



European Cancer  
Patient Coalition

# Annual Report 2019



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**European Cancer  
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# 1. The European Cancer Patient Coalition

Established in 2003, the European Cancer Patient Coalition (ECPC) works for a Europe of equality, where all European cancer patients can have timely and affordable access to the best treatment and care available, throughout their life regardless of nationality/the country they were born in, where they live, their education, sex, age, social background.

ECPC is the sole voice of the whole European cancer community, representing the interests of cancer patients diagnosed with all types of cancer: from the most common to the rarest forms of the disease. ECPC works to ensure that the scope of the entire cancer care pathway effectively includes prevention, treatment, survivorship and palliative care and that the social rights of patients and carers are respected.

Cancer patients are the most important partners in cancer control and are the ones who work tirelessly towards taking action on all cancer-related issues affecting our society. Cancer patients and their carers deserve their seat at the health and cancer policy decision making table, both in Brussels and in their own countries, with knowledge, arguments, recommendations and the living experience of the disease. Policy makers, researchers, healthcare providers and industry cannot continue to ignore any longer the cancer patient voice that has proved on many health policy fora that it is a knowledgeable, trustworthy, rich in untapped experience partner. Time has come to recognise patients as the co-creators of their own health, actively participating with their medical team in their care.

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

In 2019, 12 new organisations joined ECPC, consolidating it as Europe’s largest cancer patient association, with a total of 457 Members. ECPC welcomes all organisations across EU and non-EU countries, dealing with all types of cancer as well as organisations that specialise in patient’s rights and psychological care. This helps ECPC gain a broad knowledge of the cancer journey through our patient organisations.

New members who joined ECPC in 2019:

- Hellenic Cancer Society “Mazi gia Zoi -Together for life”, Greece
- Neovida, Belgium
- Renesansa, Kosovo
- Castiga Viata, Romania
- Asociatia Bolnavilor de Cancer Suceava, Romania
- Codice Viola, Italy
- Think Blue Vlaanderen, Belgium
- ELIDAN, France
- Foundation for patients with Rare Diseases COCORDA, Poland
- The Hania Magiera Glioma-Center Foundation, Poland
- Find Help Charity, Poland
- The Association for Information on Complementary Cancer Treatment, Denmark
- Francophone defense association of 5-FU victims and analogs with a DPD deficiency, France

## 2. The European Cancer Patient Coalition's Mission

### Our Mission is to:

- Empower our members, cancer patients, their friends and carers through training, dissemination of scientific information, educational tools, overall and ad hoc support;
- Foster co-operation and strengthen collaboration among our members across Europe through joint activities, shared good practices, aiming to develop a community spirit;
- Influence and shape the program and proposals of the Cancer Mission and play a significant role on developing the content and setting key performance indicators to assess the implementation of Europe's Beating Cancer Plan;
- Remain vigilant on sensitive and emerging topics, related to cancer as and when they arise;
- Advocate and diligently work towards creating and improving EU and national laws affecting cancer patients' outcomes and wellbeing. This would range from reducing mortality to improving patient and carer quality of life and their social rights throughout the cancer care continuum;
- Call for patient centricity in cancer research and care.

### 3. The European Cancer Patient Coalition's Strategy

The European Cancer Patient Coalition Board's 2019-2022 strategy is based upon five pillars:

#### **Governance**

Good governance is vital to the sustainability and credibility of ECPC. Good governance is at the basis of an open and transparent participation of ECPC members in the activities of the organisation and for attracting new members, partners, stakeholders and retain them.

#### **Policy and Advocacy**

Despite progress in policies that support people with cancer, their families and their carers, there remains considerable exclusion and disparities across Europe, among and within countries. ECPC works consistently with its members to empower them to advocate for best quality treatment and care, to participate in decision-making in healthcare regarding their treatment and to reduce the socio-economic disparities, associated with cancer.

#### **Health and Research**

Cancer research projects allow ECPC to be at the forefront of scientific developments in cancer treatment, and in the societal, economic and policy aspects related to cancer treatment, care and survivorship.

#### **Capacity Building**

ECPC is there to serve its Members, representing cancer patients with all types of cancer from the most common to the rarest. ECPC is working to increase each Member's capacity in understanding EU policy and research and to help them shape the national cancer landscape.

ECPC believes that engaging in a dialogue, fostering collaboration and providing members with tools to advocate and campaign is essential to build and maintain a strong network.

#### **Communication**

Strong and effective internal and external communication boosts the outreach of ECPC to its members, partners and stakeholders across all ECPC areas of work from governance to capacity-building, policy and advocacy, health and research. Using the possibilities offered by our communication channels, ECPC is positioning itself as a key, trustworthy and influential actor in all fora involved in cancer control. All while further improving the ECPC reputation, communication activities serve ECPC mission and invigorate its outreach.

**The Multi-Annual Strategy runs from 2019 to 2022**, the same period covered by the mandate of the ECPC Board and Audit Committee, elected and established in June 2019 for a duration of 3 years. The Scientific Committee Members were appointed in 2019 and the Scientific Committee will be officially established in early 2020 to ensure the scientific support of ECPC and the identification of policy and research priorities.



## 4. Messages from the Presidents



### Francesco de Lorenzo (January - June 2019)

Dear ECPC members, dear friends,

In the ECPC elections year 2019, I have covered two different positions: that of President during the first semester and Past-President and Chair of the Scientific Committee during the second semester. Passing from one position to another has occurred in a continuum in terms of policy and research activities.

ECPC continues to be represented in the following bodies in which I am a board member: the European Academy of Cancer Sciences (EACS), the Cancer Drug Development Forum (CDDF), while I represent ECPC in the EU Joint Action iPAAC - Innovative Partnership for Action Against Cancer.

As you all know, in 2018, the General Assembly introduced in the Statute the position of Past-President “to maintain continuity of knowledge and procedures in the transition from one Board to the next”. This amendment introduced an important and critical role in ECPC governance aiming to ensure that all activities of the organisation run smoothly and are not affected by the change in the board and possible changes in the staff. During my Presidency, the close collaboration with Kathi Apostolidis, the new ECPC President, has been instrumental in assisting me to carry out my duties. The results achieved during the previous years and the multiple projects that ECPC has been working on could not be achieved and completed without collegial relations and consensus in the Board of Directors and Audit Committee and the commitment and dedication of our staff.

In 2019, ECPC has become increasingly active in the field of European cancer policy as our efforts in previous years have matured and I am proud to say that I worked hard to reach these major achievements:

- The Manifesto for the European Elections 2019
- The Challenge Cancer Intergroup
- The Cancer Mission
- The EU Joint Action on Rare Cancers (JARC)

During the first semester of 2019, I continued to represent ECPC at several congresses, conferences and meetings to speak for cancer patients. ECPC has also been active in preparing position papers, white papers and other documents to support its work. Besides ECPC’s contribution to the “Rare Cancer Agenda 2030”, ECPC has co-authored the following articles published in *Molecular Oncology*: “*Cancer Core Europe: A translational research infrastructure for a European mission on cancer*”, “*Cancer*



*survivorship: an integral part of Europe's research agenda", "The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer".*

I am confident that the new Board under the leadership of Kathi Apostolidis, will continue strengthening the position of ECPC as the key cancer patient voice in Europe and I invite you all to continue your close collaboration with the new Board.

As the past President and Chair of the Scientific Committee, I will be available to advise any ECPC member that would need assistance in shaping cancer policy advocacy in their country. Thanking you all for your collegial collaboration for all these years,

*Francesco de Lorenzo*



### Kathi Apostolidis (June – December 2019)

Dear friends, dear members of ECPC,

First of all, I sincerely thank you all for the confidence in my person and for having honored me with your votes in the ECPC elections 2019.

During the last seven years, we have collaborated closely with Prof. de Lorenzo in order to elevate ECPC to its current level of recognition among EU health institutions, politicians, cancer stakeholders and patients in Europe. It is a great honor and a demanding legacy to succeed as President to Prof. Francesco de Lorenzo, and it is also a duty, coming from the trust of more than 450 ECPC Members across Europe.

Allow me to mention that I am very conscious that the important raise of ECPC visibility, reputation and results of our cancer policy advocacy, are due to the excellent work of the former President and of his

Board, seconded by our Secretariat. These same results that make us proud, render my task as ECPC President more demanding because I am called to maintain and further improve what are already excellent results.

In 2019, ECPC's persistent efforts to position cancer more prominently on the political agenda continued to yield results, from policy to capacity building to research. Our Board began its mandate in June 2019 at the same time with the newly elected European Parliament and the College of Commissioners.

ECPC, before the EU electoral campaign in 2019, drafted a political Manifesto asking MEP candidates to join our mission in the European Parliament to overcome inequalities in Europe, where all cancer patients should have timely and affordable access to the best treatment and care available. We asked candidates through our members in all EU Member States to endorse our cancer policy priorities:

- Reduce inequalities for fast, safe and affordable access to surgery, radiotherapy and medicines
- Embrace innovation in cancer research and treatments
- Enable cross-border collaboration to ensure that cancer patients receive the most appropriate healthcare, regardless of where they reside
- Promote survivorship programmes as an essential part of cancer care at all levels, and formally support the role of cancer carers

The Manifesto has been endorsed by several candidates, many of whom have been re-elected.

Together with Prof. de Lorenzo, we worked tirelessly after the European Elections to contact newly elected and re-elected MEPs to inform them about the need to establish a

Parliamentary Intergroup on Cancer. The Intergroup was envisaged to act as a two-way communication channel between the Commission, the Cancer Mission Board, the European Parliament and other EU institutions and cancer stakeholders at European and national levels and become a forum for exchange of information and ideas on various cancer and health issues. The political message to the newly elected MEPs was twofold. Firstly, presenting them the key role of the European Parliament had during the previous mandate in highlighting cancer as a priority in the European Commission's health agenda. Secondly, stressing the crucial role of MEPs in informing their national governments, national cancer stakeholders and citizens about the importance of working towards the implementation of the four ECPC cancer policy priorities, referred to in the ECPC EU Elections Manifesto.

These two high level EU initiatives, meeting key cancer policy and research goals of ECPC, as mentioned in our EU Elections Manifesto, were at the base on an extensive network of contacts, led by President Francesco de Lorenzo, with other similarly minded cancer stakeholders already in 2017 that culminated in 2018. In 2018, ECPC was invited to participate in the two "Gago Conferences on European Science Policy", starting in February 2018 in Porto, represented by the undersigned, then ECPC Vice President and in September in Vienna, represented by the President, Francesco de Lorenzo and in November 2018, at the meeting in the Vatican with the key European cancer stakeholders, members and friends of the European Academy of Cancer Sciences-EACS.

In 2018, Prof. Francesco de Lorenzo, Board member of the EACS-European Academy of Cancer Sciences and member of the Science Policy Committee, and member of the board of Cancer Core Europe, was asked to contribute to the special issue of the journal *Molecular Oncology* - towards a mission-oriented approach to cancer dedicated to boosting the social impact of innovative cancer research. Prof. de Lorenzo, together with the other members of the EACS platform co-authored a paper on translational research infrastructure for a European mission on cancer and another on cancer survivorship, an integral part of Europe's research agenda. Additionally, Prof. de Lorenzo and the undersigned co-authored the paper on the central role of the European Cancer Patient Coalition in connecting stakeholders to advance patient-centric solutions in the mission on cancer.

The foregoing and other policy activities geared to the Cancer Mission and the EU Cancer Plan laid the road for the participation of ECPC in the first and second semesters of 2019 to a number of activities towards enriching the content of the EU Cancer Plan with policy proposals and in further refining the steps towards the unmet needs in cancer research policy.

This is the context in which, the ECPC initiated the Intergroup on Cancer in early 2019, won the trust of the new elected parliamentarians and was voted first, among all Intergroups, with 110 votes. Thereafter, the Intergroup was approved in December 2019. The new Intergroup on Cancer will be chaired by long-time ECPC supporter, MEP Christian Silviu Busoi, co-chaired by MEPs Alessandra Moretti, Aldo Patriciello, and Frederique Ries, with ECPC providing the Secretariat.

The important contribution of the European Cancer Patient Coalition to cancer research has been recognized by having representatives from our organisation appointed to the Boards of the Cancer Drug Development Forum and Cancer Core Europe, as well as to the Science Policy Committee of the European Academy of Cancer Sciences and to the General Assembly of the Worldwide Innovative Networking Consortium. Our extensive participation in high level multi-annual EU funded cancer research projects consolidated

and improved our understanding of the current cancer research interests of our partners.

Most importantly ECPC received within 2019 several invitations to participate in large EU Horizon 2020 funded projects or IMI projects, and submitted over 34 project proposals to the European Commission and was awarded with six new EU projects (Instand-NGS, Qualitop, LifeChamps, E-PRO, Immune-Image and imSAVAR ). The new awarded projects concern Big Data, Artificial Intelligence, deep-learning, and immune-oncology.

A landmark activity of ECPC, complementing our earlier work in cancer disparities is "Challenging The Europe Of Disparities In Cancer - A Framework For Improved Survival And Better Quality Of Life For European Cancer Patients". It was initiated at the Annual Congress 2018 within the Working Group named Legal Network for Cancer Patients (LNWG), and it is the mapping of social disparities in cancer in EU Member States. During the 2018 meeting of the LNWG, it was decided that Roberto de Miro, ECPC member and lawyer with expertise in labor law, would assist ECPC in preparing a questionnaire on social aspects of cancer care.

The questionnaire, addressed to our members, was to be answered by lawyers, social workers or other similar professionals collaborating/supporting our members in all EU Member States. It took several months to collect the data from our members, many of which do not dispose of legal assistance, and to work towards the preparation of the relevant White Paper. A first draft of a White Paper has been prepared in 2019 and it is expected that the White Paper will be published in 2020. The survey will be an important tool to carry on ECPC advocacy for a cultural change towards the recognition of the rights and social rehabilitation of cancer patients, survivors and family carers. It will suggest which legislative changes are needed to allow a cancer survivor or caregiver to maintain its active role of citizenship, and cancel the stigma relegating these persons to social assistance services and social exclusion.

I believe I am not the only one who feels that a very important field of challenges lies in front of us: cancer research and innovation with the Cancer Mission, the EU's Beating Cancer Plan, the decision of the Council on the Commission's HTA proposal, the implementation of the Cross Border Directive, the implementation of the Directive on Work – Life Balance for Patients and Carers, are just some of the most important of them. Our organisation has already been working on these issues the last few years, but it is very important that we also have this precious forum that is the ECPC Annual Congress, bringing together the ECPC Members from across Europe, and giving us a common, more valuable, recognized and efficient voice when dealing with the European institutions.

In the three years to come, we should strengthen our collaboration to increase ECPC's activities to reinforce our close relationship of many years and the values we stand for. I start my mandate with a lot of enthusiasm, energy and the certainty to be proud of ECPC.

ECPC exists because of each one of you, you are the reason we work hard to become more efficient and responding to your needs. All our members, from large federations to small cancer specific patient groups, are essential for the work of our organisation, and I thank you all from my heart for supporting cancer patients and families across Europe.

