European Cancer
Patient Coalition

Annual Report
2020

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Patient Coalition

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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 2020, 13 new organisations joined ECPC, consolidating it as the Europe’s largest cancer patient association, with a total of 470 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.

New members who joined ECPC in 2020:

- Bladder Cancer Norway
- Bridge of Health against Cancer
- Centre of Innovative Support
- Cocorda
- Europa Donna Slovenia
- Glioma Centre Foundation
- ELIDAN
- Gynecological cancer patients in Finland
- Home Care Association
- Incontradonna Onlus
- The Health Bridge against Breast Cancer
- World Bladder Cancer
- Find Help Charity

2. The European Cancer Patient Coalition's Mission

Our Mission is to:

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

3. The European Cancer Patient Coalition's Strategy

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

Governance

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

Policy and Advocacy

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

Health and Research

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

Capacity Building

ECPC is there to serve its Members, representing cancer patients with all types of cancer from the most common to the rarest. ECPC is working to increase each Member's capacity in understanding EU policy and research and to help them shape the national cancer landscape.
ECPC believes that engaging in a dialogue, fostering collaboration, and providing members with tools to advocate and campaign is essential to build and maintain a strong network.

Communication

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

The Multi-Annual Strategy runs from 2019 to 2022, the same period covered by the mandate of the ECPC Board and Audit Committee, elected and established in June 2019 for a duration of 3 years. The Scientific Committee Members were appointed in 2019 and the Scientific Committee 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 Presidents

Ken Mastris, President (November 2020 - present)

Dear ECPC members, stakeholders, and friends,

The year 2020 was particularly difficult for the cancer community worldwide. The coronavirus pandemic has been endangering cancer patients directly and indirectly, it has severely disrupted cancer care, revealed weaknesses of health systems, and still it will have a significant impact on new cancer diagnosis in the following years.

On the other hand, the promise of the Commissioner for Health and Food Safety Stella Kyriakides to come up with a plan on how to beat cancer and the Mission on Cancer's goal to conquer cancer is a clear message for patients and patient advocates that the position of cancer as a European priority to be tackled did not subside.

I am grateful and honoured for the trust that Board Members of ECPC have placed in me to serve as President of the largest European cancer patient association, particularly during this time of change for the organisation. I am fully engaged to create an organisation that is working with and for our members and the cancer community under my presidency. Our members are the backbone of ECPC and set us apart with their knowledge and insight into the cancer community across Europe.

As the ECPC President, I am truly committed to promote patients' equality in cancer treatment and better quality of life for cancer patients and cancer survivors, in all of Europe. For that reason, during my mandate, I will focus on working more closely with ECPC Members. They are the cornerstone of our organisation and we must listen to them closely as patients' needs must be represented in the policy-making process and in the research arena at the European level. We, patients, need to be empowered and our voice needs to be heard.

Having been a board member of ECPC during the past mandate and a cancer survivor and dedicated cancer advocate for several years, I understand the need for the patient representation in its own care. I believe that with the help of the current board and secretariat, ECPC can solidify its representation as the leading umbrella cancer patient organisation in Europe and continue our work towards equality and quality care for all cancer patients across Europe.

With this said, I see the year 2021 to be full of changes and opportunities for our community and particularly for ECPC being the largest cancer patient association in Europe.

Ken Mastris

Kathi Apostolidis, President
(June 2019 - November 2020)

Dear members, partners, sponsors and friends of ECPC,

I was privileged that my presidency followed that of Prof. Francesco de Lorenzo with whom we have worked closely and harmoniously for more than eight years reinstating ECPC, as the leading, highly reputable and respected European umbrella of cancer patient organizations.

Reflecting on what we had received as a newly elected board in June 2013 and the ECPC legacy that we leave behind in December 2020, I feel really proud of the achievements that we have been able to materialize the previous years, in close collaboration with ECPC boards and a small team of highly professional and dedicated to the ECPC mission staff. The impact and magnitude of these achievements is such that it was sufficient to cover a great number of the activities of two years of the current board.

Among the achievements of ECPC that developed in the previous years and matured in 2020 are:

- The launch of the Challenge Cancer Intergroup in July 2020, following the ECPC's success in establishing the first and only European Parliament Intergroup in Dec. 2019 following the European elections in May 2019
- The ECPC's involvement and participation in the works of the Commission towards the Europe's Beating Cancer Plan
- The participation and close collaboration with the EACS-European Academy of Cancer Sciences towards the Cancer Mission

The Challenge Cancer Intergroup's launch and kick-off was delayed due to the pandemic declaration in February 2020. The Intergroup launch took place on July 1, 2020 with a virtual high level event chaired by MEP Cristian Bușoi, and co-chaired by MEPs Alessandra Moretti, Aldo Patriciello, Frederique Ries, and honoured by opening remarks by the Health and Food Safety Commissioner, Stella Kyriakides, Prof. G. Walter Ricciardi, Chair of the Cancer Mission Board, and Prof. Dr. Anton Berns, President European Academy of Cancer Sciences. ECPC organized the event as we provide Secretariat services to the Challenge Cancer Intergroup.

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

ECPC with the assistance of Francesco de Lorenzo, past President and Chair of the Scientific Committee, developed the approved 2021 thematic agenda of the Intergroup, while in October a briefing of the MEPs and their assistants took place on foreseen activities of the Intergroup.

The Europe's Beating Cancer Plan was at the top of the cancer policy agenda in 2020. ECPC, with its President, Kathi Apostolidis and past President and Chair of the Scientific Committee, Francesco de Lorenzo, participated in 2020 as also in 2019, in all meetings organized by DG Sante and the Health and Food Safety Commissioner for the preparation of the Commission's Beating Cancer Plan.

ECPC has collaborated for more than three years with the European Academy of Cancer Sciences for the preparation of a platform of key European cancer stakeholders in cancer research, care, prevention, survivorship that aims to participate to the works and activities of the **EU Cancer Mission**. ECPC's representation in the Board of Directors of the EACS-European Academy of Cancer Sciences by Prof. Francesco de Lorenzo was instrumental in recognizing the unique role of ECPC as a bridge between cancer research and care. The members of the platform have published their proposals for a Mission in Cancer in a Special Issue of the Journal of Molecular Oncology, published on March 1, 2020. Among the papers featuring ECPC are those co-authored by Prof. de Lorenzo, as the paper on cancer survivorship "Cancer survivorship: an integral part of Europe's research agenda"and "The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer", presenting the key cancer policy and research role of ECPC as an active partner in cancer research, care and survivorship.

