

CANCER PATIENTS EUROPE ASBL

Annual Activity Report 2022

Presented at the General Assembly of 22 May 2023

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FOREWORD

The year 2022 has been an incredible year for Cancer Patients Europe. We started with a lot of enthusiasm and goodwill. Our aim was to create a new, patient centred organisation based on sound ethics and principles.

Ten of our members met several times to discuss the nature of the new association, the governance, the statutes, the name, the introduction, and the website. For ease of administration, we decided to limit the official number of the founding members to three (the minimum required by the Belgian law). This process took over 6 weeks, but finally we managed to establish CPE.

We are particularly grateful to the European Association of Urology and Prof Hein Van Poppel for allowing us to temporarily base ourselves in their Brussels office at no cost.

It is well known that we faced huge administrative challenges opening a bank account. Finally, after more than a year, we now have a bank account.

We managed to achieve a lot in 2022 despite having no staff. As well as establishing the association, we grew in membership and set up several good relationships liaising with relevant key stakeholders at the EU level such as the European Association of Urologists (EAU), the European Society of Medical Oncology (ESMO), the European Hematology Association (EHA), the European Cancer Organisation (ECO), the Anticancer Funds, and the European Federation of the Pharmaceutical Industry Association (EFPIA). We were partners in four European Proposals of which three were approved and started in 2023.

We set up an entirely new initiative, the my Cancer my Concern (myC) with the aim to raise awareness of the benefits and value of genomic testing in cancer. Personalised treatment decisions are key to this effort and genomic testing is an example of current progress in the field. Breast cancer was chosen as a pilot and has applicability in other cancers. We launched the survey results conducted to investigate the barriers to the effective implementation of genomic testing for breast cancer patients at the European Breast Cancer Conference (EBCC) in Barcelona.

We are the leading patient organisation working on the new European Health Technology Assessment Regulation which will come into force in January 2025 for cancer medicines.

We have been present at several large and important events on various issues, such as Clinical Trials Innovation, Patient Centricity in research projects, Patient's Preference, Oral Potentially Malignant Diseases (OPMD), Cancer and multimorbidities, HTA, Advanced Therapy Medicinal Products (ATMPs), Inequalities in Lung Cancer, and the relevance of Smoking Cessation for cancer patients.

We have worked to expand the membership and have approached several organisations. Many have joined and many more may do so shortly.

We are very proud to have, often against the odds, brought CPE so far. We are pleased to present to you a new, fresh and vibrant association ready to conduct another intense year full of successes.

Onwards and upwards!

OUR MEMBERS

Cancer Patients Europe was established in Belgium in March 2022, thanks to the efforts of ten members. Three founding members were identified for administrative reasons and are the following:

- Northern Ireland Rare Disease Partnership,
- Federación Española de Cáncer de Mama (Spanish Federation of Breast Cancer)
- Blærekreft Norge (Bladder Cancer Norway)

Since then, the membership has increased to **18 members**, as of 31 December 2022, of which 16

are full members and 2 are associated members, all together representing 13 countries (14 in the map, updated to May 2023).



The members' geographical scope varies, 11% operate at the local level, 11% at the regional level, 50% work at the national level, and 28% at the international level.

CPE ACTIVITIES IN 2022

PROJECTS

my Cancer my Concern (myC) Initiative

During 2022, CPE started the project, supported by Exact Sciences and Lead-Up. The initiative aims to raise awareness of the benefits and value of genomic testing in cancer. This project fits with CPE's goal to improve the management of cancer patients across Europe. Personalised treatment decisions are key to this effort and genomic testing is an example of current progress in the field. In 2022 we launched a Survey on genomic testing and breast cancer to understand how genomic testing is perceived among breast cancer patients. In a little over one month over 3.400 people answered the survey. We launched the results at a side event during the European Breast Cancer Conference in Barcelona in November 2022. We hope to soon expand this project to other cancer types.