*Kathi Apostolidis*

## 5. Message from the Director

Dear Cancer Patients, ECPC Members and Stakeholders,

The year 2019 was not just a year of change on the political level, but a year of change and growth for ECPC. The end of 2018 saw our previous director Lydia Makaroff step down from her role, we welcomed new Board and Audit Committee Members and we continued to grow our ECPC team. With these new changes internally, ECPC changed externally too. This year we began the process of rebranding with a new logo and website to create an altogether more user-friendly experience for our expanding network of members. We also started a process to differentiate our funding resources with an overall increase in revenues of 30% and a decrease of Pharmaceutical revenues from 90,50% to 65,00%.

Despite the new changes, ECPC's ethos remained and we continued our mission towards a Europe of fairness and equality for all cancer patients.

This was reflected in our campaigns, research and projects that we as a team worked relentlessly on throughout the year. In June, we brought our members together for the Annual Congress. This was held with great success, with over 200 participants sharing discussions, best practices and enjoying various sessions from a diverse range of topics including Social Disparities, Digital Health and Personalised Medicine. We also held many workshops and meetings with members throughout Europe, giving us a chance to strengthen the collaboration and gain feedback from them.

I would like to thank our Presidents for the two halves of the year, the Board, the Audit Committee and Staff for their dedication, collaboration, and passion to achieve our combined goal. Thank you to our stakeholders and partners who support us and make our work possible and, of course, a massive thank you to our members who continue to inspire us with their motivation and input in our work.

I am proud of the work and efforts put in by all involved in this report and I am excited to move into the new decade with a strong team, dedicated board and audit committee and encouraging members. ECPC will continue to work towards the goal of giving cancer patients in Europe a voice in 2020 and beyond.

*Antonella Cardone*



## 6. Overview of 2019

### 6.1 New branding, New Board, New Audit Committee, New Website, New EU Parliament and EU Commission

Year 2019 was a year of changes for ECPC, starting with the new Director and new staff members joining the Secretariat at the beginning of the year, and a new Board, Audit Committee members and new branding in June. 2019 was also a year of major changes on the political level in Europe, with elections in several countries that also influenced the European elections that led to a completely changed new European Parliament and a new Commission.

Ursula von der Leyen, the President of the European Commission, in her speech in December 2019, said that the EU Commission will **“take the lead in the fight against cancer”**. The mandate of the well-known to cancer patient advocates, new Health Commissioner, Stella Kyriakides, carried the ambitious EU Cancer Beating Plan.

2019 was also the year of a totally new approach to research and innovation: that of the **“mission”**. The Horizon Europe 2021-2026, the biggest EU research and innovation funding programme, will include five missions. These are Adaptation to climate change including societal transformation, Cancer, Climate-neutral and smart cities, Healthy oceans, seas, coastal and inland waters, Soil health and food.

#### 6.1.1 ECPC Board and Audit Committee Elections

Between April 15<sup>th</sup> and May 15<sup>th</sup> of 2019, ECPC held the election of the new ECPC Board and Audit Committee. Full Members nominated and voted upon new members of the Board and Audit Committee for the years 2019 - 2022.

14 candidates were nominated for the Board and 6 candidates for the Audit Committee. Full Members received a paper ballot via registered email. Their votes were sent to a third party. A lawyer received paper ballots from 122 Full ECPC members.

Outgoing Board Members were Francesco de Lorenzo, President; Kathi Apostolidis, Vice-President; Jana Pelouchová, Secretary; Ken Mastris; Matti Järvinen and Maude Andersson

Newly elected Board Members were Kathi Apostolidis, President; Pietro Presti, Vice-President; Beata Ambroziewicz, Treasurer; Jacqueline Daly, Secretary; Maude Andersson; Robert Greene and Vasile Ianovici

Outgoing Audit Committee Members were Pietro Presti, chair; István Balogh and Nicolas Phillipou

Newly elected Audit Committee Members were Constantine N. Nicolaidis, chair; James Caldwell and Roberto Persio



### 6.1.2 Death of ECPC Board Member Andrew Winterbottom

In May 2019, it was with great sadness that we received the news of ECPC Treasurer Andrew Winterbottom's death. Andrew died on May 31st after a diagnosis of bowel cancer in 2018.

In October 2018 Andrew Winterbottom revealed he had a terminal diagnosis and stepped down from his day-to-day management of the charity to concentrate on his own health.

Since he began the charity after his bladder cancer diagnosis in 2009, his determination and courage have been an inspiration to many. His campaigning passion and immense compassion for patients saw him forge strategic relationships around the world and particularly in Europe where he was an active member of the board at European Cancer Patient Coalition. He represented bladder cancer patients in Europe and the UK, forging relationships with the pharmaceutical industry, particularly over clinical trials.

## 6.2 Calendar of main activities in 2019

### January

- EORTC – STOA workshop
- LEGACy and DIAdIC kick-off meeting
- EAU EP Event
- Novartis/ECPC – Transforming Breast Cancer Together
- All.Can key messages workshop – patient survey
- The Digital Pharma Advances Conference - Digital Strategies Delivering Real Results
- European Society for Radiotherapy and Oncology event
- ESTRO Event at the EU Parliament
- HTA expert meeting at the EU Commission

### February

- EAU Patient Info Session
- CDDF Multi-stakeholder Workshop on Impact of Nutrition on Microbiome
- All.Can Italy Launch

### March

- IEEPO
- ECPC EU Elections Manifesto 2019 - Project Kick-Off
- All.Can Patient survey communications workshop
- EAU EPAG launch Barcelona
- ELBA workshops
- Transforming Breast Cancer Together: Meeting with the European Commission
- ENSP conference
- ECPC Romanian members meeting in Bucharest

- ECPC Meeting with Princess Dina Mired in Bucharest

## **April**

- Pancreatic Cancer Europe Advocacy Workshop
- PACAW Preparatory meeting
- Pancreatic Cancer Europe - strategy planning session
- Prostate Cancer Net symposium
- EORTC QoL event
- Multi-Stakeholder Summit on Occupational Skin Cancer

## **May**

- ESMO Breast Cancer
- eSMART Final Event
- International Gastric Cancer Congress
- IMI PIONEER General Assembly
- iPAAC event
- SIOPE Meeting

## **June**

- ECPC Annual Congress 2019
- PREFER webinar esketamine study
- EHA, Amsterdam
- HTAi Congress
- EFPIA Oncology Data Summit.
- World Congress on Thyroid Cancer
- OECl Oncology Days
- EACR Cancer Genomics
- EFPIA 2019 Annual Conference
- All.Can Research Working Group

## **July**

- iCPS European Pancreatic Cancer Roundtable
- ESMO Gastrointestinal Cancer
- STD - AGM PCE Barcelona
- All.Can: communications working group

## **August**

- PRESSURE Research Consortium
- EU Health Coalition - All partners meeting

## **September**

- All.Can Research and Evidence working group meeting
- BMS International Advocacy Meeting at ESMO
- JARC Final Conference

- EFPIA Rentree Connecting Healthcare
- JARC EP Event
- INMiND Immune-Image board meeting
- CECOG Governmental International Affairs (GOIA) Expert Meeting 3.0
- ESMO Congress 2019
- NGO Round Table Gastein
- ECPC/ECCO/EFPIA Gastein Session

## October

- Palliative Sedation General Assembly
- EuropaBio Patients Bio-Forum Meeting: A Look beyond 2020 – Policy and Research Prospects for Healthcare
- Conference on the Future of EU Health Policy
- Discussion of All.Can data paper
- ETHA event at the EU Parliament
- PREFER Annual Meeting 2019
- EC Biosimilar Stakeholder Event
- ECPC ELBA Workshop

## November

- Cancer parliamentary intergroup - MEP Busoi & ELSI
- ECPC - Make sense campaign event at the EU Parliament
- ECCO event
- ESTRO NMSC training session
- ABC Global Alliance GA Steering Committee election
- EPAG EAU general assembly
- European Antibiotic Awareness Day 2019
- EMA Annual Training Day
- DIAdIC Consortium meeting
- Janssen Europe, Middle East & Africa (EMEA) Advisory Board focusing on Precision Medicine
- EU Health Summit

## December

- iPAAC Stakeholder Forum
- EAPM Congress
- BMS SE Europe Congress

## 6.3 ECPC Board Members engagement with external stakeholders

Collectively, in 2019, our current Board Members are active members of 29 other boards and steering committees throughout Europe, such as European Cancer Organisation, EMA PCWP and ENCePP Steering Committee, European Commission Initiative on

Breast Cancer. ECPC is represented in the European Commission Initiative on Breast Cancer's Quality Assurance Scheme Development Group (QASDG) and several of its sub-committees by its President, Kathi Apostolidis. Past President Francesco de Lorenzo was in 2019 representing cancer patients' voice in boards and steering committees of ESMO, European Academy of Cancer Science - EACS, CDDF, Cancer Core Europe and iPAAC. Board Members and Chair of the Scientific Committee also hold important positions in cancer patient federations on national level for example in Italy (FAVO), Greece (ELLOK), Poland (Polish Union of Patient Organisations), and Romania (FABC).

### 6.3.1 4<sup>th</sup> ENSP-SRP International Conference on Tobacco Control 2019

From 26<sup>th</sup> to 29<sup>th</sup> of March 2020, ECPC attended the 4<sup>th</sup> ENSP-SRP International Conference on Tobacco Control 2019 in Bucharest. This event brought together global health leaders including President of UICC HRH Princess Dina Mired of the Hashemite Kingdom of Jordan, EU Commissioner Vytenis Andriukaitis, Executive Director of International Union Against Tuberculosis and Lung Disease Jose Luis Castro and Head of Secretariat WHO Framework Convention on Tobacco Control Dr Vera Luiza Da Costa e Silva to discuss ways to advance worldwide efforts to combat the tobacco epidemic. As global deaths from tobacco use continue to rise, the aim of the event was to unite the global community in a collaborative effort to end the tobacco epidemic. ECPC organised a session during the conference on the impact of Tobacco smoke on cancer patients with high level speakers. ECPC was represented by President Francesco de Lorenzo and ECPC Director Antonella Cardone that used this opportunity to meet with ECPC Members based in Romania.

## 6.4 Communication

ECPC communications cover design, planning and implementation of awareness campaigns, dissemination of campaign materials and publications, website updates, social media posts and the distribution of the ECPC **news to membership**. Our aim is to keep members, stakeholders and the wider cancer community informed and up to date with all ECPC activities.

### 6.4.1 ECPC Website

The ECPC website received over 50,000 visitors over the year, achieving a 34.7% rise in comparison to the previous year. The most popular webpages were the homepage, followed by pages with information about Merkel Cell Carcinoma, our clinical trials database, pancreatic cancer and information about our members, the Secretariat and the Board.

ECPC continued to work on a new website to be launched in early 2020. The new website will have a completely new design and structure to improve user's experience, putting the cancer patient in the center of its focus. Through this online platform, ECPC aims to offer to cancer patient organisations all over Europe and beyond information about its

activities, developments in cancer policy, new treatments and provide members with practical educational tools such as a HTA e-learning module and the Immuno-oncology portal, available in five languages.

### 6.4.2 Social Media Accounts

The ECPC Twitter account rose to 4,942 followers (500 more than last year), the ECPC Facebook account accumulated 8,711 likes (250 more than last year) and the LinkedIn account has 738 followers.

Our ECPC social media channels allow us to interact with our followers, share important updates, engage in surveys and campaigns and share our members updates. As a patient organisation operating at the EU level, we aim to engage patients but also stakeholders, policy makers, health care professionals and organisations. Our social media channels allow us to engage all these people at once.

ECPC uses live-posts on Twitter and Facebook from conferences and events to share worth mentioning news, inform its members about its and our partners' activities, share members' news, share news about developments in cancer research and care, and enhance participation in surveys. ECPC aims to develop a live online community of its members, partners, sponsors and friends with content relevant to our mission and activities. All ECPC campaigns and awareness-raising activities run on ECPC social media platforms is to ensure we reach targeted audience. Platforms are also an important tool helping us engage and maintain relationships with our current and protentional members.

### 6.4.3 Newsletter

The ECPC newsletter is distributed to more than 1294 high-level stakeholders and European cancer patient organisations. ECPC regularly updates the newsletter's subscribers about all initiatives and activities of the organisation and opportunities for cancer patients and cancer patient advocates to participate in projects. The content of the newsletters varies from invitations to events and clinical trials, to surveys dissemination and promotion of ECPC's awareness campaigns. Throughout 2019, ECPC sent out 60 newsletters.

The main objective of ECPC's newsletters towards ECPC members is to:

- continue raising their understanding of the complex European public health policy panorama
- explain the impact of European health policies on cancer patients' lives
- invite them to proactively contribute to ECPC's policy work.

### 6.4.4 Publications

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

- The Merkel Cell Carcinoma brochures
- The ECPC-ESMO Survivorship Guide
- The 'Living Well During Cancer treatment' Nutrition Patient Guide
- ECPC European Election Manifesto
- HTA e-module leaflet
- Biosimilars e-module leaflet
- Head and Neck Cancer Call to Action
- Head and Neck Cancer Fact Sheet
- 2016 Nutrition Survey results published in Journal of Cachexia, Sarcopenia and Muscle
- A translational research infrastructure for a European mission on cancer, Journal of Molecular Oncology
- Cancer survivorship: an integral part of Europe's research agenda, Molecular Oncology
- Towards a Cancer Mission in Horizon Europe, Molecular Oncology
- The European Cancer Patient Coalition and its central role in connecting stakeholder cookbooks to advance patient-centric solutions in the mission on cancer Journal of Molecular Oncology
- What could be a cancer mission objective if we join our forces in the fight against cancer?
- White Paper: Improved Protection of Outdoor Workers from Solar Ultraviolet Radiation

#### 6.4.5 Media

Throughout the year ECPC has published 10 press releases, all of them were featured in the independent pan-European media network Euractiv. In 2019, ECPC was featured in POLITICO Pro Morning Health Care, and other publications and media.



## 7. Campaigns

In 2019 ECPC led 7 awareness campaigns which are presented below.

### 7.1 World Cancer Day

On the occasion of World Cancer Day (4<sup>th</sup> February), ECPC has launched an online education module on Health Technology Assessment. Aimed at patients and advocates, the module explains why, how and where cancer patients and patient organisations can get involved in this decision-making process. The module aims not only to offer information on HTA but also, following the on-going political debate on future EU cooperation on HTA, to empower all patient organisations to become stronger advocates of patient involvement in HTA at national level. The launch of the e-module was promoted on our social media accounts, in News section of the website and in a press release.

### 7.2 Nutrition and physical activity

Building on a highly successful campaign in 2018, ECPC launched its second Nutrition and Physical Activity Campaign. Celebrated every year in March, the Nutrition and Physical Activity Awareness Month is aligned with the American National Nutrition Month, a nutrition education and information campaign held annually by the American Academy of Nutrition and Dietetics. ECPC remains steadfast in its belief that nutrition and physical activity can positively impact the well-being of people living with cancer. ECPC believes in the value of empowering individual patients and patient organisations by producing more information on cancer patients' nutritional needs.



Nutrition Campaign Logo

In 2019, ECPC carried on with the Cancer and Physical Activity Awareness Month in March and translated the “Living Well During Cancer Treatment” booklet into Italian, Greek, Spanish, Polish, Finnish, Danish, Slovak and Bulgarian. The results of the 2016 survey were also published in two editions of the Journal of Cachexia, Sarcopenia and Muscle. ECPC is committed to continue its collaboration with various stakeholders to ensure Nutrition is a priority on the EU agenda.

