allocated in 2018 the budget (costs and income) of five EU Projects with an estimation of **96 000 EUR**. Even though most of the work and costs occurred in 2018, the cash flow can only be secured and booked in 2019 and beyond.

## Revenue breakdown

Projects which were supported by ECPC's industry partners, covered a large part of the budget in 2018. Financial contributions correspond mainly to industry grants to support the implementation of short to medium term projects. Most of the projects funded by the industry are one-year projects. The industry does not fund ECPC by itself, but all the grants received are finalized to specific projects.

Public funding from the European Union derives from the 7th Research Framework Programme (FP7) and the 2nd Health Programme. All the projects last from 2 to 5 years and the grant instalments are provided by the European Commission regularly during the lifetime of the projects.

The Board intends to diversify the source of funds and significantly increase funds coming by different sources other than the Pharma Industry. As a result, by April 2019, 19 proposals were submitted to the European Commission, which could bring a revenue of up to over 4 million EUR for a period of 3 to 5 years. This shows a clear commitment of ECPC board to differentiate the source of ECPC funds, considering that all this work was done in less than 4 months.

| Source of Revenue in 2018  | Amount (€)  | Percentage   |
|--|---|--------------|
| <b>EU-funded Projects</b>  | <b>€ 71.752</b>   | <b>7%</b>    |
| <ul style="list-style-type: none"> <li>JARC</li> <li>EURACAN</li> <li>PREFER</li> <li>PIONEER</li> <li>DENIM mesothelioma</li> </ul>   | € 20.000<br>€ 2.045<br>€ 27.005<br>€ 21.596<br>€ 1.105  |              |
| <b>Donations</b>   | <b>€9.953</b>   | <b>1%</b>    |
| <b>Miscellaneous revenue</b>   | <b>€ 15.542</b>   | <b>1,5%</b>  |
| <ul style="list-style-type: none"> <li>Reimbursements</li> <li>other</li> </ul>  | € 10.542<br>€ 5.000   |              |
| <b>Total non-industry revenue</b>  | <b>€ 97.247</b>   |              |
| <b>Grants from pharmaceutical companies for:</b>   |   | <b>90,5%</b> |
| <ul style="list-style-type: none"> <li>Annual Congress 2018</li> <li>Carers work-life balance</li> <li>Clinical Trials</li> <li>HTA</li> <li>Personalised Medicine Month</li> <li>Immuno-Oncology</li> <li>White Paper Cancer Patients' Carers</li> <li>Make Sense</li> <li>Nutrition and Physical Activity</li> <li>Bladder Cancer</li> <li>Supportive Care Roundtable</li> <li>Supportive Care Survey</li> <li>Merkel Cell Carcinoma</li> <li>Survivorship</li> <li>Pancreatic Cancer</li> </ul> | € 108.995<br>€ 20.000<br>€ 20.000<br>€ 205.000<br>€ 195.000<br>€ 40.000<br>€ 10.000<br>€ 25.000<br>€ 50.000<br>€ 65.500<br>€ 14.254<br>€ 80.000<br>€ 29.386<br>€ 48.750<br>€ 15.000 |              |
| <b>Total Industry revenue</b>  | <b>€ 926.885</b>  |              |