The members of the platform have contributed in authoring the position and proposals of the EACS platform that were submitted to the Board of the **Cancer Mission**. Moreover, they have been active presenting the EACS platform and its proposals at high level congresses, as the EU Presidency ones. Namely, several members of the EACS, as well as ECPC President Kathi Apostolidis, were invited speakers at the conference on research policy entitled "Europe: Unite Against Cancer", held under the German Presidency of the Council of the European Union, in October 2020 to discuss joint approaches to strengthening cancer research in Europe.

The last year was marked not only by the pandemic that disrupted cancer care and changed the lives of millions globally, but also by serious differences prevailing in ECPC Board of Directors on how the organization should be governed.

ECPC has faced more than one crisis in its history and has been successful in overcoming them, continue its mission and honor the trust of its more than 450 members across Europe and beyond. It is hoped that ECPC with the support and trust of its members, partners and friends will succeed in overcoming the current one and walk into the post-covid19 era wiser and stronger.

I would like to thank you all and each of one you personally for the trust and collaboration with which you have entrusted ECPC and me all these years, and to assure you that now as a Board Member I will take every care to ascertain that ECPC activities are honoring its almost twenty years legacy of high level cancer policy and research,
With collegial regards

Kathi Apostolidis
ECPC Board Member

5. Message from the Director

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

The year 2020 was an incredibly challenging year with the pandemic changing how we live and work in a short amount of time. This took a particular toll on the healthcare sector with hospitals overrun and many ongoing treatments postponed, affecting high-risk groups, with cancer patients among them.

At the beginning of the pandemic, we set up our dedicated COVID-19 web hub providing resources and guidelines for cancer patients during this pandemic. We worked with an international oncology panel to coordinate and oversee our guidelines that were translated into 24 languages to reach as many patients across Europe and beyond as possible. Our COVID-19 survey translated into all EU languages gave us an important insight into what cancer patients across Europe faced.

Despite the pandemic taking the forefront of healthcare, ECPC is thankful that the EC President Ursula von der Leyen and Commissioner Stella Kyriakides kept the word of making cancer a healthcare priority. In the last year, ECPC joined forces with the European Cancer Organisation (E.C.O.) and European Federation of Pharmaceutical Industries (EFPIA) to propose a European Cancer Dashboard to support the implementation of the Plan and to monitor success. Through the newly established Initiative on Cancer Related Complications and Comorbidities, we also succeeded to have comorbidities addressed into the plan.

The successful launch of our own Challenge Cancer parliamentary Intergroup saw MEPs show their strong support and political will to act on cancer to the next level. This new Intergroup was conceived by ECPC because of its ongoing commitment and involvement in supporting the “Mission” concept in Research and Innovation, adopted by the European Commission, together with prominent scientists, physicians and researchers, members of the European Academy of Cancer Sciences (EACS).

Although a challenging year for cancer, I am proud of the work and efforts put in by all involved in this report and I am excited to move into the new decade with a strong team, dedicated board and audit committee and encouraging members. ECPC will continue to work towards the goal of giving cancer patients in Europe a voice in 2021 and beyond.

Antonella Cardone

6. **Overview of 2020**

6.1 **EU Beating Cancer Plan and Mission on Cancer**

On February 4, 2020, on World Cancer Day, the European Commission launched an EU-wide public consultation for the “Beating Cancer Plan”. The consultation will help shape the Plan, identify key areas, and explore future action of the European Health Union. The consultation promises to identify strategies for all key stages of cancer – preventive measures, early detection and diagnosis, treatment and care and quality of life. ECPC joined forces with European Cancer Organisation (E.C.O.) and European Federation of Pharmaceutical Industries (EFPIA) to propose a European Cancer Dashboard to support the implementation of the Plan and to monitor its implementation.

Despite efforts to address caner care and research in recent years, cancer remains one of the leading medical and societal challenges of our time. This is why the European Commission has selected cancer as one of its five new Research and Innovation Missions of the EU. The goal of the Cancer Mission is to achieve 75% survival rate by 2030, from 47% today, by focusing on cancer prevention, treatment, survivorship care, social innovation and ensuring the reduction of existing inequalities in all abovementioned areas.

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 virtual launch event brought together MEPs and a range of high-level speakers, including Health Commissioner Stella Kyriakides and the Chair of the Cancer Mission Board, Prof. Walter Ricciardi, to discuss the importance of the ‘Mission’ concept in the field of cancer in times of pandemics like COVID-19 and the role of policymakers and stakeholders, including patient organisations such as ECPC. Thanks to the involvement of Francesco de Lorenzo and Kathi Apostilidis the number of collected signatures was enough to have the Intergroup established. The Challenge Cancer Intergroup has been the most voted and first Intergroup of the current EP mandate.

“Beating cancer can’t be done by a single actor, it is an opportunity for stakeholders at all levels and across a range of experiences and backgrounds to collaborate for the benefit of all Europeans. The parliamentary intergroup on cancer will help us to bridge the gap between European institutions, national governments and stakeholders as well as European citizens to address the growing cancer burden in EU,” said the Romanian MEP Cristian-Silvu Busoi (EPP), Chair of the Challenge Cancer Intergroup.

With the launch of the Challenge Cancer Intergroup, MEPs show their strong support and political will to take action on cancer to the next level. Intergroup members will be able to dedicate themselves more fully to the fight against cancer and to engage in dialogue with patients, cancer survivors and carers, scientific and medical societies, research institutions, think tanks, medical practitioners and researchers, policy makers and leaders of the health industry, civil society at large, national governments and institutions.

ECPC developed a visual identity of the intergroup together with the web page and social media channels dedicated to the project. By the end of 2020, the Intergroup consisted of 36 MEPs:

- Cristian Silviu BUSOI
- Alessandra MORETTI
- Frédérique RIES
- Aldo PATRICIELLO
- Tudor CIUHODARU
- Sunčana GLAVAK
- Pietro BARTOLO
- Giuliano PISAPIA
- Romana JERKOVIC
- Margarita DE LA PISA CARRIÓN
- Angelo CIOCCA
- Gianna GANCIA
- Patrizia TOIA
- Giuseppina PICIERNO
- Brando BENIFEI
- Caterina CHINNICI
- Maria ARENA
- Katrin LANGENSIEPEN
- Fulvio MARTUSCIELLO
- Véronique TRILLET-LENOIR
- Raffaele FITTO
- Liudas MAZYLIS
- Juozas OLEKAS
- Gheorghe FALCĂ
- Chrysoula ZACHAROPOULOU
- Stelios KYMPOUROPOULOS
- Eva KAILI
- Frances FITZGERALD
- Tomislav SOKOL
- Eero HEINÄLUOMA
- Giuseppe MILAZZO
- Silvia SARDONNE
- Stefania ZAMBELLI
- Dino GIARRUSSO
- Massimiliano SALINI
- Carlo FIDANZA

The launch of the Intergroup Challenge Cancer was promoted in various media across Europe including Politico, Euractiv, Romanian media Politici de santate, Mediafax, Capital, Italian TgVercelli, News Biella, German Aerzte Zeitung, Spanish El Global and Greek iNewsGr, Toavriotisygeias and Iatronet.