We are very glad to have had the support of a high-profile Advisory Committee including representatives in each of the five countries the project focuses on, the UK, Spain, France, Italy and Germany and well known international stakeholders. Please, see the list below:

Oncologists	Patient Associations/Societies
Prof. Francesco COGNETTI (Italy) Prof. Dr. med. Michael Patrick LUX (Germany) Dr. Ana SANTABALLA (Spain) Dr. Richard SIMCOCK (UK) Dr. Johanna WASSERMAN (France)	Ms. Dany BELL - Macmillan Cancer Support (UK) Ms. Conchi BIURRUN – FECMA (Spain) Dr. Fatima CARDOSO – ABC Global Alliance Ms. Bianca CASIERI – Susan Komen (Italy) Ms. Rosanna D’ANTONA – Europa Donna (Italy) Dr. Csaba DEGI – International Psycho-Oncology Society (IPOS) Ms. Laure Guérout-Accolas - Patients en Rreseau (France) Dr. Isabel RUBIO – European Society of Breast Cancer Specialists (EUSOMA) Ms. Alexandra VON KORFF – Yes we can!cer (Germany)

We have submitted four proposals to the European Commission of which three have been funded and commenced in 2023.

PREVENT

This project will look at the upscaling of primary interventions for weight control management during childhood and adolescence to reduce cancer risks in adulthood. This relies on current evidence that relates excess body weight with increased cancer risk.

Duration: 48 months (January 2023 – December 2026)

Type of Action: HORIZON-RIA Action Grant

THERMOBREAST

The main goal of the ThermoBreast project is to test an alternative technology to mammography for breast cancer screening to change the course of breast cancer detection and patient monitoring.

CPE was mentioned as a best practice of patient involvement in a Cancer Mission research project at an event at the EU Parliament by a representative of the European Commission.

Duration: 4 years from January 2023

Type of Action: HORIZON-MISS-2021-CANCER-02-01: Develop new methods and technologies for cancer screening and early detection.



INTERCEPTOR – INTERception of oRal CancEr developMent

It addresses the challenge of unmet oral cancer prevention and brings a new paradigm to disease management of oral potentially malignant disorders (OPMD).

This is a network project and CPE will be in charge of the Working Group on Dissemination with over 45 members.

Duration: May 2022 – April 2025

Type of Action: COST Action

ELDORADO - intEgrating multiLayer data to identify risk factors and health Determinants in erythro-/leuko- /plakia, ORAL mucosa field of cancerization and exposome to improve Oral cancer prevention (NOT FUNDED)

The poor prognosis of oral squamous cell carcinoma (OSCC) is due to late diagnosis and its intrinsic aggressiveness. Oral leukoplakia, erythroplakia or erythroleukoplakia, referred to as ELP, are the most frequent oral potentially malignant disorders that precede OSCC development. Studying ELP is a unique opportunity to shift the paradigm in the prevention of OSCC. ELDORADO will bring a new angle to the management of patients with ELP, to envision the interception of OC development through an in-depth understanding of the risk factors, the determinants, and the biological changes underlying the oral mucosa transformation.

Duration: 5 years

Type of Action: HORIZON RIA

EVENTS

CPE representatives spoke at the following events:

WORLD BI Clinical Trials Innovation Programme

3rd March 2022, online. Speaker and moderator

Astellas. Individual, sustainable, holistic: improving the support for people living with multimorbidities

30th March 2022, online

PREFER. Finding Out What Patients Prefer: Why, When And How To Assess And Use Patient Preferences In Medical Product Decision-Making

28th April, online

Will the EU HTA Regulation provide 'Added Value' for Patients?

EAA Convention 2022. Copenhagen and virtual, 20-21 May 2022

Bridge the gap between healthcare stakeholders to improve patient outcomes: is there a role for pharma?

Elevate the patient voice to drive patient-centric innovation: the role of pharma industry, Lugano 14 June 2022

Tackling the unmet needs of life after cancer diagnosis, treatment and survivorship

EAU 2022. Life After Cancer Treatment, Amsterdam, 04 July 2022

Patients Advocates and their Expertise, how to get Involved?