**Total revenue €1.024.132**

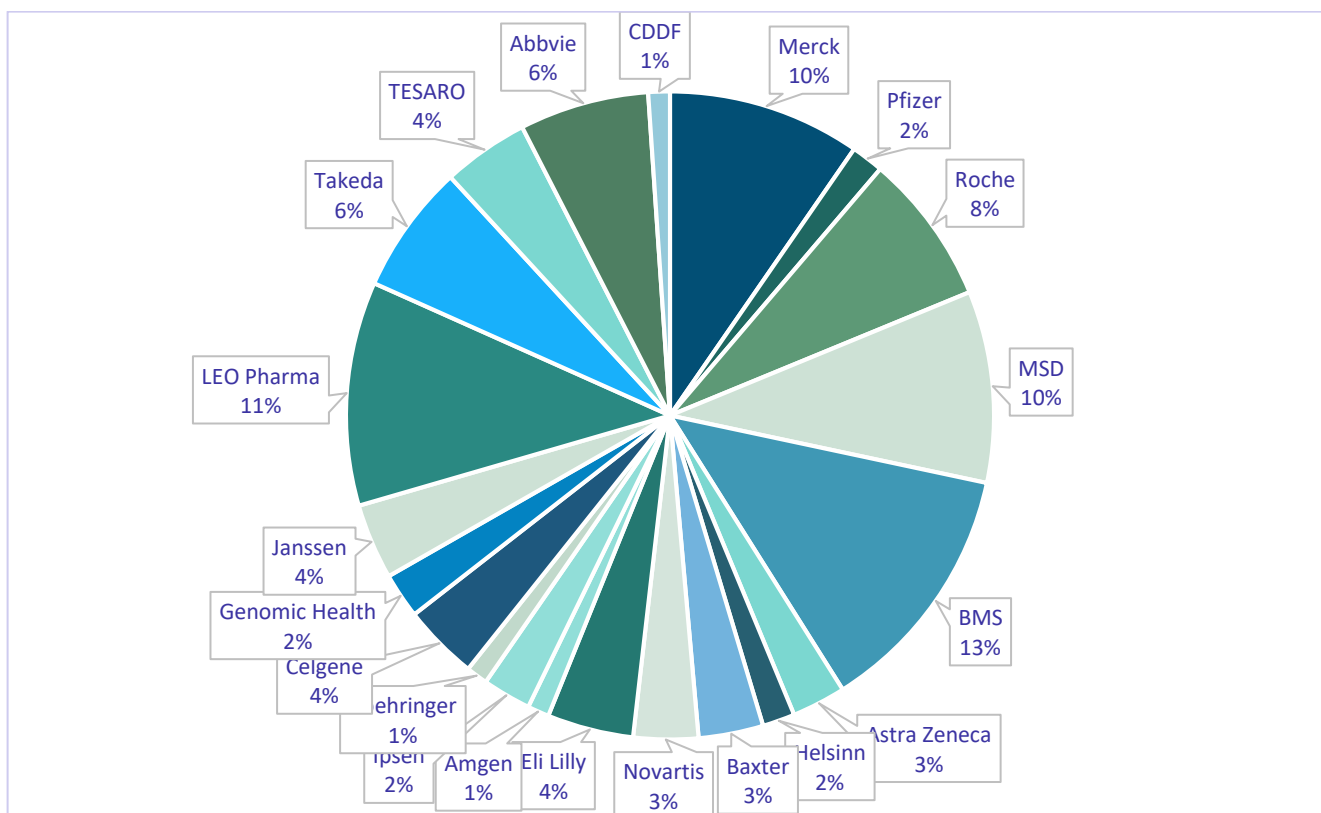
In 2018, industry funding contributed to most of the total budget.

| Revenues from Industry funding  | Amount (€)   | Percentage |
|---|--|------------|
| Merck   | € 89.386   | 10%        |
| <ul style="list-style-type: none"> <li>Carers work-life balance</li> <li>Clinical Trials</li> <li>Merkel Cell Carcinoma</li> <li>Make Sense</li> <li>HTA</li> </ul>   | € 10.000<br>€ 10.000<br>€ 29.386<br>€ 25.000<br>€ 15.000 |            |
| Pfizer  | € 15.000   | 2%         |
| <ul style="list-style-type: none"> <li>Annual Congress</li> </ul>   | € 15.000   |            |
| Roche   | € 70.000   | 8%         |
| <ul style="list-style-type: none"> <li>HTA</li> <li>Personalised Medicine</li> <li>Bladder Cancer</li> </ul>  | € 25.000<br>€ 20.000<br>€ 25.000                         |            |
| MSD   | € 88.750   | 10%        |
| <ul style="list-style-type: none"> <li>HTA</li> <li>Personalised Medicine</li> <li>Survivorship Guide</li> </ul>  | € 20.000<br>€ 20.000<br>€ 48.750                         |            |
| BMS   | € 118.000  | 13%        |
| <ul style="list-style-type: none"> <li>Bladder Cancer</li> <li>HTA</li> <li>Annual Congress</li> <li>Immuno-Oncology Portal</li> <li>Personalised Medicine</li> </ul> | € 33.000<br>€ 25.000<br>€ 10.000<br>€ 25.000<br>€ 25.000 |            |
| Astra Zeneca  | € 25.000   | 3%         |
| <ul style="list-style-type: none"> <li>2018 Action Plan</li> </ul>  | € 25.000   |            |
| Helsinn   | € 15.000   | 2%         |
| <ul style="list-style-type: none"> <li>Supportive Care</li> <li>Annual Congress</li> </ul>  | € 10.000<br>€ 5.000                                      |            |
| Baxter  | € 30.000   | 3%         |
| <ul style="list-style-type: none"> <li>Nutrition &amp; Physical Activity</li> </ul>   | € 30.000   |            |
| Novartis  | € 30.000   | 3%         |