ECPC continued to support this campaign by launching a successful social media campaign also using the hashtag #recipeagainstcancer. The ‘twibbon’ was also used this year following its popularity in 2018.

## 7.3 Bladder cancer campaign



Bladder Cancer Campaign Logo

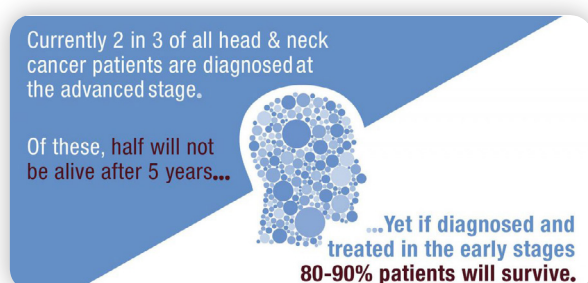
Bladder cancer is the fifth most common cancer in Europe and can affect everyone. There are 150,000 new cases each year in Europe. Only 1% of money spent on cancer research is spent on bladder cancer. Bladder cancer can often be overlooked by patients and General Practitioners due to symptoms often being associated with less serious, more common issues such as urinary infections. It is the only top 10 cancer whose prognosis is getting worse.

ECPC marked Bladder Cancer Awareness Month in May 2019 with their third Bladder Cancer Awareness Campaign. In 2019, the bladder cancer awareness

campaign focused on educating, raising awareness, and making sure that bladder cancer is no longer a forgotten disease. ECPC supported the awareness month with an extensive social media campaign seconded by the Bladder Cancer social media toolkit ready to use by ECPC members with messages, banners and images involving key messages such as 'Have you heard about Bladder Cancer? It's time you did' and 'Bladder Cancer – It's time to fight. ECPC also made their Bladder Cancer social media toolkit available, with messages and images to use along with the #BladderCancer as well as BCAM 19 Facebook photo frames.

ECPC also planned activities for the awareness month using large orange Zorbs from last year's campaign and sharing details of activities people can plan to help raise awareness such as small- or large-scale walking events. 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.

## 7.4 Transforming the Face of Head and Neck Cancer Care in Europe



Head and Neck Cancer Campaign

Head and Neck Cancer (HNC) is the seventh most common type of cancer in Europe. Yet it is considered a rare cancer and it is a multi-faceted disease. This type of cancer is curable if diagnosed in early stage. However, currently 2 out of 3 of all HNC are diagnosed at the advanced stage, killing 376,000 people every year globally. Despite major advances in the treatments over the past three decades, patient outcomes remain disappointingly unchanged.

In November 2019, ECPC continued to promote awareness on Head and Neck cancers in Europe, participating in the **#Make Sense Campaign**, working together with the European Head and Neck Society. On November

5<sup>th</sup>, 2019, ECPC organised an event at the European Parliament hosted by MEP Patrizia Toia. The objectives of the event were to raise awareness of head and neck cancer and of its impact at EU level, highlight the urgent need to address quality of care challenges in Europe and explore opportunities to Transform the Face of Head and Neck Cancer Care in Europe. Dr. Annalisa Trama, Dr. Lisa Licitra and Member of ECPC Audit Committee and H&N survivor Roberto Persio all spoke at the event highlighting the need for educational resources, coordination of free screening clinics, engagement in a network of policy and patient advocacy groups.

ECPC further raised awareness through the H&N cancer factsheet targeting all policy makers and with a call to action to get them involved in the fight against head and neck cancer.

The Make Sense Campaign is a pan-European head and neck cancer awareness initiative, run by the European Head and Neck Society (EHNS). The event was a true success. Over 30 stakeholders, including policy makers, industry, researchers, scientific societies and head and neck cancer patients attended the event.

## 7.5 Personalised Medicine Awareness Month

Personalised Medicine Awareness Month is November. Earlier in the year, at the Annual Congress of ECPC, in June 2019, more than 200 ECPC members and other stakeholders attended a dedicated session, chaired by ECPC Board Member Matti Järvinen, on personalised medicine. The session included speakers Danijela Koppers-Lalic from the VU Medical Center at the Cancer Center Amsterdam presenting “European Liquid Biopsy Academy” and Francesco Florindi, Strategy and Partnership Manager at BBMRI-ERIC presenting “What is biobanking and why it matters to cancer patients? Diagnostics, genomics and personalised medicine”. Marc Van Den Bulcke, Head of Service, Cancer Center at Sciensano, who is working on genome sequencing to foster “personalised medicine” stated that “Through initiatives like this, improving the general understanding of cancer and making the voices of cancer patients heard, we can change our mindset from reaction to prevention, resulting in a better society long term with improved quality of life and public health.”



Personalised Medicine Awareness Month logo

The 2019 Personalised Medicine Awareness Month in November aimed to improve patient care by accelerating the delivery and uptake of personalised medicine and high-quality diagnostics across all EU Member States. The campaign sought to achieve this, following-up the success of the 2018's campaign, by promoting the importance of future-proof regulatory frameworks to facilitate the uptake of innovative therapies and by raising awareness and understanding of the important role that cancer diagnostics have in the personalised treatment of cancer.

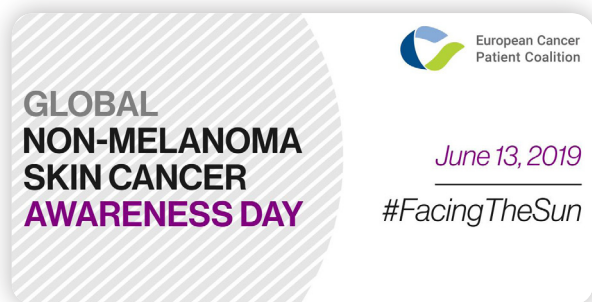
The Personalised Medicine month was organized around a communications campaign, that was supported by a campaign toolkit, available in 12 languages. The multi-language

availability of the toolkit facilitated the dissemination of the campaign messages in several channels (LinkedIn, Facebook, and Twitter).

The 2019 Personalised Medicine month campaign offered to our members the possibility to be informed about the important role that advanced new cancer diagnostics have in personalised cancer treatments. This improved understanding and knowledge of the role of biomarkers and of the possibilities offered by personalised medicine. This will in turn, empower and offer the tools to our members to advocate for high-quality cancer diagnostics across all Member States and to engage policymakers in their countries, seconding our efforts at EU level. ECPC aims to advocate for regulatory frameworks that facilitate the uptake and access to innovative personalised cancer treatments.

The Meeting Report of a Workshop organized by CDDF in September 2018 in Brussels in which Francesco de Lorenzo, ECPC President and Kathi Apostolidis, Vice President had participated in was also published in 2019 called “CDDF MULTI – STAKEHOLDER WORKSHOP on Biomarkers and Patient Access to Personalised Oncology Drugs in Europe 24th and 25th of September 2018”. The CDDF workshop aimed to give an overview of the status quo, challenges and developments in this space, as well as facilitating a collaborative discussion between regulatory bodies, HTAs, healthcare providers, academics, patients and industry on the challenges of equal access to personalised therapy within and between European countries. The unmet need for minimally invasive tests to determine subgroups of patients with a high probability of response to therapy is critical to accelerate drug development, reduce costs, increase efficacy and bring new and effective agents to patients as quickly as possible.

## 7.6 Non-melanoma Skin Cancer Awareness Day



Global Non-Melanoma Skin Cancer Awareness Day  
2019 logo

Non-melanoma skin cancer (NMSC) results from excessive exposure to solar ultraviolet radiation and has a disproportionate impact on people who work outdoors for most of their working hours. After five years of outdoor work, the risk of developing NMSC doubles. In Europe alone, 15 million outdoor workers spend most of their working lives exposed to the sun without knowing the risks. As it stands, EU occupational safety and health directives still do not sufficiently protect outdoor workers from skin cancer, due to the fact that chronic workplace UVR exposure

is generally excluded from potentially relevant legislation. As a result, outdoor workers lack access to adequate education and prevention measures, diagnosis and effective treatments.

To draw attention to the threat of UVR to outdoor workers and improve access to better and earlier treatments, a coalition of nine organisations – including ECPC, launched a Global Call to Action to End the NMSC Epidemic in Outdoor Workers in April of 2019. We called for the implementation of a systematic approach to addressing the Non-Melanoma Skin Cancer Epidemic and urged policy makers, doctors and other health professionals, employers, workers and patient advocacy groups to take five actions to address the unmet needs of NMSC patients, among them strengthening legislation and

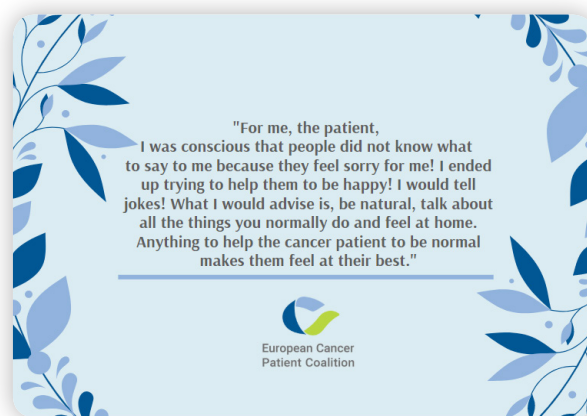
enhanced cooperation and attention to the issue.

The Global Call to Action was followed up with the first ever NMSC global awareness day on June 13<sup>th</sup> which was marked with an event in the European Parliament hosted by then MEP Lieve Wierinck. The leading expert on NMSC Prof Swen John and ECPC President, Kathi Apostolidis, together with representatives of ILO, the EU Commission and construction industry presented the current situation and made recommendations towards the recognition of the UV radiation as an occupational safety risk. The event coincided with the launch of a joint White Paper co-written with EADV, the European Academy of Dermatology and Venereology on NMSC. Later in the summer we co-wrote an op-ed with EADV on NMSC that helped spread awareness about the disease and reiterated our call for better protection for outdoor workers. The op-ed was published in Euronews.

## 7.7. Christmas campaign

ECPC ran a campaign before and around Christmas to express care and compassion with cancer patients and their family members as this festive period might be particularly difficult for people that were just diagnosed or they are undergoing an exhausting treatment, and their families.

The campaign featured 12 real and practical advices from cancer patients and cancer carers for their friends and relatives as sometimes the pressure to say and to do the right thing can be overwhelming. The aim of the campaign was to show how to best support a friend or a relative with cancer. The campaign was using the hashtag #patientsadvice.



Example of Christmas Campaign social media post

In 2019, ECPC participated in 15 third parties' cancer awareness campaigns including:

- Childhood Cancer Day
- World Cancer Day
- World NGO Day
- International HPV Awareness Day campaign
- Bowel Cancer Awareness Month
- Activities of TBCT "String of pearls"
- Europa Colon awareness campaign #MyBest10Seconds
- AllCan's #PatientInsights campaign
- Make Sense Campaign's campaign on a cookbook
- European Week Against Cancer
- Antibiotic Awareness Day
- EMA's campaign #SafetyOfMedicine
- EMA's campaign #FromLabToPatient
- Human Rights Day
- TBCT's #BreastCancerManifesto campaign



## 8. Health Policy

**Enable cross-border collaboration to ensure that cancer patients receive the most appropriate healthcare, regardless of where they reside**

- 1 Apply the recent European Parliament resolution on the Implementation of the Cross-border Healthcare Directive (CBHD), and continuously assess its implementation in the Member States.
- 2 Facilitate the development of reimbursement procedures in EU Member States, especially to support rare cancer patients, in full implementation of the CBHD.
- 3 Develop a plan for uptake of the Joint Action on Rare Cancers recommendations and their implementation in the European Reference Networks and Member States.
- 4 Drive consensus in the Council of the EU to put forward recommendations on the full implementation of the CBHD, to guarantee it allows patients to seek advice, treatment and care where it is available.

### Cross Border Healthcare Directive example

legislative and College of Commissioners and the announcement of both the EU Mission on Cancer and Europe's Beating Cancer Plan. The year was clearly marked by the election of the new European Parliament and foreseeing this ECPC launched a Manifesto with key policy asks that garnered the support of incoming MEPs. ECPC worked closely with the newly elected MEPs in order to establish an inclusive intergroup on cancer that will serve as a forum for exchange of views between civil society, cancer patients, scientists and MEPs on issues central to Europe's Beating Cancer Plan and the Cancer Mission. The intergroup was established by the end of the year and will have its first meeting in 2020, with ECPC acting as its secretariat.

The Work-life Balance Directive entered into force in 2019 and represents the first tangible European effort to ensure social inclusion. We were happy to see that our suggested amendments were included and will work with our members to support them during its transposition in the Member States, since Member States have the possibility to add more provisions in the directive transposition. The year also marked the culmination of the three-year Joint Action on Rare Cancer with the launch of the '**Rare Cancer Agenda 2030: Ten recommendations from the EU Joint Action on Rare Cancers**'. The launching event was organised at the EU Parliament jointly by ECPC and ESMO. Our Working Group on Rare Cancers contributed throughout the project to the final recommendations. In 2019, ECPC also reinvigorated the fight against non-melanoma skin cancer by lending its support to the global call to action and launching the first ever world non-melanoma skin cancer day on June 13<sup>th</sup> in the European Parliament.

In addition, ECPC was also involved in three Third Health Programme projects (ERN EURACAN, JARC, iPAAC) and ECIBC – European Commission Initiative on Breast Cancer funded by the European Commission with a strong policy impact.

ECPC believes that patients are co-creators of their own health and therefore works within several stakeholder partnerships, where we lend our contributions and ensure that all relevant health policy discussions remain patient centred. Through the "**Transforming Breast Cancer Together**" initiative for instance we have worked with industry leaders, advocates, and legislators to offer solutions for how to better care for Breast Cancer patients. ECPC is proud to have launched the Cancer-related Complications and Comorbidities Initiative in the end of the year with a joint statement from a diverse group of stakeholders that work on cancer related health issues. ECPC will chair this initiative and we will ensure that comorbidities that so often are overlooked remain high on the research and policy agenda in the coming years.

ECPC plays an essential role in Europe by effectively acting as the voice of cancer patients and is committed to representing patients' interests and proposing patient-centric solutions to cancer-related issues. In many ways 2019 could end up being looked back at as a turning point in European cancer policy with the introduction of important new legislations, a new



## 8.1 EU Joint Action on Rare Cancers (JARC)

The EU Joint Action on Rare Cancers (JARC) was a joint action funded by the EU's 3rd Health Programme started in 2016 and ended in 2019. As more than 4 million people are affected by rare cancers across the European Union, the JARC was set up to produce recommendations aimed at optimising the development of ERNs (European Reference Networks). Three of the ERNs are specifically devoted to rare cancers, by providing operational solutions and professional guidance in the areas of quality of care, epidemiology, research and innovation, education and state-of-the-art definitions for prevention, diagnosis and treatment of rare cancers. ECPC was an associated partner of the project and established the Working Group on Rare Cancers (WGRC) which worked in parallel with the Joint Action to guarantee that rare cancer patients and their organisations were able to contribute directly to the activities, among other consolidating the definition of rare cancers, creating a list of rare cancers, defining the need for medical and patient education and issuing guidance for harmonisation of clinical practices in rare cancers.

