European Cancer
Patient Coalition

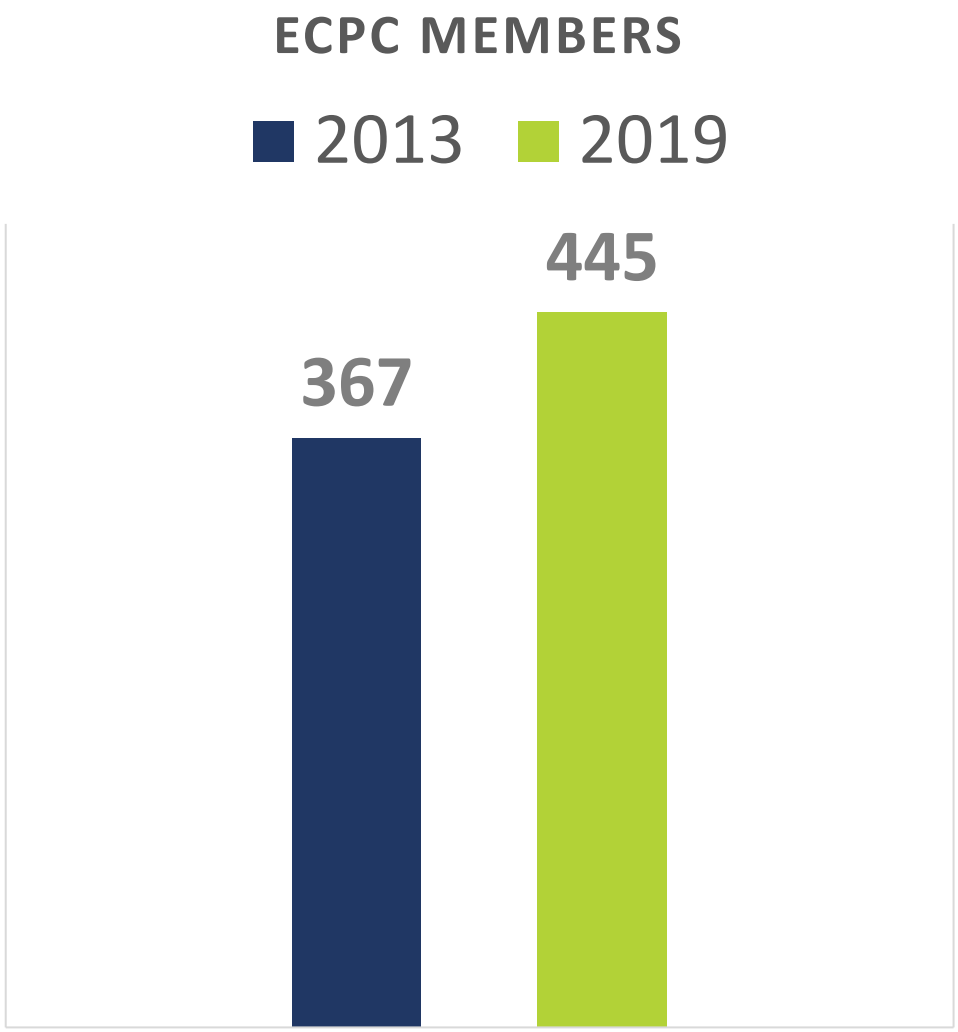
ECPC Achievements in 2013-2019

Francesco de Lorenzo

President

European Cancer Patient Coalition

From strength to strength



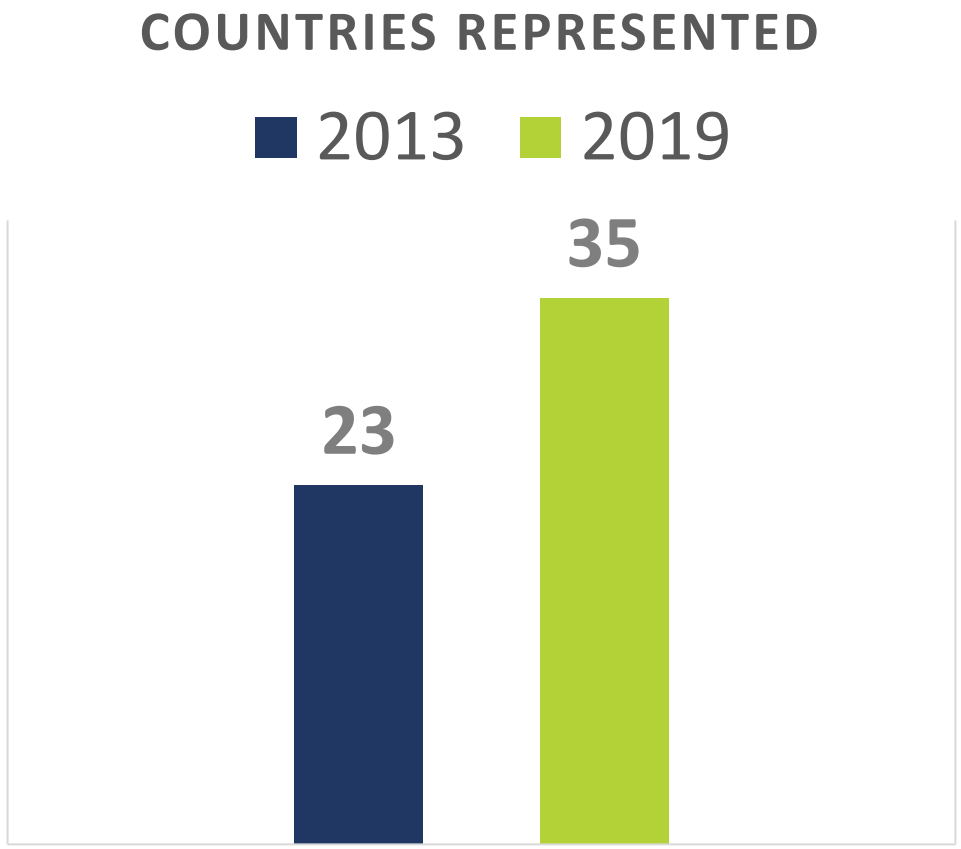
- In 2013, the ECPC relocated from the Netherlands and **legally established and set-up the Secretariat in Brussels**, Belgium!
- 2013 was also the year when the **ECPC Statute was changed**, bringing stronger and more transparent governance of the organization
- In 2018, the ECPC Statute was updated and the **ECPC General Regulations** were established.
- In 2013, the ECPC had 367 members**, today we have grown to 445!**

