



European Cancer
Patient Coalition



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**European Cancer
Patient Coalition**

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European Cancer Patient Coalition

Avenue des Arts 6

1210 Brussels

Belgium

info@ecpc.org

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Current European Cancer Patient Coalition Board (March – May 2022)

Kathi Apostolidis, President & Treasurer

Matti Järvinen, Secretary of the Board

Maude Andersson

Alina Comanescu

Maria Begona Barragan Garcia

Previous European Cancer Patient Coalition Board

(January – June 2021)

Ken Mastris, President

Pietro Presti, Vice President

Jacqueline Daly, Secretary

Kathi Apostolidis

Maude Andersson

Vasile Ianovici

Robert Greene

(June - December 2021)

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Juan Jose Ventura

Adela Maghear

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Alexander Rodriguez Timaran

Lorina Lamçaj

Ioanna Panagiotopoulou

Chris Russ

Grazia Scocca



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

In 2021, 26 new organisations joined ECPC, consolidating it as the Europe’s largest cancer patient association with more than 450 members. ECPC welcomes all organisations across EU and non-EU countries, dealing with all types of cancer.

This helps ECPC gain a broad knowledge of the cancer journey through our patient organisations.

The European Cancer Patient Coalition welcomed in 2021 26 new members:

- Van Association Against to Breast Cancer
- European Lung Foundation
- Asociacion Saray
- African Cancer Organisation
- HPV Global Action
- Lymphoma Association Flanders
- Male Breast Cancer Coalition
- Hodgkin & non-Hodgkin vzw
- Bulgarian Lymphoma Association
- Association of Woman Affected by Breast and Gynecological Cancer of Albacete AMAC
- Kidney Cancer Support Network
- PAY-W Clinic
- AELCLES - Spanish Network for Leukemia and Blood Disorders

- AEACAP- Asociación Española de Afectados de Cáncer de Pulmón
- AGAMAMA Breast Cancer Association in Cádiz
- Breast and gynecological cancer diagnosed association ADICAM
- Mutagens
- Comitato Oltre il nastro rosa
- Fra Parentesi
- Italian Cholangiocarcinoma Patients Charity
- Charity Foundation Inspiration Family
- Solihull Prostate Cancer Support Group
- ONCONAUTS ASSOCIATION
- Torbay Prostate Support Association (TPSA)
- Associazione per l'Assistenza Domiciliare al Malato Oncologico
- EDITH CHATIKOBO TRUST

2. The European Cancer Patient Coalition's Mission

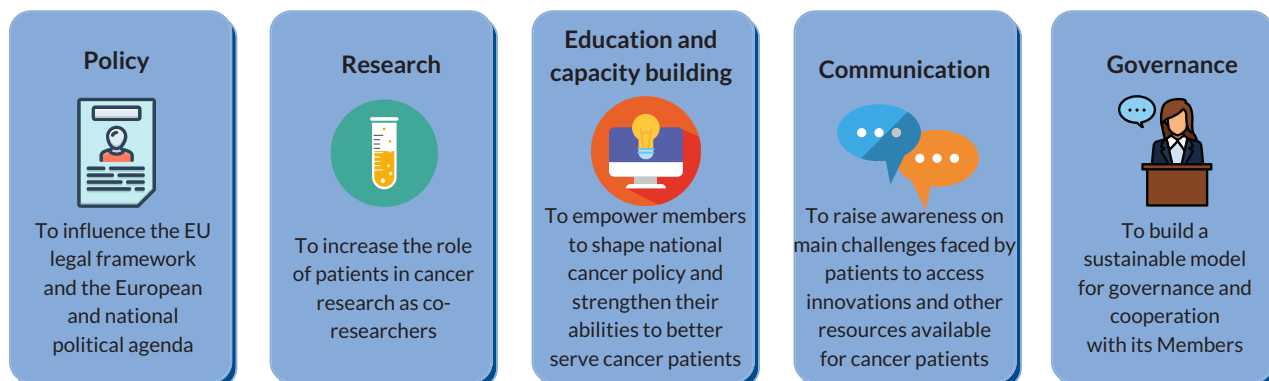
Our Mission is to:

- 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:

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 was officially established in early 2020 to ensure the scientific support of ECPC and the identification of policy and research priorities.

4. Messages from the President



Dear ECPC members, stakeholders, and friends,

The second year of the pandemic was particularly challenging for the cancer community worldwide. The coronavirus pandemic has been endangering cancer patients directly and indirectly, has severely disrupted cancer care, revealed weaknesses of health systems, and its results appear already in new advanced cancer diagnoses and neglected cancers.

Besides affecting individuals, the pandemic has also affected the operation of cancer patient organizations and several of our members had to considerably reduce their activities due to lockdowns and social distancing measures, affecting their sustainability. Despite the problems and challenges posed by the pandemic, the

members of ECPC across Europe have proven their dedication to their mission and they stood by the cancer patients and their families, in their communities, offering support and information.

For ECPC too, 2021 was a challenging year, as we had to overcome several disruptions, among them, the change of leadership with the appointment of Ken Mastris, as ECPC President and Treasurer, in December 2020 and the resignation of the Vice President Pietro Presti in July 2021, followed by the appointment of Matti Jarvinen as Board Member. ECPC had also another major decision to make in 2021, regarding moving its offices from its headquarters of the last ten years at 40, Rue Montoyer, to shared office premises at 6, Ave. des Arts. Moreover, ECPC had changes in the staff due to new hires needed to cover existing needs but also due to replacement of staff and trainees who left the organization seeking new professional experiences. For most of 2021, ECPC staff worked remotely, while now ECPC follows a hybrid mode of work as most of the European Organizations and has the possibility to work from the office and request to work remotely, if necessary.

On the EU cancer policy and research level, 2021 was the year of the ambitious EU's Beating Cancer Plan and of the Cancer Mission, the two emblematic actions of the European Commission, as the fight against cancer is a key priority in of the von der Leyen Commission and a key pillar of a strong European Health Union. The EU Cancer Plan sets out a new EU approach to cancer prevention, diagnosis, treatment, care, quality of life and survivorship and it focuses on actions where the EU can add the most value with new technologies, research, and innovation as the starting point. In 2021, ECPC participated in several calls for expression of interest for EU funded projects of the EU Cancer Plan and 11 of them were approved in late 2021 and are due to launch in 2022. The Challenge Cancer Intergroup that was launched in July 2020, accepted the action plan 2021 presented by ECPC, that assures its Secretariat, and during 2021 co-organized with ECPC 20 events on Europe's Beating Cancer Plan, EU Joint Action on Rare Cancers, the establishment of the European Survivorship Day among other. Despite the restrictions imposed by the

pandemic, ECPC succeeded in 2021 to execute its Action Plan thanks to the dedication of our staff to the mission of ECPC.

Resuming my mandate as ECPC President, for the period March – May 2022, after serving as a Board Member from Dec. 2020 to March 2022, my priority is to lead the organization towards its AGM 2022 and elections for a new Board of Directors and Audit Committee, assure with the Board and the Secretariat a smooth transition to the new Board of Directors, work for strengthening the position of ECPC as the leading European cancer patient umbrella organisation in Europe and continue our dedicated work towards cancer equity and quality care for all cancer patients across Europe.

The year 2022, will be for ECPC a new start with a new Board and Audit Committee, and mostly new, well educated, young and dedicated to the ECPC mission, staff members in our Secretariat, working diligently to face the challenges of the post-covid19 era, implement the lessons learnt by the pandemic and welcome the opportunities offered by the EU Cancer Plan and Cancer Mission for our community and all Europeans.

Kathi Apostolidis

5. Message from the Director



Dear Cancer Patients, ECPC Members, Stakeholders, and Friends,

In year 2021 the challenges of year 2020 continued for both the cancer community worldwide and ECPC. The COVID19 pandemic continued to spread around the planet, sending billions of people into lockdown as health services struggle to cope. As this disease can endanger cancer patients directly or indirectly, ECPC has been strongly committed to provide its members and the larger cancer community with the most updated information also on the vaccines to ensure that cancer patients are safe and protected during the pandemic.

The coronavirus pandemic has severely disrupted cancer care, revealed weaknesses of health systems, and it will have a significant impact on new cancer diagnosis in the following years. This situation has led ECPC to prove its resilience,

adaptability and commitment to its mission: a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available, throughout their life. For that reason, ECPC has continued working to ensure that the rights of cancer patients are respected.

Furthermore, exactly one year after the launch of the consultation period for Europe's Beating Cancer Plan, ECPC, as the voice of cancer patients in Europe, has taken a prominent role in the dialogue with the European institutions and will continue to engage with the oncology community for the implementation of the Cancer Mission and the Europe's Beating Cancer Plan. ECPC with the contribution of the members of the Cancer Complications and Comorbidities Initiative, prepared and submitted to 22 MEPs who are also BECA committee members, 75 amendments on the BECA Committee draft report, proposed by MEP Véronique Trillet-Lenoir, on "Strengthening Europe in the fight against cancer - towards a comprehensive and coordinated strategy". It is worth noting that 43 of the proposed amendments were proposed by several MEPs to be included in the final version.

The "Challenge Cancer" Parliamentary Intergroup on Cancer strengthened its presence and action, and several events were organised and endorsed with the support of ECPC which is managing the secretariat of the Intergroup. ECPC continued its involvement in Working Parties and Committees. Work on other European Union funded projects continued, including 13 EU Funded projects, 3 Innovative Medicine Initiative (IMI) projects, over 50 new project proposals were submitted and 11 projects to kick off in September 2022. The "Right to be Forgotten", building on the success of the relevant laws in France, Belgium and Luxemburg fostered the implementation of the law in The Netherlands and Portugal.

Although a challenging year for cancer, I am proud of the work and efforts put in by all involved in this report. After more than two years in the position of the ECPC EU Affairs Manager and now as the newly appointed ECPC Director, (since March 2022), after the resignation of the former Director Antonella Cardone, I am excited to move into the new ECPC era 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 2022 and beyond.