6.1.2 **Death of ECPC Founder Lynne Fauld Woods**

In April 2020, we suffered a huge loss for cancer advocacy patients: Lynn Faulds, UK TV presenter, ground-breaking journalist, one of founders[1] of European Cancer Patient Coalition in 2003 and President for seven years, passed away. After being diagnosed with colon cancer in 1992, Lynn set up the very successful Lynn's Bowel Cancer Campaign in the UK and later, being a very active cancer patient advocate with unusual communication capacity, had the great intuition to raise awareness of the disease at European level to give voice to the cancer patients organisations operating in the European Union with 15 Member States at the time.

Lynn worked very hard to realise what she had promised, bringing together cancer patients, health care professionals, scientists, scientific societies, and politicians from

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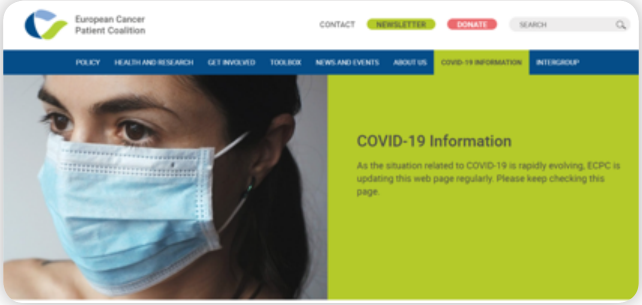
[1] ECPC Founders: Kathy Redmond, Lynn Faulds Wood, Jan Geissler, Dr. Jesme Fox and Tom Hudson

across Europe to join the fight against cancer. She was instrumental in marshalling the collective voice of patients from the big cancer groups such as breast, colon, cervical, prostate, to the rarer cancers to speak with one voice. Under Lynn's guidance, ECPC established a stable strong relationship with Members of the European Parliament and the European Commission.

After 7 years of presidency, Lynn left ECPC but remained a close friend of ECPC, joining us for ECPC's 10 years celebration, in Bucharest as the principal speaker in the Session: "Ten years of ECPC: Identifying the past and constructing the future". Thanks to Lynn and the founding goals of ECPC, unity, mutual support, hard work, continuous learning, and empowerment of our members are our guiding principles and the ones that will guide our steps in playing the major role in the Mission on Cancer and to help overcome the inequalities in cancer prevention, treatment, rehabilitation, and survivorship care.

6.1.3 **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 2020[2] 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.



COVID-19 Information

As the situation related to COVID-19 is rapidly evolving, ECPC is updating this web page regularly. Please keep checking this page.

COVID-19 and Cancer Web Hub

Web hub

In response to the pandemic, in April 2020 ECPC launched a COVID-19 Web Hub highlighting relevant resources and providing cancer patient community with information on funding opportunities, ECPC members' responses to the situation in their languages and requests for support.

Later, ECPC included on the web page guidelines on Covid-19 and cancer patient that was developed in collaboration with 48 physicians from 27 countries. These comprehensive

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[2] 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-timesfor-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/

guidelines have been translated into 24 languages and have been summarised into six sections for a more readable and accessible approach:

1. General guidelines for Covid-19 and cancer patients
2. Specific guidelines cancer patients can take to avoid Covid-19
3. What to do if you or someone you know displays symptoms
4. Guidance on how to manage mental health during the pandemic
5. Trusting your doctor and following the advice they give you
6. Protocols for patients presenting at cancer centres

In May 2020, the guidelines have been featured in the online version of The Lancet journal under 'Summary of international recommendations in 23 languages for patients with cancer during the COVID-19 pandemic.' The article was available in the print version in June.

Dr. Davide Mauri of the Department of Medical Oncology, University Hospital of Ioannina, Greece was the lead contributor to the guidelines: *"With these guidelines and their translations, we aim to provide a robust message to as many cancer patients we can at global level. The production of valid guidance for patients is determined both by their level of scientific strength and their capability to reach the target audience. I must thank the physicians who volunteered their time and efforts helping with the translation in 24 languages. Having our work feature in The Lancet Oncology further contributes to their success and I am very happy to have led this collaboration. Supporting patients and finding the best way to communicate with them is our mission."*

Survey on COVID-19 and cancer

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 translated in all EU languages and was closed by the end of the year.

689 participants from 42 countries provided us with a valuable input that will be analysed and published in 2021.

6.2 Calendar of main activities in 2020

January

- E-PRO Kick off meeting
- Cancer-related comorbidities and complications - 2020 activities meeting
- LIFECHAMPS Kick-Off Meeting
- Call to Action with the EAASM - Nanomedicines: Ensuring patient safety through regulatory and market access clarity
- IMI-PREFER Patient Communications Workstream
- Immune-Image Kick-Off
- QUALITOP kick-off
- European Cancer Forum (MSD)
- Instand-NGS4P KOM

February

- all.can Sustainable cancer care in Europe: building on patient insights & best practice
- Europe's Beating Cancer Plan
- Europe's Beating Cancer Plan - The next steps in the consultation process
- EU Health Coalition - Meeting with the planning group
- Medicine for Europe catch up
- Shaping the future EU Mental Health Strategy: priorities and activities
- Cancer Comorbidities Initiative - Europe's Beating Cancer Plan

March

- Horizon 2020 eTHRIIVE
- ULYSSES - Consortium call
- BI & ECPC - COVID-19 support
- Consortium meeting PalliativeSedation

April

- IMI-PREFER Patient Communications Workstream- Plain Language Briefing Book final review and pilot plan discussion
- EU Health stakeholders group meeting
- ESC, ECPC and cancer comorbidities
- 10th IKCC Global Kidney Cancer Summit
- IMI-PREFER PATIENT COMMUNICATION WORKSTREAM- UPDATE MEETING
- EFPIA webinar on Covid 19
- PREFER Steering Committee virtual meeting part 1 and 2

May

- EU Health Coalition meeting of all partners
- 5th International UV & Skin Cancer Prevention Conference
- PIONEER General Assembly
- DIAdIC Consortium Meeting - Session 1 and 2
- INTERVENE TDS04 - ECPC introduction meeting
- LEGACy General Assembly
- LifeChamps Project Meeting
- Cancer Plan with Stella Kyriakides
- Survivorship & Quality of Life Network webinar

June

- UICC Special Focus Dialogue - Older Cancer Patients and COVID-19
- Transforming Breast Cancer Together and the Health Policy Platform
- The right to be forgotten webinar
- FEAM policy forum meeting
- What can Europe learn from Germany's 'National Decade Against Cancer'?
- WIN 2020 Symposium
- Speakers: Europe's Digital Health Future
- MSD - Digital Europe

- MASCC/ISOO Annual Meeting 2020
- UICC dialogue series cover 19 and elderly
- Maintaining Public Trust in use of Digital Health for health Science in a Covid and Post Covid World Confirmation
- HTx Forum 2020

July

- Launch of the European Parliamentary Challenge Cancer Intergroup
- All.Can: Data Project Working Group Meeting
- European Cancer Organisation/ECPC - RE: ‘Outcomes-based Healthcare’ event under the patronage of the Croatian Presidency
- EAU Congress

August

- POLITICO Health Care Summit: PANEL DISCUSSION: Revolution in the EU’s cancer approach?