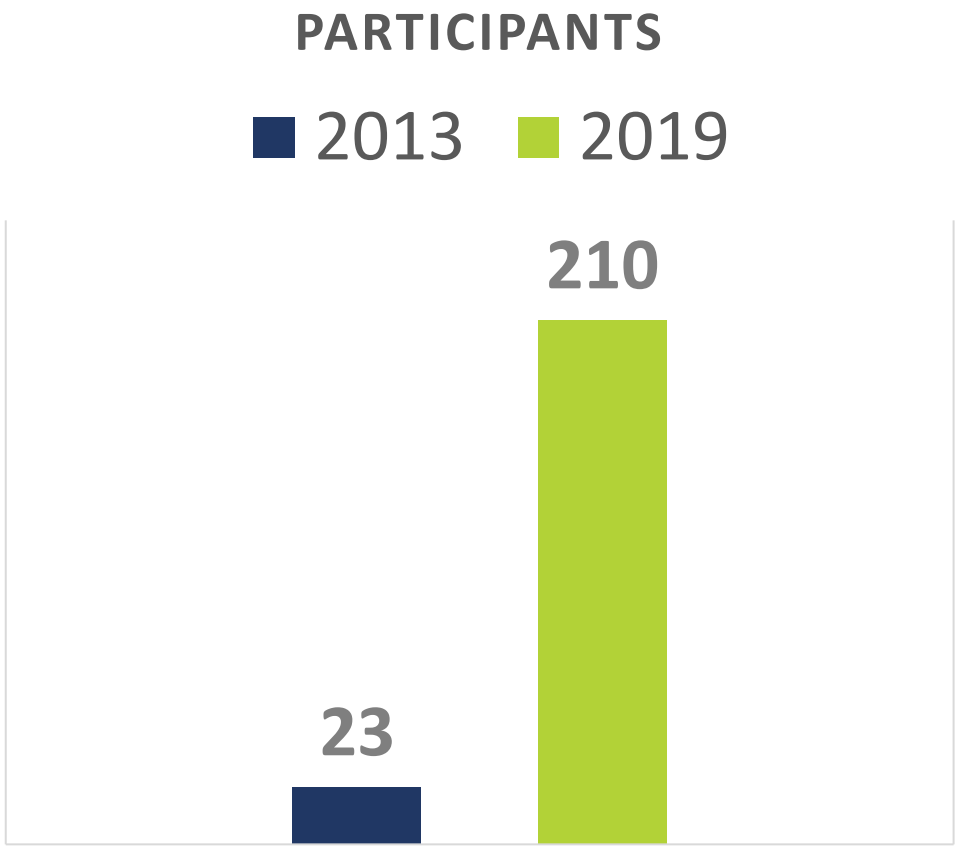
European Cancer Patient Coalition

From strength to strength

ECPC Annual Congress 2019

The Largest Gathering of Cancer Patients in Europe!