The ten EU JARC recommendations that resulted from the Joint Action were presented at an event ECPC organised in collaboration with ESMO in the European Parliament on September 11<sup>th</sup>, hosted by MEP Fulvio Martusciello. The JARC was aimed to integrate and maximize the efforts of the European Commission, EU Member States and all stakeholders to advance the quality of care and research on rare cancers through the ERNs network. ECPC contribution has been summarised within chapter 10 - **Rare cancer patients should be engaged...** of the JARC final Book, where ECPC emphasised the need for the European Commission to support Member States in implementing JARC recommendations through the Council of the Public Health Ministers, following the European Parliament Report of 2019 on the implementation of the EU Cross-Border Healthcare Directive. Furthermore, ECPC's WGRC engaged to work with patient organisations representing rare cancer patients at the national level, to ensure the timely and appropriate implementation of these recommendations and that the EU Cross-Border Healthcare Directive is functional and its provisions accessible.

## 8.2 Transforming Breast Cancer Together

The Transforming Breast Cancer Together initiative was established in November 2017, under the leadership of Lieve Wierinck (ALDE) and Elena Gentile (S&D), Members of the European Parliament (MEPs) and ECPC was among the founding members. The ultimate goal of this initiative is to improve services for patients in an area of still high unmet needs and reduce the societal impact of breast cancer by elevating it as a health policy priority in order to improve breast cancer prevention, diagnosis and care across Europe.

In 2019, Transforming Breast Cancer Together released its white paper which **provides a comprehensive** evaluation of the status of breast cancer prevention, diagnosis and care across Europe and identifies concrete actions which would help to ensure equal access and better outcomes for patients across Europe. The paper outlined the high economic burden, inequalities across and within EU member states in breast cancer

care, psychological impact and the need for multi-disciplinary breast specialists' units among its key findings.

## 8.3 Cancer Mission Europe

Through Horizon Europe Framework Programme for Research and Innovation (2021-2027), the European Commission has established a set of European Research and Innovation Missions with the aim to deliver solutions to some of the greatest challenges facing Europe. Due to its increasing burden, cancer is one of the leading medical and societal challenges today. Coordinated by a Board of European Experts, the Mission on Cancer is meant to *"define an ambitious and measurable goal with a substantial impact on and relevance for society and citizens of Europe"*.<sup>1</sup>

Following the crucial role played by our organisation in November 2018 within the Vatican meeting of the representatives of key European cancer related scientific societies, at a starting point for generating ideas into the framework of the Mission on Cancer, ECPC collaborated with several of the participating scientific cancer organisations and cancer centres (Cancer Core Europe, Cancer Prevention, OECl, EORTC, European Academy of Cancer Sciences and ESMO) to develop a unified insight towards a mission-oriented approach in cancer. As a result of this collaboration, a paper entitled "Toward a Cancer Mission in Horizon Europe" was published in Molecular Oncology journal in October 2019. The aim of this paper, co-authored by Francesco de Lorenzo, was to address the goals, structure the activities and areas of priority required to accomplish the Mission.

ECPC engaged very early in the debate about the mission-oriented approach to cancer, participated in the two Gago Conferences in February 2018 in Porto with Kathi Apostolidis and in the 2nd in Vienna in September 2018 with Francesco de Lorenzo and has collaborated closely, for more than three years now, both within the European Academy for Cancer Sciences (EACS) Governing Body and the Policy Committee, and with Cancer Core Europe, where Francesco de Lorenzo is a member of the Board. On these occasions, ECPC presented the cancer patient perspective on defining cancer missions in Europe, with a focus on putting survivorship on the research agenda.

The Mission on Cancer will remain a high priority on the agenda of the organisation in the coming years. ECPC aims to support its member organisations to implement the goals of the Mission in each Member State.

## 8.4 Parliamentary Intergroup on Cancer

The Parliamentary Intergroup on Cancer was formed in 2019 in response to the strong support and political motivation to have a dedicated, full-time platform for cancer on the EU level. ECPC found many stakeholders and MEP's ready to prioritise and explore

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<sup>1</sup> European Commission Directorate-General for Research and Innovation, 2020, p 2: CONQUERING CANCER: MISSION POSSIBLE

the numerous aspects of cancer control. This led to an official launch of the Intergroup in 2020.

This first and only EU Parliamentary Intergroup on cancer will serve as a forum for MEPs from all political parties to engage in dialogue with patients, cancer survivors and carers, scientific and medical societies, research institutions, think tanks, medical practitioners and researchers, policy makers and leaders of the health industry, civil society at large, national governments and institutions. It will act as a two-way communication channel by holding hearings and debates and leading fact-finding missions on salient topics such as prevention, access to treatment, medicine shortages, cancer research on quality of life, innovation in cancer care, and survivorship.

The efforts made by Francesco de Lorenzo and Kathi Apostolidis last year, immediately after the EU elections, to contact as many MEPs as they could, had very positive results since MEPs from different political parties voted in great numbers, ranking the Cancer Intergroup first with 110 votes, among Intergroups approved for the current European Parliament mandate.

The new Cancer Intergroup will be established in 2020 with a launch event at the European Parliament. ECPC will assure the Secretariat.

## 8.5 Social Disparities Survey

ECPC Legal Network for Cancer Patients (LNCP) launched in 2018 a European survey on the Socio-economic Burden of Cancer throughout Europe, collecting data from almost all EU Member States, as well as Norway and Switzerland. This survey did not concern medicines or cancer care, but instead it investigated Labour, Welfare and Taxation issues. Based on the assumption that millions of people face a cancer diagnosis during their working age (or during higher education) and most of them will succeed in getting cured or in stabilizing the disease, the survey analyses social exclusion, discrimination and dropout that may occur to cancer survivors or to people in the task of informal caregiver for a relative fighting against cancer.

The answers to the survey questionnaire are currently under evaluation, but some findings can already be highlighted, and a number of issues arising from the findings are concerning, including: long waiting times for disability assessment in many countries and, in some cases, assessment processes that do not factor in the specific effects of cancer or its treatment.

Cancer patients with the same diagnosis and a similar level of impairment would be likely to receive very different levels of support in different member states: differing employment rights, variable access to paid sick leave and workplace adjustments and, in some countries, a lack of protection from unfair dismissal.

Self-employed workers are particularly vulnerable when diagnosed with cancer: financial support is typically very limited or completely absent. Self-employed carers also face disadvantage in similar respects. Only half of the countries represented in the survey have

provisions for pension contributions that are missed as a result of illness and even fewer offer protection for carers in these circumstances.

Access to financial products such as health and life insurance, loans and mortgages is often restricted or more expensive as a result of a cancer diagnosis, whilst only France, Belgium and Luxembourg have enforced the right to be forgotten (i.e. a law prescribing that long term survivors are to be considered as any ordinary person). For example, in Bulgaria a disability of more than 50 per cent means a patient has rights to benefits; in Greece the threshold is 67 per cent and above; in Hungary a reduction of health of more than 40 per cent is required whilst in Italy different percentage levels of disability lead to different entitlements (cancer patients are classified for an impairment of either 11, 70 or 100% - only 70 and 100 entitling to benefits). In Lithuania the criteria is set at less than 55 per cent of working capacity; in Portugal the criteria is 60 per cent and in Slovakia a decrease in 'capacity to perform gainful activity' of 41 per cent or more qualifies for payment of some benefits.

Disability or partial inability entitlement allows the person to receive social benefits such as:

- Financial Assistance, in 18 countries (Belgium\*, Bulgaria, Cyprus\*, Czech Republic\*, Denmark\*, Estonia\*, France\*, Greece\*, Hungary\*, Latvia\*, Lithuania\*, Malta\*, Norway\*, Poland, Portugal\*, Romania\*, Sweden\*, Switzerland\*);
- Pension credits acknowledged in 11 countries (Belgium\*, Denmark\*, Estonia\*, France\*, Greece\*, Latvia\*, Lithuania\*, Portugal\*, Slovenia\*, Sweden\*, UK\*. Tax exemptions or tax reductions were reported just in Finland\*, Greece\*, Hungary\*, Italy\*, Latvia\*, Malta\*, Portugal\*, Romania\*)

An important section of the survey is about caregivers: former studies have demonstrated the necessity of acknowledging and promoting caregiving to assure the sustainability of Welfare Systems. This 2019 survey indicates that many countries still fail to provide sustainable caregiving: fewer than half of European countries involved in ECPC LNCP survey reported social benefits for carers. Respondents from ten EU member states (Bulgaria, Czech Republic, Estonia, Latvia, Lithuania, Luxembourg, Malta, Poland, Portugal, Spain) complain about the lack of such provisions. In some countries there is entitlement to financial support only if the family member needing care is under 18, and sometimes restricted to carers of children under 12. Time limits (e.g. a year) can apply, which are problematic when illnesses are long-lasting or terminal. Most caregivers are women and as a consequence of lack of equitable adjustments they are outcast from the labour market in spite of any existing gender employment equity strategy.

A specific aspect of caregiving considered in the survey concerns the possibility for a working caregiver to obtain a leave permit from her/his job. There is a lack of harmonisation across Europe on this matter notwithstanding the five days of paid leave introduced under the Directive on the Work-Life Balance for Parents and Carers. Respondents from Cyprus, France, Latvia, Lithuania\*, Portugal, Romania, Spain complain that no entitlement to leave for caregiving, even unpaid, is foreseen.

**PRELIMINARY CONCLUSIONS:** Despite an EU-wide commitment to Equality and Human Rights at work, the employment rights of people with cancer appear to differ significantly at national level. A thorough analysis of survey data is expected to lead to the publication

of a white paper in 2020. The survey is going to be an important tool to carry on ECPC advocacy for a cultural change towards the rights and social rehabilitation of cancer patients and family carers, suggest which legislative changes are needed in order to allow a cancer survivor or caregiver to maintain its active role of citizenship, and cancel the stigma relegating these persons to social assistance services and social exclusion.

## 8.6 ERN EURACAN

The European Reference Network (ERN) on Rare Adult Solid Cancers (EURACAN) is a network connecting healthcare providers and centres of expertise covering highly specialised healthcare, for the purpose of improving access to diagnosis, treatment and the provision of high-quality healthcare for rare adult solid cancer patients in Europe. EURACAN splits rare cancers into 10 domains corresponding to the 10<sup>th</sup> revision of the International Statistical Classification of Diseases and Related Health Problems (ICD10) and RARECARE.

## 8.7 iPAAC

Targeting both EU-level policy-makers and decision-makers at national, regional and local level, iPAAC focuses on implementation of the outcomes of the European Partnership for Action Against Cancer (EPAAC) and of the Joint Action on Cancer Control (CanCon), and constantly expands its activities to new cancer control issues such as genomics, innovative therapies and the use of registries.

This Joint Action also hopes to provide better efficacy for dealing with **“neglected cancers”**, through the development of new key indicators to assess clinical patient pathways and healthcare-related costs of cancer, particularly in the case of pancreatic cancer. Pancreatic cancer is one of the most lethal tumours, and it is the fourth cause of cancer death in Europe. Despite its important public health impact, there are no effective treatments or high-visibility research efforts.

At the European Union level, iPAAC adds value by enhancing collaboration in the field of cancer with extensive exchange of good practices, successful implementation of different programmes and gradual reduction of the cancer burden. At Member State level, iPAAC employs its Roadmap on Implementation and Sustainability of Cancer Control Actions to support national, regional and local decision-makers in implementing innovation.

ECPC integrates the patient’s voice within iPAAC by contributing to guidelines for cancer information and registries, advising on the selection of epidemiological indicators on cancer prevalence and survivorship, participating in a consensus meeting to define neglected cancers using the case of pancreatic cancer, and supporting a paradigm shift on the use of genomics. ECPC also contributes to the successful dissemination of the project’s deliverables and is collaborating to organise an expert workshop and 2 conference meetings actively supporting networking and mapping of contacts.

## 8.8 Cancer Related Complications and Comorbidities

### Initiative

Cancer-related complications and comorbidities are a highly significant burden on patients across Europe – in many cases fatal – but are all too often neglected when it comes to policy and research. At present, there is a strong momentum in the EU policy landscape to bring attention to this area. The idea for this initiative on cancer-related complications and comorbidities came up after the European Cancer Patient Coalition (ECPC) and the European Thrombosis and Haemostasis Alliance (ETHA) organised a series of events and projects on cancer associated thrombosis. The experience of these projects highlighted that the broader challenge of cancer-related complications and comorbidities requires further policy attention.

The purpose of this initiative is to amplify each organisation's voice and help to create momentum for EU action on better integrated care for patients, looking not only at the impact of comorbidities on cancer patients, but also the impact of cancer on other diseases and conditions. Many organisations showed interest at ECPC meeting on June 12<sup>th</sup> 2019 and a consensus meeting on a joint statement on November 29<sup>th</sup> 2019. **In December 2019 the joint statement on cancer related complications and comorbidities was launched addressing issues such as Cancer Associated Thrombosis, Cardio-oncology complications, Neurotoxicity and Mental health, Obesity, Celiac disease and Malnutrition, Pain. Members of this initiative in 2019 include the following organisations:**

- European Association for the Study of Obesity (EASO)
- Eurocarers
- European Federation of Neurological Associations (EFNA)
- European Society of Cardiology (ESC)
- European Specialist Nurses Organisation (ESNO)
- European Thrombosis and Haemostasis Alliance (ETHA)
- International Society on Thrombosis and Hemostasis (ISTH)
- Thrombosis Ireland
- Thrombosis UK



## 9. Education

### 9.1 eLearning Module on Health Technology Assessment

In 2019, ECPC launched the e-learning module on health technology assessment (HTA). The module aims to equip our members and the broader patient community with knowledge for participating in the HTA of cancer treatments. The module covers a range of information from the process for developing medicines and their examination as part of the HTA, why cancer treatments might be reimbursed in some countries but not in others, and how cancer patient organisations can get involved in the HTA. It also covers the recent legislative developments on the HTA at the EU level and the importance of involvement of patient organisations and patient advocates in the HTA. The HTA e-learning module was translated in several languages and it is now available on our website in 6 languages including English, Greek, Italian, Polish, Spanish and Portuguese.

### 9.2 eLearning Module on Biosimilars

This patient toolkit has been developed by ecancer in collaboration with ECPC to provide patients with a comprehensive resource on biosimilar medicines. Six interactive modules provide key information and practical advice to support cancer patients in making informed decisions on a cancer treatment. A biosimilar is a highly similar copy of an off-patent biological medicine which is already available on the market under a different trademark. Biosimilars have the potential to increase access to medicines by improving the financial sustainability of our healthcare systems. The e-learning module on biosimilars is now available in 3 languages on ECPC website. A campaign to introduce the module was held on social media.

### 9.3 Immuno-oncology portal

The Immuno-oncology Portal (IOP) was created to provide up-to-date and accessible information about cancer immunotherapies, which are treatments that stimulate the body's own immune system to seek out and destroy cancer. The field of cancer immunology is growing and changing rapidly as is the number of possible treatments. Some cancers such as advanced melanoma that previously was considered untreatable can in some instances now be treated by immunotherapies. As a contrast to the promising outlook these new therapies bring to cancer patients, we found it very difficult to easily access understandable information about them. The IOP was updated through 2019 and it is now available in 7 languages on ECPC website.