2022 ESMO Congress, Paris, 9 September 2022

Why is Cancer high on the political agenda: Research opportunities and patient involvement

EULAR Pare Conference 2022, Brussels, 21 October 2022

Stakeholder Involvement & Europe's Evolving HTA Framework

EAA FALL CONVENTION, Vlerick Business School, Brussels 28 October 2022

European Parliament roundtable. Fighting lung cancer together as equals. How fast access to diagnosis and treatment saves lives across the EU

Hosted by MEP Cristian Silviu BUȘOI, Brussels, 25 October 2022

Patients for effective implementation of the HTAR in January 2025

DIA Brussels 29 Nov 2022

More than 10 Years of ATMPs in Europe

DIA Brussels 30 Nov 2022

Integrating Innovation Into Health Systems: Early Action And Ambitious Targets

4th European Cancer Forum, Brussels 6 December 2022

EVENTS ATTENDED

4th Edition Cracking Cancer Forum

Torino, 22/23 September 2022

2022 Global Kidney Cancer Summit

Milan, 13th October 2022

Third Global Patient Organisation Advisory Board

Paris 8th November 2022

Kidney Cancer Roundtable

Brussels, 29th November 2022

IPSEN, Taking Patient Centricity to the Next Level - 3rd Global Patient Organisation Advisory Board

Paris 30th November 2022

Pancreatic Cancer Patient Advocacy Exchange (PAE) Non-Promotional Meeting

Online, 25th and 26th May

All.Can's virtual Global Summit 2022 on 'Taking actions: implementing efficiency in cancer care'

Online, 15th and 16th June 2022

Orphan Medicines Regulation. The Lifeblood of Blood Cancer Innovation

Hosted by MEPs Deirdre Clune, MEP and Nicolás González Casares

Brussels, 21st June 2022

European Commission, The Regulation On Health Technology Assessment—What's Next

Brussels 22nd June 2022.

INSTITUTIONAL ACTIVITIES

The association has been registered according to Belgian Law in the Moniteur Belge, with the

number 783762176, on the 24th of March 2022. Ten cancer patients' associations met several times to find consensus around the Statutes before consulting with a local lawyer in Brussels. They also agreed on the visual identity, the vision, mission and values of the association and the introductory presentation of CPE, the first roadmap of the association with its priorities and objectives.

The association management

The present Board of Directors is composed of three members as they were the founding members at the incorporation of the Association for a 2-year term. The board needs to be completed with two additional members, as, according to the Statutes, the minimum number of board members is five.

The current members are Ranveig Rotterud, Conchi Biurrun and James Caldwell; find more at this [link](#).

In order to be able to submit projects to the European Commission, CPE was registered in the EU Portal and a PIC code was allocated. Ranveig Rotterud was appointed and indicated as LEAR (Legal Entity Appointed Representative).

On 31 October 2022, UniTS - Università del Terzo Settore (Italy) was appointed for the daily management of the Secretariat. UniTS is a non-profit association based in Italy with long-standing experience in the management of non-profit activities and projects. UniTS is also managing the secretariat of Pancreatic Cancer Europe.

On 18 November 2022, Antonella Cardone was appointed as CEO. She has strong experience in Patients Advocacy and a solid background in the management of non-profit organizations. Find more at this [link](#).

Opening the association's bank account has been a huge administrative challenge, as in Belgium special attention is put on non-profit organisations, and without a bank account we could not function. So, the Board gave a mandate to UniTS to open a temporary bank account under the name of CPE. In this way, CPE could start to receive some funds.

Now, after more than a year since we initiated the process, we, finally, have a bank account in Belgium (April 2023).

Communication activities

Visual identity: one of the first operational steps for CPE was to have a name and a visual identity. This was preliminary to any communication activity. So, we chose a name and created a logo, as well as the colour palette. The logo is intended to represent all the colours of the different cancer types under the umbrella of CPE.

Website implementation and content creation: Our website focuses on CPE's vision, mission, goals and activities: events, projects and statements. The site includes an 'about us' section with CVs and photos of the governance team and staff. A dedicated members' section and a more up-to-date and comprehensive News and Events section are in the pipeline.