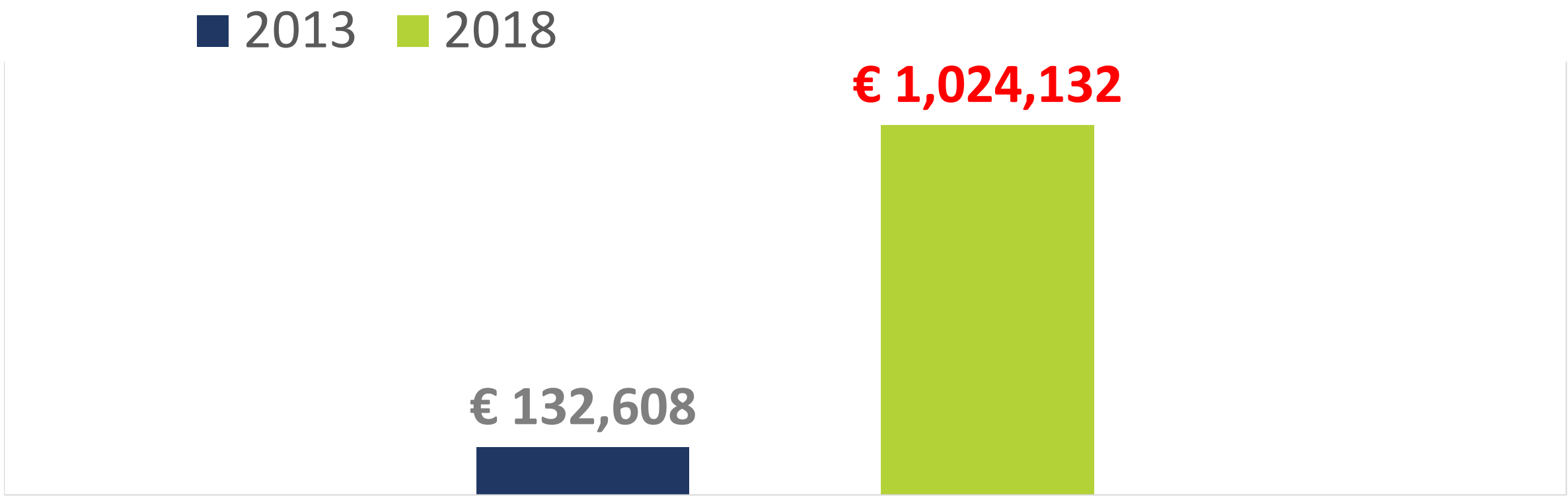




European Cancer Patient Coalition

From strength to strength

ECPC funding has grown exponentially since 2013



European Cancer Patient Coalition

Milestones

2013

ECPC legally establishes in Brussels

ECPC Strengthens relationship with EMA, European Commission and European Parliament

2014

The launch of the Bill of Cancer Patients Rights

The launch of the ECPC Call to Action to take up the fight against cancer

The Conclusion of the European Partnership on Action Against Cancer (EPAAC)

The launch of the Joint Action on Cancer Control (CanCon)

ECPC joins the European Commission Expert Group on Cancer Control

The launch of the ECPC *Immuno-Oncology Policy Action Framework*

2015

The launch of ECPC White Paper *Challenging the Europe of Disparities in Cancer*

The launch of *ECPC Immuno-Oncology Portal*

The launch of the *Written Declaration on Cancer Patients Rights* in the European Parliament

ECPC signs the Memorandum of Understanding with OECI

European Cancer Patient Coalition

Milestones

2015

Publication in the Tumori Journal "*The Value of Accreditation for Cancer Patients: From End Users to Partners*"

ECPC extends its participation in patient advisory roles at EMA, ESMO and ECCO

ECPC becomes a Member of UICC

2016

ECPC membership exceeds 400 for the first time

The launch of the Joint Action on Rare Cancers (JARC)

ECPC signs the Memorandum of Understanding with EORTC

2017

The launch of the ECPC White Paper *The Value of Innovation in Oncology*

The adoption of the European Parliament resolution on *Access to Medicines*

The launch of the *ECPC-ESMO Survivorship Guide*

The launch of the ECPC *White Paper on Cancer Carers* in partnership with Eurocarers

Publication in the Journal of Cancer Policy *"Value of innovation in oncology: The position of European cancer patients on access to innovative treatments."*

European Cancer Patient Coalition

Milestones

2017

The launch of the European Reference Networks for rare cancers

ECPC joins the European Commission HTA Network Stakeholder Pool

2018

The Launch of the Innovative Partnership on Action Against Cancer (iPAAC)

ECPC strengthens advocacy on Health Technology Assessment

Publication in the Journal of Cancer Policy *"Improving European policy to support cancer survivors"*

The launch of the first ever ECPC Personalised Medicine Awareness Month

The Work-Life Balance Directive for Parents and Carers

The Vatican Meeting and The Cancer Mission Europe

2019

Three publications in the Journal of Molecular Oncology:

"The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer" and

"Cancer Survivorship: an integral part of Europe's research agenda"

"Cancer Core Europe: A translational research infrastructure for a European mission on cancer"

European Cancer Patient Coalition

Advocacy Milestones

2014

- *Immuno-oncology policy action framework*
- *The European Bill of Cancer Patients Rights*
- ECPC Call to Action

2015

- *White Paper on the Value of Innovation in Oncology*
- Changes to European Regulation 726/2004

2016-17

- *White Paper on Challenging the Europe of Disparities in Cancer*
- European Parliament Declaration on World Cancer Day
- European Parliament Written Declaration on the rights of Cancer Patients

2018

- ECPC Amendments adopted by EP Employment Committee on the Directive on Work-Life Balance
- EP ENVI Committee adopts compromise amendments on the European Commission's proposal on HTA
- ECPC HTA Position Paper

2019

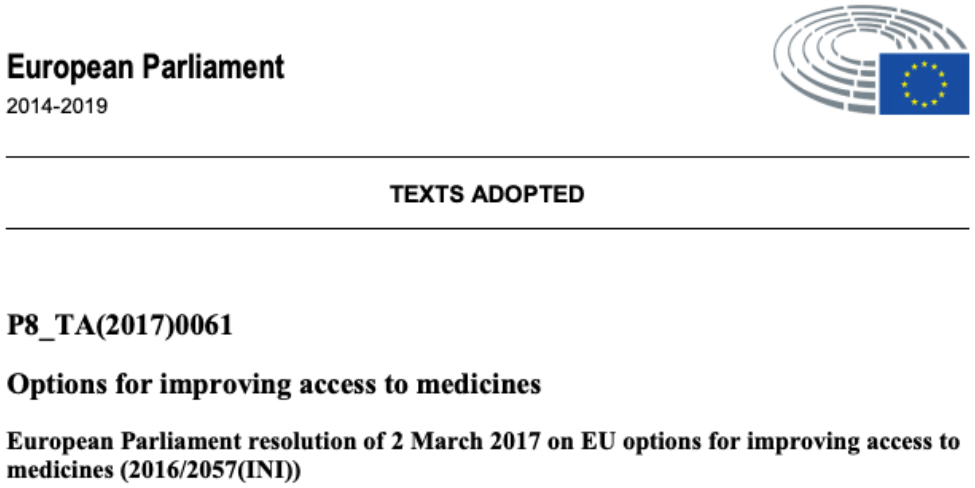
- Response to European Commission Consultation on HTA Cooperation
- ECPC Position on EU Options for Improving Access to Medicines
- CanCon Joint Action on Cancer Control
- White Paper on Cancer Carers

