



European Cancer Patient Coalition

Welcome to the **ECPC Newsletter!** Here you will find an overview of the latest information of **the EU cancer patient community, recent policy developments, upcoming events, and other exciting opportunities.**

Check it out

ECPC Board Members Update

Kathi Apostolidis, has been appointed as ECPC President and Treasurer. Kathi was ECPC's elected President from June 2019 to December 2020, an ECPC Board Member from January 2021 to March 2022 and she has served as ECPC's Vice President from June 2013 to June 2019.



Furthermore, she is also a very active cancer patient advocate at the national level and President of the Hellenic Cancer Federation – ELLOK, the Greek national cancer patients umbrella organization.

Matti Jarvinen, ECPC Board Member, has been appointed, Secretary to the Board. Matti joined the ECPC Board in September 2021 and he is also a Board Member of the Association of Cancer Patients in Finland.

ECPC also welcomes Maria Begoña Barragán García, President of GEPAC (Grupo Español

de Pacientes con Cáncer) and **Alina Comanescu**, President of Asociata Sănătate pentru Comunitate in Romania, **who have kindly accepted to be part of the new ECPC Board Member**, according to the results of the 2019 elections.

Ken Mastris, former ECPC President, from January 2021 until 15th March 2022, sent his resignation to the Board, which was accepted.

ECPC Elections

A promotional banner for the ECPC Board Elections 2022. The background shows a person's hand in a red sleeve placing a white envelope into a ballot box. The text 'ECPC Board Elections 2022' is in a yellow box, and '12 April - 18 May 2022' is in a blue box. A white circular sticker on the right says 'Nominate your candidate until 10th April'. The European Cancer Patient Coalition logo and website 'www.ecpc.org' are at the bottom.

ECPC Board Elections 2022

12 April - 18 May 2022

Nominate your candidate until 10th April

European Cancer Patient Coalition

www.ecpc.org

We would like to remind you that this year **ECPC will elect its new Board and Audit Committee. ECPC Full and Associate members can also propose names for the ECPC list of experts.**

We urge all ECPC members to use the opportunity to nominate your preferred candidates that have the knowledge, expertise, skills and passion to represent you in Brussels and are able to bring back to your organization and to your country the lessons learnt in Brussels.

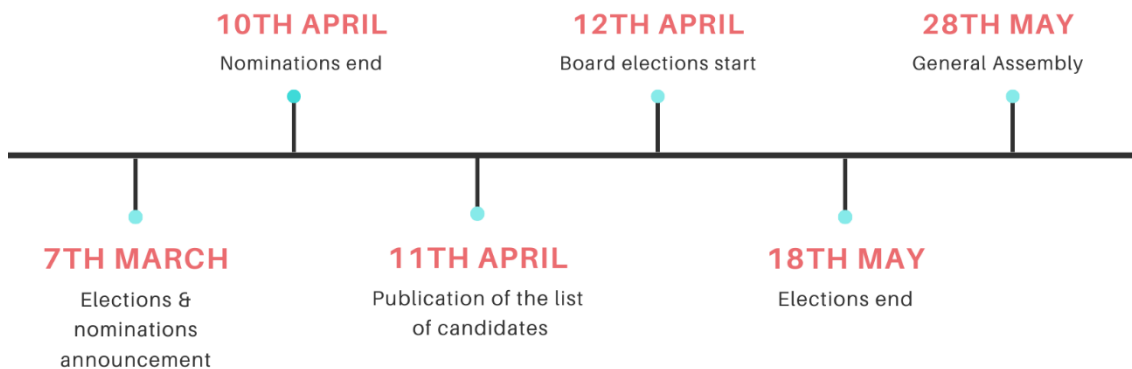
The years to come, cancer and cancer patients will be in the spotlight of the European policy and it is our duty to be strong, present and fight for a Europe where all patients have timely and affordable access to the best treatment and care available.