Technical features of the CPE website:

- Intuitive design (it is easy to navigate and has a straightforward user interface)

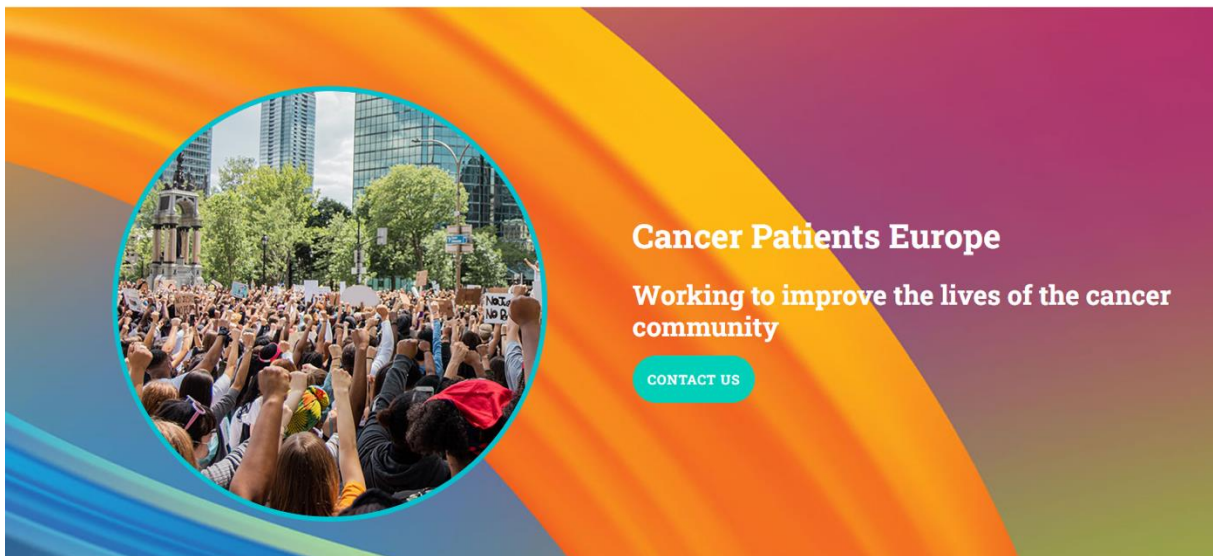
CANCER PATIENTS EUROPE

Rue de l'Industrie 24, 1000 Brussels – Belgium

info@cancerpatientseurope.org

Registration n. 783762176

- Optimised for SEO (Search Engine Optimisation - consistent structure and relevant keywords help search engines)
- Responsive (it is optimised for all devices and therefore easy to navigate and view on different screen sizes)
- Security (follows security protocols such as HTTPS)
- Ease of updating, so that it can be maintained efficiently and accurately.

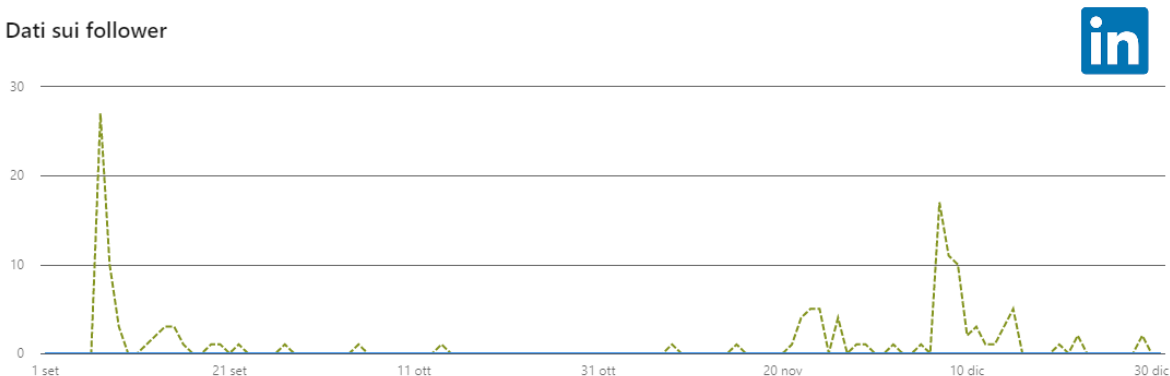


Social media analysis, enrolment, and implementation of a social media calendar:

CPE uses the following social media: Facebook, LinkedIn, Twitter, Instagram. Its objectives in using social media are:

- to raise awareness about a particular issue
- to engage supporters in our organization's activities
- to share information
- to draw attention to events and occasions
- to interact with our audience to gather feedback
- to administer surveys.

