

European Cancer Patient Coalition

Monday, 2 May 2022 - n. 4

Welcome to the new edition of the ECPC Newsletter.

ECPC brings you the latest news from the European cancer patient community, policy developments, upcoming events, and new opportunities.

In this edition: While preparation is ongoing for the upcoming Conference and General Assembly, the Right to Be Forgotten in steadily developing in Europe and an interesting opportunity for organisations dealing with cancer and aging has been lunched. If you fancy traveling, fast your seatbelt and meet an Indian member that has spearheaded a novel approach to cancer consultations for disadvantaged patients.

Check out the new edition of the ECPC Newsletter for this and more.

News



Ready for the ECPC Conference and the General Assembly 2022?



The **ECPC Conference 2022** will take place on **27 May 2022** at the Renaissance Hotel in Brussels. The event will be an opportunity for the European cancer patients community to gather, build networks, and shape ECPC and cancer patients' future.

- 27 May 2022, 14:30 - 19:00 CEST - ECPC Conference

This year's conference will focus on "The Cancer Policy & Research Landscape in the meta-Covid Era." Partners, patient organisations, and healthcare professionals from all over Europe will have the chance to attend two sessions to discuss EU cancer policies, the current phase of the pandemic, and the role of cancer patients in advancing them.

You can register here.

The full programme of the Conference will be published soon on the <u>dedicated section on our website</u>. There, you will find all the instructions to register and attend the event.

ecancer and ECPC launch a new platform to help patients navigating genetic and genomic testing



ECPC together with ecancer has launched today a new toolkit to provide patients with a comprehensive resource on genetic and genomic tests.

The e-module <u>Genetics and Genomics Testing – A guide for patients E-module</u> aims at improving the awareness and understanding of genetic and genomic testing for cancer patients, their families, and caregivers. The new resource will help patients and their families understanding these tests and make an informed choice.

Five modules will guide users to several questions they might want to ask themselves and others before getting tested. Also, users will be able to understand what it means to have a positive or uncertain result and what can be done next, for example risk-reducing surgeries. A module will help patients understand what data are collected, the risks ensuing from their usage, and the safeguards put in place to protect them.

The e-module is already available in English, German, Spanish, Italian and French on our website.

Sanofi to support organisations working on cancer and aging



Sanofi has launched a new initiative to support local, regional, and global organisations working to address systemic challenges and/or **improve the patient journey for vulnerable communities**, including the aging.

The **2022 Contributions Initiative program** is open to patient advocacy groups and professional organisations active in the field of oncology - with priority given to areas where Sanofi is currently working. Contribution can be directed to support **live or virtual activities and programs aimed at educating** patients, patients' families/caregivers, patient organisations, and programs that raise awareness.

"Since the program launch [in 2020], Sanofi has provided support for a wide range of initiatives that aim to improve the patient journey for aging people with cancer," explains the company. "These efforts around the world are instrumental as we look to better **support people living with cancer across our oncology therapeutic areas**, including multiple myeloma, skin, lung, and breast cancers."

Organisations that meet the conditions and requirements specified in the call can **apply via the online portal by 30 June 2022**.

Call to action



Prostate cancer: how is your doctor-patient communication?

The Disease Understanding and Outcome
Definitions team at PIONEER is conducting a
survey to better understand the communication
between patients diagnosed with prostate
cancer and their treating physician.

The results will help the EU-funded Project, of which ECPC is part, reach its research goals. The more responses received the more accurate and helpful this process will be in focusing healthcare resources.



PIONEER aims at transforming the field of prostate cancer care with a particular focus on improving prostate-cancer related outcomes, health system efficiency, and the quality of health and social care across Europe.

The short survey is available in six languages:

English Français

Español <u>Italiano</u>

<u>Deutsch</u> <u>Nederlands</u>

Nutrition and cancer: what is your experience?









Nutrition is critical in the therapeutic journey of cancer patients. Nutrition does not only improve physical conditions and help tolerate the negative consequences of therapies. Broadly speaking, nutrition helps the organism better cope with the illness.

However, given the focus on cancer and its treatment, nutrition is often neglected, leaving patients and their families with doubts, questions and the need for practical guidance on how to eat better daily, especially during therapy.

By participating in this survey, you will help the cancer patient community in Europe gain a better understanding of the different issues with nutrition that patients deal with in European countries.

With this information, we will be better equipped to advocate for change to help improve the lives of cancer patients everywhere.