|  |   |            |
|--|---|------------|
| <ul style="list-style-type: none"> <li>Annual Congress</li> <li>HTA</li> </ul>   | € 10.000<br>€ 20.000  |            |
| <b>Lilly</b> <ul style="list-style-type: none"> <li>Annual Congress</li> <li>Carers work-life balance</li> <li>HTA</li> <li>Nutrition &amp; Physical Activity</li> </ul> | <b>€ 40.000</b><br>€ 10.000<br>€ 10.000<br>€ 10.000<br>€ 10.000 | <b>4%</b>  |
| <b>Amgen</b> <ul style="list-style-type: none"> <li>Carers work-life balance</li> </ul>  | <b>€ 10.000</b><br>€ 10.000                                     | <b>1%</b>  |
| <b>Ipsen</b> <ul style="list-style-type: none"> <li>Bladder Cancer</li> <li>Annual Congress</li> </ul>   | <b>€ 22.500</b><br>€ 15.000<br>€ 7.500                          | <b>2%</b>  |
| <b>Boehringer Ingelheim</b> <ul style="list-style-type: none"> <li>Core funding 2018</li> </ul>  | <b>€ 10.000</b><br>€ 10.000                                     | <b>1%</b>  |
| <b>Celgene</b> <ul style="list-style-type: none"> <li>Clinical Trials</li> <li>Nutrition &amp; Physical Activity</li> <li>Pancreatic Cancer</li> </ul>                   | <b>€ 35.000</b><br>€ 10.000<br>€ 10.000<br>15.000               | <b>4%</b>  |
| <b>Genomic Health</b> <ul style="list-style-type: none"> <li>Personalised Medicine</li> <li>Annual Congress</li> </ul>   | <b>€ 21.000</b><br>€ 15.000<br>€ 6.000                          | <b>2%</b>  |
| <b>Janssen</b> <ul style="list-style-type: none"> <li>Core funding 2018</li> <li>Personalised Medicine</li> </ul>  | <b>€ 35.000</b><br>€ 10.000<br>€ 25.000                         | <b>4%</b>  |
| <b>LEO</b> <ul style="list-style-type: none"> <li>Supportive Care Survey</li> <li>Supportive Care Roundtable</li> </ul>  | <b>€ 103.813</b><br>€ 83.813<br>€ 20.000                        | <b>11%</b> |
| <b>Takeda</b> <ul style="list-style-type: none"> <li>Annual Congress</li> <li>HTA</li> <li>Personalised Medicine</li> </ul>  | <b>€ 60.000</b><br>€ 10.000<br>€ 25.000<br>€ 25.000             | <b>6%</b>  |
| <b>TESARO</b>  | <b>€ 40.000</b>   | <b>4%</b>  |

|  |  |    |
|--|--|----|
| <ul style="list-style-type: none"> <li>Annual Congress</li> <li>HTA</li> <li>Immuno-oncology Portal</li> </ul>       | € 10.000<br>€ 15.000<br>€ 15.000             |    |
| AbbVie <ul style="list-style-type: none"> <li>Annual Congress</li> <li>HTA</li> <li>Personalised Medicine</li> </ul> | € 60.000<br>€ 10.000<br>€ 25.000<br>€ 25.000 | 6% |
| CDDF <ul style="list-style-type: none"> <li>Core funding 2018</li> </ul>   | € 10.000<br>€ 10.000                         | 1% |
| Total funding from industry  | € 926.885                                    |    |