- ECPC EU Elections Manifesto
- Adoption of the Work-Life Balance Directive
- European Parliament adopts position on HTA
- Parliamentary Question on Rare Cancers
- Proposal for a resolution on Rare Cancers

European Cancer Patient Coalition

Access to Medicines Report

- The European Parliament passed in 2017 a report, by its own initiative, on the options for improving access to medicines.
- ECPC published a detailed position paper and presented amendments to improve the report.



European Parliament
2014-2019

TEXTS ADOPTED

P8_TA(2017)0061

Options for improving access to medicines

European Parliament resolution of 2 March 2017 on EU options for improving access to medicines (2016/2057(INI))

- **ECPC welcomed the final resolution, as it contains nearly all the amendments proposed by ECPC and recommends:**
- Believes that the opinions of European citizens voiced in petitions to the European Parliament are of fundamental importance and should be addressed by the European legislator as a matter of priority;
- Stresses that patients' organisations should be involved in a better way in the definition of private and public clinical trials research strategies, to ensure that they meet the true unmet needs of the European patients;

European Cancer Patient Coalition

Access to Medicines Report

- Notes that it is in the interests of patients, in cases of unmet medical needs, to obtain fast access to new innovative medicines; stresses, however, that the fast-tracking of marketing authorisations should not become the rule, but should only be used in cases of high unmet medical need and must not be motivated by commercial considerations; recalls that robust clinical trials and thorough pharmacovigilance monitoring are necessary to assess the quality, efficacy and safety of new medicines;

- Believes that the real therapeutic added value of a medicine, the social impact, the cost benefit, the budget impact, and the efficiency for the public health system, all need to be taken into account when determining the pricing and reimbursement procedures for medicines;

- Calls on the Member States to develop closer collaboration in order to fight such market fragmentation, in particular by developing shared HTA processes and results, and to work on shared criteria to instruct price and reimbursement decisions at national level;

- Calls on the Commission to enhance dialogue on unmet medical needs between all relevant stakeholders, patients, healthcare professionals, regulators, HTA bodies, payers and developers throughout the life spans of medicines;

European Cancer Patient Coalition

EU Joint Actions

2009 - 2014

The **European Partnership for Action Against Cancer (EPAAC)** supported member states in the development of the **National Cancer Plans.** ECPC worked with several leading European cancer organisations to explore the feasibility of the progressive harmonisation of **clinical guidelines for rare cancers**

2014 - 2017

The **Cancer Control Joint Action (CanCon)** delivered the **European Guide on Quality Improvement in Comprehensive Cancer Control**, presenting key recommendations to potentiate EU countries' capacity to fight cancer. **ECPC was a key partner of CanCon**, and contributed to the work of several Work Packages, the guide and drafting of the policy papers. ECPC specifically worked on placing **survivorship cancer plans** on the EU policy agenda.

2016 - 2019

The **Joint Action on Rare Cancer (JARC)** works to maximize efforts of the European Commission and EU Member States to advance quality of care and research on rare cancers, around the **European Reference Networks**. ECPC has established **a Working Group on Rare Cancers (WGRC)** together with 54 organisations supporting ECPC's JARC activities. Within the JARC, ECPC has mapped educational material on rare cancer and surveyed on the educational needs of rare cancer patients.

2018 - 2021

The **Innovative Partnership for Action Against Cancer (iPAAC)** aims to develop innovative approaches tackling unaddressed issues in cancer control, by delivering a **Roadmap on Implementation and Sustainability of Cancer Control Actions**. Within iPAAC, ECPC will work on the topics of '**Genomics in cancer control and care**', '**Cancer Information and registries**' and '**Challenges in Cancer Care**'.

European Cancer Patient Coalition

CanCon Joint Action

CanCon Cancer Control Joint Action

The Joint Action on Cancer Control – CANCON was a common effort between representatives from **17 EU Member States**, co-funded by the European Commission to create guidelines for harmonization of national cancer plans.

European Cancer Patient Coalition was an important partner in this Joint Action

WP5: policy paper on inequalities

- **Unacceptable situation in Europe**
- Identification of key needs directly from patients' organisations
- Support in setting priorities / making the document actual and politically actionable

WP5: policy paper on disinvestment

- **Identified what the role of patients organisations can be**
- Setting up a roadmap to better involvement of patients
- Helped to set the priorities and examples

WP8 Survivorship and rehabilitation

- Help defining cancer patients needs (different types of rehabilitation, return to work, socio-economic issues);
- Strong support to SCP
- **Connection between the recommendations and medical societies**

European Cancer Patient Coalition

ECPC role in iPAAC

iPAAC
INNOVATIVE PARTNERSHIP FOR ACTION AGAINST CANCER

The innovation consists of:

- further development of cancer prevention
- **comprehensive approaches to the use of genomics in cancer control**
- **cancer information and registries**
- **improvements and challenges in cancer care**
- mapping of innovative cancer treatments and governance of integrated cancer control, including a new analysis of National Cancer Control Plans.