September

- Clinical Trials Europe
- Chatham House webinar on causes of unequal access to innovative medicines and brainstorming on possible solutions
- UniTS Europe’s Zoom Meeting - European Parliament Conference
- MSD: Who pays for hope? – treating cancer early
- WP 8 iPAAC webinar
- EU Health Coalition | All partners meeting
- ESMO Congress 2020
- 6th Annual Clinical Trials Patient Experience Summit
- Launch of the European Code of Cancer Practice with EU Commissioner for Health and Food Safety, Stella Kyriakides
- Immune-Image Annual Meeting 2020
- PIONEER General Assembly
- EHFG 2020 - EFPIA Oncology Platform session
- EU4Nutrition LIVE

October

- EHFG 2020 Tackling Access Inequalities with Europe s Beating Cancer Plan
- Multi-Stakeholder Summit NMSC 1st Workshop
- FEAM European Biomedical Policy Forum
- DIGITAL EuropaBio Patients BioForum Meeting
- PREFER Annual Meeting 2020
- Europe’s Beating Cancer Plan: Bridging the gap in breast cancer care
- ESMO Congress 2020
- World Vaccine Congress Europe 2020
- CTRL CANCER Media Summit
- EU HEALTH SUMMIT 2020 - A SHARED VISION FOR THE FUTURE OF HEALTH IN EUROPE

- Challenge Cancer Intergroup Kick-Off Meeting
- Fighting Cancer: The CECOG Cancer dashboard for CEE
- NTRK Patient Care Partner Summit

November

- World Orphan Drug Congress
- ABC Global Alliance's virtual General Assembly
- Economist intelligence event
- ECL 40th Annual Conference | The Future of Cancer Prevention & Control in Europe
- Pfizer cancer control summit
- Cancer & Immunotherapy FEAM
- I-Com Health Symposium "Designing the Future European Health Union?
- DIAdIC Consortium Meeting
- PCE Annual General Assembly
- CRC Screening Summit
- ECPC AGM 2020

December

- POLITICO's virtual event "Making Mental Health Matter"
- EUnetHTA Stakeholder Meeting
- INTERVENE consortium meeting
- EU Health Coalition | EU Health Summit debriefing, new partners & next steps
- Bayer Patient Summit

6.3 ECPC Board Members and Secretariat engagement with external stakeholders

Collectively, in 2020, our current Board Members are active members of 29 other boards and steering committees throughout Europe, such as European Cancer Organisation, EMA PCWP and ENCePP Steering Committee, European Commission Initiative on Breast Cancer. ECPC is represented in the European Commission Initiative on Breast Cancer's Quality Assurance Scheme Development Group (QASDG) and several of its sub-committees by Kathi Apostolidis. Past President Francesco de Lorenzo was in 2020 representing cancer patients' voice in boards and steering committees of ESMO, European Academy of Cancer Science - EACS, CDDF, Cancer Core Europe and iPAAC. Board Members and Chair of the Scientific Committee also hold important positions in cancer patient federations on national level for example in Italy (FAVO), Greece (ELLOK), and Romania (FABC). Jacqueline Daly, Board Member of ECPC, is part of the Let's Talk Prostate Cancer (LTPC) Expert Group focused on prostate cancer as well as E.C.O HPV Action focused on HPV eradication. Robert Greene is involved in the Patient Advocate Committee of E.C.O and in several working groups such as EU Health Coalition and EFPIA – Time to Patient Access. Moreover, Maude Andersson takes part in the Steering Group of All.Can Sweden and Pietro Presti is a Board Member of the IMASC Steering Committee focused on personalised medicine and biomarkers. Radu Ianovici represents ECPC at the European Haematology Association (EHA) and actively participates at the EHA – Patient Organizations Leadership Meeting..

In September 2020, ECPC Director Antonella Cardone joined IMASC Steering Committee. She currently represents ECPC on the Board of Pancreatic Cancer Europe, in which she is vice-chair. Adela Maghear Senior EU Affairs Officer is Co-Chairing All.Can 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 41,722 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.

ECPC's new website was launched in February 2020 with a completely new design and structure to improve user experience. The new website features an easy-to-use dropdown menu designed for users to be able to find what they need quickly and efficiently. Through this online platform, ECPC aims to offer to cancer patient organisations all over Europe and beyond information about its activities, developments in cancer policy, new treatments and provide members with practical educational tools such as a HTA e-learning module, biosimilars module and the Immuno-oncology portal, available in five languages.

We completely changed our approach. When you search through the website now, you will see that a cancer patient is really the centre of our focus. We rewrote the information of all activities we were, or are involved in, to explain why they are relevant for the cancer patient community. Now more than ever, ECPC's role in projects is visible, how we contributed to European policy and research, and what we have achieved.

6.4.2 **Social Media Accounts**

The ECPC Twitter account rose to 5,583 followers (over 600 new followers), the ECPC Facebook account accumulated 8,937 likes (over 200 more than last year) and the LinkedIn account has 1,446 followers (over 700 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 is 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 3rd 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 1519 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 2020, ECPC sent out 116 newsletters.

In September 2020, ECPC launched a new edition of monthly newsletters providing readers with overview of the latest information from EU cancer patient community, recent policy development, upcoming events and other opportunities for cancer patients.

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

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

6.4.4 **Publications**

Throughout the year, ECPC disseminated the following publications that were distributed solely online due to COVID-19:

- Personalised Medicine: A guide for Patients
- EU Joint Action on Rare Cancers (JARC) recommendations towards implementing the Rare Cancer Agenda 2030
- Guidelines on COVID-19 for cancer patients
- HEAD AND NECK CANCER: A preventable, yet widely unknown European health crisis
- Non-melanoma skin cancer as an occupational disease: Fact sheet for the general public
- Non-melanoma skin cancer as an occupational disease: Fact sheet for policymakers
- Access to Personalised Oncology in Europe (reviewed by ECPC)
- A right to be forgotten for cancer survivors: A legal development expected to reflect the medical progress in the fight against cancer

6.4.5 **Media**

Throughout the year ECPC has appeared in the press and media 39 times including publications such as the Brussels Times, EURACTIV and Artze Zeitun, Politico, Corriere della Sera, Reporter Cyprus, Corriere Nazionale, EU Reporter and various news websites across Europe.