Charis Girvalaki

6. Overview of 2020

6.1 EU Beating Cancer Plan

On 3 February 2021, on the eve of World Cancer Day, the European Commission presented its long-awaited Europe's Beating Cancer Plan, delayed by the COVID-19 crisis. The Plan is a comprehensive political commitment building on the long-standing EU fight against cancer that started in 1985. Europe's Beating Cancer Plan represents a turning point in European cancer policy. The Plan was based on extensive stakeholder consultation and is very comprehensive as a result. It sets out lofty ambitions to improve access to the latest innovations in cancer prevention, early detection, diagnosis, and treatment while also seeking to improve quality of life of patients and survivors. The Commission allocated €4 billion, including €1.25 billion from the future EU4Health, to support the implementation of the Plan.

Following the publication of the Plan and in view of its implementation, the European Commission organised a virtual Europe's Beating Cancer Plan stakeholder contact group on the Health Policy Platform and members were asked to declare their interest in joining the thematic groups that will be set up under the umbrella of the contact group, namely:

1. Prevention
2. Early detection, diagnosis, and treatment
3. Quality of life
4. Research, innovation, and digitalisation
5. Reducing inequalities
6. Childhood cancer

ECPC Board members and staff have expressed their interest to participate in the stakeholder group to represent the voice of the cancer patients within these sub-working groups.

6.1.1 Challenge Cancer Intergroup



On 1st July 2020, ECPC launched the Challenge Cancer Intergroup the first EU parliamentary intergroup on cancer. This informal group of cross-party Members of the European Parliament (MEPs) is chaired by MEP Cristian Bușoi (EPP) and co-chaired by MEPs Alessandra Moretti (S&D), Aldo Patriciello (EPP), Frédérique Ries (Renew), with the European Cancer Patient Coalition (ECPC) providing the Secretariat.

The Intergroup will be active till the end of current political mandate, in 2024.

During its first internal meeting in October 2020, the MEPs members of the Intergroup have adopted the work agenda for 2021. The main topics covered were:

- Rare Cancers
- Survivorship care
- Personalised medicine
- Social disparities
- Paediatric cancers
- Cancer and COVID-19
- The Mission on Cancer
- Cancer-Causing Substances in the Environment
- Healthy living – The role of nutrition and physical activity in cancer care
- Access to preventative and novel cancer therapies
- Efficiency in cancer care
- Cancer-related complications and comorbidities
- Head and Neck Cancers
- Non-melanoma Skin Cancer (NMSC)
- Patient safety

In 2021, MEPs showed their strong support and political will to take action on cancer. In this sense, the Challenged Cancer Intergroup endorsed 20 public events, where MEPs, members of the Intergroup, chaired different sessions, expressed views and dedicated themselves to the fight against cancer.

By the end of 2021, the Intergroup consisted of 37 MEPs:

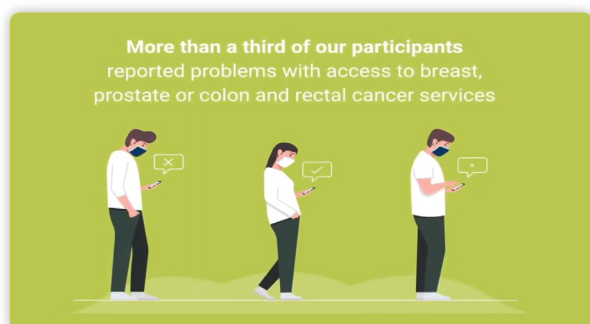
- | | |
|--------------------------------|----------------------------|
| ● Cristian Silviu Busoi | ● Veronique Trillet-Lenoir |
| ● Alessandra Moretti | ● Raffaele Fitto |
| ● Frédérique Ries | ● Liudas Mazylis |
| ● Aldo Patriciello | ● Juozas Olekas |
| ● Tudor Ciuhodaru | ● Gheorghe Falcă |
| ● Sunčana Glavak | ● Chrysoula Zacharopoulou |
| ● Pietro Bartolo | ● Stelios Kypmpouropoulos |
| ● Giuliano Pisapia | ● Eva Kaili |
| ● Romana Jerkovic | ● Frances Fitzgerald |
| ● Margarita De La Pisa Carrión | ● Tomislav Sokol |
| ● Angelo Ciocca | ● Eero Heinaluoma |
| ● Gianna Gancia | ● Giuseppe Milazzo |
| ● Patrizia Toia | ● Silvia Sardonne |
| ● Giuseppina Picierno | ● Stefania Zambelli |
| ● Brando Benifei | ● Dino Giarrusso |
| ● Caterina Chinnici | ● Massimiliano Salini |
| ● Maria Arena | ● Carlo Fidanzal |
| ● Katrin Langensiepen | ● Cyrus Engener |
| ● Fulvio Martusciello | |

Events endorsed by the Challenge Cancer Intergroup in 2021

1. “Europe Beats” Cancer Plan - Dancing with the elephants - European Health Forum Gastein – 30/09/2020
2. Europe’s Beating Cancer Plan: Bridging the gap in breast cancer care – 15/10/2020
3. Fighting Cancer: The CECOG Cancer dashboard for CEE -29/10/2020
4. PancreOS – Pancreatic Cancer Overall Survival Registry – 24/11/2020
5. Head and Neck Cancer: What should patients know – 25/11/2020

6. 14 Million Reasons to Discuss Life after Cancer: Implementing the Right to be Forgotten across Europe – 19/02/2021
7. EU Joint Action on Rare Cancers (JARC) recommendations towards implementing the Rare Cancer Agenda 2030 – 24/02/2021
8. How can Europe's Beating Cancer Plan help tackle women's cancers? – 06/05/2021
9. White Paper Launch: Tackling cancer-related complications and comorbidities – 25/05/2021
10. Overcoming the burden of cancers caused by viral infections – 26/05/2021
11. How to care for your nutrition as a cancer patient? – 27/05/2021
12. Cancer-Associated Thrombosis (CAT)/ Venous Thromboembolism (VTE) and Cardiovascular Complications and how they affect cancer patients' survival and quality of life – 28/05/2021
13. The crucial steps to combat cancer – 31/05/2021
14. 20 Million Reasons to Discuss Life After Cancer: Establishing a European Survivorship Day -29/06/2021
15. Re-thinking the future of cancer care – European Health Forum Gastein – 27/09/2021
16. Governance of Integrated and Comprehensive Cancer Care – 30/09/2021
17. Opportunities for Hepatitis Related Cancer Prevention in Europe's Beating Cancer Plan – 28/10/2021
18. Cancer And Quality of Life – 24/11/2021
19. Delivering the vision of personalised medicine in oncology across the EU – 07/12/2021
20. The role of Research & Innovation in the enhancement of older cancer patients care & treatment options, accessibility and Quality of Life during survivorship – 09/12/2021

6.1.2 COVID-19 Pandemic

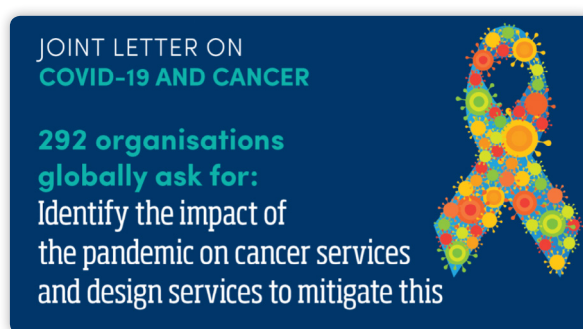


The COVID-19 pandemic has severely disrupted healthcare systems across Europe, not excluding cancer care and cancer detection. Regrettably, with approximately a 40 per cent drop in diagnoses of cancer in 2020¹ the pandemic will negatively affect cancer outcomes in the near future. Moreover, the coronavirus is endangering cancer patients directly, putting them at higher risk for more severe forms of the disease.

Video presentation of the main COVID 19 survey results sample, available here: <https://youtu.be/yvvEa8aM7II>

- 1 a. De Vincentiis L, Carr RA, Mariani MP, et al Cancer diagnostic rates during the 2020 'lockdown', due to COVID-19 pandemic, compared with the 2018–2019: an audit study from cellular pathology Journal of Clinical Pathology 19 June 2020 doi: 10.1136/jclinpath-2020-206833 (<https://jcp.bmj.com/content/early/2020/06/19/jclinpath-2020-206833>)
- b. Elisabeth Mahase Covid-19: Urgent cancer referrals fall by 60%, showing “brutal” impact of pandemic BMJ 2020; 369 doi: <https://doi.org/10.1136/bmj.m2386>
- c. Maringe C, et al The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study The Lancet August 2020 doi: <https://www.thelancet.com/action/showPdf?pii=S1470-2045%2820%2930388-0>
- d. NHS England Waiting times for suspected and diagnosed cancer patients for April 2020 June 2020 doi: www.gov.uk/government/statistics/waiting-times-for-suspected-and-diagnosed-cancer-patients-for-april-2020
- e. Harvey W, et al Changes in the Number of US Patients With Newly Identified Cancer Before and During the Coronavirus Disease 2019 (COVID-19) Pandemic August 2020 doi: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7403918/>

More than 290 international, national and regional cancer organisations around the globe including the Association of Community Cancer Centers (ACCC), the Union for International Cancer Control (UICC) endorsed the Joint Letter launched by ECPC on Covid-19 and Cancer, on the occasion of the World Health Day, 7th April 2021. The letter was presented to the general public and media in an online event, and it is being distributed to policymakers globally.



A social media toolkit was created to promote on social media the content available. Meetings were organized with representatives of the French Permanent Representation, the Italian ministry of Health, WHO.

In 2020, ECPC Launched the survey 'Mapping EU Member States' response to the COVID 19 pandemic and cancer' to monitor the experience of cancer patients, cancer survivors or cancer carers from all parts of the EU. The survey was available in all EU languages. The survey was filled in by 689 participants from 42 countries. Based on these findings, ECPC prepared a video campaign that was shared on our social media and website. The full report of findings is to be published in a peer reviewed scientific journal.

Build on previous success, ECPC accepted the proposal of Prof. Davide Mauri to publish and broadly promote the compendium of guidelines on covid-19 and cancer, aimed at cancer patients at risk of covid-19, that he, Greek and European oncologists prepared and translated in 27 languages. Firstly, ECPC helped to map the situation across the EU and the guidelines compendium, by Prof. D. Mauri and team, based on the guidelines published by ASCO, ESMO and national ones, aimed to offer concrete guidance to cancer patients around the globe.