## 9.4 Workshops and meetings with Members

Throughout the year, ECPC organised several workshops and meetings with members in their respective countries.

In March, ECPC representation met with Romanian members in Bucharest to strengthen the collaboration and to present ECPC and its main achievements but also to hear about our members' needs in Romania and how we can help from the international perspective. At the end of the meeting two high-level speakers presented on the impact of tobacco smoke on urological and lung cancer patients.

In April, ECPC met with members in Lisbon, including the Portuguese Association of Prostate Patients (APDP) and Live Woman Live Association to present the latest activities of ECPC and to debate on HTA module, nutrition, tobacco control and access to treatment.

During the International Gastric Cancer Conference in Prague in May 2019 ECPC held a meeting with ECPC members, including the Alliance of Women with Breast Cancer, Mamma Help and League Against Cancer Prague to verify opportunities for better collaboration and to present the latest projects of ECPC.

While attending the ESMO Congress 2019 in September in Barcelona, ECPC organised two meetings with ECPC Members, including Sarcoma Patients EuroNet (SPAEN), the Federation of Women with Breast Cancer (FECAM), Group Agata and the Catalan Association of Women Affected by Breast Cancer. The aim of the meeting was to discuss the latest ECPC's and members' communication activities and capacity-building opportunities.

In December 2019, a large group of cancer patients attended the East Galway & Midlands Cancer Support Centre in Ireland for the launch of the booklet "Living well during Cancer Treatment". ECPC Board Member Robert Greene delivered a presentation about taste alteration and its effect on cancer patients' ability to eat and Lisa O'Looney, Centre's Physiotherapist, gave a very insightful talk on the benefit of exercise during and beyond cancer treatment.

## 10 Advocacy and capacity-building activities

### 10.1 ECPC Annual Congress 2019

The ECPC Annual Congress was organised under the high patronage of the then-President of the European Parliament Antonio Tajani who stated:

*"I am pleased to see that yet another initiative of this kind is being organised, giving the opportunity to cancer patients and their families, experts from the health sector working at European or national level and researchers to exchange information on the most recent treatments, and to share their needs, challenges and best practices in this respect."*

On 7<sup>th</sup> – 9<sup>th</sup> of June 2019, ECPC convened cancer patients, cancer advocates and other stakeholders in Brussels to attend the Europe's largest gathering dedicated to people with cancer hosting more than 200 participants from 32 countries in Europe and beyond. Among these participants, 135 of them were ECPC Full and Associate Members, actively participating, contributing to the discussions, and sharing best practices.

Pre-congress meetings provided opportunities for the Working Group (WG) on Rare Cancers, the Working Group on Urological Cancers and the Legal Network for Cancer Patients to meet face-to-face and discuss more in-depth on specific areas of development in their respective fields. Discussions were guided by below-mentioned distinguished speakers.

WG on Rare Cancers:

- Jana Pelouchova, ECPC General Secretary and WGRC Chair
- Laura D'Avanzo, WGRC Co-Chair
- Maude Andersson, ECPC Board member
- Matti Järvinen, ECPC Board member
- Isabelle Manneh, ECPC Head of Health & Research programmes
- Annalisa Trama, Istituto Italiano Dei Tumori
- Josep Maria Borras, Catalan Institute of Oncology
- Evangelia Legaki, University of Athens

WG on Urological Cancers:

- Ken Mastris, ECPC Board Member
- Hein Van Poppel, European Association of Urology
- André Deschamps, Europa Uomo
- Berit Eberhardt, International Kidney Cancer Coalition
- Susan Mullerworth, Fight Bladder Cancer UK
- Maria Theodoridou, ELLOK Board Member

Legal Network for Cancer Patients:

- Francesco de Lorenzo, ECPC President
- Roberto de Miro, Chair of the ECPC Legal Network for Cancer Patients

- Alex Filicevas, ECPC
- Francoise Meunier, FEAM Vice President
- Antonella Cardone, ECPC Director
- Claire Champeix, Policy Officer at Eurocarers
- Kathi Apostolidis, ECPC Vice President
- Osvaldo Correia, President of the Associação Portuguesa de Cancro Cutâneo
- João Maia Silva of the Associação Portuguesa de Cancro Cutâneo

The ECPC Annual Congress included sessions on Health Technology Assessment, Work-Life Balance Directive, Social Disparities, Digital Health and Personalised Medicine. The speeches were delivered by the following distinguished representatives from the European Parliament, European Commission and key opinion leaders and experts from the world of oncology:

- Lieve Wierinck, Member of the European Parliament, Welcome address
- Flora Giorgio, Head of Sector HTA, DG SANTE, European Commission, European Commission Proposal on Health Technology Assessment Cooperation and Patient Involvement in HTA
- Francesco de Lorenzo, President of ECPC, Opening Session and ECPC highlights of last year
- Kathi Apostolidis, ECPC Vice President, Social Disparities & Work-Life Balance Directive and Introduction to Digital Health
- Francoise Meunier, FEAM Vice President, Social Disparities & Work-Life Balance Directive
- Efi Anastasiou, European Commission, DG EMPL, Work-Life Balance Directive and European Pillar of Social Rights, from regulation to implementation
- Marc van den Bulcke, Head of Service, Cancer Centre, Sciensano, The era of new advanced cancer diagnosis
- Antonella Cardone, ECPC Director, Europe of Social Disparities, Financial Report, Action plan and budget.
- Roberto De Miro, Chair of the ECPC Legal Network for Cancer Patients, Europe of Social Disparities
- Mihaela Militaru, Senior Director, EU Patient Advocacy, Merck Group, Embracing Carers
- Ken Mastris, ECPC Board Member, Digital Health
- Roma Maguire, Professor of Digital Health and Care, University of Strathclyde, eSMART
- Danijela Koppers-Lalic, VU Medical Center, Cancer Center Amsterdam, European Liquid Biopsy Academy
- Matti Järvinen, ECPC Board Member, Personalised medicine
- Francesco Florindi, Strategy and Partnership Manager, BBMRI-ERIC, What is biobanking and why it matters to cancer patients? Diagnostics, genomics and personalised medicine
- Maude Andersson, ECPC Board Member, ECPC Members share their best practices
- Max Schravendeel, Health & Research Officer, ECPC, HTA Educational module
- Isabelle Manneh, Head of Health & Research Programmes, ECPC, Malnutrition and Cancer

During the General Assembly, the new ECPC Board with mandate for the period of years 2019 - 2022 was officially established electing Kathi Apostolidis as the President of ECPC who said: *"I am honoured to fill this role, and, although I understand that it is a huge responsibility and commitment, I am excited for what the future will bring."*

New ECPC logo, which is currently used, was also launched during the ECPC Annual Congress.

# 11. EU Health and research programmes

## 11.1 European Health & Research Projects

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 2019, ECPC was an active member in the 7<sup>th</sup> Framework project (eSMART) and 14 Horizon 2020 projects (DIAdIC, EUCANCan, H2020MM04, HTx Forum, ImmunoSABR, LEGACy, PalliativeSedation, TRANSCAN-2), including four Innovative Medicine Initiative projects (BD4BO DO-IT, BD4BO PIONEER, Immune-Image, PREFER) and two Innovative Training Networks (ELBA, PREDICT). These involvements allow ECPC to be on the forefront of scientific developments in the field of cancer by providing the patient's perspective and driving fundamental knowledge on the science behind cancer.

ECPC also contributed to 34 proposals for EU funded projects, of which 4 received funding. In 2020, the European Cancer Patient Coalition will begin work on its first project funded by the European Institute of Innovation and Technology (EIT) Health to empower European patients in radiation oncology (E-PRO). The Coalition will also be kicking off 3 additional Horizon 2020 projects (LifeChamps, Instand-NGS4P, QUALITOP).

## 11.2 IMI BD4BO DO-IT (2017 -2019)

PIONEER is one of the BD4BO disease-specific projects and serves as the European Network of Excellence for Big Data in Prostate Cancer. The project is using big data to address key knowledge gaps related to screening, diagnosis and treatment of prostate cancer by standardising and integrating already existing big data in clinical trials and electronic health records from diverse populations of prostate cancer patients across different stages of the disease into a single, innovative data platform. PIONEER is working for meaningful improvement in clinical practice, improved health outcomes and increased health-system efficiency by providing evidence-based data, so patients can benefit from the best possible care.

ECPC is contributing to the overall project by providing a voice to prostate cancer patients through offering expert patient input and advice during the entire life cycle of the project. The participation of ECPC ensures that the patients engage in their disease management, thus leading to better treatment adherence and improved Quality of Life (QoL). This includes and is not limited to reviewing informed consent forms, surveys, study protocols and guidelines, setting up patient focus groups, drafting

patient information leaflets and brochures, and the successful communication and dissemination of the project's deliverables. ECPC is also working to ensure that the visual identity of PIONEER is aligned with the branding of the DO-IT communication and support action for all BD4BO projects supported by the IMI.

In 2019, ECPC reviewed the PIONEER patient brochure and animated video, and participated in the 2<sup>nd</sup> Annual General Assembly Meeting.

### 11.3 IMI BD4BO PIONEER (2018 – 2023)

The Big Data for Better Outcomes (BD4BO) programme was launched with the objective of harnessing the opportunities of big data to promote patient-centred, outcomes-focused healthcare in Europe and to develop innovative methods for integrating, analysing and using this big data. The BD4BO, Policy Innovation, and Healthcare Systems Transformation (BD4BO DO-IT) consortium acts as the Coordination and Support Action for 4 disease-specific projects: Alzheimer's disease (ROADMAP), hematologic malignancies (HARMONY), cardiovascular diseases (BIGDATA@HEART) and prostate cancer (PIONEER).

ECPC led the coordination of focus groups to review project documents and provide critical insight to further develop the Informed Consent Forms (ICFs) by integrating patient experts' input. As an active member in the project's Communications team, ECPC worked closely on overall project branding, communication planning, website development and outreach activities, contributing to the successful dissemination of the project's deliverables and overall project sustainability beyond the project expiration date.

In 2019, ECPC helped finalise the BD4BO DO-IT ICFs and participated in the BD4BO DO-IT Final Event before the project came to an end.

### 11.4 DIAdIC (2019 – 2023)

DIAdIC will develop and evaluate two different methods of administering psychosocial and educational interventions: a face-to-face method provided in the patient and caregiver home by a specially trained professional and a self-administered electronic tool. Both interventions are aimed at the patient-caregiver dyad (something consisting of two parts or persons, from Latin/Greek *duas* or *dyás*) and will be available across Europe to provide good psychosocial and educational support to patients and their family caregivers.

ECPC leads the project's Work Package on Dissemination and Communication, ensuring engagement with the public, patients and other stakeholders. ECPC designed the project's visual identity, developed and maintains a project website and multiple social media platforms, and disseminates a biannual newsletter and press releases. ECPC is also helping in drafting implementation guidelines for the DIAdIC interventions



to ensure further implementation, writing a position paper with policy and awareness recommendations, and hosting the final stakeholder event at the completion of the project.

In 2019, ECPC wrote the DIAdIC Dissemination, Exploitation and Communication Plan. Additionally, ECPC developed and maintained the project website (<http://diadic.eu/>). Twitter and Facebook accounts were created. Additionally, a press release and newsletter were disseminated.

## 11.5 IMI PREFER Patient Preferences (2016 -2021)

PREFER is working to provide a set of systemic methodologies and recommendations to assess, engage and include patient perspectives during the development, approval and post-approval of new therapies, providing a better understanding of recommended best-practice approaches. The project gives an indication of how patient preference studies can provide valuable information to support decision-making and establishing recommendations to support the development of guidelines for industry, regulatory authorities and HTA bodies on how and when to include patient perspectives on the benefits and risks of medicinal products.

ECPC leads three other patient organisations in the Patient Advisory Group (PAG) to ensure that the methodologies identified are consistent with the specific views, experiences and preferences of patients, from contributing to the overall project design, setting up patient focus groups, and reviewing surveys, study protocols and guidelines, to the successful communication and dissemination of the project's deliverables. ECPC sits on the project Steering Committee and Advisory Board as the Lead Patient Representative influencing research priorities to match patients' needs and the inclusion of quality of life indicators.

In 2019, ECPC was part of the development of the case study on Lung Cancer, actively disseminated any project interim results and participated in the PREFER Annual Meeting.

## 11.6 H2020 ImmunoSABR metastatic lung cancer (2017 - 2022)

ImmunoSABR is treating NSCLC with fewer than 10 metastases with a combination of radiotherapy and immunotherapy, testing the synergistic effects of the two therapies. It is proposed that this will result in longer survival without progression of the disease.

ECPC supports the management, dissemination and exploitation of the ImmunoSABR project. This entails conveying information about the ImmunoSABR trial to our own network, other relevant European patient organisations, and the public. ECPC is also organising a dedicated patient consultation session to discuss the ImmunoSABR trial, providing a platform for panel discussions with patients regarding clinical trial

design. ECPC has already provided input for the development of the project's informed consent forms and the related patient brochure. Furthermore, ECPC is hosting the final ImmunoSABR conference combined with a stakeholder workshop at the European Parliament to disseminate project results.

In 2019, ECPC contributed to a revised Dissemination Strategy and created the project's Twitter and Facebook accounts. Additionally, ECPC attended the ImmunoSABR Consortium Meeting.

## **11.7 FP7 eSMART mHealth symptom management (2014 - 2019)**

eSMART conducted a clinical trial to evaluate the impact of a mobile phone-based symptom management intervention which records patient-reported outcomes and the delivery of care during chemotherapy and 1 year after treatment. eSMART demonstrates the effects of a real-time remote patient monitoring and care system that will help reduce symptoms experienced during chemotherapy and improve quality of life and survivorship. The project results will facilitate changes in clinical practice and lead to improved delivery of cancer care across Europe.

ECPC participated within the eSMART Project Technical Management Board, the Publications Committee and the Exploitation Committee, offering advice and feedback to ensure that the trial is designed and conducted in line with patient needs and preferences. ECPC also contributed to the communication and dissemination of the project, from communication planning and website development to various outreach activities to disseminate project results, including organising the final eSMART conference.

In 2019, ECPC organised the eSMART final conference before the project came to an end.

## **11.8 LEGACy (2019 - 2022)**

Through personalised medicine, gastric cancer treatment is chosen based on who the patient is, instead of the type of tumour, leading to an improved prognosis of gastric cancer. LEGACy will use a personalised approach that will improve gastric cancer treatment by improving the knowledge of which treatment that will work best for each patient. Additionally, the project will identify and educate those with higher risk of getting gastric cancer earlier and improve the early detection of gastric cancer when the prognosis is still higher.

ECPC leads the project's Work Package on Communication and Dissemination, ensuring an effective external stakeholder network and the engagement of patients and the public. ECPC developed and maintains a project website and multiple social media platforms and disseminates a triannual newsletter and press releases. ECPC is also responsible

for patient information, reviewing informed consent forms, involving expert patient advocates in the online training courses, and hosting a final stakeholder event at the completion of the project.

In 2019, ECPC co-wrote the project Plan for Exploitation and Dissemination of Results (PEDR). Additionally, ECPC developed and maintained the project website (<https://legacy-h2020.eu/>) and Twitter, Facebook and Vimeo accounts were created. In total, 3 newsletters (May, August, December), 5 videos, 4 events, 10 news articles and a press release were published. Social media posts reached an audience of 15.185, the news articles gathered 1.127 visitors, and the videos gained 1.486 views.