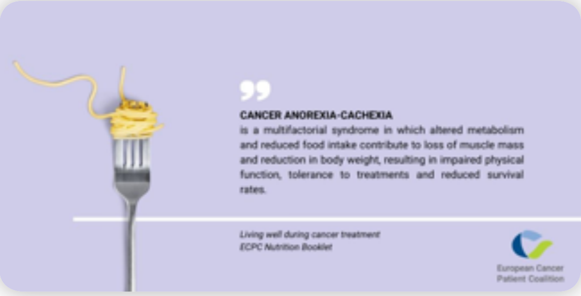
7. **Campaigns**

In 2020 ECPC led 7 awareness campaigns which are presented below.

7.1 **World Cancer Day**

On the occasion of World Cancer Day (4th February), 2020 marks the midway point of the UICC's 'I Am and I Will' campaign that ECPC proudly joined. ECPC Board Members joined the initiative "What is the bravest thing you can do about cancer?" to present their personal commitments on fighting cancer.

7.2 **Nutrition and physical activity**



CANCER ANOREXIA-CACHEXIA
is a multifactorial syndrome in which altered metabolism and reduced food intake contribute to loss of muscle mass and reduction in body weight, resulting in impaired physical function, tolerance to treatments and reduced survival rates.

Living well during cancer treatment
ECPC Nutrition Booklet

Nutrition and physical activity

ECPC launched its third Nutrition and Physical Activity Campaign in 2020. Celebrated every year in March, the Nutrition and Physical Activity Awareness Month is aligned with the American National Nutrition Month, a nutrition education and information campaign held annually by the American Academy of Nutrition and Dietetics. ECPC remains steadfast in its belief that nutrition and physical activity can positively impact the well-being of people living with cancer.

ECPC promoted further during the social media campaign the educational booklet "Living Well During Cancer Treatment" available in 10 languages (Bulgarian, Czech, Danish, French, German, Greek, Italian, Romanian, Slovak and Spanish) with focus on the impact nutrition and physical health has on the treatment and rehabilitation of cancer patients. Fact sheets in same languages were developed and promoted within the campaign.

ECPC continued to support this campaign by launching a set of social media images and quoting the booklet, their authors and relevant information for patients (such as recipes) from other organisations highlighting how nutrition is affected by different cancers and treatments.

7.3 **Bladder cancer campaign**

Example of Christmas Campaign social media post

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 2020 with their fourth Bladder Cancer Awareness Campaign. In 2020, ECPC partnered for the first time with the World Bladder Cancer Patient Coalition in the campaign. The campaign consisted of shared messages and the use of #BladderCancerAware and #BladderCancerAwarenessMonth. The messages included facts and statistics on bladder cancer as well as quotes form our bladder cancer members across Europe. Ahead of the campaign, a webinar for ECPC members was hosted to present the toolkit and invite them to take part in the project.

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.

During the H&N Cancer Awareness Week in September 2020, Make Sense Campaign launched the White Paper "HEAD AND NECK CANCER: A preventable, yet widely unknown European health crisis" that was endorsed by ECPC and Parliamentary Intergroup on Cancer. The white paper is based on the survey results from over 5,700 people across 5 countries (Germany, Italy, Poland, Portugal and Turkey). To further raise awareness on H&N cancer, ECPC joined social media campaign of Make Sense Campaign to wider dissemination of the white paper.

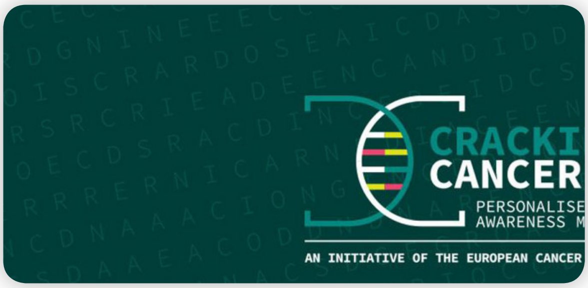
In November 2020, ECPC organised a Head and Neck Cancer webinar to raise awareness. The event was chaired by Roberto Persio, a head and neck cancer survivor, healthcare professionals and several H&N cancer patients who shared their personal experience of diagnosis and treatment. Other speakers presented updates on the White Paper on HNC and survey, the link between HNC and COVID-19, as well as other patient stories.

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

7.5 **Personalised Medicine Awareness Month**

In November 2020, 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.

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



Personalised Medicine Awareness Month logo

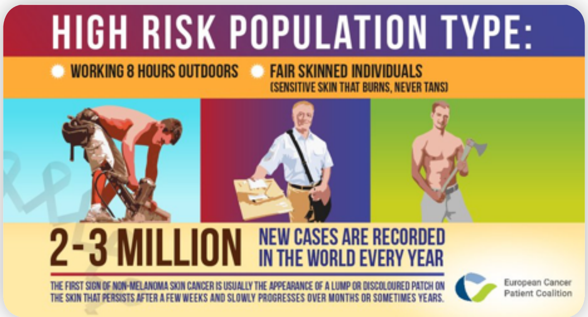
in cancer care across Europe. ECPC and our member organisations believe that people living with cancer should be informed about all available treatment options and be empowered to make the best decisions for their health, together with their healthcare team. That's why ECPC is working towards ensuring 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.

Member of the ECPC Scientific Committee, Prof. Mark Lawler developed the ***"Personalised Medicine: A Guide for Patients"*** with Francesco de Lorenzo and Kathi Apostolidis as co-authors. The aim of this booklet is to address the opportunities and challenges that personalised medicine provides, so that the needs of cancer patients across Europe are met. Speaking at the launch Prof Lawler said *"I am delighted to have worked with cancer patients and patient advocates to develop this booklet. Information is key to empowering citizens and patients to make an informed decision about their personal health, and I hope that this booklet and the 10 questions that we pose will be of benefit to patients, particularly when making what can be difficult decisions."*

7.6 **Non-melanoma Skin Cancer Awareness Day**

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



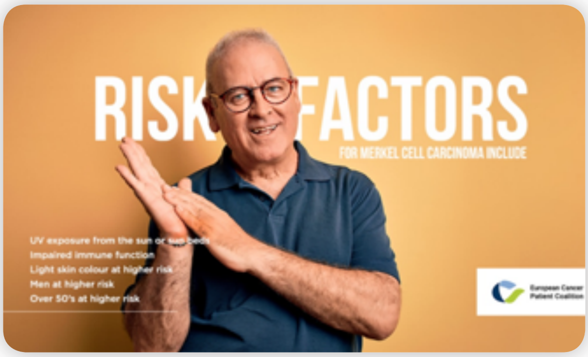
Global Non-Melanoma Skin Cancer Awareness Campaign 2020 social media post

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

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

7.7. 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 another 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.