6.2 Calendar of main activities in 2021

January

- European Cancer Dashboard/ Europe's Beating Cancer Plan
- Instand-NGS4P WP4 Kick-off meeting
- Cancer comorbidities initiative meeting
- QUALITOP annual meeting
- T2EVOLVE kick-off meeting
- Personalized Preventive Medicine of Oral Cancer
- All.Can PA Working Group Meeting
- FEAM forum internal meeting

February

- EORTC-BioMed Alliance Webinar
- EHA-EBMT 3rd European CAR T-Cell Meeting
- All.Can National Initiatives Working Group
- EASO Policy conference
- 14 Million Reasons to Discuss Life after Cancer: Implementing the Right to be Forgotten across Europe

- POLITICO's Working Group on "Tackling cancer comorbidities"
- Ending Tobacco epidemic – an essential step for beating cancer
- TIGER - kick-off meeting
- Global Patient Organisation Summit 2021
- EU Plan for Beating Cancer: has it met the great expectations?
- ECPC – EURACAN event on rare cancers
- EU Joint Action on Rare Cancers (JARC) recommendations towards implementing the Rare Cancer Agenda 2030

March

- PREFER Steering Committee
- SIP Virtual Cancer Pain Policy Event
- European Obesity Policy Conference 2021
- OPTIMA Consortium meeting
- COVID-19 Vaccination in Patients with Liver Disease Webinar
- MAC iPAAC event | Tackling Challenges in Cancer Care and improving its Governance in the EU
- All.Can Research and Evidence WG
- BBMRI Stakeholder Forum based on Lessons from the Pandemic
- 25th Anniversary Congress of EAHP
- PIONEER study-a-thon
- PREFER Steering Committee
- SIP Virtual Cancer Pain Policy Event
- European Obesity Policy Conference 2021
- OPTIMA Consortium meeting
- COVID-19 Vaccination in Patients with Liver Disease Webinar
- MAC iPAAC event | Tackling Challenges in Cancer Care and improving its Governance in the EU
- All.Can Research and Evidence WG
- BBMRI Stakeholder Forum based on Lessons from the Pandemic
- 25th Anniversary Congress of EAHP
- PIONEER study-a-thon

April

- European Digital Conference Health Innovation: "No Citizen left behind"
- Public hearing at the EESC on Europe's Beating Cancer Plan
- European Digital Conference Health Innovation: "No Citizen left behind"
- Launch event: Joint letter on COVID-19 and Cancer
- Immune-Image: Exploitation & sustainability workshop
- EU4Nutrition LIVE - Implementing Optimal Nutritional Cancer care at EU member state level
- T2EVOLVE 1st Multistakeholder Meeting
- Consortium meeting Palliative Sedation
- UICC European virtual roundtable series - Sustaining impact in a resource-constrained environment
- Innovative Partnership for Action Against Cancer (iPAAC)
- Think, Act, EUnite: A post-COVID-19 paradigm shift in European healthcare
- PREFER webinar on patient preferences & value in the Medical Product Life Cycle (MPLC)

- Patient Engagement to Impact Cancer Care Policy
- All.Can International - General Meeting 2021
- DIAdIC Consortium Meeting

May

- High-level Conference on the Mental Health Impact of COVID-19
- EWAC: How can Europe's Beating Cancer Plan help tackle women's cancers?
- EWAC: White Paper Launch: Tackling cancer-related complications and comorbidities
- EWAC: Overcoming the burden of cancers caused by viral infections
- EWAC: How to care for your nutrition as a cancer patient?
- EWAC: Cancer-Associated Thrombosis (CAT)/ Venous Thromboembolism (VTE) and Cardiovascular Complications and how they affect cancer patients' survival and quality of life
- EWAC: The crucial steps to combat cancer
- European Cancer Research Summit 2021
- EAVH Partner Meeting
- XV European Patients' Rights Day
- Cancer survivorship AI for wellbeing meeting
- EADV Policy Roundtable Discussion "Beating Cancer: How to step up EU efforts on melanoma and skin cancer prevention?"
- COVID-19 Impact on patient organisations and recommendations for future health systems
- EFPIA Patient Think Tank Session
- Patient Engagement in HTA: a collaborative project with HTAi, EPF & EUPATI –
- EFPIA Patient Think Tank Session
- EPP Hearing on the Right to be Forgotten for Cancer Patients
- PREFER Steering Committee meeting
- PIONEER General Assembly meeting
- ESMO Public Policy Webinar on the General Data Protection Regulation and its impact on clinical research

June

- 20 Million Reasons to Discuss Life After Cancer: Establishing a European Survivorship Day
- Non Melanoma Skin Cancer webinar
- EU Cancer Survivorship Day event
- UICC European virtual roundtable series - Sustaining impact in a resource-constrained environment
- PREFER webinar: Patient preferences workshop
- Lessons from the crisis: how a value-based approach can make health systems more resilient
- International Pharmacovigilance days
- International Round Table Discussion "COVID-19 and cancer care during the global Pandemic, Post-COVID Rehabilitation and Vaccination".
- SIOG webinar on the impact of COVID-19 on ageing cancer patients
- UICC Virtual Dialogue for Europe
- Beating cancer: Looking ahead, learning from the past

July

- EAU 21 life after cancer - Patient Day
- "Towards a high-performance oncology research system" - Current thoughts and future developments
- Politico: Improving Europe's Health Technology Assessments
- PREFER Steering Committee
- All.Can National Initiatives Working Group
- Launch of the WHO Report on the Global Tobacco Epidemic 2021
- "Towards a high-performance oncology research system" - Current thoughts and future developments

August

- Roadmap Initiative Plenary Meeting

September

- UICC World Cancer Leaders Summit panel discussion
- first accompanying ESMO congress reporting for patients
- Let's break the taboo around cancer & sexuality!
- iPAAC recommendations
- ESPEN – ONCA – MNI Joint Session 2021 "Delivering optimal nutritional care for all throughout the cancer journey: what will it take?"
- EONS14
- 5th International UV & Skin Cancer Prevention Conference
- UICC European virtual roundtable series - Sustaining impact in a resource-constrained environment
- WCLC2021: Optimizing Clinical Outcomes in Lung Cancer: The Value of Tobacco Cessation
- TIGER consortium meeting
- ESMO Congress 2021- Virtual Patient Apéro
- ECPC's Personalised Medicine Awareness Month 2021
- Immune-Image Annual Meeting 2021
- Re-thinking the future of cancer care – European Health Forum Gastein
- Europe Beats" Cancer Plan - Dancing with the elephants - European Health Forum Gastein
- The role of Research & Innovation in the enhancement of older cancer patients care & treatment options, accessibility and Quality of Life during survivorship
- Governance of Integrated and Comprehensive Cancer Care

October

- PREFER Steering Committee
- NMSC in Europe: Tackling health inequalities, raising awareness of patients and caregivers and improving their quality of life
- Palliative Sedation Executive Board Meeting
- Virtual OPTIMA kick-off meeting
- Integrative Medicine and Health in Pain Management
- PREFER annual meeting
- Palliative Care and End of Life on Patient's Perspective (DIAdIC and H2020 projects)

- LEGACY 2nd General Assembling Meeting
- Health Systems and Treatment Optimisation Session at European Cancer Summit 2021
- Community 365 Roundtable Meeting on Metastatic Cancer
- Opportunities for Hepatitis Related Cancer Prevention in Europe's Beating Cancer Plan
- Europe's Beating Cancer Plan: Bridging the gap in breast cancer care
- Fighting Cancer: The CECOG Cancer dashboard for CEE

November

- OPEN at Obesity Week 2021 - National obesity strategies and guidelines: where do we go from here?
- EU40 Event: "Building Resilience: What have we learnt from COVID-19 and how to move forward?"
- EAVH Partner Meeting
- DIAdIC Consortium Meeting
- EPC policy dialogue "The impact of COVID-19 on cancer care: learning the lessons from the pandemic"
- Challenge Cancer Intergroup internal debate - "Europe's beating cancer plan: why a personalised approach matters"
- 34th International Papillomavirus Conference - IPVC 2021
- E.C.O Summit
- PancreOS – Pancreatic Cancer Overall Survival Registry
- Head and Neck Cancer: What should patients know
- Cancer And Quality of Life

December

- Lung Cancer Collaboration: Early Detection and Screening Working Group
- LIFECHAMPS – European Parliament Event
- Coalition Recommendations for Reducing Bureaucracy in CTs
- Roche European Patient leaders café
- Cardiovascular Cancer Co-morbidities and complications: the opportunities for action
- iPAAC Final Conference
- RCE Partnership meeting
- Delivering the vision of personalised medicine in oncology across the EU

6.3 ECPC Board Members and Secretariat engagement with external stakeholders

Collectively, in 2021, 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 EMA/PCWP and in the European Commission Initiative on Breast Cancer's Quality Assurance Scheme Development Group (QASDG) and several of its sub-committees by Kathi Apostolidis. Past President Francesco de Lorenzo was in 2021 representing cancer patients' voice in boards and steering committees of European Academy of Cancer Science - EACS, CDDF, Cancer Core Europe and iPAAC. Board Members also hold important positions in cancer patient federations

on national level for example Greece (ELLOK), and Romania (FABC). Jacqueline Daly, Board Member of ECPC, was member of the Let's Talk Prostate Cancer (LTPC) Expert Group of Astellas, focused on prostate cancer as well as E.C.O HPV Action focused on HPV eradication. Robert Greene was involved in the Patient Advocate Committee of E.C.O as well as in EU Health Coalition and EFPIA – Time to Patient Access. Moreover, Maude Andersson is a member of the Steering Group of All.Can Sweden and Pietro Presti a Board Member of the IMASC Steering Committee focused on personalized medicine and biomarkers. Radu Ianovici represents ECPC at the European Haematology Association (EHA) and actively participates at the EHA – Patient Organizations Leadership Meeting. Adela Maghear Senior EU Affairs Officer is Co-Chairing All.Can Intl. Public Affairs Working Group and she is a member of Euripid Stakeholder Dialogue Platform.

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 and recent health policy development in the EU.

6.4.1 ECPC Website

The ECPC website received over 193,519 visitors over the year. The most popular webpages were the homepage, followed by pages with information about Non-Melanoma Skin Cancer, Intergroup, COVID-19 web hub and our news section, as well as information on the Secretariat and the Board.

6.4.2 Social Media Accounts

The ECPC Twitter account rose to 6,040 followers (over 457 new followers), the ECPC Facebook account accumulated 9,695 followers (over 758 more than last year) and the LinkedIn account has 3,218 followers (over 1772 followers from last year).