Please, note that only Full Members are eligible to vote and to nominate the Board candidates. Both Full and Associate Members can nominate candidates for the Audit Committee and propose names for the ECPC list of experts. If you do not know whether you are a Full or an Associate Member, Please [contact the ECPC office](#) or [check our website](#).

Full members

Associate members

The election of the new Board will take place between 12th April - 18th May 2022. We have started to collect candidatures from 7th of March, and the process will close on the 10th of April, midnight CET. The completed form should be sent to elections@ecpc.org.



In order to make sure that all ECPC Full Members have access to the platform, we will offer you all the possibility to test the platform in advance.

According to our statutes, only ECPC Full members have voting rights, therefore, only ECPC Full members will receive the invitation for the test on Wednesday, 6th of April 2022.

Only one email account per full member organization will have voting rights. For that reason, on Wednesday 6th of April, we will send a test email to the main contact email from each organization that we currently have on our database. Please do not forget to check your spam folder.

We will follow up with you on Wednesday, 6th of April, to remind you to check! In case you don't receive it, we will kindly ask you to immediately contact us at: adriana.groba@ecpc.org.

ECPC Conference & General Assembly



The 2022 ECPC Conference and General Assembly will take place the 27th and the 28th of May 2022 in a hybrid mode (online and on site). On Friday, 27th May 2022 from 16:00 to 19:30h CET, we will have the ECPC Conference followed by a cocktail dinner; and on Saturday, 28th May 2022, from 09:30 to 16:00, will take place the ECPC General Assembly 2022. We will share with you the agenda soon.

In the meantime, we are happy to inform you that the **registration for the 2022 ECPC Conference & General Assembly is now open.**

In order to attend the meeting, Full and Associate Members should register in advance. **All registrations must be submitted by Friday 22nd April 2022, midday CET, to allow us to verify your membership status and voting rights. After that date, no more applications will be accepted.**

By registering for the on site participation, you automatically can apply for full travel expense coverage to Brussels. The ECPC Members awarded will be provided directly by ECPC with tickets/travel arrangements to participate at ECPC General Assembly.

All members may attend the General Assembly, **but only Full Members have the right to vote**. Only one representative per Full Member organisation can exercise the organisation's voting rights. **The email address used in the registration form will be the only one valid for future notifications regarding the General Assembly as well as for the voting process.**

In case you are not able to attend the General Assembly, you can appoint another Full Member to vote on your behalf by completing and sending this [Proxy Form](#) to paulina.gono@ecpc.org by **Friday 22nd April 2022, midday CET**.

Please bear in mind that one full member cannot receive more than one proxy.

[Register here](#)

We look forward to virtually meeting you all on the 28th of May.

Take part in our Survey on Nutrition!



Nutrition is a fundamental aspect during the therapeutic course of your cancer journey.

It contributes to the improvement of physical conditions and allows to undergo therapy while better tolerating its negative consequences. In a broader sense, nutrition helps the organism to better cope with the illness.

Click [here](#) to take part on this survey! The questions have been designed to be short and patient friendly. **By participating in this survey, you are helping the cancer patient community in Europe gain a better understanding of the different issues with nutrition that patients deal with in European countries.**

This survey has been developed by the non-profit organization Das Lebenshaus in cooperation with the European Cancer Patient Coalition (ECPC), The European Nutrition for Health Alliance (ENHA) and cancer nutrition researchers from the Sapienza University of Rome, Italy and the University Hospital Jena, Germany. It will take 15 to 20 minutes to complete the questionnaire.

Call for abstracts for UICC World Cancer Congress



World Cancer Congress
Geneva, Switzerland
18–20 Oct 2022

Call for abstracts
until 15 April
Present your work and
achievements to a
global audience



[The Union for International Cancer Control \(UICC\)](#) is calling for abstracts for their World Cancer Congress that will take place in Geneva, Switzerland in October. This would be an exciting opportunity to present your work to a global audience and receive valuable

feedback and new perspectives.