## 2018 Expenses breakdown

| Expenses  | 2017   | 2018  | Difference         | %           |
|---|--|---|--------------------|-------------|
| <b>Staff Costs<sup>1</sup></b>  | <b>€ 276.934</b>   | <b>€ 417.820</b>  | <b>+ € 140.886</b> | <b>+50%</b> |
| <ul style="list-style-type: none"> <li>• Employer Contributions</li> <li>• Gross salaries <ul style="list-style-type: none"> <li>◦ Employee Contributions</li> <li>◦ Net salaries</li> </ul> </li> <li>• Other costs (training, team building)</li> </ul>   | € 127.493<br>€ 149.446<br>€ 19.428<br>€ 130.018  | € 162.448<br>€ 254.086<br>€ 38.113<br>€ 215.973<br>€ 1.573  |                    |             |
| <b>Management and Running Costs</b>   | <b>€ 71.099</b>  | <b>€ 88.429</b>   | <b>+ € 17.330</b>  | <b>+24%</b> |
| <ul style="list-style-type: none"> <li>• Office rent &amp; maintenance</li> <li>• Energy consumption</li> <li>• Office supplies</li> <li>• IT maintenance &amp; costs</li> <li>• Telephone &amp; internet</li> <li>• Fee subscriptions</li> <li>• Other office costs (printing, coffee machine, postage, etc.)</li> <li>• Legal / Notary costs</li> <li>• IT investment</li> <li>• Bank costs</li> <li>• Insurance costs</li> </ul> | € 42.169<br>€ 1.384<br>€ 2.414<br>€ 4.202<br>€ 4.851<br>€ 2.379<br>€ 2.678<br>€ 3.400<br>€ 6.691<br>€ 429<br>€ 501 | € 54.579<br>€ 1.556<br>€ 4.471<br>€ 8.412<br>€ 8.308<br>€ 2.154<br>€ 4.852<br>€ 2.845<br>€ 326<br>€ 926 |                    |             |
| <b>Board</b>  | <b>€ 24.790</b>  | <b>€ 28.142</b>   | <b>+ € 3.352</b>   | <b>+13%</b> |
| <ul style="list-style-type: none"> <li>• Board Institutional travel<sup>2</sup></li> <li>• Board advocacy travel<sup>3</sup></li> </ul>   | € 18.895<br>€ 5.895  | € 18.545<br>€ 9.597   |                    |             |
| <b>Annual Congress</b>  | <b>€ 107.569</b>   | <b>€ 138.997</b>  | <b>+ € 31.552</b>  | <b>+29%</b> |
| <b>Advocacy &amp; Awareness</b>   | <b>€ 12.012</b>  | <b>€ 14.752</b>   |                    |             |
| <ul style="list-style-type: none"> <li>• Staff advocacy travel<sup>3</sup></li> </ul>   |  |   |                    |             |
| <b>Projects</b>   | <b>€ 76.030</b>  | <b>€ 334.419</b>  |                    |             |
| <ul style="list-style-type: none"> <li>• Biomarkers</li> <li>• HTA</li> <li>• Immuno-Oncology</li> <li>• World Cancer Day</li> <li>• Make Sense</li> <li>• Nutrition and Physical Activity</li> </ul>   | € 6.911<br>€ 7.584<br>€ 13.239<br>€ 2.180<br>€ 10.973<br>€ 6.622   | € 44.124<br>€ 72.600<br>€ 40.800<br>€ 13.559<br>€ 31.009<br>€ 65.040                                    |                    |             |

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

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

<sup>3</sup> As common practice, travels of the Board and staff are reimbursed by the conference organisers or specifically allocated to projects' budgets. ECPC intervenes with further financial support only if the organizer does not cover the full costs. This is decided on a case by case basis.