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, patient advocates but also relevant stakeholders such as policy makers on EU level, healthcare professionals, caregivers, and industry partners.

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 to ensure we reach targeted audience. ECPC Facebook account is a key social media channel to engage and maintain relationship with our current member organisations and their members. The account on Twitter serves for live tweeting on important events organised by ECPC or by 3-rd parties and for interaction with policymakers and healthcare professionals.

ECPC LinkedIn account connects us with industry partners, policymakers, and other professional patient advocates.

6.4.3 Newsletter

The ECPC newsletter is distributed to more than 1891 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 2021, ECPC sent out 184 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 2021, ECPC disseminated the following publications that were distributed solely online due to COVID-19 restrictions: :

- Nutrition: Patient Stories
- Pan-tumor therapies briefing sheet
- Non-melanoma skin cancer as an occupational disease. What is the impact on the society and the welfare system?
- 4 million reasons to discuss life after cancer: Implementing the Right to be Forgotten Across Europe
- HTA toolkit
- How Well do European Patients Understand Cancer-Associated Thrombosis? A Patient Survey
- Guidelines on COVID-19 for cancer patients
- Non-melanoma skin: Fact sheet for carers
- Non-melanoma skin cancer : Fact sheet for prevention
- Non-melanoma skin cancer: infographics
- Access to Personalised Oncology in Europe (reviewed by ECPC)
- White Paper; The impact of cancer-related comorbidities on patient treatment, treatment efficacy, survivorship, and quality of life.
- White Paper Summary: The impact of cancer-related comorbidities on patient treatment, treatment efficacy, survivorship, and quality of life

6.4.5 Media

Throughout the year ECPC has appeared in the press and media 37 times including publications such as The Brussels Times, EURACTIV, Politico, and various news websites across Europe.

7. Campaigns

In 2021, ECPC led 8 awareness campaigns which are presented below.

7.1 World Cancer Day

One day before the World Cancer Day, the European Commission launches the much-awaited Europe's Beating Cancer Plan as the EU's response to the growing burden of cancer deaths. ECPC focused all communication related to World Cancer Day to this occasion and prepared a series of visuals to communicate needs of cancer patients within the Cancer Beating Plan. Together with the visual campaign, ECPC published a statement that was featured in Euractiv and The Brussels Times.

We partnered with EFPIA, and the European Cancer Organisation (E.C.O.) to organise a press brief where we all together urged emphasis on early implementation consistent with the principles of the European Cancer Dashboard, called for during the consultation period by all three organisations.

7.2 Nutrition and physical activity

To capture patient's views, experience and perceptions towards nutrition and nutrition care throughout their cancer survival journeys are of vital importance. Many hospitals and oncology centres are now increasingly aware of this need and there are more and more opportunities for patients to participate and engage in their care. Therefore, to amplify voice of patients in regard of nutrition care, ECPC published a booklet with patient stories from various part of Europe. The promotion of the booklet was supported by a visual campaign and a banner campaign at Euractiv website. The booklet was endorsed by MNI, EFAD and The European Nutrition for Health Alliance.

As a follow-up from this activity, ECPC developed during 2021, together with our partner member, Das Lebenshaus, and researchers from the "La Sapienza" University in Rome, Italy, a new survey to better understand the gaps and needs that cancer patients have over Nutrition.

The results of the survey the results will be analysed and presented during 2022. The idea is to create awareness in the European political landscape, among cancer patients and the general public of the role that Nutrition plays in the treatment and quality of life in cancer.

7.3 Bladder cancer campaign

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 2021 with their fifth Bladder Cancer Awareness Campaign. Following the success of 2020 campaign, ECPC partnered with the World Bladder Cancer Patient Coalition to raise awareness about this type of cancer.



Bladder Cancer Campaign Banner

2021 World Bladder Cancer Awareness Month campaign theme was all about conversation and commitment to ask someone that important question “Have you ever heard about bladder cancer?” According to the official WBCPC website “the awareness month hashtags reached over 40 million people globally and our activities on our social media channels alone, reached over 1.5 million people, with 50,000 people interacting with the content.”

7.4 Head and Neck Cancer Care in Europe

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.

ECPC has worked on the Head and Neck Awareness Week 2021 in the “Mouth, nose and throat tumours shouldn’t be taken lightly” campaign. ECPC developed a web hub, an interactive prevention test and a social media campaign where some Members of the European Parliament took part. ECPC created a web page dedicated to the campaign to make all the information available for our visitors. It has received 418 views. Besides that, ECPC set up a prevention quiz that got 23 responses.

The campaign was announced on 20 September in a special newsletter disseminated among ECPC members and stakeholders lists, a total of 1913 email addresses received these notifications. This mailing was opened 883 times by the recipients.

This newsletter included general information about the disease as well as specific information and links to the web hub and the prevention quiz.

ECPC also created a social media campaign in all our main social media platforms: Facebook, LinkedIn, Instagram and Twitter.

7.5 Personalised Medicine Awareness Month

In November 2021, the European Cancer Patient Coalition promoted the importance of access to cancer molecular testing during a month-long annual advocacy campaign, “Cracking the Cancer Code”. Too many people diagnosed with cancer do not have access to the personalised treatment they need and deserve.



Personalised Medicine Awareness Month logo

ECPC launched the first ever Personalised Medicine Awareness Month in 2018 with the goal of raising awareness of, and increasing access to, molecular and biomarker testing in cancer care across Europe. ECPC and our member organisations believe that people living with cancer should be informed about all available treatment options and be empowered to make the best decisions for their health, together with their healthcare team. That's why ECPC is working towards ensuring all Europeans with cancer and at

risk of getting cancer have appropriate access to cancer molecular testing. This will help to promote better diagnosis, more targeted follow-up and a truly personalised treatment.

Throughout the month of November, ECPC promoted the importance of access to cancer molecular testing during a campaign – 'Cracking the Cancer Code'. The social media toolkit together with communication tools and materials in English and other 11 languages were made available. ECPC developed a toolkit to help our member patient organisations and all supporters to participate in the Personalised Medicine Awareness Month campaign and make the most of the tools and materials. This toolkit included a new infographic for patients to raise awareness on what Personalised Medicine is and how it can improve patients' health and quality of life while describing the opportunities and challenges that personalised medicine provides to empower citizens and patients to make an informed decision about their personal health. Besides this, ECPC also promoted "Personalised Medicine: A Guide for Patients" – an updated booklet to address the opportunities and challenges that Personalised Medicine provides so that the needs of cancer patients across Europe are met.

In 2021, a working group of leading experts and stakeholders from the EU oncology community was convened to create a report with actionable policy recommendations to address barriers to the delivery of personalised medicine – and specifically to support the implementation of one flagship in Europe's Beating Cancer Plan, 'Cancer Diagnostic and Treatment for All' initiative. The recommendations called on the European Commission to lead awareness campaigns on biomarker testing, develop EU-wide guidance on personalised medicine, build the required infrastructure, facilitate the development of a specialised workforce and mobilise resources to promote equal access.

The report – endorsed by the European Cancer Patient Coalition, Lung Cancer Europe and EU40 – was launched in December 2021 during a virtual event co-hosted by MEP Cyrus Engerer, the ECPC and the Challenge Cancer Parliamentary Intergroup.

7.6 Non-melanoma Skin Cancer Awareness Day

Non-Melanoma Skin Cancer (NMSC) accounts for approximately 90 percent of all skin cancers, with an estimated 2-3 million cases recorded in the world every year, and the number of diagnosed cases increasing by 3-8 percent annually. In 2021, ECPC held a webinar during Global NMSC Awareness day (15 June) aiming to identify the main barriers that prevent health professionals and other relevant stakeholders from reporting or taking measures to prevent occupational skin cancer, and in particular NMSC, in

order to assure that the risks of acquiring NMSC through exposure to natural UVR are addressed in the implementation of the Europe's Beating Cancer Plan, and to further pursue recognition of NMSC as an occupational disease and increase awareness on relevant stakeholders and the general public. The webinar, which was co-organised by the Challenge Cancer Intergroup, identified how these barriers can be tackled, discussed the importance of introducing legislative and soft measures to reduce exposure to natural UVR at the workplace as well as identified priority instruments for reducing exposure to UVR and improving awareness. Finally, the webinar addressed ways which NMSC could be addressed during the implementation phase of the Europe's Beating Cancer Plan integrating and promoting the conclusions of the work that has been done during the past years.



Non-Melanoma Skin Cancer Factsheets

Additionally, on the 28th of October, ECPC, in collaboration with EADV and Eurocarers, hosted a webinar aiming to provide a holistic overview of the state of play in NMSC and seek to tackle the importance of awareness among the NMSC patient community, carers, vulnerable populations and the general population. This webinar provided an overview of the socio-economic inequalities affecting NMSC patients across Europe, discussed differences within and between European Member States in terms of disease awareness and patient experience throughout the care pathway – including prevention, diagnosis, treatment and quality of life.

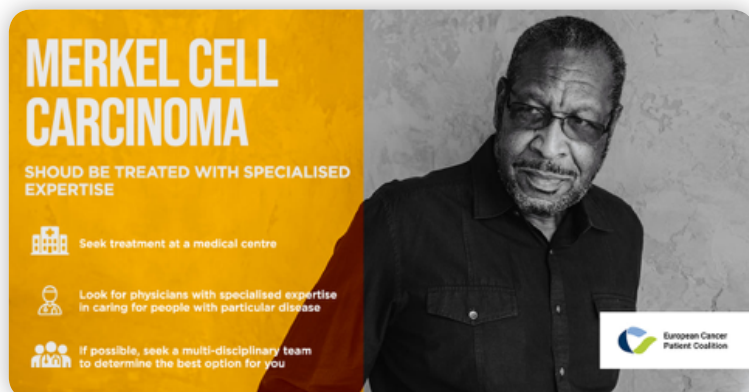
Following this webinar, ECPC also launched three factsheets: a factsheet on prevention, a factsheet on carers, and an infographic, all three comprising some recommendations. Moreover, a NMSC webhub (<https://ecpc.org/tool-box/non-melanoma-skin-cancer-web-hub>) was created on the ECPC website, with a collection of relevant patient material on NMSC.