Example of Merkel Cell Carcinoma social media post

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 dedicated to the campaign to make all campaign documents available to download for all the website visitors.

The hashtags #MerkelCellCarcinoma and #skincancer were used throughout the campaign.

In 2020, ECPC participated in 9 third parties’ cancer awareness campaigns including:

- Childhood Cancer Day
- Cervical Cancer Awareness Month
- Colorectal Cancer
- International Survivors Day
- International Human Solidarity Day
- Rare Cancer Awareness Day
- Social Awareness Day
- Antibiotic Awareness Day
- SCAW Campaign
- World Pancreatic Cancer Day
- Transforming Breast Cancer Together

8. **Health Policy**

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

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

The JARC was aimed to integrate and maximize the efforts of the European Commission, EU Member States and all stakeholders to advance the quality of care and research on rare cancers through the ERNs network. ECPC contribution has been summarised within chapter 10 - *Rare cancer patients should be engaged* of the JARC final Book, where ECPC emphasised the need for the European Commission to support Member States in implementing JARC recommendations through the Council of the Public Health Ministers, following the European Parliament Report of 2019 on the implementation of the EU Cross-Border Healthcare Directive. This was done under the guidance and with the contributions of Francesco de Lorenzo.

Furthermore, ECPC's WGRC engaged to work with patient organisations representing rare cancer patients at the national level, to ensure the timely and appropriate implementation of these recommendations and that the EU Cross-Border Healthcare Directive is functional and its provisions accessible. In 2020, ECPC has successfully introduced rare cancers on the working agenda of the Challenge Cancer Intergroup with the aim to organise an event in 2021 to discuss with policy makers the current challenges that the ERNs face, namely the lack of infrastructure and financial support and the importance of implementing the recommendations of both JARC and the European Parliament Report of 2019 mentioned above.

At the same time, ECPC has collaborated with the EURACAN ePAGs to develop a laymen version of the JARC Book that could be further used by the members of the RCWG to promote the JARC recommendations at the national level. JARC recommendations were featured in social media campaign launched ahead of the Rare Disease Day.

8.2 **Transforming Breast Cancer Together**

The Transforming Breast Cancer Together initiative was established in November 2017, under the leadership of Lieve Wierinck (ALDE) and Elena Gentile (S&D), Members of the

European Parliament (MEPs) and ECPC was among the founding members. The current chair of the initiative is MEP Frances Fitzgerald (Christian Democrats) and the co-chairs are MEP Patrizia Toia and MEP Cristian Silviu Bușoi.

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 October 2020, to mark the Breast Cancer Awareness Month, Transforming Breast Cancer Together members organised an event aimed to shed light on the challenges and realities of living with early and advanced breast cancer. The event focused on recent studies and ongoing initiatives on addressing the unmet needs in early and advanced breast cancer care, raised awareness about the burden of the disease and enabled the discussion between EU stakeholders and policy makers about the daily challenges that cancer patients face. The event also brought into discussion the upcoming Europe's Beating Cancer Plan and how this EU strategy could lead to better outcomes for the European patients and their families. On this occasion, ECPC presented our work on the Right to be Forgotten project.

8.3 **Cancer Mission Europe**

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

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

The Mission on Cancer will remain a high priority on the agenda of the organisation in the coming years. ECPC aims to support its member organisations to implement the goals of the Mission in each Member State. The then Past President Francesco de Lorenzo and the then President Kathi Apostolidis contributed to an important paper entitled "Towards a cancer mission in Horizon Europe: recommendations" published in Molecular Oncology

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[1] European Commission Directorate-General for Research and Innovation, 2020, p 2: CONQUERING CANCER: MISSION POSSIBLE

Journal in 2020 that was aimed to continue the previous collaboration ECPC has had with several cancer organisations and institutes to detail the vision and mission of the cancer mission.

8.4 **Parliamentary Intergroup on Cancer**

The Parliamentary Intergroup on Cancer was formed in 2019 in response to the strong support and political motivation to have a dedicated, full-time platform for cancer on the EU level. ECPC found many stakeholders and MEP's ready to prioritise and explore the numerous aspects of cancer control. This led to an official launch of the Intergroup in 2020.

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

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

The new European Parliament Challenge Cancer Intergroup is the first and only EU Parliamentary Intergroup on cancer. It will be chaired by MEP Cristian Bușoi, and co-chaired by MEPs Alessandra Moretti, Aldo Patriciello and Frédérique Ries, with the European Cancer Patient Coalition (ECPC) providing its Secretariat.

This new Intergroup was conceived by ECPC to ensure continuity in the European Parliament's work on cancer during the previous and the current mandates. The Intergroup will serve as a forum for MEPs from all political parties to engage in dialogue with patients, cancer survivors, carers, scientific and medical societies, research institutions, think tanks, medical practitioners and researchers, policy makers and leaders of the health industry, civil society at large, national governments, and institutions. It will act as a two-way communication channel by holding hearings and debates and leading fact-finding missions on salient topics such as prevention, access to treatment, medicine shortages, cancer research on quality of life, innovation in cancer care, and survivorship.

The launch event of the Intergroup took place on 1st July 2020 with a large attendance. The virtual launch event brought together MEPs and high-level speakers, including Health Commissioner Stella Kyriakides and the Chair of the Cancer Mission Board, Prof. Walter Ricciardi, to discuss cancer challenges in times of pandemics like COVID-19 and the role of policy makers and stakeholders, including patient organisations such as ECPC.

The kick-off meeting of the Intergroup took place in October 2020, when MEPs approved the work agenda for 2021. In the same month, The Challenge Cancer Intergroup hosted the first official online webinar on The Cancer Momentum: Fighting Inequalities in Europe in collaboration with Central European Cooperative Oncology Group (CECOG).

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.

The project Starting an Adult Rare Tumour European Registry (STARTER) began on April 1st, 2020, financed by the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) and coordinated by Fondazione IRCCS Istituto Nazionale dei Tumori (Milan, Italy) and Centre de Lutte Contre le Cancer Leon Berard (Lyon, France).

ECPC is collaborating on this project with: EURORDIS – Rare Diseases, Belgian Cancer Registry, Leuven Cancer Institute, University Hospital Leuven, The Netherlands Comprehensive Cancer Organisation (IKNL), Università degli Studi di Padova (ERN PaedCan) and Vall d’Hebron Research Institute - University Hospital Vall d’Hebron (ERN EuroBloodNet).