European Cancer Patient Coalition

Cross-Border Healthcare

- **Cross-Border Healthcare Directive** sets out rules for patients' travel to another EU country to receive medical care and reimbursement. It covers healthcare costs, as well as the prescription and delivery of medications and medical devices.
- The European Parliament recently approved the **Report on the Implementation of the Directive** focusing on measures to improve its implementation, but it failed to mention and capture the importance of the European Joint Action on Rare Cancers (JARC) in this context.
- The JARC aims to optimise the process of creations of the ERNs, by providing them with operational solutions and professional guidance in the areas of quality of care, epidemiology, research and innovation, education and state of the art definition, diagnosis and treatment of rare cancers.
- **ECPC together with MEPs proposed a Motion *Resolution on Rare Cancers in the context of the European Reference Networks in 2019***

- ***ECPC together with MEP Gardini also tabled a Parliamentary Question to the European Commission on the same issues.***

European Cancer Patient Coalition

ERNs on Rare Cancers

European Reference Networks

Since the launch in 2017, there are European Reference Networks for Rare cancers

ERN on Heamatological Diseases (EuroBloodNet)

ERN on Genetic Tumour Risk Syndromes (ERN GENTURIS)

ERN on Paediatric Cancer – haemato-oncology (ERN PaedCan)

ERN on Adult Cancers – solid tumours (ERN EURACAN)

ERN EURACAN – 61 healthcare providers from 17 countries:

BE, CZ, FI, FR, DE, DK, HU, IT, LV, NL, NO, PL, PT, SI, ES, SE, UK

European Cancer Patient Coalition

Strong partner in Science

European Society for Medical Oncology

ECPC and ESMO have signed a Memorandum of Understanding with the aim of enhancing the existing cooperation. Topics of collaboration include survivorship care and immuno-oncology.

ECPC also continues its efforts in the ESMO Patient Advocates Working Group and is directly involved in drafting of updates of ESMO Clinical Practice Guidelines.

European Organisation for Research and Treatment of Cancer

EORTC aims to improve the standards of cancer treatment by testing more effective therapeutic strategies based on drugs, surgery and/or radiotherapy. ECPC and EORTC have signed a Memorandum of Understanding in 2017 to formalise and strengthen their partnership. Collaborating activities include the organisation of seminars, meetings, roundtables, projects, trainings and publications.

Cancer Core Europe

ECPC is a Board Member of Cancer Core Europe, a European cancer association of 7 leading cancer centres carrying out innovative research propelling cancer medicine into a new era.

European Academy of Cancer Sciences

EACS is an independent advisory body of eminent oncologists and cancer researchers, placing science at the core of policies to sustainably reduce the burden of cancer in Europe. ECPC is part of its Science Policy Committee, identifying issues that are of importance to the cancer community and provides evidence-based advice to implement policies.

Cancer Drug Development Forum

ECPC is a Board Member of CDDF, an international non-profit organisation providing a platform for all stakeholders involved in the development of oncology drugs, which works to accelerate the delivery of effective oncology therapies to patients.

WIN Consortium in personalized cancer medicine

ECPC is one of 43 institutional members of WIN, an organization aiming to improve patient outcomes worldwide by increasing access to innovative, global clinical trials in the area of genomic-based cancer therapeutics.

European Cancer Patient Coalition

Patient-centered research

ECPC participated in 23 EU-funded projects to date

6 concluded EU projects

17 currently ongoing

Two funded funded by the 7th Framework Programme

12 funded by the Horizon 2020

- 4 Innovative Medicine Initiative projects
- 2 Innovative Training Networks

1 European Reference Network

2 Joint Actions

19 pending EU funded project proposals

€4,245,759.37 potential funding for ECPC

European Cancer Patient Coalition

Partnership with ESMO

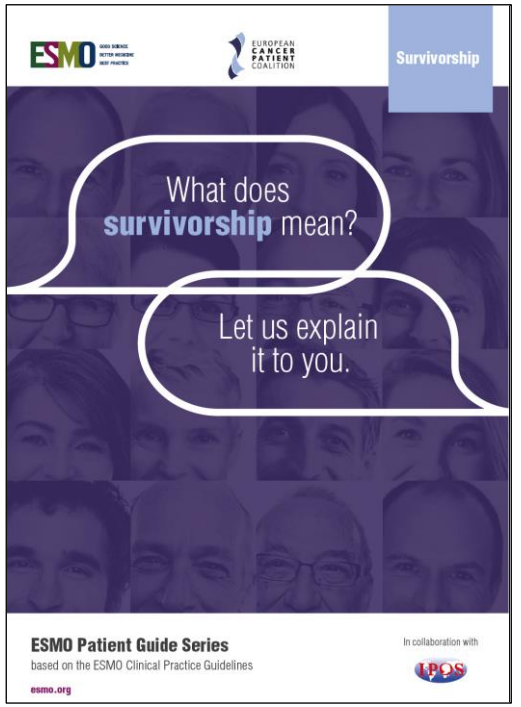
- ECPC enhanced the cooperation with the European Society for Medical Oncology (ESMO) since 2013, and have since signed the **Memorandum of Understanding to increase collaboration.**

- In 2017, the **ECPC-ESMO Survivorship Guide was launched**, transferring policy recommendations into concrete action. The guide concise but comprehensive summary for patients and physicians on diagnosis, treatment and follow-up.