7.7 Merkel Cell Carcinoma

Since many years now, ECPC has led the efforts to raise awareness among EU Member States about this aggressive form of skin cancer - Merkel Cell Carcinoma (MCC). ECPC has developed an information brochure about prevention, risk factors and treatment that was then translated in 14 languages, printed, and distributed in respective countries. In 2020, ECPC launched the first social media campaign to bring the attention of this rare disease to broader audience.

As this type of skin cancer can progress and spread rapidly, it is difficult to be treated when detected later. ECPC emphasises the importance of educating the public about prevention, self-examining and warning signs. Merkel Cell Carcinoma, as other types of skin cancer, can be detected early as this cancer develops on outside of the body. With early detection, MCC can be cured successfully. Moreover, it is possible to reduce the risk of developing MCC by taking the preventive measures.

May is the skin cancer awareness month, therefore the campaign started on the last week of May. ECPC launched the campaign with the MCC Awareness Campaign Toolkit made up of a social media calendar and six social media posts to be featured on Twitter, Facebook, Instagram, and LinkedIn. ECPC created a web page (<https://ecpc.org/merkel-cell-carcinoma/>) dedicated to the campaign to make all campaign documents available to download for all the website visitors.



During the period of 18th May - 16th June 2021, the web page was visited 760 times and the campaign toolkit was downloaded 22 times. The hashtags #MerkelCellCarcinoma were used throughout the campaign.

The campaign was disseminated via mailing to 1.812 individual email addresses. In total, the email was opened 1.034 times by the email receivers (447 individual opens).

In the mailing we shared the toolkit and our informative web page on MCC with translations.

The campaign was featured in the Euractiv flagship newsletter “The Capitals” during the week of 24th - 28th May 2021. The Capitals is a daily politics and policy roundup delivered every weekday in the morning. The newsletter included an awareness message on MCC with a link to our campaign web page. Euractiv recorded 145 clicks on the message in total throughout the week.

7.8 European Week Against Cancer

In the light of the EU Beating Cancer Plan, the European Cancer Patient Coalition (ECPC), the Cancer Complications and Comorbidities Initiative Members and the European Parliamentary Intergroup “Challenge Cancer” co-organised five webinars during the European Week Against Cancer 2021, which took place from Tuesday 25th to Monday 31st of May 2021. These webinars presented various issues surrounding Cancer Complications and Comorbidities, to ensure that Cancer complications and comorbidities are addressed in the implementation of the Europe’s Beating Cancer Plan and increase awareness on the relevance of these comorbidities among relevant stakeholders and the public. The events reached a broad and varied audience, composed of medical and research professionals, non-governmental organisations, general public, as well as patients, patient advocates, and policy makers, titled as follows:

1. White Paper Launch: Tackling cancer-related complications and comorbidities
2. Overcoming the burden of cancers caused by viral infections
3. How to care for your nutrition as a cancer patient?
4. CAT/VTE and Cardiovascular Complications and how they affect cancer patients’ survival and quality of life
5. The crucial steps to combat cancer.

On the 25th May took place the first webinar titled “White Paper Launch: Tackling cancer-related complications and comorbidities”, which treated about subject surrounding the impact on cancer-related complications and comorbidities on patient treatment, treatment efficacy, survivorship, and quality of life.

On the 26th of May, took place the second event titled “Overcoming the burden of cancers caused by viral infections”, which touched upon the prevention of cancer-causing virus infections, with a major focus on HPV and Hepatitis.

The 27th of May took place the third event “How to care for your nutrition as a cancer patient?”, which revolved around Cancer, Nutrition, and Nutritional Care.

On the 28th of May took place the fourth webinar titled: “Associated Thrombosis (CAT)/ Venous Thromboembolism (VTE) and Cardiovascular Complications and how they affect cancer patients’ survival and quality of life”.



On the 31st of May took place the fourth webinar titled: “The crucial steps to combat cancer.”, touching upon subject of Cancer prevention, screening, and early detection.

During this week’s events we could notice a widespread interest in the cancer related complications and comorbidities across various groups. The organisation of the webinars was successful thank to the work and collaboration of the various organisations and experts, whose input and participation brought great insights into the cancer related complications and comorbidities subjects. During this week, we have highlighted the importance of the past work that has contributed to bring these subjects to light until now, and the importance of continuing the to take actions towards a better recognition of the various cancer-related complications and comorbidities.

8. Health Policy

8.1 The establishment of the EU Cancer Survivorship Day

In February 2020, the European Commission unveiled the Europe's Beating Cancer Plan and the new EU approach to tackle the entire disease pathway, from prevention to quality of life of cancer patients and survivors.

ECPC acknowledges the strong value of the Cancer Plan as a new European strategy for cancer prevention, treatment and care. Particularly regarding cancer survivorship, the Plan proposes measures to improve the quality of life of cancer patients and survivors, including potential tumour recurrence, metastatic disease, and rehabilitation measures to support social integration and re-integration into the workplace. In this regard, the **'Better Life for Cancer Patients Initiative'**, together with the **'Cancer Survivor Smart-Card'** and the **'European Cancer Patient Digital Centre'** are valuable initiatives and unique opportunities to improve rehabilitation standards and quality of life of cancer survivors in the EU.

However, the increasing number of cancer survivors in the EU emphasises the urgency to identify former cancer patients as a specific vulnerable group with proper needs, demanding specific care, and promote social and economic measures to allow them to resume their life after cancer.

At present, there are more than 14 million cancer survivors in the EU (20 million according to some estimations). In spite of the rising number of cancer survivors, cancer survivorship can be a lifelong struggle.

Given the ad hoc needs of cancer survivors and the persisting inequalities among EU countries, ECPC has started an initiative towards establishing an EU Cancer Survivorship Day by organising targeted events, such as "There is Life after Cancer: Putting an End to the Discrimination" (9 June 2020), "14 Million Reasons To Discuss Life After Cancer: Implementing The Right To Be Forgotten Across Europe" (19 February 2021) and "20 Million Reasons to Discuss Life after Cancer: establishing a European cancer survivorship day" (29 June 2021).

Cancer Survivorship Day is already being celebrated on the first Sunday of June in several countries all around the world, such as the USA, Canada, India, South Africa, and Australia, as well as in several EU member states.

The institutionalization of an annual Cancer Survivorship Day will provide us with a unique opportunity to set up a dialogue with patients, their families and stakeholders, establishing a proper forum to discuss their specific needs and priorities to achieve a good quality of life after beating cancer, with an emphasis each year on a specific pattern of unmet needs.

The establishment of an annual Cancer Survivorship Day will also be an opportunity to promote the scope of the European Beating Cancer Plan and to support adequate policies to ensure rehabilitation and smooth reintegration of cancer survivors into social and professional life.

To succeed in our endeavour, ECPC and the Challenge Cancer Parliamentary Intergroup drafted a letter co-signed by MEPs asking the European Commission President Ursula von der Leyen, European Parliament President Roberta Metsola and Commissioner on Health and Food Safety Stella Kyriakides to endorse the establishment of the annual EU Cancer Survivorship Day. The letter will be sent out in 2022.

8.2 Transforming Breast Cancer Together

The Transforming Breast Cancer Together (TBCT) 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 were among the founding members. The current chair of the initiative is MEP Frances Fitzgerald (Christian Democrats) and the co-chairs are MEP Patrizia Toia and MEP Cristian Silviu Buşoi.

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 March, to mark International Women's Day, the Transforming Breast Cancer Together Initiative (TBCT) organised a virtual event to raise awareness about the increasing health threat for women due to advanced and metastatic breast cancer. The webinar was chaired by MEP Frances Fitzgerald and brought together breast cancer patients, physicians and policymakers to discuss this pressing issue. Speakers discussed important challenges that breast cancer patients and survivors face daily and addressed key questions related to the disease.

In August-September, ECPC contributed to the amendments presented by TBCT members for the Special Committee on Beating Cancer (BECA) report "Strengthening Europe in the fight against cancer" drafted by MEP Véronique Trillet-Lenoir. The table with the amendments was sent to relevant MEPs in the BECA Committee.

In October, to mark the Breast Cancer Awareness Month, representatives from all member organisations were asked to film a video with a message for breast cancer patients in order to raise awareness on the importance of prevention, screening and early diagnosis. On behalf of ECPC, Alina Comanescu, founder of 'Health for the Community' (ECPC member organisation), discussed the importance of screening to prevent breast cancer.

8.3 Cancer Mission Europe

In June 2020, the European Parliament voted to set up the Special Committee on Beating Cancer (BECA) with the aim to develop actionable recommendations for the EU and its Member States to strengthen their collective response against cancer. The committee's activity has started in September 2020 with French MEP Veronique Trillet-Lenoir as rapporteur and ended 18 months later, in December 2021. The committee had 33 members, MEPs from all political groups in the European Parliament and was chaired by the Polish MEP Bartosz Arłukowicz.

After several months of hearings with high-level researchers and speakers, in July 2021, MEP Veronique Trillet-Lenoir presented the first draft report of this committee. ECPC, in collaboration with Cancer Related Complications and Comorbidities and Transforming Breast Cancer Together initiatives drafted 75 amendments that were further shared with 22 MEPs.

In December 2021, the BECA committee adopted its final report “Strengthening Europe in the fight against cancer” where 43 of our amendments were proposed by several MEPs and finally adopted.

The Parliament will adopt the final report in February 2022.

8.4 Parliamentary Intergroup on Cancer

The kick-off meeting of the Intergroup took place in October 2020, when MEPs approved the work agenda for 2021.

2021 has been a very fruitful year for the Challenge Cancer Intergroup: 20 public events on different cancer topics have been endorsed by the Intergroup with the direct participation of MEPs. At the same time, ECPC has organised two thematic internal meetings for the MEPs and their policy assistants. The first meeting took place in February and two members of the ECPC Scientific Committee – Dr. Francoise Meunier and Prof. Mark Lawler, spoke about the importance of celebrating cancer survivorship in Europe and the need to establish an EU Cancer Survivorship Day. This proposal was well taken by the MEPs and next steps in implementing this initiative were agreed. The second internal meeting was organised in November, on the occasion of the Personalised Medicines Awareness Month and MEPs, members of the Intergroup, had the opportunity to discuss with relevant stakeholders (Prof. Mark Lawler, Stefan Schreck - Adviser for stakeholder relations at DG SANTE, Tobias Helmstorf - Global Oncology Policy lead at Bayer and Jacqueline Daly – ECPC Board Member) the improvements that have already taken place in the field of personalised oncology to win the fight against cancer and the challenges that are still hampering progress in this field, as well as foreseen solutions to overtake them.