## 11.9 Advisory roles

ECPC is involved in several EU funded projects with a consultative role sitting in advisory boards. They are listed below.

### 11.10 Transcan-2 European Research Area (2015 - 2019)

The **ERA-NET: Aligning national/regional translational cancer research programmes and activities - TRANSCAN-2** was a five-year project (2015-2019) funded by the European Commission under the EU framework programme **Horizon2020**. The ERA-NET TRANSCAN-2, aimed at linking translational cancer research funding programmes among the partners, most of which were also participants in the previous TRANSCAN project. Therefore, the network had already established a model of transnational cooperation encouraging high quality research through competitive funding, as exemplified by the successful implementation of 3 joint transnational calls in the past years. This model allows an efficient use of the dedicated national resources and the coordination of the financial management of multinational research projects aiming as much as possible at the harmonisation of administrative procedures.

The ERA-NET TRANSCAN-2, in continuity with the preceding ERA-NET on translational cancer research TRANSCAN, has been devoted to linking translational cancer research funding programmes. As a result of the 7 calls, 79 research projects were funded in total within both projects, involving 406 principal investigators from 19 countries.

30 projects were funded with the amount of EUR 33 million in the framework of the three calls of TRANSCAN, whilst in TRANSCAN-2, 49 projects were funded with the amount of EUR 52.2 million in the framework of the four calls.

The ERA-NET TRANSCAN-2 is a collaborative network of ministries, funding agencies and research councils with programmes in translational cancer research, funded by the European Commission under the EU framework programme Horizon 2020. The network is composed of 28 partners from 19 Countries. Kathi Apostolidis represented ECPC in the SAB-Scientific Advisory Board that discussed and decided

on the topics submitted for calls. TRANSCAN II ended in 2019 in Milan with the 3rd and final Symposium on Tumour Heterogeneity that brought together 15 of the 16 funded consortia from JTC2014 in order to present the outcomes of these projects, as well as to increase networking and scientific discussion amongst researchers from related research fields and to increase the opportunities for new collaborations and sustainability of the invested funds.

### 11.11 ELBA (2018 - 2021)

ELBA will educate 15 Early Stage Researchers with the skills to face obstacles within the development and commercialisation of liquid biopsy approaches including in key disciplines of molecular biology and medicine, bioinformatics, biostatistics, mathematics, computer science, social sciences, health economics and technology assessment. ELBA will make scientific advances towards widespread implementation of blood-based diagnostics tests, create a sustainable network to foster long-term multidisciplinary relationships and publish a roadmap towards liquid biopsy test development.

ECPC provides the Early Stage Researchers with training courses and workshops on communicating complex research results to a public audience, understanding the patient perspective, and scientific writing. ECPC uses its communication channels to share information about the project, its results and its participants. ECPC is also represented on the Project Advisory Board to monitor project progress and provide input on the design and direction.

In 2019, ECPC organised and managed a workshop on “Patient Involvement in Research & Development” during the ELBA Annual Meeting in Siena (IT).

### 11.12 HTx (2019 - 2023)

HTx will facilitate the development of methodologies to deliver more customized information on the effectiveness and cost-effectiveness of complex and personalised combinations of health technologies. HTx will also provide methods to support personalised treatment advice that will be shared with patients and their physicians. Finally, HTx will in close collaboration with the European Network for HTA (EUnetHTA) and its stakeholders pilot the implementation of these methods in Europe.

When the HTx project will hold a stakeholders’ event, a fellowship programme will allow patients’ advocates to attend the event and to engage directly with the project team. When HTx will present its findings to other conferences of interest, the same fellowship programme will help dedicated patient advocates to attend the conference to listen to the presentations and to interact with the audience.

ECPC Director Antonella Cardone sits on the project’s Stakeholder Advisory Board, the HTx Forum. She ensures the project activities are in line with the needs of cancer

patients by actively participating in discussions and providing feedback and input on research activities, use cases and outputs.

### 11.13 **PREDICT (2017 - 2021)**

PREDICT educates 15 Early Stage Researchers (ESRs) in the fields of radiomics and personalised medicine, training them to analyse large amounts of radiographic images to determine tumour heterogeneity and predict how patients will respond to treatment.

ECPC provides the Early Stage Researchers with training courses and workshops on communicating complex research results to a public audience, understanding the patient perspective, and scientific writing. ECPC uses its communication channels to share information about the project, its results and its participants. ECPC is represented on the Project Advisory Board to monitor project progress and provide input on the design and overall direction.

### 11.14 **Palliative Sedation (2019 - 2023)**

The Palliative Sedation (PS) project aims to test the concept of proportional PS, where sedatives are titrated to the point of symptom control, with the goal of improving the patient's overall comfort. The project is investigating current practices and guidelines, as well as conducting a clinical study into PS, measuring patient comfort as the primary outcome, which is being carried out at five European palliative care centres. Furthermore, the Palliative Sedation project is formulating recommendations for an updated framework for the use of sedation in palliative care, working towards producing a free online educational programme and an e-book, and helping organise a policy workshop for further development and implementation, along with a closing conference to support the final dissemination of project results.

ECPC sits on the Palliative Sedation Scientific, Clinical and Ethical Advisory Board represented by President, Kathi Apostolidis, to encourage policymakers, researchers, doctors, and industry to recognise cancer patients as co-creators of their own health.

ECPC directly engages with expert patient representatives to ensure research is designed and adapted to better respond to patient needs. Through its members, ECPC contributes to a PS country survey and supportive interviews that reveal the level of integration of clinical sedation guideline recommendations in healthcare practice across Europe.

ECPC also supports the revision of the current European Association for Palliative Care (EAPC) framework for PS, and the design of the PS educational programme and e-book containing clinical and ethical guidance that can be adopted for PS.

In 2019, ECPC contributed to the project's first press release and attended two face-to-face meetings.

## 12. Collaborations & Partnerships

### 12.1 European Medicines Agency



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

Kathi Apostolidis, ECPC President and Rafal Swierzewski, Phd, past ECPC Board Member, represent ECPC at the Patient and Consumer

Working Party (PCWP), while Rafal Swierzewski also sits in other expert groups and scientific sub-committees. The Patient and Consumer Working Party provides a platform for exchange of information and discussion of issues of common interest between EMA and patients and consumers. It provides recommendations to EMA and its human scientific committees on all matters of interest in relation to medicines.

In 2019, Kathi Apostolidis was a member of the Digital Health Committee within PCWP responsible for the mHealth sub-committee. The purpose of the Digital Health Committee with membership from both the PCWP and the HCPWP-Health Care Providers Working Party had as objective to come up with recommendations to the EMA regarding information to the various EMA audiences on medicines and their use, with primary focus on patients, patient organisations and the public.

ECPC representatives have participated in the meetings of the PCWP and in workshops organized by the EMA, they have reviewed EPAR summaries for the public, reviewed and commented on various documents and consultations, and led sub-committees and recommended patients for participation in the hearings of the EMA Scientific Committee.

Kathi Apostolidis additionally represents the EMA/PCWP in the Steering Committee of ENCePP – European Network of Centres for Pharmacoepidemiology and Pharmacovigilance and has actively participated in activities of the network. Her proposal to include the patient perspective in the revision of the Code of Conduct was accepted and for the first time it is enshrined in the ENCePP Code of Conduct.

### 12.2 ESMO Patient Guides

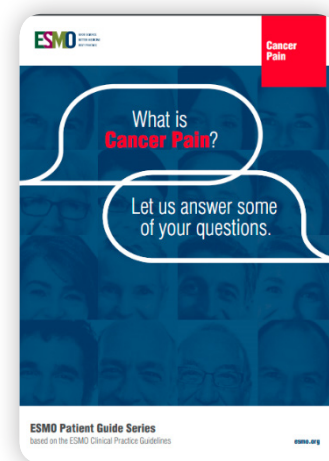
ESMO Guides for Patients are the most reliable and evidence-based resources designed to help cancer patients, their families and caregivers to get a better understanding of different types of cancer and to help them to evaluate the best available treatment choices.



With the aim of enhancing the existing cooperation and increasing the efforts to achieve common goals and objectives in the field of cancer to satisfy the new needs and new rights of cancer patients across Europe, ECPC and the European Society for Medical Oncology (ESMO) continued in their ongoing joint activities in 2019.

ECPC was invited to collaborate as co-author in the new guide on cancer pain. Francesco de Lorenzo and Kathi Apostolidis accepted the challenge and contributed as co-authors and reviewers in the development of the new Guide. It is worth mentioning that the guide has been promptly translated into Greek and Italian for the easy reference of patients in the respective countries.

The ESMO Cancer Pain Management Guide for Patients was presented during the ESMO Congress in Barcelona. The patient guide aims to inform and support cancer patients to better understand their pain and its treatment. ECPC President Kathi Apostolidis participated in the presentation of the guide.



Esmo Patient Guide  
Example

### 12.2.1 ESMO Guidelines

ECPC is directly involved in updating the new ESMO Clinical Practice Guidelines providing ESMO with a revision on guidelines from a patient perspective. ECPC invites its Members to review the manuscript and to assess that the information in guidelines is understandable for patients.

### 12.2.2 Survivorship Guide

For years, ECPC continues the collaboration with ESMO on the Survivorship Guide that was originally published in 2017. The guide is offering a comprehensive summary of cancer diagnosis, treatment, prevention and detection of cancer recurrence, and follow-up care. In 2019, the Survivorship Guide was made available in Romanian, Slovak and Hungarian languages. All guides can be found on both ECPC and ESMO websites as well as in print, and they were distributed at key events throughout the year.

ECPC also supported launching events of the German and Romanian Survivorship Guides that were organised by ECPC members.

### 12.2.3 2019 ESMO Congress in Barcelona

The ESMO Annual Congress 2019, the biggest European gathering for oncology community, took place between 27<sup>th</sup> of September and 1<sup>st</sup> of October 2019 at Fira de Barcelona in Spain. The congress attracts more than 22,000 oncology stakeholders from all over the world which makes it a great opportunity for cancer patient advocates to get together with clinicians, researchers, and the pharmaceutical industry to discuss and learn about the latest advances in oncology, and how to translate science into better cancer patient care.

ECPC President Kathi Apostolidis, ECPC Vice President Pietro Presti, ECPC Secretary Jacqueline Daly, ECPC Treasurer Beata Ambroziewicz, Board Members Maude Andersson, Robert Greene, and ECPC Chair of the Scientific Committee and Past President Francesco de Lorenzo together with the ECPC Secretariat were representing the unique voice of EU cancer patient community at the congress closely following Patient Advocacy Track sessions, as well as attending meetings with partners and discussing joint activities and ECPC Action Plan for 2020.

ECPC President Kathi Apostolidis presented at the session of the Patient Guide on Cancer Pain Management launch as she together with Francesco de Lorenzo are co-authors and reviewers of this new guide. ECPC Board Members represented the organisation at EONS Symposium, Robert Greene presented on Advanced Symptom Management and Jacqueline Daly delivered a presentation on Patient/Public involvement in cancer care.

ECPC Secretariat was also maintaining a booth at the “Society Village” in the exhibition part to present ECPC activities, network with the exhibition visitors and discuss vital issues and challenges faced by cancer patients. ECPC also set up the “Breast Wall” made of plaster breast casts of women with breast cancer but also healthy women to reflect on the importance of prevention in fighting breast cancer. This art exhibition is called Closely Watched Breasts and it was shared with ECPC by its member organisation Aliance žen s rakovinou prsu (Alliance of Women with Breast Cancer) from Czech Republic. Author of the artistic part of the campaign is Matyáš Fuchs. The art exhibition was a good attraction to the ECPC booth, which had thousands of visitors.

## 12.3 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”.

Robert Greene, ECPC Board Member is representing ECPC in the ePAG (ECCO Patient Advisory Group).

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

## 12.4 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 important to cancer patients. All.Can currently is established in 15 countries, with nearly 300 stakeholders across the world. 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 July 2019, All.Can published the results of their All.Can Patient Survey, which they disseminated to patient organisations across Europe. The survey collected views from several countries in Europe and globally, on what needs to improve or change in the delivery of care for cancer patients throughout the care pathway. ECPC supported the dissemination of the report findings through social media using the #patientinsights.

The survey results were further presented at the ESMO Summit 2019.

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



## 12.5 Union for International Cancer Control (UICC)

ECPC is a full member of UICC and follows the successful annual UICC campaign on World Cancer Day on February 4<sup>th</sup>. UICC is a trusted partner and they participated together with ECPC in various projects.

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



## 12.6 Organisation for European Cancer Institutes (OECI)

ECPC and the Organisation of European Cancer Institute (OECI) continued their collaboration for the fourth year. The signing of the Memorandum of Understanding in 2015. resulted initially in a common activity of the patient experience in a large comprehensive cancer centre but the initiative did not continue. In 2019, ECPC and OECI renewed their collaboration in view of the Cancer Mission and the EU Cancer Plan.



In 2019, ECPC Past President Prof Francesco de Lorenzo acted as moderator for a session entitled 'Supporting Cancer Survivors' as part of the Patient Day at the OECI's

Oncology Days Congress ECPC also had their publication 'The European Cancer Patient Coalition's role in securing meaningful patient involvement in Health Technology Assessment' included in the Special Issue Tumori Journal published by OEI for the Oncology Days.

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

## 12.7 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.

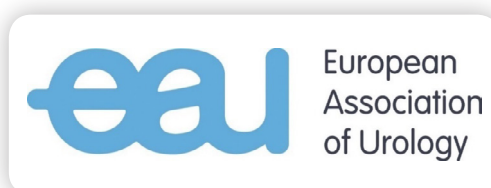
In 2019, ECPC supported EORTC's **"Manifesto for a new approach for better medicine in Europe establishing treatment optimization as part of a personalised medical development"**. The manifesto called for the support of stakeholders to make treatment optimization a standard step in medicine development in Europe.

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.

Kathi Apostolidis participated and presented at the Annual Conference of HRQoL/EORTC and co-authored the report based on the proceedings of the conference. Said report was later published as a journal article.

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

## 12.8 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.

Since signing a Memorandum of Understanding (MoU) in 2018, ECPC and EAU have continued to collaborate and facilitate the implementation of joint projects.

ECPC is represented in EAU by its past President and Chair of the Scientific Committee, Francesco de Lorenzo. Director Antonella Cardone attended the EAU19 in Barcelona and served as chair for the EAU19 Patient Information Session. ECPC also collaborated with EAU in raising awareness of kidney cancer by contributing to their Scientific and Policy Briefing on Kidney Cancer. The publication highlighted the key challenges faced in patient outcomes for kidney cancer.

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

## 12.9 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 2019, ECPC continued to collaborate with EAPM on the 2nd Personalised Medicine Awareness Month in November. A 2019 campaign toolkit was set up and distributed among our members. The toolkit was based on the 2018 one and contributed to a more successful campaign thanks to the engaging social media posts and translations of the content into 12 languages.

On the 2<sup>nd</sup> and 3<sup>rd</sup> of December, 2019, ECPC and EAPM organised a Molecular Diagnostics Roundtable with 26 relevant stakeholders including clinicians, public health experts, biomarker experts, and patients.