- **ESMO Guidelines** – ECPC is directly involved in drafting of updates of the new ESMO Clinical Practice Guidelines setting standards for best practice of a variety of cancers. These now include more patient-friendly and solid information.

- Together with ESMO, ECPC submitted a response to a consultation on the guidelines on consent, in relation to the **General Data Protection Regulation (GDPR).** We proposed further clarifications within the guidelines to avoid any discrepancies in the implementation of GDPR, as it is of fundamental importance to the future of medical breakthroughs and bringing better outcomes for patients.

- ECPC is a member of **the ESMO Patient Advocates Working Group** (PAWG and joins the ESMO Annual Congress each year.



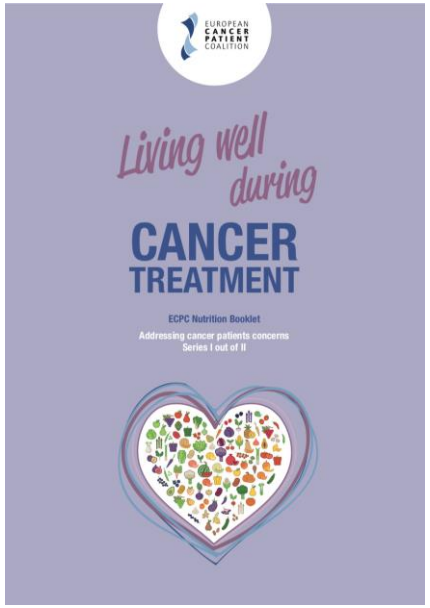
European Cancer Patient Coalition

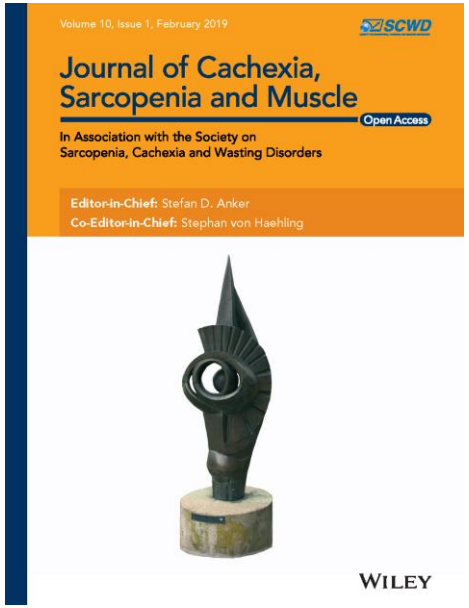
Supportive Care

'**Nutritional and metabolic derangements in Mediterranean cancer patients and survivors: the ECPC 2016 survey**' was published in the **Journal of Cachexia, Sarcopenia and Muscle** in **February 2019**.

The '**Living Well During Cancer Treatment**' booklet, addresses common questions patients might have about diet, nutrition and physical activity during cancer treatment. This booklet will be translated into multiple languages and is already available in **English**, **Romanian** and **Czech**.

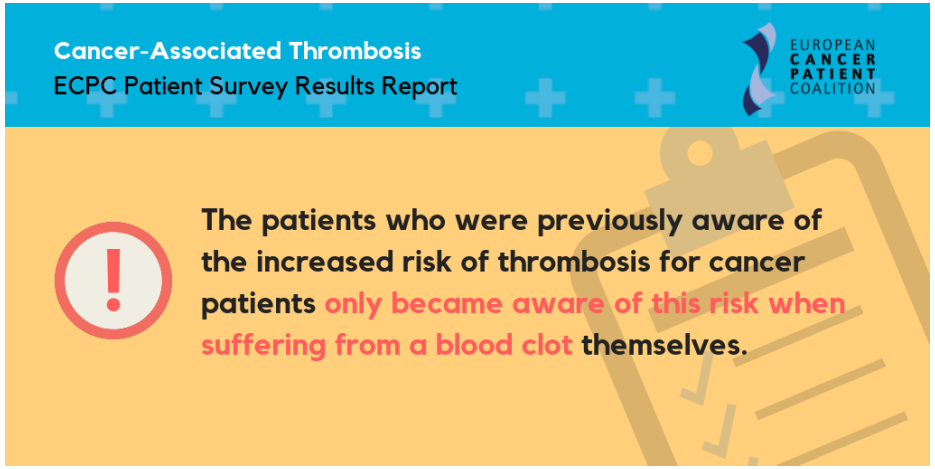
The booklet also contains the **ECPC Cancer Patients' Bill of Rights for appropriate and prompt nutritional support**, aiming to empower cancer patients and raise awareness to their nutritional rights while sensitising the public opinion and the European Institutions on the challenges of malnutrition in oncology.





On **World Thrombosis Day – 13 October 2018**, ECPC launched the **report on the Cancer-Associated Thrombosis Awareness Survey** survey, which measured the patient awareness of cancer-associated thrombosis in 5 European Countries. The survey revealed **72% of respondents were not aware** that people with cancer have a higher than normal risk of developing thrombosis.