This project aims to set-up the registry for the ERN EURACAN and it will be an hospital-based, disease registry i.e. defined by patients having the same diagnosis. In details, this project will: 1) build the IT infrastructure of the EURACAN registry; 2) promote EURACAN-registry-based research; 3) assess the feasibility of integrating additional data sources (administrative, population-based cancer registries) to the EURACAN registry to study long-term impact in cancer survivors.

STARTER will last 3 years (April 2020-April 2023). Thus, it should be strategically used to optimize the process to create the EURACAN registry, by providing operational solutions and professional guidance on the registry design and IT infrastructure, the registry interoperability, the core variable to collect, the legal and ethical issues for data sharing.

The role of ECPC is to ensure the involvement of the RAC (rare aggressive cancer) patients in this project and patients’ understanding of the significance of the Registry to sensitise them to provide a onetime consent to guarantee the best use of their data that will be included in the registry.

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. ECPC also contributes to the successful dissemination of the project's deliverables and is collaborating to organise an expert workshop and 2 conference meetings actively supporting networking and mapping of contacts.

8.7 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 28 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)

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 as follows:

1.Cancer-associated thrombosis (CAT)/ venous thromboembolism (VTE)

- The potential impact of CAT/VTE in cancer management
- The potential impact of VTE/CAT on cancer patients' quality of life and treatment costs
- The effectiveness and safety of thromboprophylaxis in cancer patients

2.Cancer and cardiovascular complications

- Cardioprotective strategies on the prevention, early identification, and management of cancer treatment toxic effects

3.Cancer and nutrition

- Availability of nutritional support
- Nutrition and course of treatment, disease progression, and recovery

4.Cancer and coeliac disease

5.Cancer and obesity

- The impact of obesity in cancer progression, treatment efficacy, and recurrence
- The impact of obesity in cancer patients QoL

6.Cancer and mental health

Cancer treatment and patients' mental health

- The impact of mental health on cancer patients' treatment and disease progression
- Cancer treatment and caregivers' mental health

7.Cancer and Neuro(-psycho) logical complications

- Cancer neurological or cognitive complications during and after cancer treatment. The impact on survivorship and quality of life

8.Cancer and pain

- Pain and impact on survivor's quality of life
- Opioids for cancer pain management and overall health of cancer patients

9.Cancer and ageing

- Access to innovative cancer treatments by older cancer patients with comorbidities
- Polypharmacy as a factor that negatively affects the course of treatment and therapy for older cancer patients
- Cost-effectiveness of cancer screening for certain cancer types in older ages

The results of the literature review will guide a White Paper which is to be published within 2021.

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.

The main goal of the project is to contribute by offering an instrument to improve the quality of life and restore the wellbeing (including the economic one) affected by the illness condition of cancer survivors. The strategy is focused on the awareness-raising and the empowerment of the civil society, offering legal argumentations to implement an EU legal framework, in order to support the project and the ECPC mission to affirm a right to be forgotten across Europe.

To achieve the objectives and the goal of the project, during this first year of legal research activity the legal expert's tasks aimed to study and analyse the existing legislation on the Right to be forgotten for cancer survivors implemented in France, Belgium, Luxembourg and the Netherlands. The research activity also included a preliminary collection of data concerning the practices to access financial instruments in all other EU Member States and the analysis of the EU principles and legal sources able to provide legal argumentations to approach the issue and reinforce the advocacy strategy.

In parallel it has been planned and carried out an advocacy strategy, to develop policy argumentations and to influence policymaking both at the EU level and for each Member States. The latter has been adapted to the context of social restrictions with online meetings imposed by the Covid-19 pandemic.

In this regard, a strong network of stakeholders has been established with representatives of cancer patients' organizations, researchers and academics, experts of cancer institutes and policymakers at the national and European level.

Particularly intense has been the exchange with members of the EU Parliament and the EU Commission through bilateral meetings and hearings, as for the BECA public hearing in January 2021 and the Parliamentary Intergroup Challenge Cancer, internal meeting in February 2021.

At the EU political level, the years 2020 and the beginning of 2021 have been marked by the policy campaign and the publication of the EU Beating Cancer Plan. The latter together with the EU Cancer Mission report expressively mentioned the Right to be Forgotten as a common concern and European challenge to tackle. For this reason, we have been actively involved in providing support and advocacy for the dissemination of the project, to ensure the acknowledgement of the right to be forgotten as a key issue to include among the priorities for the new EU cancer Plan and EU Cancer Mission.

In the same period, the legal expert worked daily to organise and promote two public events on the Right to be forgotten: the first one on 9th June 2020 to honour the Cancer survivors' day and the second on February 19th to welcome the launch of the EU Beating Cancer Plan.

As a guest speaker, the legal expert attended two external public events: "Transforming Breast Cancer Together: Bridging the Gap in Breast Cancer Care" (organised by Transforming Cancer Together Initiative, October 2020) and "Ensuring Europe's Beating Cancer Plan addresses cancer pain in quality of life, survivorship, and palliative care" (organised by the Societal Impact of Pain (SIP), March 2020).

As for the next steps of the project, the legal expert will proceed with the research activity promoting a survey supported by a network of national cancer patients' organizations and prepare a submission for a fourth publication for advocacy and policy purposes. The latter is needed as an update of the framework concerning the legislative initiatives currently implemented at the national level, and it will include also an insightful analysis of the EU's competence on the matter.

A toolkit to create strong evidence-based and effective advocacy for the introduction of "Right to be Forgotten" legislation across the EU through fact sheets, scientific articles, policy and white papers and recommendations are being disseminated via ECPC Members, MEPs EU Commission staff, etc.

Moreover, the advocacy activity at the EU level and national level will continue with the scope to provide assistance in the implementation phase of the EU Beating Cancer Plan and cancer mission and to push for new national legal initiatives on the matter. Besides, an EU campaign to promote a Cancer survivors' day across Europe will be launched in cooperation with ECPC stakeholders. The initiative aims to have a European Cancer Survivors' day as existing already in the USA and other Anglophone countries. This campaign would be beneficial for the Right to be Forgotten project, promoting the empowerment of cancer survivors in Europe.

9. Education

9.1 Toolkit on Health Technology Assessment

In 2020, ECPC developed a toolkit on health technology assessment (HTA) which is to be launched in 2021. 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 will be available online in English but also adapted and translated in Spanish and Portuguese.

In addition, two webinars were co-organized along with our Spanish and Portuguese 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.

9.2 **eLearning Module on Biosimilars**

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

10 **Advocacy and capacity-building activities**

10.1 **ECPC Annual General Meeting 2020**

ECPC Virtual AGM 2020 that took place on Saturday 21st November 2020 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 management and administrative issues that led to several members disappointment. Some members left ECPC and, as a follow up, the board decided to elect a new President in the person of Ken Mastris.