During our Annual Congress in June 2019, over a hundred ECPC members met to participate in a dedicated session to discuss personalised medicine chaired by ECPC Board Member Matti Järvinen and moderated by Tamsin Rose.

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

## 12.10 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 vice president Francesco de Lorenzo represents the organisation in the Board of CDDF and actively contributes to committees of various events organised by CDDF. In 2019, Francesco represented ECPC at CDDF's 2019 multi-stakeholder Workshop on Involving Patients in Oncology Drug Development which took place in Amsterdam.

Our involvement in this workshop highlighted the ongoing collaborations we have aiming to improve patient access to care in Europe and our belief that patients are the most important partners in the fight against cancer.

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

## 12.11 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.

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.

ESSO established BRESO, an initiative supported by many scientific and patient organisations aiming to promote accredited specialist breast surgical care for breast cancer patients and women at high risk of breast cancer by offering a dedicated certification programme in breast cancer surgery.

To achieve this goal, BRESO has a widely inclusive approach gathering representatives from leading educational, training, research and accreditation organisations. It thrives to work in a collaborative manner, keeping in mind the best interests of our patients across Europe. Kathi Apostolidis, ECPC President, and breast cancer survivor, sits at the Patient Advocacy Group of ESSO that actively supported within the ESSO Board the establishment of BRESO.

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



## 12.12 Biobanking And Biomolecular Resources Research Infrastructure

The Biobanking And Biomolecular Resources Research Infrastructure - European Research Infrastructure Consortium (BBMRI-ERIC) 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 (BBMRI-ERIC) 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.

BBMRI-ERIC is an indisputable partner in cancer research and ECPC is a member of its Stakeholders Forum.

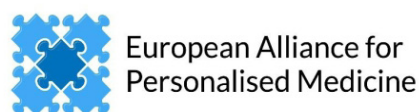
## 12.13 WIN - Worldwide Innovative Networking Consortium

The Worldwide Innovative Networking (WIN) Consortium in personalised cancer medicine's members include 43 leading organisations representing all stakeholders in the personalised cancer medicine field, covering 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 2019, the event was dedicated to *Innovation and global deployment of Precision Oncology* and was held from 23<sup>rd</sup> to 24<sup>th</sup> of June. Francesco de Lorenzo represents ECPC in WIN and has been an invited speaker several times at the WIN Symposia.

## 12.14 Public Entities and Non-Profit Organisations



## 12.15 Industry Partners

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

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

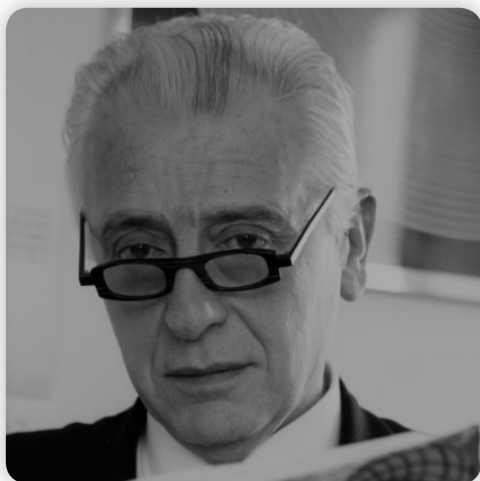
## 12.16 ECPC industry partners:

- AbbVie
- Amgen
- AstraZeneca
- Bayer HealthCare Pharmaceuticals Inc
- Baxter
- MS Bristol-Myers Squibb
- Boehringer Ingelheim Int GmbH
- Celgene
- Daiichi Sankyo
- Debiopharm
- Eli Lilly and Company
- Helsinn
- Ipsen
- Janssen Pharmaceutica NV
- Johnson & Johnson
- LEO Pharma
- Merck Healthcare
- MSD International GmbH
- Novartis
- Pfizer
- Roche
- Sanofi
- Takeda Pharmaceuticals Int
- Tesaro

## Appendix

### Meet ECPC Board Members Until June 2019

#### Francesco de Lorenzo, ECPC President until June 2019



Francesco de Lorenzo is a colon cancer survivor with 22 years of experience in patient advocacy, capacity building, research, networking building, policy, partnership and project design and management.

In ECPC since 2004 (co-Founder): from 2010 to 2013 as Vice President, from 2013 to 2019 as President, now as Past President and Chair of the Scientific Committee.

His vision during the Presidency was to work towards Europe of Equality, where all European cancer patients have timely and affordable access to the best treatment and care available. He has been Member of the European Commission Expert Group on Cancer Control (2014/2018) and co-author of the European Cancer Patients' Bill of

Rights. In collaboration with MEPs, proposed amendments to the Work-Life Balance Directive, which have now been included in the Directive and include formal recognition of the role of the carer.

Involved in several European research projects and collaborating with the consortium Cancer Core Europe in the Board of Directors. Board member of the European Academy of Cancer Science (EACS) and of the Cancer Drug Development Forum (CDDF).

He has been successfully working on the development of amendments to Health Technology Assessment (HTA) Regulation to harmonise HTA at the EU level, a policy recommendation first outlined in the ECPC position paper "Challenging the Europe of Disparities in Cancer" in 2015, highlighting that patients play a crucial role in advancing policies. Presently he is also President of the Italian Federation of Cancer Patients Organisation (FAVO), President of the Italian Association for Cancer Patients (Aimac) and full Professor of Biochemistry at the University Federico II of Naples.

#### Jacqueline Daly, Secretary to the board of ECPC

The ECPC Secretary is elected by the other ECPC Board members, and oversees and cooperates in the planning, implementing and assessing of administrative processes in the Board and in the office. Their tasks include: Preparing, in co-ordination with the President,

the agenda for the meetings and the organisation, ensuring the appropriate and effective processes of documentation, supporting the Director in employer activities in personnel administration, ensuring that the register of the members of the organisation is maintained and up to date, representing the Board and ECPC in line with their other Board duties and personal expertise, representing the association in regard to third parties according to the statute (Article 9 of the ECPC Statute).

She is co-founder of East Galway & Midlands Cancer Support in 2012 and Director of Services, as well as a patient advocate and campaigner, bringing awareness to local and national government agencies. Jacqueline is an active member of the Public and Patient Involvement (PPI) Group of the Irish Society of Gynaecological Oncology, patient representative on the board of the Society of Sexual Medicine Ireland. She has contributed to the ECPC Publication 'Living Well During Cancer Treatment', wrote the Structured Education Programme (STEP) to support men with Prostate Cancer and participated in ESMO Rare Cancer Patient Advocate Training in Milan 2018 and spoke at the ESMO Conference in Munich 2018. On top of this I am a complimentary therapist in Bio Energy, Healing Touch, Indian Head Massage, Reiki, Rahanni and a developer and presenter of community outreach programmes, including facilitator for Survive and Thrive Self-Management programme for Cancer Survivors run by the Cancer Control Programme in Ireland. And facilitator of Climb program for children between age 5 – 12.



## Kathi Apostolidis, President

Kathi became President of ECPC in 2019. Her diverse background includes being a Public Affairs Consultant with broad and diversified experience in regulatory and public affairs, trade diplomacy, strategy, marketing and communications. At the national level, she is a founding member and President of the Hellenic Cancer Coalition-ELLOK (ellok.org) and a Director/Board Member of other Greek cancer patient associations. Honoured to represent cancer patients at the Board of Directors of the recently legalized and under establishment Greek National Cancer Institute and in the Patient Registries Committee of the Greek Ministry of Health. Also, she is a member of the National Network of Precision Medicine representing cancer patients. Surviving breast cancer twice, Kathi has been involved for many years in cancer policy advocacy, survivorship and cancer patient rights advocacy on the national and international level. Her advocacy covers issues of access to cancer care, health technology assessment, digital technology in cancer care, informed shared decision making in cancer, patient involvement in cancer research, cancer care delivery, health and digital literacy, patient safety.



## Pietro Presti, Board Member and Vice President



As Vice President, Pietro is a key external representative of the Board, in partnership with the President, and works with the Secretariat and Board to produce the Board strategy document. In particular, as VP, his goals are achieving and supporting the sustainable development of ECPC's Advocacy activities and strategy and its institutional position at European and international level exploiting my network; strengthen and promoting the role of ECPC in innovative and research project and promoting and developing the ECPC's Fundraising strategy.

Pietro holds a Master's degree in Law and PhD in Business and Management at University of Turin, and MBA at University of Geneva. Dynamic and goal-oriented manager with a broad experience in the healthcare sector, especially in oncology, including prevention, screening, advocacy, cancer control and research. Currently, he serves as General Secretary at "Fondo Edo Tempia", an Italian private association primarily involved in cancer prevention and advocacy, palliative care, psycho-oncology and support to the public health-care system. He is also Managing Director at "Edo ed Elvo Tempia Foundation", a private foundation operating in the field of oncological prevention, diagnosis, genomic and research. As a volunteer, he serves as board member at international and national associations and organisations in cancer advocacy, education and research.

## Beata Ambroziewicz, Treasurer



President of the Polish Union of Patient Organisations "Citizens for Health", Board Member of Polish Cancer Patient Coalition and President of Let's Win Health Foundation, Member of National Development Council & National Health Council in Poland, Deputy Editor-in-Chief of Cancer Patient Voice Magazine, Member of the Steering Committee for Coordination of EFSI intervention in the health sector.

Graduated from the University of Warsaw, for over 10 years represents patient organisations for over 10 years, actively cooperates with non-governmental organisations, PAGs, representatives of health-related institutions, Ministry of Health, National Health Fund, Patient Rights Ombudsman and many others. Coordinates implementation of nationwide projects financed from EU and Norwegian



funds such as: "Citizens for Health", "Civil Agreement for Oncology" or "Social monitoring of implementation of oncology package by Ministry of Health.

Organises and participates in many national and international conferences, symposia, trainings on health and patient empowerment. Promotes the constitutional principles of subsidiarity, social dialogue and cooperation, openness, solidarity and mutual support for unions, associations, federations, foundations and other patient organisations.

### **Robert Green, Board Member**

The board supervises compliance with the articles of association and regulations, as well as resolutions adopted by the Association. Robert also worked as a nurse and assistant anesthetist.

Robert has diverse experience in sales and marketing and currently is an owner of a professional and social networking organisation and a fashion, art and music platform, Concept Developer. HE is also a patient advocate for Inspire2Live and Imerman Angels' Ambassador.



### **Maude Andersson, Board Member**

Represents ECPC at various meetings in Europe informing about ECPC's work. Lectures at conferences and congresses, about gynaecological cancer, personal medicine, contact nurses, HPV, biosimilars, HTx, and more. Member of ECPC's working group on rare cancers. Maude holds a Master of Science in Engineering and Technical Information as well as bachelor's degrees in Interculture, in Environmental Science and in Ecophilosophy from the University of Karlstad, Sweden. Previously worked as an engineer and manager at Ericsson for 30 years worldwide (Sweden, North America, Mexico, Italy, Greece, and other countries) as well as Engineer (Physic and Electrical Engineering) University of Karlstad, Sweden. ECPC Board Member since 2017. She is currently President at the Gynecological Cancer Patients Coalition in Värmland, Sweden since 2002, editor at Gynsampoosten (Medical Journal), since 2006, Board member of The Swedish Disability Rights Federation (all diseases), Patient Representative in the Regional Cancer Centrum, Chairman of the Cultural Association for the Disabled, and support person for cancer patients and their relatives.



## Vasile Ianovici, Board Member



Representing ECPC as one of the members, understanding issues and needs of CEE countries, as well as promoting and working on good practices on EU and national level, with collaboration with cancer patients advocates from all over Europe. Support ECPC actions, and the patient's associations to have quick access to the latest medical information about cancer, strengthening collaboration and relationships between ECPC and members and supporting for developing patient's organisations. Vasile has a bachelor's degree in economy from the University of Economic Studies and Public Administration, Suceava as well as a master's degree in management of trade, tourism and services from the University of Suceava. Previously worked as Sales Manager, Marketing Director and Environmental Protection Officer. Currently Censor of

Romanian Cancer Patients Federation and Vice-President of MIELOPRO Association (The Association of Patients with Chronic Myeloproliferative Neoplasia).

## Outgoing Board Members 2019

### Ken Mastris, Treasurer



Representing ECPC as one of the members and promoting and working on good practices on EU and national level with collaboration with cancer patients advocates from all over Europe. Responsible for transparency and effective allocation of ECPC founding as well as supporting implementation of new projects and setting up partnerships.

Before retiring in 2005, Ken worked in management for 43 years: he has been part of the Committee of management of Benenden Healthcare Society Limited and of the Board of Governors of the Hospital, but he has also been Chairman of the Internal Audit Committee and Director of the Friends of Benenden.

Ken has served as Chairman of Europa Uomo. Currently, he is Chairman at couple of organisations such as Tackle Prostate Cancer UK and Association of prostate Cancer Patients in London and Essex. Ken is also involved in other organisations including EMA, EAU and ECCO.

## **Jana Pelouchova, Board Member**

Jana was diagnosed with chronic myeloid leukemia in 2002. Challenges in access to information and different therapies motivated her to help other patients. Inspired by colleagues in Western Europe, she took action to establish and run a patient-governed society Diagnoza CML (since 2006), transformed into Diagnoza leukemie (2015) in the Czech Republic.

Jana became co-founder of the worldwide CML Advocates Network, President of the Swiss based Leukemia Patient Advocates Foundation and member of the Steering Committee for global summits CML Horizons. Currently involved in building CLL Advocates Network (chronic lymphocytic leukemia). In her second election term as ECPC Board member/ Secretary, she focused on rare cancers (representing ECPC in the Rare Cancers Europe) and member of ECCO PAC.



## **Andrew Winterbottom, Board Member**

Diagnosed with Stage 4 bladder cancer in 2009 and almost immediately after major surgery, set up the UK charity Fight Bladder Cancer as the first patient advocacy group in the UK for bladder cancer patients and their families.

The charity, under his direction, grew to be a significant voice for bladder cancer across the UK and across Europe where he has helped draft the recent Bladder Cancer White paper that launched in April 2016.

Andrew was a representative of the UK National Cancer Institute's Bladder Cancer Clinical Studies group and two specialist sub-groups for invasive and non-invasive bladder cancer. In addition, he also was the patient specialist representative on the NICE panel developing the latest UK Bladder Cancer Quality Standards and a patient advisor to the Scottish Medicines Coalition.



## **Matti Jarvinen, Board Member**

Matti is a former lymphoma patient (2012). He is Member of the board in the Association of Cancer Patients in Finland; key qualifications: strategy planning, communication, management.

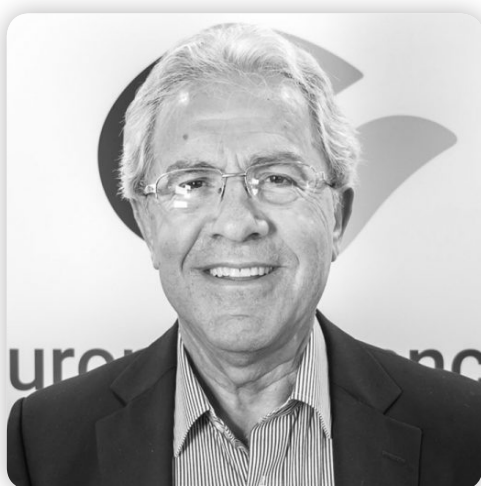


He previously was managing director in a Finnish NGO expert organisation of road safety (public awareness campaigns, education in schools and driver training), Chairman of the Nordic Traffic Safety Committee 2000 – 2012, Member of la Prévention Routière Internationale (PRI) Executive Committee 2000 – 2012.