The deadline for submissions is 15th April 2022. All accepted abstracts will be collected in an e-Library available to all participants on the Congress online platform. The highest scored abstracts will also be presented on-site in Geneva and eligible for an Awards recognition.

The Congress online platform will allow abstract presentations to be delivered online and facilitate meetings to present abstracts on-site in lounge areas for participants attending in-person in Geneva.

More information is available through the following [link](#).

MOOC Diagnosing Rare Diseases: from the Clinic to Research and back

The poster features a red background with a yellow ribbon in the top left corner. At the top, it displays the 'EUROPEAN JOINT PROGRAMME RARE DISEASES' logo. The main title 'FREE MOOC' is in large white letters, followed by 'DIAGNOSING RARE DISEASES: FROM THE CLINIC TO RESEARCH AND BACK' in yellow. Below this, it states 'STARTS APRIL 18TH - OPEN 7 WEEKS'. The central illustration shows a person with dark hair and glasses sitting at a desk, working on a computer. The background of the illustration includes icons for a clock, a calendar, a laptop, and various data charts and graphs. On the left side of the poster, there are three key features listed with corresponding icons: 'DURATION: 5 WEEKS' with a clock icon, 'FREE ACCESS' with a calendar icon containing a checkmark, and '100% ONLINE MOOC' with a laptop icon. At the bottom, the URL 'WWW.FUTURELEARN.COM/COURSES/RARE-GENETIC-DISEASE' is provided. The footer contains logos for 'ATHACA', 'EUROPEAN JOINT PROGRAMME RARE DISEASES', the European Union flag, and the 'FOUNDATION FOR Rare Diseases'.

EUROPEAN JOINT PROGRAMME
RARE DISEASES

FREE MOOC

DIAGNOSING RARE DISEASES: FROM THE CLINIC TO RESEARCH AND BACK

STARTS APRIL 18TH - OPEN 7 WEEKS

DURATION: 5 WEEKS

FREE ACCESS

100% ONLINE MOOC

WWW.FUTURELEARN.COM/COURSES/RARE-GENETIC-DISEASE

ATHACA EUROPEAN JOINT PROGRAMME RARE DISEASES EUROPEAN UNION FOUNDATION FOR Rare Diseases

The third run of the [MOOC \(Massive Open Online Course\) “Diagnosing Rare Diseases: from the Clinic to Research and back”](#) co-developed by the European Joint Programme on Rare Diseases, [ERN Ithaca](#), [ERN Genturis](#) and the Foundation for Rare Diseases will start on April 18th. Registrations are free and open at this [link](#).

We specifically encourage medical and biomedical science students to register and follow the MOOC.

You can check the syllabus [here](#).

Latest news on the Right to Be Forgotten among Europe



[The Irish Cancer Society](#) recently published the report: 'The Right to be Forgotten beyond cancer: Access to financial products and services'.

This report highlights that:

- Refusal and unfair treatment were the greatest reported difficulties experienced by those affected by cancer, at a higher rate than the general population.
- Only 1 in 4 people affected by cancer feel that they have been treated fairly when buying financial products in Ireland, compared to half the general population.
- Seven in 10 people in the general population and 9 in 10 affected by cancer believe that a cancer diagnosis should not mean having an additional premium on insurance costs or be a barrier to getting credit.
- Nine in 10 people believe that the Right to be Forgotten should apply to people affected by cancer.

Take a look at the full document [here](#).

InCARE survey on experiences, attitudes, and expectations on long-term care!



[Eurocarers](#) would like to understand how people view care for older people with support needs and how they assess long-term care systems, more generally. How do people want those close to them or themselves to be looked after, should they need it? What are their experiences with receiving or providing care? And what are their expectations for the future?

For that, they have created this [survey](#) in order to collect information on the attitudes, experiences and expectations on long-term care, and to design better support systems for older people with care needs, for their families and communities.

Members' corner

Please, [share with us](#) your news and activities so we can include them in the next newsletter



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