8.5 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 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD10) and RARECARE.

In February, ECPC in collaboration with the Challenge Cancer Intergroup organised the virtual event entitled “EU Joint Action on Rare Cancers (JARC) recommendations towards implementing Rare Cancer Agenda 2030” with the aim to raise awareness about the JARC recommendations, open the debate about their implementation at the national level and the need to activate the ERNs network to make it more accessible for patients. Prof Jean-Yves

Blay (Chair of EURACAN), Prof. Paolo Casali (ESMO), Prof. Ruth Ladenstein (ERN PaedCan) and Francesco de Lorenzo (FAVO) presented their views in this high-level event co-chaired by MEP Cristian Busoi, the Chair of the Challenge Cancer Parliamentary Intergroup and MEP Alessandra Moretti (Co-Chair of the Challenge Cancer Parliamentary Intergroup).

This event brought to the attention of policymakers and relevant stakeholders the fact that ERNs are currently blocked, as they lack financial support for infrastructure and patients don't have access to these networks. In parallel with this event, a 'call to action' letter has been drafted by Paulo Casali, Jean-Yves Blay and Francesco de Lorenzo that will be used by MEPs to call on the EC to support the implementation of the Cross-Border Healthcare Directive and the EU Joint Action on Rare Cancers (JARC) recommendations.

Within the same period of time, ECPC organised a virtual meeting with the Working Group on Rare Cancers to discuss means of dissemination of the JARC recommendations at the national level and the scope and involvement of ECPC in the STARTER project (STarting an Adult Rare Tumor European Registry) that had begun on April 1st 2020 and would last 3 years (till April 2023) and is aimed at developing a clinical registry for the European Reference Network (ERN) on rare adult solid cancers (EURACAN).

8.6 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.

On the 30th of September 2021, the Innovative Partnership for Action Against Cancer (iPAAC) held an online webinar entitled “Governance of Integrated and Comprehensive

Cancer Care – the case for Comprehensive Who Cancer Care Networks” aiming at connecting the project partners with decision-makers and other stakeholders to discuss the recommendations from the iPAAC Joint Action on how to tackle challenges in Cancer Care and improve its Governance in the EU. The Webinar was organised by ECPC and endorsed by the Challenge Cancer Parliamentary Intergroup.

On the 11th of November, ECPC organised with a national umbrella cancer patient association ROPI (Rete Oncologica Pazienti Italia), a webinar in Italian to support the implementation of the Right to be Forgotten. The event was organised together with ISS and Roberta De Angelis leading WP7 to promote the outcomes of WP7. The event was endorsed by the European Parliament, the Ministry of Health in Italy, the Italian Parliament, the Italian Cancer League among others. Eighty participants attended the event with very positive outcomes and with the members of the Italian Parliament committed to put the law to the discussion of the Parliament. ECPC is translating the existing laws so that the MPs in Italy can easily adapt the text to the Italian situation.

8.7 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 12th 2019 and a consensus meeting on a joint statement on November 29th 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. Today, the Initiative consists of 31 organizations who have signed the Joint statement as presented below:

1. European Cancer Patient Coalition (ECPC) - CHAIR
2. Associations Collaboration on Hepatitis to Immunize and Eliminate the Viruses in Europe (ACHIEVE)
3. European Association for the Study of Obesity (EASO)

4. European Association for the Study of the Liver (EASL)
5. European Association of Urology (EAU)
6. European Brain Council (EBC)
7. European Cancer Organization (E.C.O.)
8. Eurocarers
9. European Federation of the Associations of Dietitians (EFAD)
10. European Federation of Neurological Associations (EFNA)
11. European Geriatric Medicine Society (EuGMS)
12. European Hematology Association (EHA)
13. European Network for Smoking and Tobacco Prevention (ENSP)
14. European Nutrition for Health Alliance (ENHA)
15. European Pain Federation (EFIC)
16. European Society of Surgical Oncology (ESSO)
17. European Society of Cardiology (ESC)
18. European Society for Clinical Nutrition and Metabolism (ESPEN)
19. European Society of Oncology Pharmacy (ESOP)
20. European Specialist Nurses Organisation (ESNO)
21. European Thrombosis and Haemostasis Alliance (ETHA)
22. International Psycho-Oncology Society (IPOS)
23. International Society on Thrombosis and Hemostasis (ISTH)
24. International Society of Geriatric Oncology (SIOG)
25. Leuven Cancer Institute (LKI)
26. Thrombosis Ireland
27. Thrombosis UK
28. University KU Leuven (KU)
29. European Federation of Nurses (EFN)
30. Obesity Policy Engagement Network (OPEN-EU)
31. Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe)

During 2020, we conducted a literature review to highlight the paramount significance of comorbidities and their impact on cancer treatment, treatment efficacy, survivorship, and quality of life and to identify the most recent scientific evidence per comorbidity. Build on this literature review, in 2021, we have launched a White Paper on “The impact of cancer-related comorbidities on patient treatment, treatment efficacy, survivorship, and quality of life.” during one of the webinars held during the European Week Against Cancer.

Indeed, for 2021’s European Week Against Cancer, the European Cancer Patient Coalition (ECPC), European Parliamentary Intergroup “Challenge Cancer” and Cancer Complications and Comorbidities Initiative Members organized several online events in form of webinars, taking place from the 25th to the 31st of May 2021 and titles as follows:

1. White Paper Launch: Tackling cancer-related complications and comorbidities
2. Overcoming the burden of cancers caused by viral infections
3. How to care for your nutrition as a cancer patient?
4. CAT/VTE and Cardiovascular Complications and how they affect cancer patients’ survival and quality of life
5. The crucial steps to combat cancer.

The Cancer-related Complications and Comorbidities Initiative joined forces and drafted various documents proposing Amendments to the BECA report and **reached out to**

22 MEPs to suggest them to adopt said amendments. Many of the CrCC proposed amendments were finally adopted by the special committee. In total, there were **75 amendments submitted, 43 were proposed** by several MEPs.

Moreover, based on the White paper and previous literature review, ECPC with the support of the Initiative is working on a Policy paper of the same title. . The Initiative aims to publish this Policy Paper in a Journal during the following months of 2022, in order to increase the outreach to various specialists.

8.8 The Right to be forgotten for cancer survivors



The Right to be forgotten is focused on legal research to assess the discriminatory practices and facilitate the promotion for equal access to financial services for cancer survivors in Europe. The objectives consist of facilitating the advocacy activity, providing a clearer legal background about the access to financial services for cancer survivors in the EU Member States, and developing the opportunity of the new regulatory framework at the EU level.

In 2021, the main tasks aimed to consolidate the work of advocacy and research carried out in the previous year in relation to reach a Right to be Forgotten for cancer survivors without being discriminated for access to financial services, once they are declared cured.

Within 2021, the Right to be forgotten for cancer survivors reached relevant achievements and visibility:

- the implementation of the Right to be forgotten for cancer survivors in Portugal, following major input from our research activities
- the strong support provided within the European Parliament's Special Committee on Beating Cancer, leading to the inclusion of the Right to be Forgotten within their priorities
- the conclusion of the Employment, Social Policy, Health and Consumers Affairs (Council of the European Union)
- the survey activity launched by the European Commission on access to financial products for cancer survivors in all EU countries where ECPC provided input
- the preliminary law-making proposal in the field raised in Italy, Slovenia and Ireland.

At the EU level, 2021 has been marked by the implementation of the EU Beating Cancer Plan. In that regard, it is important to highlight that on behalf of the European Commission's Directorate-General Health and Food Safety (DG SANTE), the EU Health

Support consortium conducted a survey on access to financial products for cancer survivors. The consultation activity was organised in two different surveys addressed to national governments and other stakeholders. Prof. Françoise Meunier and Grazia Socca were invited for a briefing with the EUHealth Support Consortium before the consultation was published. The results of this consultation will be published in February 2022.

An additional study campaign was carried out by the German Cancer Research Institute, the Dutch Cancer Institute, European Fair Pricing Network (EFPN) and Organisation of European Cancer Institutes (OEI) regarding the "Survey on the financial impact of your cancer diagnosis". ECPC disseminated the study through its network via newsletters and social media campaign.

Another relevant activity was the report from the European Parliament Special Committee on Beating Cancer and its rapporteur, MEP Veronique Trillet-Lenoir. The report voted in December 2021 stressed on the importance to adopt an EU legislation on the Right to be Forgotten for cancer survivors, inviting all EU Member states to implement a national provision by 2025. Also in that regard, Prof. Françoise Meunier and Grazia Socca were involved in a series of bilateral meetings and email exchanges to ensure strong support to the Right to be Forgotten from the BECA Committee.

In addition, the setup of a working group of MEPs to work on the implementation of this report and the drafting of a legislative proposal were also discussed. Several MEPs already accepted to get involved.

In this regard, Prof. Meunier and Grazia Socca have been actively involved in providing support and advocacy for the dissemination of the project, updating the key research documents ("Factsheet on the Right to be forgotten for cancer survivors in the EU National Legislations" and "Towards an EU legislation on access to financial services for cancer survivors based on the Right to be Forgotten") and preparing a new document focused the EU Competency, to be used in meetings with MEPs, EU institutions' representatives and relevant stakeholders.

Moreover, numerous meetings have been organised with National Representatives for the 2021-2022 trio Presidency of the EU Council and in particular with representatives from France taking the lead in EU Presidency in January 2022.

In November 2021, the EU Commission (DG FISMA) launched a public consultation for the revision of the EU mortgage credit directive where Prof. Françoise Meunier and Grazia Socca submitted a feedback to revise the legislation taking into consideration the Right to be Forgotten.

In October 2021, the Portuguese Parliament adopted the Right to be forgotten for cancer survivors and chronic diseases. A strong collaboration has been set up with national stakeholders for the implementation of the law.

Also, in September and November 2021 two cancer patients' organisations (AIL - Associazione Italiana Leucemia and ROPI- Rete Oncologica Pazienti Italia) organised a conference in Italy on the Right to be Forgotten with the aim of sensitizing national politics to the topic.

During the ECO Cancer Summit (17-18 November 2021) the Slovenia Health Ministry declared to start working on a draft for the provision.