Matti is a member of OECD Expert Committees Marketing of Road Safety 1992, Modification of Road User Attitudes 1994 and Mobility Needs and Safety of Ageing Society 2000.

## Meet ECPC's Audit Committee

### Constantine N. Nicolaides, Audit Committee Chair



The Audit Committee is responsible for overseeing the financial and operational management and approving European Cancer Patient Coalition budgets and end-of-year Financial Accounts. The Audit Committee can also make recommendations and suggestions to the Board and to the Secretariat on organisational, operational and strategic topics and/or issues. Following his graduation from Pancyprian Gymnasium, he served military service at the National Guard in the Office of the Commander of the anti-aircraft Artillery as the Artillery's cryptographer and was the officer in charge of the camp's education and training and the Artillery's 2<sup>nd</sup> office. He studied law at the Universities of London and Wolverhampton and obtained appropriate degrees with honours followed with a postgraduate course for the Barrister-at-law of the Council of Legal Education in London. He lived in

England for many years and worked in various departments of the British Government, such as the Department of the Environment as a legal liaison officer and the Crown Prosecution Service as a legal officer. As from November 1996, he has been practicing law with my own office in Nicosia and at the same time have been acting as a consultant to the Government of Cyprus Attorney General's office in difficult or complicated criminal cases.

### James Caldwell, Audit Committee member

His job as a member of the audit committee is to assist the board in fulfilling its

responsibilities in respect of the financial and operational management of ECPC. The audit committee also approves annual budgets and the annual accounts of the organisation.

James also acts as a support to the secretariat, assisting and advising when necessary. James is a trustee and treasurer of an umbrella rare disease charity in Northern Ireland – my specific interests are rare cancers. He is a Chartered Accountant and a Registered Auditor and is senior partner in a small accountancy practice. He also co-own a care home for frail elderly people and those with dementia. James is also a Registered Nurse.



### **Roberto Persio, Audit Committee Member**

We are responsible for overseeing the financial and operational management of European Cancer Patient Coalition, minimizing any associated risk, monitoring relevant procedures and internal policies, approving European Cancer Patient Coalition Budgets and end-of-year Financial Accounts and reviewing the Board decisions that are implemented.

Roberto is a programme manager working on infrastructure mega projects for a global infrastructure player in Italy, dealing with the design, appraisal and delivery process, with an eye on sustainability, resilience and innovation. Civil engineer, he is currently enrolled as part time student in the MSc course in Major Programme Management at University of Oxford.



## **Outgoing Audit Committee Members 2019**

### **Istvan Balogh, Audit Committee Member**

Istvan's high position at the Children Cancer Foundation, which includes economic leadership as well, has provided success and confident future for the organisation for over 18 years. As the leader of the strongest and biggest non-profit organisation in Hungary, he has been managing the billions worth business of the foundation. He has





responsibilities such as coordinating economic matters, planning budgets, and conducting analysis and research.

His expertise, legal knowledge about taxes and finances, and hardworking and proactive way of thinking makes him capable of managing financial matters. As the president of the foundation, he is responsible for making economical and financial decisions.

Thanks to his expertise, he has also been on board of other organisations in Hungary and in the USA, so has dealt with several international financial transactions as well.

### **Nicolas Philippou, Audit Committee Member**



He serves as the General Manager of The Cyprus Association of Cancer Patients and Friends (PASYKAF) since 2010. His values have been to be patient centred, goal oriented, transparent and professional, with the aim to grow this organisation and be able to create impact towards achieving best patients' outcomes.

He has a Business background, holding a BA in Management and an MBA in Finance. He has 10 years of experience in the Private Sector including two international companies with operations in Cyprus, Greece and the UK. These positions gave him the opportunity to work in diverse environments, cooperating and communicating with people from all calibre and professional backgrounds.

In 2014, he was elected as the General Secretary of the Cyprus Patients Federation, an umbrella organisation member of EPF and he has excellent working relations with colleagues and board members from other European and International Cancer Associations.



## Meet ECPC's Scientific Committee Members

### Francesco de Lorenzo, Past President and Scientific Committee Chair

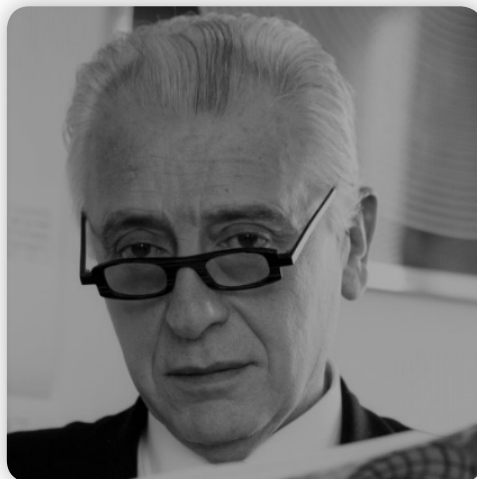
Francesco de Lorenzo is a colon cancer survivor with 22 years of experience in patient advocacy, capacity building, research, networking building, policy, partnership and project design and management.

In ECPC since 2004 (co-Founder): from 2010 to 2013 as Vice President, from 2013 to 2019 as President, now as Past President and Chair of the Scientific Committee.

His vision during the Presidency was to work towards Europe of Equality, where all European cancer patients have timely and affordable access to the best treatment and care available. He has been Member of the European Commission Expert Group on Cancer Control (2014/2018) and co-author of the European Cancer Patients' Bill of Rights. In collaboration with MEPs, proposed amendments to the Work-Life Balance Directive, which have now been included in the Directive and include formal recognition of the role of the carer.

Involved in several European research projects and collaborating with the consortium Cancer Core Europe in the Board of Directors. Board member of the European Academy of Cancer Science (EACS) and of the Cancer Drug Development Forum (CDDF).

He has been successfully working on the development of amendments to Health Technology Assessment (HTA) Regulation to harmonise HTA at the EU level, a policy recommendation first outlined in the ECPC position paper "Challenging the Europe of Disparities in Cancer" in 2015, highlighting that patients play a crucial role in advancing policies. Presently he is also President of the Italian Federation of Cancer Patients Organisation (FAVO), President of the Italian Association for Cancer Patients (Aimac) and full Professor of Biochemistry at the University Federico II of Naples.



## **Claudia Allemani, Scientific Committee Member**



Dr Claudia Allemani is an Associate Professor of Cancer Epidemiology in the Cancer Survival Group at the London School of Hygiene and Tropical Medicine. Claudia's background covers a range of skills from applied mathematics to public health and education, via epidemiology and medical statistics.

She graduated in Mathematics from the University of Turin, then completed a Masters in Statistical and Informatic Methods for data analysis in the University of Milan, followed by a specialisation [PhD equivalent] in Medical Statistics, and a PhD in Public Health and Education, both from the University of Pavia.

She has 20 years' experience in international comparisons of cancer survival, "high-resolution" studies and the estimation of avoidable premature deaths, with a focus on their impact on cancer policy. She leads the data management, quality control and survival analyses for the global surveillance of cancer survival (CONCORD), for which she is co-Principal Investigator.

In 2017, she obtained European Research Council Consolidator grant to carry out a world-wide study on inequalities in patterns of care and survival from cancers of the breast, cervix and ovary (VENUSCANCER). She collaborates with several international organisations such as the Economic Co-operation and Development (OECD), the International Atomic Energy Agency (IAEA), the World Health Organisation (WHO), the US Centers for Disease Control and Prevention (CDC) and the American Cancer Society (ACS).

## **Fabien Calvo, Scientific Committee Member**



Professor Fabien Calvo is currently the Emeritus Professor of Clinical Pharmacology at University of Paris Medical School. Professor Calvo has extensive expertise in the field of cancer. From April 2007 to September 2014, he was Deputy Director General of the National Cancer Institute of France (INCa), in charge of Research and Innovation Programmes.

Through his contribution to two successive cancer plans, he supported precision medicine for all cancer patients in France in 2009, funding 28 regional genomic platforms, eight Comprehensive Cancer Centers, and 12 platforms for early phase clinical trials.

He also launched the International Cancer Genome Consortium (ICGC) in 2008 and the Global Alliance for Genomics and Health (GA4GH)

in 2010 with colleagues from the USA, Canada, UK and Germany. Professor Calvo was previously Head of the Clinical Research Department at Saint Louis Hospital in Paris and served as Chief Scientific Officer for Cancer Core Europe at Gustave Roussy Cancer Campus Grand Paris from December 2014 to August 2019. He is the author or co-author of >300 publications and reviews in biology or medical cancer research and cancer medicine policy.

## **Meletios A. Dimopoulos, Scientific Committee Member**

Meletios A. Dimopoulos, MD is Professor and Chairman of the Department of Clinical Therapeutics at the National and Kapodistrian University of Athens, School of Medicine, Athens, Greece, where he obtained his medical degree in 1985. Dr. Dimopoulos has also completed residency in internal medicine at the Royal Victoria Hospital, McGill University, Montreal, Canada and a fellowship in hematology/oncology at the University of Texas M.D. Anderson Cancer Center, Houston, Texas, USA. Dr. Dimopoulos has authored more than 1060 publications (July 2020) in peer-reviewed journals, as well as numerous abstracts and several textbook chapters primarily focusing on plasma cell dyscrasias and genitourinary and gynecologic cancers. He is on several editorial boards as well as being an Associate Editor of the *European Journal of Internal Medicine* (2001-2007) and *Current Hematologic Malignancy Reports*.



He serves on the Scientific Advisory Boards of the International Myeloma Foundation, of the International Waldenström's Macroglobulinemia Foundation and he is member of the Board of the European Myeloma Network and International Myeloma Society. Currently, he is the chairman of the Greek Myeloma Study Group and of the Balkan Myeloma Study Group. Dr. Dimopoulos has won several awards including the Robert A. Kyle Award for outstanding contributions to Waldenström's macroglobulinemia, the CoMy Excellence Award, the Robert Kyle Life Achievement Award and the MD Anderson Distinguished Alumnus Award.

## **Mark Lawler, Scientific Committee Member**

Prof Mark Lawler, Associate Pro-Vice-Chancellor, Professor of Digital Health, and Chair in Translational Cancer Genomics, Faculty of Medicine, Health and Life Sciences, Queen's University Belfast (QUB). He is an internationally renowned scientist, with a strong commitment to patient-centred research/care and to addressing cancer inequalities.

Mark has a particular interest in addressing cancer challenges in Central and Eastern Europe (CEE) and he is now leading the Lancet Oncology Groundshot Commission to provide the evidence base and road map for cancer research focusing on this area. He has published



many high impact papers included in key publications such as New England Journal of Medicine, Lancet, Nature Medicine, Lancet Oncology and Cancer Discovery.

Mark launched the European Cancer Patient's Bill of Rights (BoR), with ECPC Past President Francesco de Lorenzo in the European Parliament in 2014. The BoR was adopted by 25 countries and it has been a catalyst for change and empowerment for cancer patients. It was recently adopted by ECCO, the largest interdisciplinary cancer organisation in Europe.

He is currently Associate Director of Health Data Research Wales-Northern Ireland, one of 6 Health Data Research UK (HDR-UK) Substantive Sites, which is driving innovative precision medicine and public health approaches through the use of Big Data.

Mark is also the Queen's Lead of the Stratified Medicine in Colorectal Cancer Consortium (S:CORT), a UK-wide consortium investigating novel precision medicine approaches in colorectal cancer (CRC). He is a member of many scientific boards including the Board of the European Alliance for Personalised Medicine (EAPM), where he led the development of EAPM's research strategy, the Scientific Advisory Board of the European Cancer Patient Coalition and the Strategic Advisory Board of Genomics England.

## **Françoise Meunier, Scientific Committee Member**



Françoise Meunier served as EORTC Director General from 1991 through to 2015 and oversaw the growth of the EORTC into an international world-class cancer clinical research infrastructure. Upon stepping down as Director General in 2015, Françoise Meunier remained active until 2018 as EORTC Director Special Projects where she was a driving force behind activities such as EORTC cancer survivorship initiatives.

She is a member of the Belgian Royal Academy of Medicine since 2006. In 2007, she was conferred the title of Baroness by His Majesty, The King Albert II of Belgium. In 2009, she received the Pezcoller Foundation award as a recognition for her contribution to oncology.

She is a Fellow of the European Academy of Cancer Sciences, Board Member of "Centre Scientifique de Monaco" and she is also Vice-President of FEAM (Federation of European Academies of Medicine). She has been a Board Member of Alliance for Biomedical Research in Europe from 2015 to 2018. In July 2015, she was admitted to the degree of Doctor of Medical Science (Honoris Causa) by the Queen's University of Belfast, Northern Ireland, UK. Since 2017, she is member of the Scientific Panel for Health (SPH) of the European Commission.

## Ulrik Ringborg, Scientific Committee Member

Ulrik Ringborg completed his doctoral thesis at the Karolinska Institute (Sweden) in 1971 and was appointed as Associate Professor the same year. He became Associate Professor of General Oncology in 1978, qualifying as an oncology specialist in 1979.

In 1992, he was made Senior Consultant at the Department of General Oncology, Radiumhemmet, Professor of Oncology at the Karolinska Institute, and Head of the Department of Oncology, Karolinska Hospital.

From 1993, he was Prefect at the Institute of Oncology-Pathology and continued his long-running service with Karolinska Hospital heading their Oncologic Clinic, becoming a member of the Executive Group, and now Senior Physician, Professor of Oncology, and Director of the Cancer Center Karolinska.

He has served as a member on countless boards and assemblies including the King Gustaf V Jubilee Fund, the Nobel Assembly and the Swedish Cancer Society. Ulrik Ringborg was also a member of the Scientific Advisory Committee of EORTC and Member of Policy Committee of ECCO – the European Cancer Organisation. Since 2009, Ulrik is Secretary General of the European Academy of Cancer Sciences.



## Giorgio Stanta, Scientific Committee Member

Prof. Giorgio Stanta of the University of Trieste is an expert in molecular pathology and diagnostics for oncology. He began his working career in molecular pathology in human tissues at the Department of Pathology of the Yale University (CT) working with some of the first groups developing molecular methodologies in human tissues.

He is actively involved in many European organisations such as BBMRI.IT (Italian Biobanking Infrastructure), CEN (European Committee for Standardization) for molecular in-vitro diagnostic examinations, the European Society of Pathology (ESP) for the Molecular Pathology WG, the Organisation of European Cancer Institutes (OEI) for the Biobanking and Molecular Pathobiology WG, the European Commission Initiative on Breast Cancer (ECIBC) and the European Molecular Pathology Master (EMPM) steering committee.

He is involved in several active European projects such as the HERCULES project on high grade serous ovary carcinoma heterogeneity, the SPIDIA4P project on pre-analytical conditions of clinical material, and InstandNGS4P on the clinical evaluation of NGS commercially available products.







# European Cancer Patient Coalition



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