To advocate for more action on the issue, ECPC hosted the **Saving Lives by Increasing Awareness of Cancer-Associated Thrombosis (CAT) e**vent at the European Parliament



European Cancer Patient Coalition

Cancer Carers

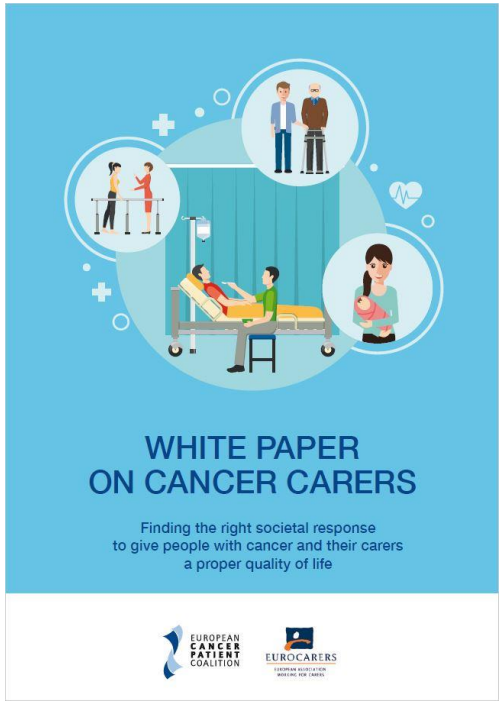
White Paper on Cancer Carers – key recommendations for policy actions at EU level and at national level in the Member States

Building on these key recommendations with the ECPC Legal Network for Cancer Patients, ECPC together with several Members of the European Parliament proposed **amendments to the Work-life Balance Directive.**

ECPC engaged with policymakers and Members of the European Parliament to bring the attention to the recommendations published in the ECPC-Eurocarers White Paper on Cancer Carers. In particular, ECPC advocated for the proposal to reinforce the formal recognition of carers and to introduce minimum standards for paid carers' leave and flexible working arrangements.

The **Directive on Work-Life Balance for Parents and Carers was agreed by the European Parliament and the Council to**:

- Adopt a legal definition of a carer
- Adopt the minimum 5 days carer leave, and build upon this where possible to accommodate the impact of disease such as cancer.
- Provide flexible work arrangements for carers, addressing the needs of those caring for a person with a chronic condition, such as cancer, to ensure that caregiving does not prohibit active employment, particularly for women.



European Cancer Patient Coalition

Personalised Medicine

Molecular diagnostics, involving genomic testing and immunotyping, are prerequisites for personalised medicine and are becoming a reality throughout Europe.

However, it remains to be seen **whether the EU Member States are able to build** the complex infrastructure required to support personalised medicine

The role of the comprehensive cancer centres in **Cancer Core Europe** and the **OECI** and of **patient organisations in the ECPC** will be important in disseminating such information about the new and more complex approaches to cancer diagnosis and treatment

The **ECPC continuously and diligently aims to offer to its member organisations** and the general public information validated by renowned cancer experts about cancer and cancer treatments.

First ever Personalised Medicine Awareness Month campaign launched by ECPC in 2018, in partnership with EAPM, CDDF and IQN-Path, supporting collective awareness raising efforts of our members in 12 languages.

More than 30 partners supported the Personalised Medicine Awareness Month 2018, helping us **reach over 180,000 people** online across many countries in Europe and beyond.

European Cancer Patient Coalition

Capacity-building

- **ECPC strives for capacity-building of our member patient organisations:**
  - The Immuno-Oncology Portal
  - HTA eLearning Module
  - Cancer-Associated Thrombosis, Biobanking Patient Education, Merkel Cell Carcinoma etc.
  - Awareness raising: Bladder Cancer, Head & Neck, Pancreatic, Personalised Medicine etc.
- **ECPC will be launching the new website later this year**
- **ECPC Social media has grown steadily:**
  - Twitter: 4,445 followers to date
  - Facebook: 8,461 likes to date
- **ECPC currently leads three Working Groups with more to come, focusing on:**
  - Working Group on Urological Cancers (previously Bladder Cancer Working Group)
  - Working Group on Rare Cancers
  - Legal Network for Cancer Patients

European Cancer Patient Coalition

Cancer Mission Europe

- In 2018, the European Commission proposed a **mission-oriented approach to research in Horizon Europe** – the next EU Research & Innovation Programme
- **ECPC President joined the meeting in The Vatican** in November 2018 with over 60 leaders in global oncology community – a key starting point for generating and contributing ideas to the **framework and functioning of the Cancer Mission.**
- A primary aim of the Cancer Mission should be to achieve the long-term survival of 75% of patients with cancer by 2030 by combining innovative prevention, treatment strategies, rehabilitation and multidisciplinary follow-up. Better handling of economic and social inequalities in countries with less-developed systems should be an essential part of the Cancer Mission.
- As many as 13 million patients will be considered long-term survivors in 2035, in need of professional and social support and demanding continuous research efforts, especially in order to facilitate full reintegration into society in all aspects.
- **The successful cancer mission must benefit the advancement of cancer research, care and survivorship for all.**

European Cancer Patient Coalition

Driving the Cancer Mission

Molecular Oncology

FEBS PRESS

REVIEW ARTICLE

The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer

Francesco de Lorenzo and Kathi Apostolidis

Molecular Oncology

FEBS PRESS

REVIEW ARTICLE

Cancer survivorship: an integral part of Europe's research agenda

Pernilla Lagergren[1,2], Anna Schandl[1,3], Neil K. Aaronson[4], Hans-Olov Adami[5,6], Francesco de Lorenzo[7,8], Louis Denis[9], Sara Faithfull[10], Lifang Liu[11], Françoise Meunier[11] and Cornelia Ulrich[12,13] on behalf of the European Academy of Cancer Sciences

Molecular Oncology

FEBS PRESS

REVIEW ARTICLE

Cancer Core Europe: A translational research infrastructure for a European mission on cancer

Alexander M. M. Eggermont[1], Giovanni Apolone[2], Michael Baumann[3], Carlos Caldas[4], Julio E. Celis[5], Francesco de Lorenzo[6,7], Ingemar Ernberg[8], Ulrik Ringborg[8], John Rowell[1], Josep Tabernero[9], Emile Voest[10] and Fabien Calvo[11]

European Cancer Patient Coalition

ECPC & FAVO-ECPC Manifestos

A Europe for cancer patients, survivors and carers

MANIFESTO FOR THE EUROPEAN ELECTIONS 2019

EUROPEAN CANCER PATIENT COALITION

Every year, more than 3 million people are diagnosed with cancer.