In December 2021, a group of stakeholders, including the Irish Cancer Society promoted an amendment to the Central Bank Bill 2021 promoting the adoption of the Right to be Forgotten in Ireland.

In all the mentioned initiatives, Prof. Françoise Meunier and Grazia Socca played the role of contact points to support such initiatives by providing requested advice and recommendations.

Prof. Françoise Meunier and Grazia Socca participated in the Porto European Cancer Research Summit 2021 (May 2021). Following this event, a paper has been published "The Porto European Cancer Research Summit 2021", in Molecular oncology. In the same journal, they also published an article on "Challenges and solutions to embed cancer survivorship research and innovation within the EU Cancer Mission" that described the results of the activity done by the survivorship committee of the European Academy of Cancer Sciences, chaired by Prof. Françoise Meunier.

Prof. Françoise Meunier and Grazia Socca also established strong cooperation with academic research groups throughout EU. In that regard, they have been asked to join the ELOCAN Project, Inserm Université de Paris and COAST Action project, University College Cork.

8.8 CAR-T therapy platform

ECPC in collaboration with a few pharma companies decided to create a CAR-T Platform. In 2021, in order to collect ample and relevant scientific data regarding CAR-T therapy, the first task was to perform systematic research on various scientific databases, which started mid-April 2021. This review finalised and ECPC will soon start the publishing process. Based on the literature review, a white paper was created aiming to reach a wider audience, which is now in the final stage and getting ready for publication.

9. Education

9.1 Toolkit on Health Technology Assessment

In 2020, ECPC developed a toolkit on health technology assessment (HTA) which was launched in February 2021, and later translated in other languages. The ultimate purpose of this toolkit is to leverage the existing resources by combining the most up to date information and country specific examples (Spain and Portugal) and finally provide cancer patients and their organizations with a comprehensive overview of how to be directly involved in the work of Health Technology Assessment (HTA) agencies.



This toolkit proposes a step-by-step approach that begins with a general focus, and that is tailored later-on to the different local contexts. Thus, the toolkit is organized around three key 'building blocks' that are not designed to be read chronologically or in any particular order: users can read them separately, according to their expertise and depending on their needs.

Specifically, this toolkit aims to:

- **SECTION A:** to improve the general understanding of the HTA process and the actors involved, with a brief theoretical overview.
- **SECTION B:** to increase the skills of non-professionals involved in HTA, such as individual patients and their organizations, to have a practical overview of how they can share their experiences in the most efficient and effective way.
- **SECTION C:** to provide, as a toolbox, national-specific as well as international sources and guidelines useful to support network-building and develop detailed action-plans: e.g., lists of HTA agencies to engage with, related ongoing projects in cancer care, as well as a list of cancer patient organizations for the selected countries.

At the national level, the toolkit aims to help patient organizations should try to build up a local relationship with HTA agencies and their respective Committees. This engagement is strongly necessary to foster successful systems of networks that can ensure inclusion of patients in (e.g., that patients are frequently and timely informed about the opportunities of being involved, as well as about what kind of evidence they have to provide).

The HTA toolkit is available online in English but also adapted and translated in Spanish, and Portuguese. Additionally, we have worked on an Italian version, which is set to be launched in 2022.

For that, like the two webinars co-organized in 2020 for Spanish and Portuguese, one workshop was co-organized in November 2021 with our Italian members to introduce the e-learning module on HTA to them and help them equip with knowledge for participating in the HTA of cancer treatments. The module covered 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 covered 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.

10 Advocacy and capacity-building activities

10.1 ECPC Annual General Meeting 2021

ECPC Virtual AGM 2021 that took place on Saturday 27th of November with 119 Full and Associate Members registered to attend. Our final participants list, including board members, came to 117 attendees with 98 Full and Associate Members.

There was a lively discussion during the AGM on some AGM organization, management and administrative issues that led to several members disappointment. Some members left ECPC in the following months.

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 2021, ECPC was an active member in 19 Horizon 2020 projects (DIAdIC, ERN EURACAN, H2020MM04, ImmunoSABR, LEGACy, PalliativeSedation, LifeChamps, Instand-NGS4P, QUALITOP, E-PRO, Instand-NG, TIGER), including three Innovative Medicine Initiative projects (BD4BO PIONEER, Immune-Image, PREFER, T2Evolve) 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 more than 50 proposals for EU funded projects, of which 12 received funding and will kick off during 2022.

11.2 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. ECPC supported the project with recruitment of advanced prostate cancer patients for the study. As an active member in the project's Communications team, ECPC worked closely on overall communication planning, and outreach activities, contributing to the successful dissemination of the project's deliverables and overall project sustainability beyond the project expiration date. To raise visibility about the project among patients, ECPC started to regularly promote the project on ECPC social media accounts. Moreover, ECPC reached out to prostate cancer patients to promote the project and to raise an awareness on this type of cancer through patient stories shared on social media. ECPC President Ken Mastris and ECPC Board Member Robert Greene also took an active part in PIONEER studyathon in March 2021, and they shared their cancer journeys with participants. Furthermore, ECPC also participated in a review of the PIONEER dissemination and communication strategy via a focused patient survey that

was disseminated among ECPC members. This survey was also translated into Spanish upon request from ECPC Spanish member.

11.3 QUALITOP (2020 – 2024)

QUALITOP aims at developing a European immunotherapy-specific open Smart Digital Platform and using big data analysis, artificial intelligence, and simulation modelling approaches. This will enable collecting and aggregating efficiently real-world data to monitor health status and QoL of cancer patients given immunotherapy.

ECPC leads the communication and exploitation of the project. In 2020, ECPC developed and maintained the project website (<https://h2020qualitop.liris.cnrs.fr/>) and created social media accounts on Facebook and Twitter. The press release announcing the beginning of the project was launched and visual branding of the project was created. A dedicated project newsletter was created, ECPC is in charge of the newsletter dissemination. In October 2021, ECPC hosted a workshop dedicated to stakeholders 'Qualitop: Workshop for stakeholders'. The event was specifically designed to give them an overview on the main activities that have been undertaken within the project, as well as, disseminate some of the main results of the project.

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.

ECPC is maintaining the project website (<http://diadic.eu/>) and social media accounts on Twitter, YouTube and Facebook. Additionally, ECPC oversees the newsletter distribution. In 2021, ECPC created a campaign to promote the project towards external stakeholders. The campaign was hosted on social media to collect external subscribers for the newsletter that was then sent out in XXX.

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 2021, ECPC was part of the development of the case study on Lung Cancer, provided feedback on the content of the study and revisions, actively disseminated any project interim results and participated in the PREFER Annual Meeting. To be able to take on a role as advocates for patient preferences, PAG (ECPC, EPF, IAPO and MDUK) will make sure PREFER develops materials that are easy-to-use and translate. Because for PREFER successful patient advocacy on patient preferences, goes hand in hand with patient education through training in plain and clear language.

11.6 H2020 ImmunoSABR metastatic lung cancer (2017 - 2022)

Non-small cell lung cancer (NSCLC) comprises 85% of all lung cancer cases. The majority of these patients are diagnosed at the time the cancer has metastasised, meaning it has spread beyond the primary tumour. This is when treatment options are limited, and survival rates are very low. These patients mainly receive care to relieve pain, but without aiming to cure the cancer itself. Radiotherapy uses radiation to kill cancer cells, while immunotherapy uses the immune system to fight cancer, but neither provides a cure by itself. 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.

In February 2020 the first patients were enrolled in the ImmunoSABR clinical trials and more are actively being recruited. Due to COVID-19 and the restrictions that followed, enrolling patients have become difficult and more of a challenge than thought. However, the number of enrolled patients has gradually increased during the year and with the development of patient brochures for dissemination throughout the clinics as well as COVID-19 being more manageable during 2021 we only see good things in the future for the ImmunoSABR clinical trial.

ECPC reviewed several patient-facing materials and developed campaigns and banners to further disseminate information regarding clinical trials and project itself. The trial

Patient Decision Aids tool was reviewed by ECPC and ECPC members to access its user-friendliness. ECPC reached out to more experts within the project to create video interviews to promote clinical trials.

11.7 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 including YouTube and Vimeo 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. ECPC actively participated in dissemination of a project survey in English, Spanish, Portuguese, Catalan and Dutch via social media and e-mail marketing in the respective languages.

11.8 LifeChamps (2020 – 2023)

LifeChamps delivers a novel, context-aware and large-scale analytics framework capable of delivering multi-dimensional Quality of Life (QOL) support to all the different cancer life champions during and after their treatments. LifeChamps is providing support to middle aged and older (pre-frail and frail) cancer patients, as well as their caregivers and healthcare professionals, with an integrated Big Data-driven solution capable to improve their QOL via a timely and more accurate clinical decision support at the point of care. Its Artificial Intelligence (AI) and analytics engine, running both at the cloud and at the mobile edge, can determine accurately which factors affect the oncological patients' QOL the most, during and after their treatment. Furthermore, complemented by a health recommender system LifeChamps offers personalized healthcare services (such as symptom monitoring, treatment and rehabilitation) to these patients and their caregivers. Finally, a multi-factorial frailty model will allow to stratify sub-clinical frail groups of geriatric cancer patients towards more personalized treatment.

In 2021, we contributed to WP2 and more specifically Task 2.2 by reviewing the content of the patient, care givers and healthcare professionals' surveys. We also contributed to the dissemination activities of the project by publishing posts on our social media channels and our newsletter. Finally, we led the liaison and interaction with relevant stakeholders from industry, SMEs, patients, healthcare professionals and policy makers at EU and country level. For 2021, we contributed to the identification and collaboration of 9 projects funded under the same funding call. In addition, a project dedicated European Parliament event hosted by MEP Sokol was organized. A series of events presenting the developments of the projects and collecting feedback from relevant stakeholders will follow during 2021.

11.9 Instand-NGS4P (2020 – 2024)

INSTAND-NGS4P is an EU-funded Pre-Commercial Procurement (PCP) project, driven by patients' and clinical needs seeking to improve cancer patients' benefits from Next Generation Sequencing (NGS). It does so by developing an integrated and standardized NGS workflow. In order to be able to develop the workflow, the project will gather information from cancer gene testing, pharmacogenetics testing and e-medication in a proper presentation format to medical doctors who will then also present the results to the patient in an appropriate format. This will enable support to medical doctors when they decide on therapy options widely used in health systems.