|   |  |   |           |      |
|---|--|---|-----------|------|
| <ul style="list-style-type: none"> <li>• Bladder Cancer</li> <li>• Supportive Care Roundtable</li> <li>• Supportive Care Survey</li> <li>• Merkel Cell Carcinoma</li> <li>• Survivorship</li> <li>• EORTC Patient Days</li> </ul> | <p>€ 8.021</p> <p>€ 2.320</p> <p>€ 18.180</p>                | <p>€ 4.502</p> <p>€ 41.808</p> <p>€ 16.521</p> <p>€ 4.456</p> |           |      |
| <b>EU Projects</b>  | <b>€ 32.889</b>  | <b>€ 3.768</b>  |           |      |
| <ul style="list-style-type: none"> <li>• Project travel</li> <li>• Project publications</li> <li>• Project conferences &amp; catering</li> <li>• Other project expenses</li> </ul>  | <p>€ 19.857</p> <p>€ 3.154</p> <p>€ 2.455</p> <p>€ 7.423</p> | <p>€3.768</p>   |           |      |
| • TOTAL EXPENSES  | € 614.503  | € 1.026.327   | € 411.824 | +67% |
| • RESULT  | € 152.507  | -€ 2.196  |           |      |

## Expenditures explained

### Staff costs

In 2018 we hired a new staff member and we had 7 interns that worked for ECPC, on a full-time basis for 6 months each. We also had several salary increases:

1. One staff member started at the end of November 2017 and his salary was higher than his predecessor. He also received a salary increase in April 2018
2. Two staff members received a salary increase at the end of 2017 that impacted on the budget of 2018
3. One staff member received a salary increase in January 2018

Furthermore in 2018 ECPC started a group insurance for all staff members, a hospitalization insurance, Eco vouchers, a sport and culture voucher and the end of year bonus.

The above-mentioned salary costs have resulted in an overall cost increase of staff costs.

Belgium has one of the highest rates of taxation for average salaries out of all EU and OECD countries.<sup>4</sup>

As an international non-profit organization under the Belgian legal system, ECPC employs five full time employees, three interns and a service provider. This means that almost half of the expenses for staff consists of social security, insurance and other social taxes.

More information on the Belgian social security legislation can be found here: [www.socialsecurity.be](http://www.socialsecurity.be)

## Management and Running Costs

These costs cover the overall office management and overheads, including office rent & maintenance, energy consumption, telephone, internet, IT, office supplies, subscriptions to journals, Notary, Insurance and bank costs. Office costs also increased due to a 5% annual increase in the rental costs and also a protective door was installed, since the office had been burgled several times. This was a large investment. An additional insurance

<sup>4</sup> <http://www.amcham.be/blog/2013/08/belgium-ranks-1st-highest-labor-costs-eu...-again>

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for the office was required and so the insurance costs have increased. The overall increase of activities in 2018 is reflected in the increase of staff, office supplies and overall industry project costs.

### **Annual Congress and AGM**

Costs for the annual congress have increased due to a larger number of participants that went from 168 in 2017 to 198 in 2018. The increase of over 30 participants reflected on the overall costs of the Annual Congress.

### **Board Costs**

Board costs are due to exclusively travel and accommodation costs for board members travelling on specific projects. All travel costs both for staff and board members are covered by the organisers of the event or meetings or by the projects. These costs cover both institutional travels to participate to board meetings and travels to participate to external meetings or events.

### **EU Projects**

Since 2011, ECPC's Secretariat in Brussels has been working on several projects financed by the European Commission. These projects have a limited financial risk but require an important long-term financial effort.

A significant percentage of payroll costs incurred in 2018 are covered by EU funded projects.

EU funded projects, if managed properly and following the rules of the European Commission present very limited financial risks. This is why the secretariat will put in place a sound management control system with detailed time sheets. Most of the deliverables of the projects are due in 2019 or beyond.

### **Foreign currencies**

The ECPC accounting system is in Euro. Transactions to other currencies have been converted into Euro, at the exchange rate indicated on the day of the transaction.