Dati sui follower



The involvement of our public is still low. Our goal is to grow to 500 followers on Facebook and as many on the other channels.

Age and gender

Men 21.60%
Women 78.40%



Location

Towns/cities Countries

United Kingdom	57
United States	21
Ireland	15
Italy	9
Norway	6
Switzerland	5
Australia	4
Canada	3
Germany	3
Spain	3

Newsletters implementation: Cancer Patients Europe sent its first Newsletter on 23 December 2022 to 494 recipients:

- Successful deliveries was 94.1%
- Open rate was 38,9%
- Unsubscribed:0



External membership

CPE is a member of the following organisations:

Pancreatic Cancer Europe: a European multi-stakeholder platform which aims at bringing together experts from all over Europe including academics, physicians, politicians, patient groups, and journalists, with a common interest and willingness to improve care for patients with pancreatic cancer.

www.pancreaticcancereurope.eu

EAU - European Association of Urologists: we are a member of the Patient Advocacy Group of the European Association of Urology. The EAU represents the leading authority within Europe on urological practice, research, and education.

<https://patients.uroweb.org/patient-advocacy/>

EFPIA - European Federation of Pharmaceutical Industries Association - Patient Think Tank: We are a member of the European Federation of Pharmaceutical Industries and Associations - EFPIA Patient Think Tank that provides a forum for an open exchange of ideas, information, and perspectives between patient organisations and the industry on topical issues impacting on patients.

<https://www.efpia.eu/relationships-code/patient-organisations/efpia-patient-think-tank/>

EFPIA Oncology Platform stakeholder group: We are a member of the European Federation of Pharmaceutical Industries and Associations – EFPIA Oncology Platform stakeholder group

<https://www.efpia.eu/about-medicines/use-of-medicines/disease-specific-groups/fighting-cancer/>

Networking

CPE is collaborating with the following networks:

- **All.Can** : We cooperate informally with All.Can that is an international multi-stakeholder not-for-profit organisation working to improve the efficiency of cancer care by focusing on what matters to patients.
- **ECO** : We cooperate informally with ECO. The ECO mission is to reduce the burden of cancer, improve outcomes and the quality of care for cancer patients, through multidisciplinary and multiprofessionalism.
- **ESMO - European Society of Medical Oncology** : We cooperate informally with ESMO, the leading professional organisation for medical oncology. ESMO's core mission is to improve the quality of cancer care, from prevention and diagnosis all the way to palliative care and patient follow-up. It is to educate – doctors, cancer patients and the general public – on the best practices and latest advances in oncology. And it is to promote equal access to optimal cancer care for all patients.
- **EHA - European Haematology Association** : We cooperate informally with the European Hematology Association which promotes excellence in patient care, research, and education in haematology.
- **WECAN** : We are in dialogue with WECAN to see how to best collaborate without overlapping or duplicating the effort.
- **European Access Academy (EAA)** : CPE is a member of the faculty of the EAA and has been part of this multi stakeholders platform working on the best development of the EU Health Technology Assessment Regulation

THE STAKEHOLDERS

During 2022 Cancer Patients Europe activities have been supported by Exact Sciences International GmbH, for the implementation of the project my Cancer my Concern.

Meetings have been organised with the following industries to introduce the newborn organisation and present the work plan: Astellas, Bayer, Gilead, MSD, Novartis, Guardant, 3M, IPSEN, BMS, Eli Lilly, Sanofi, Pierre Fabre, EUCOPE, MedtechEurope, EFPIA.

CPE also initiated lobby activities with MEPs and European institutions.

SIGNIFICANT EVENTS AFTER THE REPORTING PERIOD

No significant events have been after the closing of the reporting period



Ranveig Røtterud
Chair of the Board

CPE Board of Directors