To be able to gather all relevant information, this project provides funding for a public consortium where unmet medical and technical needs will be defined through an Open Market Consultation (OMC). The aim of the OMC is to fine-tune the specifications of the NGS workflow for the "Call for Tender" which will address companies to develop their products to better meet user needs. The OMC will be performed in two steps – a virtual meeting as well as collection of feedback using questionnaires during spring 2021.

In 2021, ECPC fully engaged in the establishment of this project, participating in the set up of a consent form to be used by patients involved in the clinical trials; design of forms to claim the right for children to decide over the data and samples when they become adults; and ECPC led the Patients Needs group, one of the Advisory Boards engaged in the selection of companies that are going to provide technical and digital support for the implementation of this project, making sure they complied with all the necessary elements that better help patients and secure their rights.

11.10 T2Evolve (2021 – 2025)

The aim of the project T2EVOLVE is to build a sustainable innovation ecosystem that will support the development of advance engineered T cell therapy to a level where every European cancer patient in need has access to safe and effective T cell products. How? The optimization of preclinical models, analytical monitoring, lymphodepletion regimens will enhance the development of safer and more effective engineered T cell therapies by reducing the toxicity observed in clinical trials and improve the success rate of clinical trials. A strategic aim of the project is to take an advantage on the tremendous potential that exists in Europe and close the gap in clinical and commercial translation to bring the EU back to the forefront of this global movement. ECPC is involved in two Work Packages. ECPC is a leader of the WP2 on patient involvement, where we have been involved in tasks such as Patient involvement in the R&D process and Co-development of patient friendly communication tools. In WP8, ECPC is a partner on Customized European Pharmacopoeia and GMP for engineered T cells. ECPC is running the Working Group for Patients and Caregivers and also contributed to the review process and development of patient materials and the development of a CART treatment patients survey.

11.11 TIGER (2021 – 2026)

TIGER delivers proof of principle (PoP) in humans for a novel best-in-class mRNA cancer vaccine platform optimized for intravenous (IV) administration, with the aim to show major

clinical efficacy. The antigens used for the PoP consists of mRNAs encoding the proteins E6 and E7 of Human Papilloma Virus strain 16 (HPV16), and TriMix mRNAs that stimulate dendritic cells to start strong T cell responses. The mRNAs will be formulated in a novel patented lipid nanoparticle format shielding the mRNA, and delivering it to immunoactive antigen presenting cells, vastly enhancing T-cell response. Safety and best-in-class efficacy of our IV mRNA product have been demonstrated in rodent experiments. Furthermore, preclinical to clinical translation has been shown for our TriMix based vaccines using different delivery strategies. Based on the preclinical and prior clinical data, our platform has the potential to cure cancer patients. The PoP study will be in patients with recurrent HPV16 positive cancer, which is categorised as a non-communicable disease by the WHO, without and with a PD-1 checkpoint inhibitor. Safety, immunogenicity and clinical benefit will be key endpoints of the study. Biomarker and PROM research will allow future informed therapeutic and care decisions by both patient and care team. Recruitment and stratification plans will be in place. Interactions with regulatory, reimbursement and ethical authorities together with patients and carers will help laying out the route to the patient not only for our product but also for all other mRNA cancer vaccines. Additionally, the project encompasses all essential elements for preparing therapy validation in later stage clinical studies, while addressing patient needs, values and choices. Upscaling mRNA vaccine GMP-production will enable these further clinical studies. Once validated, our platform will be easily translatable to a wide range of cancers using other tumour antigens, be they TAAs or neoantigens.

ECPC is involved in the regulatory and ethical management, Patient Reported Outcome Measures and market access strategy making sure that the patient voices are being represented and incorporated. We are responsible for communication, dissemination and exploitation of the project and its results.

11.12 INTERVENE (2021 – 2025)

The aim of the INTERVENE project is to develop and test next generation tools for disease prevention, diagnosis and personalised treatment by utilizing the first US-European pool of genomic and health data. The project aims to integrate longitudinal and disease-relevant omics data into genetic risk scores. If successful, the potential for prediction, diagnosis and personalised treatments for complex and rare diseases will be unprecedented. This project will demonstrate the potential and benefits of powerful AI technologies on the next generation of integrative genetic scores (IGS).

ECPC is involved in the ethical and legal framework that will be developed for Artificial Intelligence (AI) and genetics making sure that the patient voices are being represented and incorporated. We are responsible for patient involvement and also serves as a strong partner in communication and dissemination of the project and its results.

In 2021, ECPC developed the communication and dissemination plan. To ensure that all external communication of the project occurs in a visually sophisticated and consistent manner, ECPC has developed a set of standard templates for the most commonly used communication tools; these include PowerPoint presentations, brochure, email footer, newsletter, deliverable reporting, and letterhead used for public dissemination. In November 2021, ECPC organised an online kick-off meeting for the project consortium and ensured the visibility of the happening with live-tweeting activities.

11.13 DENIM (2016 – 2021)

The H2020MM04 Denim project is further testing a promising personalised immunotherapy to treat malignant mesothelioma with very limited side-effects. The study is a randomised phase II/III clinical trial. Initial clinical results show a considerably prolonged average survival with limited adverse events. The EMA and the FDA granted this therapy Orphan Designation (EU: 16 January 2014 – EU/3/13/1229; FDA – US: 06 May 2014).

ECPC enables H2020MM04 Denim to directly engage with expert patient representatives to ensure research is designed and adapted to better respond to patient needs. Specifically, ECPC is leading a patient panel consisting of ECPC members and other patient groups. ECPC is working to empower European cancer patients by ensuring the project reflects the needs of cancer patients, collaborating with project partners to organise Denim educational days specifically for patients and their caregivers, providing an easily consultable, layman-language source of information on H2020MM04 cancer therapy to patients and their caregivers, and effectively disseminating project news and results.

Advisory roles

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

11.14 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.

11.15 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 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.

11.16 **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.

11.17 **Palliative Sedation (2019 – 2023)**

Due to the rise in cancer and multiple chronic diseases, the number of patients with refractory symptoms where conventional treatment options fail is likely to increase. In such cases, palliative sedation (PS) can be indicated, and involves the intentional lowering of consciousness at the end of life. However, PS is too often restricted to continuous deep sedation and is often confused with hastening death. The Palliative Sedation 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.

During 2021 ECPC were involved in pushing for a glossary for patients with the most common medical terminology explained in an easy digestible language. We have participated in meetings, making sure that the patients ethical concerns will be taken into account and that guidelines and recommendations that are developed incorporate the patients point of view.

11.18 **Immune-Image (2019 – 2024)**

The introduction of immunotherapeutic drugs for the treatment of cancer and inflammatory disease, where the drugs encourage the body's own immune system to attack the disease, have had a significant impact. However, immunotherapies do not work for all patients. The Immune-Image approach takes advantage of a unique characteristic of immune cells: each has unique molecules on its surface, which can be

detected using molecules that specifically bind to them, called immunotracers. These molecules are labelled and can be detected by lab equipment that can reconstruct an image of our body and highlight where these cells are present. This approach is called molecular imaging. This way, it's possible to identify and track some patient's immune cells in a non-invasive manner.

The Immune-Image project involves three different methods: To generate specific immunotracers and imaging techniques; allowing to follow the location of different immune cell types. To test them in animal models; assessing if immunotracers are safe and the efficacy of imaging in vivo. Clinical trials; confirming the safety and clinical potential of a selection of validated immunotracers on volunteers.

During 2021, ECPC were involved in dissemination of the project as well as being involved in the ethical discussions when developing legal documents. As partner for communication and dissemination, ECPC worked closely on overall communication planning and outreach activities towards patients raising awareness about the project through ECPC social media accounts and newsletter. ECPC achieved that the patient-facing materials such as patient brochure and video were translated in several EU languages and distributed among patient organisations. Additionally, ECPC reached out to patients experience with immunotherapy to be interviewed for the project.

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 Board member represents ECPC at the Patient and Consumer Working Party (PCWP) that 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.

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.



12.2 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.



12.3 ESMO Congress

The ESMO Congress 2020, the biggest European gathering for oncology community, took part online during 16 – 21 September 2021. The congress attracted to its virtual platform more than 30,000 oncology stakeholders from more than 150 countries. ECPC took part in the virtual exhibition platform which is a great opportunity to get together with clinicians, researcher, industry partners, and patient advocates and to promote ECPC work.

12.4 E.C.O. Advisory Committee

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

www.europeancancer.org



12.5 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 actively participates in various working groups.

www.all-can.org

12.6 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 4th. UICC is a trusted partner and they participated together with ECPC in various projects. In 2020 ECPC the Legal Expert Grazia Scocca completed her Certificate of competition of UICC Master Course on access to cancer medicine and the EU Affairs Manager Charis Girvalaki completed the UICC Master Course on Patient Engagement.

www.uicc.org

12.7 Organisation for European Cancer Institutes (OECI)



ECPC and the Organisation of European Cancer Institute (OECI) continued their collaboration for the fifth year since the signing of the Memorandum of Understanding in 2015.

www.oeci.eu

12.8 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.

www.eortc.org/

12.9 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.

www.uroweb.org



12.10 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.

www.euapm.eu



12.11 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 is represented in the Board of Directors of CDDF by its former President Francesco de Lorenzo.

www.cddf.org



12.12 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, breast cancer survivor ECPC Board member and former President, sits at the Patient Advocacy Group of ESSO.

www.essoweb.org

12.13 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.

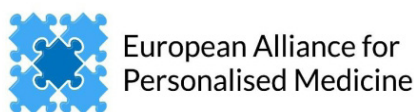
BBMRI-ERIC is an indisputable partner in cancer research and ECPC is a member of its Stakeholders Forum.

12.14 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. ECPC is represented in WIN by its former President Francesco de Lorenzo.

13. Public Entities and Non-Profit Organisations



14. 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:

- AbbVie
- Ares Trading
- Astellas
- AstraZeneca
- Bayer
- BMS
- Boehringer Ingelheim International GmbH
- Bristol-Myers Squibb (BMS)
- Daiichi Sankyo
- Eli Lilly
- GSK
- IPSEN Pharma
- kyowa Kirin
- LEO Pharma
- Merck
- MSD International
- Novartis
- Roche
- Sandoz
- Sanofi Genzyme



European Cancer Patient Coalition



Avenue des Arts 6
1210 Brussels
Belgium
info@ecpc.org
www.ecpc.org