# Forecast for 2019

## Budget and revenue

### 2019 industry funding committed

|                                  | Project                       | Requested | Secured  |
|----------------------------------|-------------------------------|-----------|----------|
| AbbVie                           | Annual Congress               | € 15.000  | € 15.000 |
| AbbVie                           | Health Technology Assessment  | € 5.000   |          |
| AbbVie                           | Personalised Medicine Month   | € 5.000   |          |
| Amgen                            | Annual Congress               | € 10.000  | € 10.000 |
| AstraZeneca                      | Health Technology Assessment  | € 25.000  | € 15.000 |
| AstraZeneca                      | Annual Congress               | € 15.000  | € 15.000 |
| AstraZeneca                      | Immuno-oncology portal        | € 25.000  | € 25.000 |
| AstraZeneca                      | MEP Handbook                  | € 25.000  | € 25.000 |
| AstraZeneca                      | Personalised Medicine Month   | € 25.000  | € 25.000 |
| Baxter                           | Nutrition & physical activity | € 20.000  | € 20.000 |
| Bayer                            | Personalised Medicine Month   | € 30.000  |          |
| Bayer                            | Rare Cancer WG meeting        | € 35.000  |          |
| Bayer                            | Annual Congress               | € 30.000  |          |
| BMS                              | Annual Congress               | € 15.000  | € 15.000 |
| BMS                              | Bladder Cancer                | € 10.000  | € 10.000 |
| BMS                              | Health Technology Assessment  | € 25.000  | € 25.000 |
| BMS                              | MEP Handbook                  | € 25.000  |          |
| BMS                              | Personalised Medicine Month   | € 25.000  | € 25.000 |
| Boehringer-Ingelheim             | Annual Congress               | € 15.000  | € 15.000 |
| Celgene                          | Bladder Cancer                | € 35.000  | € 35.000 |
| Daiichi Sankyo Cancer Enterprise | Annual Congress               | € 15.000  | € 15.000 |
| Daiichi Sankyo Cancer Enterprise | personalised Medicine Month   | € 25.000  | € 25.000 |
| Daiichi Sankyo Cancer Enterprise | Health Technology Assessment  | € 25.000  | € 25.000 |
| Eli Lilly & Co                   | Annual Congress               | € 15.000  | € 15.000 |
| Eli Lilly & Co                   | Europe of Disparities         | € 25.000  | € 25.000 |
| Eli Lilly & Co                   | Health Technology Assessment  | € 15.000  | € 15.000 |
| Eli Lilly & Co                   | Nutrition & physical activity | € 10.000  | € 10.000 |
| Genomic Health                   | Annual Congress               | € 6.000   |          |
| Genomic Health                   | Personalised Medicine Month   | € 15.000  |          |
| Helsinn                          | Personalised Medicine Month   | € 10.000  | € 10.000 |