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 2020, ECPC was an active member in 17 Horizon 2020 projects (DIAdIC, EUCANCan, H2020MM04, ImmunoSABR, LEGACy, PalliativeSedation, TRANSCAN-2, LifeChamps, Instand-NGS4P, QUALITOP, E-PRO, Instand-NGS), including three Innovative Medicine Initiative projects (BD4BO PIONEER, Immune-Image, PREFER) and two Innovative Training Networks (ELBA, PREDICT). These involvements allow ECPC to be on the forefront of scientific developments in the field of cancer by providing the patient's perspective and driving fundamental knowledge on the science behind cancer.

ECPC also contributed to 34 proposals for EU funded projects, of which 4 received funding.

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 Facebook account.

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.

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 and Facebook. Additionally, ECPC oversees the newsletter distribution.

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 2020, 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 then 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 video interview of the project coordinator Prof Lambin was created.

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 and disseminates a triannual newsletter and press releases. ECPC is also responsible for patient information, reviewing informed consent forms, involving expert patient advocates in the online training courses, and hosting a final stakeholder event at the completion of the project.

In 2020, ECPC was maintaining the project website (https://legacy-h2020.eu/) and Twitter, Facebook, and Vimeo accounts. YouTube channel of the project was created in 2020. ECPC drafted and disseminated the triannual LEGACy newsletter.

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 personalised 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 personalised treatment.

In 2020, 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 2020, we contributed to the identification and collaboration of 5 projects funded under the same funding call. 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.

During 2020 ECPC participated in the project representing the patients voice ending the year 2020 by being more involved in further task forces and gaining more responsibility.

11.10 **Advisory roles**

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

11.11 **Transcan-2 European Research Area (2015 - 2019)**

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

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

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

The ERA-NET TRANSCAN-2 is a collaborative network of ministries, funding agencies and research councils with programmes in translational cancer research, funded by the European Commission under the EU framework programme Horizon 2020. The network is composed of 28 partners from 19 Countries. Kathi Apostolidis represented ECPC in the SAB-Scientific Advisory Board that discussed and decided on the topics submitted for calls. TRANSCAN II ended in 2019 in Milan with the 3rd and final Symposium on Tumour Heterogeneity that brought together 15 of the 16 funded consortia from JTC2014 in order to present the outcomes of these projects, as well as to increase networking and scientific discussion amongst researchers from related research fields and to increase the opportunities for new collaborations and sustainability of the invested funds.

11.12 **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, biostatics, 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.

11.13 **HTx (2019 - 2023)**

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

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

ECPC Director Antonella Cardone sits on the project's Stakeholder Advisory Board, the HTx Forum. She ensures the project activities are in line with the needs of cancer patients by actively participating in discussions and providing feedback and input on research activities, use cases and outputs.

11.14 **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.

11.15 **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 2020 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.

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 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.

12.2.1 **2020 ESMO Congress**

The ESMO Congress 2020, the biggest European gathering for oncology community, took part online during two pro-longed weekends: 19 – 21 September 2020 and 16 – 18 October 2020. The congress attracted to its virtual platform more than 30,000 oncology stakeholders from more than 150 countries. ECPC took part also 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.

ECPC Board Member Robert Greene presented at the Patient Advocacy Track session “How patient advocates can improve equal access to care and services across Europe and beyond: concrete examples of success stories”.

12.3 **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".

Robert Greene, ECPC Board Member is representing ECPC in the ePAG (E.C.O. Patient Advisory Group).
www.europeancancer.org

12.4 **All.Can**

CPC 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

12.5 **Union for International Cancer Control (UICC)**

ECPC is a full member of UICC and follows the successful annual UICC campaign on World Cancer Day on February 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

12.6 **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

12.7 **European Organisation for Research and Treatment of Cancer (EORTC)**

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

12.8 **European Association of Urology (EAU)**

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

12.9 **European Alliance for Personalised Medicine (EAPM)**

ECPC is one of the founding members of the European Alliance for Personalised Medicine (EAPM), which brings together professionals and patient advocacy groups with extensive scientific, clinical, caring and training expertise in Personalised Medicine and diagnostics, as well as leading academic institutions, industry and other expert stakeholders.
www.euapm.eu

12.10 **Cancer Drug Development Forum**

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

12.11 **European Society of Surgical Oncology**

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

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

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

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

12.12 **Biobanking And Biomolecular Resources Research Infrastructure**

The Biobanking And Biomolecular Resources Research Infrastructure - European Research Infrastructure Consortium (BBMRI-ERIC) establishes, operates and develops a pan-European distributed research infrastructure of biobanks and biomolecular resources, aiming at facilitating the access to resources as well as facilities, and to support high quality biomolecular and medical research.

The activities of the (BBMRI-ERIC) are guided by the following core-values: pan-European in scope, combined with scientific excellence, transparency, openness, responsiveness, ethical awareness, legal compliance and human values.

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

12.13 **WIN - Worldwide Innovative Networking Consortium**

WIN
Worldwide innovative networking in personalised cancer medicine

The Worldwide Innovative Networking (WIN) Consortium in personalised cancer medicine's members include 43 leading organisations representing all stakeholders in the personalised cancer medicine field, covering 21 countries and 4 continents. The shared vision of the Worldwide Innovative Networking Consortium aims to deliver effective and personalised cancer medicine to patients worldwide. Two ECPC representatives sit in the General Assembly of the WIN Consortium.

12.14 **Public Entities and Non-Profit Organisations**

ECC European Cancer Concord
European Alliance for Personalised Medicine
eau European Association of Urology
european cancer ORGANISATION
EORTC European Organisation for Research and Treatment of Cancer
ESMO GOOD SCIENCE BETTER MEDICINE BEST PRACTICE European Society for Medical Oncology
OECI Organisation of European Cancer Institutes European Economic Interest Grouping
Toxic Neuropathy Consortium TNC
UICC global cancer control A MEMBERSHIP ORGANISATION FIGHTING CANCER TOGETHER
European Commission
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI
EUROPEAN MEDICINES AGENCY SCIENCE MEDICINES HEALTH
BBMRI-ERIC
esso The European Society of Surgical Oncology
WIN Worldwide innovative networking in personalised cancer medicine
The European Nutrition for Health Alliance

12.15 **Industry Partners**

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

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

12.16 **ECPC industry partners**

- ABBVIE
- Astellas
- AstraZeneca
- Baxter
- Bayer
- Boehringer Ingelheim
- Blueprint Med. Corp
- BMS
- Daiichi Sankyo
- Debiopharm Int.
- Eli Lilly and Company
- Gilead Science
- GSK
- IPSEN Pharma
- Janssen
- LEO Pharma
- Merck
- MSD
- Novartis
- Pfizer
- Roche
- Sandoz
- Sanofi

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