The survey is available in Czech, Danish, Dutch, English, French, German, Greek, Hungarian, Italian, Lithuanian, Polish, Portuguese, Romanian, and Swedish.

Go to the survey

Right to be forgotten: What's new?



Right to be forgotten makes progress in France

From 1 June 2022, all cancer survivors will have the opportunity to get loans or mortgages after five years after the end of treatment, instead of the previous ten-year period.

The Lemoine Law - unanimously voted on 17 February 2022 - provides that, under certain conditions, people will be exempted from submitting the health questionnaire to get a credit in France from 1 June 2022.



Learn more...

Researchers recommend short waiting time for some breast cancers

As part of its Right to be forgotten mission, the Belgian Health Care Knowledge Centre (KCE) published in April its **first report on breast cancer**.

Among the others, the document proposes the removal of the waiting period for *in situ* cancers and a **new waiting period of one year** – instead of the



current 10 – years for small (referred to as T0 or T1) and early invasive carcinomas (stage I).

Based on the 10.452 cases of in situ cancer identified, **no excess mortality was observed** up to 14 years after the date of diagnosis. Consequently, the researchers propose no longer imposing a waiting period for people with this type of cancer.

Learn more...

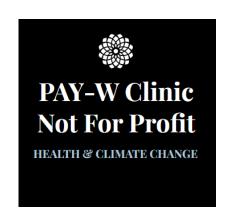
Members' corner



PAY-W Clinic:

Cancer specialist goes beyond borders with pay-as-you-wish service

Being diagnosed with cancer is never easy to understand or accept. A reality that becomes even **more challenging** when limited access to care hinders the chances to move past the disease and received proper treatment. For this reason, five years ago Dr Suryakanta Acharya decided to use his first-class experience around the world and in his home country, India, to offer a 'Pay as You Wish' consultation service to cancer patients worldwide.



"The concept is neither well known nor adopted by the medical community for obvious reasons," says Dr Acharya. "The reason to open such service is based on my prior experience of helping financially poor patients from many parts of the world."

However, the origins of PAY-W Clinic - the organisation he founded in 2017 - date back to a singular experience with a young Kosovar one year earlier, which made him aware of the **big opportunity** to offer a new model of care to disadvantaged patients. An experience that sows the seed for an organisation that 5 years later is helping patients in India, Pakistan, Iraq, Philippines, Kenya, Ethiopia, Kosovo, and Australia.

Learn more...

Please, <u>share with us</u> your news and activities so we can include them in the next newsletter.

Save the date



Telemedicine in Cancer Care Continuum: implementation and integration

Telemedicine promises to change care pathways for cancer patients, moving from hospital-centred models to **patient-centred and proximity-based** approaches.

SPCC will hold an online conference that will focus on the implementation and integration of telemedicine in the Cancer Care Continuum, looking - among the others - at **critical success factors**, technical barriers, and organisation and legal issues. The event will also be an opportunity to enhance cooperation between clinicians, HCPs, and management, to **share patient's perspective and implications in telemedicine**, and to show the best practice experiences at regional/national level.

When: 6-7 May 2022 14:30 CEST Where: Online

Taking on health inequalities: How work in other fields can help accelerate policy change in obesity

Organised by the Obesity Policy Engagement Network during the European Congress on Obesity, this hybrid panel discussion will bring together individual and organisation that helped enabling **impactful policy changes** in other disease areas where **misconceptions and stigma** have shaped the public discourse, thus exacerbating health inequalities.

During the event, speakers from the HIV and mental health field will talk about advocacy efforts and will explore **how disrupting perceptions have enabled attitudinal shifts**, improved policies, and build better health system resilience outside of obesity.

When: 6 May 2022 11:00 CEST Where: Online

Learn more...

Cancer Awareness Dates - May

Skin Cancer Awareness Month
Bladder Cancer Awareness Month

25-31 May - European Week Against Cancer

8 May - World Ovarian Cancer Day18 May - European Cancer Nursing Day31 May - World No Tobacco Day

Worth checking



Read:

- o <u>ECPC Senior EU Affairs Officer Adela Maghear interviewed by the Financial Times</u> (ECPC)
- Paper: How well do European patients understand cancer-associated thrombosis? A patient survey (ECPC)
- Discovery of bacteria linked to prostate cancer (The Guardian)

Watch:

 <u>'Recovered, but not under the law'</u> (TV package on the Right to be forgotten by Italian Public Broadcaster RAI)

• Listen:

o Julie - The Unwinding of the Miracle (Apple Podcast)

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