|                              |   |                    |                  |
|------------------------------|---|--------------------|------------------|
| <b>Ipsen</b>                 | Annual Congress   | € 10.000           | € 7.500          |
| <b>Ipsen</b>                 | Bladder Cancer  | € 7.500            | € 7.500          |
| <b>Johnson &amp; Johnson</b> | Personalised Medicine Month                                       | € 15.000           |                  |
| <b>LEO Pharma</b>            | Manifesto and handbook for new members of the European Parliament | € 10.000           | € 10.000         |
| <b>Merck</b>                 | Europe of Disparities   | € 15.000           | € 15.000         |
| <b>Merck</b>                 | Health Technology Assessment                                      | € 20.000           | € 20.000         |
| <b>Merck</b>                 | Make sense of head & neck   | € 20.000           | € 20.000         |
| <b>Merck</b>                 | Merkel Cell Carcinoma   | € 20.000           | € 20.000         |
| <b>Merck</b>                 | Personalised Medicine Month                                       | € 15.000           | € 15.000         |
| <b>MSD</b>                   | Health Technology Assessment                                      | € 10.000           | € 10.000         |
| <b>MSD</b>                   | Personalised Medicine Month                                       | € 20.000           |                  |
| <b>MSD</b>                   | Annual Congress   | € 15.000           |                  |
| <b>MSD</b>                   | MEP Handbook  | € 15.000           |                  |
| <b>Novartis</b>              | Annual Congress   | € 15.000           | € 15.000         |
| <b>Novartis</b>              | Europe of Disparities   | € 10.000           | € 10.000         |
| <b>Novartis</b>              | Health Technology Assessment                                      | € 10.000           | € 10.000         |
| <b>Pfizer</b>                | Annual Congress   | € 10.000           | € 15.000         |
| <b>Roche</b>                 | Bladder Cancer  | € 25.000           | € 25.000         |
| <b>Roche</b>                 | Annual Congress   | € 25.000           | € 25.000         |
| <b>Roche</b>                 | Personalised Medicine Month                                       | € 25.000           |                  |
| <b>Roche</b>                 | Rare Cancer Working Group meeting                                 | € 25.000           | € 25.000         |
| <b>Sanofi</b>                | Annual Congress   | € 20.000           |                  |
| <b>Sanofi</b>                | Europe of Disparities   | € 65.000           | € 65.000         |
| <b>Sanofi</b>                | Health Technology Assessment                                      | € 20.000           | € 10.000         |
| <b>Takeda</b>                | Annual Congress   | € 10.000           | € 15.000         |
| <b>Takeda</b>                | Health Technology Assessment                                      | € 15.000           | € 15.000         |
| <b>Takeda</b>                | Europe of Disparities   | € 25.000           | € 25.000         |
| <b>Tesaro</b>                | Annual Congress   | € 10.000           | € 10.000         |
| <b>Tesaro</b>                | Health Technology Assessment                                      | € 25.000           | € 15.000         |
| <b>Tesaro</b>                | Personalised Medicine Month                                       | € 25.000           | € 15.000         |
|                              |   | <b>€ 1.128.500</b> | <b>835.000 €</b> |

## EU Funded Projects

| Project             |                                    | Expected  |
|---------------------|------------------------------------|-----------|
| DIAdIC              | (H2020, Jan 2019 - Dec 2023)       |           |
| EURACAN             | (3HP, March 2017 - Feb 2023?)      |           |
| LEGACy              | (H2020, Jan 2019 - Dec 2022)       | € 15.000  |
| ImmunoSABR          | (H2020, Jan 2017 - Dec 2022)       |           |
| PIONEER             | (Jan 2018 - Dec 2022)              | € 20.000  |
| IMMUNISA            | (IMI1, Dec 2017 - Nov 2022)        |           |
| ELBA                | (H2020 - ITN, Jan 2018 - Dec 2021) |           |
| PREDICT             | (H2020 ITN, Oct 2017 - Sep 2021)   |           |
| PREFER              | (IMI2, Oct 2016 - Sep 2021)        | € 20.000  |
| iPAAC               | (3HP, Apr 2018 - Mar 2021)         |           |
| H2020MM04           | (IMI1, Jan 2016 - Dec 2019)        | € 500     |
| TRANSCAN-2          | (IMI1, Jan 2015 - Dec 2019)        |           |
| JARC                | (3HP, Oct 2016 - Sept 2019)        | € 20.000  |
| eSMART              | (H2020, Feb 2014 - Jan/Jul 2019)   | € 65.000  |
| DO-IT               | (IMI2, Feb 2018 - Feb 2019)        | € 25.000  |
| Palliative Sedation |                                    |           |
| Immune-Image        |                                    |           |
|                     |                                    | € 165.500 |

## Details on the costs forecasted for 2019

| Foreseen Expenses 2019                    | 2018        | 2019        | Ratio |
|---|-------------|-------------|-------|
| Staff                                     | € 417.820   | € 500.000   | +20%  |
| Office Management                         | € 92.249    | € 90.000    | 0%    |
| Board                                     | € 28.037    | € 30.000    | 0%    |
| AGM                                       | € 138.997   | € 140.000   | 0%    |
| Industry Projects                         | € 334.419   | € 200.000   | n/a   |
| EU funded Projects                        | € 3.768     | € 90.000    | n/a   |
| Advocacy & Awareness                      | € 14.752    | € 10.000    | n/a   |
| Election of the Board and Audit Committee |             | € 20.000    | n/a   |
| • TOTAL EXPENSES                          | € 1.026.327 | € 1.080.000 | 0%    |

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## ANNEX 1 – Audit Report