An estimated 3.9 million people were faced with a diagnosis of cancer and 1.9 million have died from cancer in the European Union in 2018.

The right to health is a human right recognised in the international human rights treaties ratified by the Member States. For this right to be guaranteed, access to medicines, treatment and high-quality care must be ensured equally to all cancer patients in the EU. **The European Parliament and the Council of the European Union have the power and responsibility to adopt measures** setting high standards for accessibility, quality and safety of medicinal products, treatments and cancer care.

The European Cancer Patient Coalition (representing 448 cancer patient associations in all Member States) in partnership with Members of the European Parliament have achieved a number of accomplishments today, and we count on you to continue our collaboration.

We call on You

… to join our mission in the European Parliament to overcome inequalities in Europe, where all cancer patients have timely and affordable access to the best treatment and care available, throughout their life, by actioning the following.

For more information contact:
Alex Filicevas, Head of EU Affairs
alex.filicevas@ecpc.org
+32 (0) 2 721 41 14

Reduce inequalities for fast, safe and affordable access to surgery, radiotherapy and medicines

Embrace innovation in cancer research and treatments

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

Promote survivorship programmes as an essential part of cancer care at all levels, and formally support the role of cancer carers

ecpc.org facebook.com/ECPCfb twitter.com/cancereu

F.A.V.O. Federazione Italiana delle Associazioni di Volontariato in Oncologia

EUROPEAN CANCER PATIENT COALITION

Il nuovo Parlamento EU per i malati oncologici e le loro famiglie

Manifesto per le Elezioni europee 2019

Il diritto alla salute

In Europa, ogni anno 3,9 milioni di persone si ammalano di cancro, a fronte di quasi 2 milioni di decessi. In Italia, 373.300 sono le nuove diagnosi, 178.000 i decessi e 3.368.569 (6% della popolazione) i cittadini che vivono con una pregressa diagnosi di cancro, di cui oltre 900.000 guariti.

Il diritto alla salute è parte integrante dei diritti umani fondamentali internazionalmente riconosciuti nei trattati ratificati dagli Stati Membri. Questo diritto può essere garantito solo assicurando a tutti i malati di cancro europei pari opportunità di accesso ai trattamenti terapeutici e a un'assistenza socio-sanitaria di qualità.

Il Parlamento e il Consiglio dell'Unione Europea, attraverso la promozione di politiche comuni negli Stati membri, hanno il potere di assicurare standard elevati per l'accessibilità alle cure e il dovere di assicurare tutele giuridico-economiche-sociali ai pazienti e ai loro familiari.

ECPC, la Coalizione Europea dei Malati di Cancro in rappresentanza di 447 Associazioni nei 28 Paesi membri (www.ecpc.org), con la partecipazione attiva di FAVO, Federazione italiana delle Associazioni di Volontariato in Oncologia in rappresentanza di 500 organizzazioni operanti su tutto il territorio italiano (www.favo.it), ha già raggiunto risultati importanti con i membri del Parlamento europeo delle passate legislature e auspica che tale sinergia continui anche dopo le prossime elezioni.

ECPC e FAVO invitano pertanto, i candidati a condividere i seguenti obiettivi:

1 ***Ridurre le disparità e consentire un accesso tempestivo e sicuro ai trattamenti chirurgici e radioterapici, in collaborazione con gli Stati membri e attraverso le seguenti azioni:***

- *Redigere standard di riferimento per garantire un'assistenza chirurgica di qualità e rendere pubblici i dati sui numeri delle prestazioni dei CENTRI di chirurgia oncologica.*
- *Fare della radioterapia un cardine dell'iter terapeutico dei malati oncologici attraverso l'elaborazione di apposite linee guida e la pianificazione di programmi di adeguamento/aggiornamento delle attrezzature e del personale.*
- *Favorire l'innovazione attraverso investimenti in apparecchiature e formazione su chirurgia e radioterapia con pari accesso a livello europeo.*

Via Barberini 11 - 00187 Roma Tel - Fax 06.42012079 Numero Verde: 800 90 37 89 Email: info@favo.it www.favo.it

Special thanks to the Members of European Parliament that signed to the FAVO-ECPC Manifesto:

- **Isabella Adinolfi** (MoVimento 5 stelle)
- **Tiziana Beghin** (MoVimento 5 stelle)
- **Rosa D'Amato** (MoVimento 5 Stelle)
- **Eleonora Evi** (Movimento 5 Stelle)
- **Raffaele Fitto** (Fratelli d'Italia)
- **Aldo Patriciello** (Forza Italia)
- **Antonio Tajani** (Forza Italia)
- **Patrizia Toia** (Partito Democratico)
- **Marco Campomenosi** (Lega)

European Cancer Patient Coalition

Thank you!

Francesco de Lorenzo

President