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

If someone forwarded this newsletter to you, you can subscribe here.

LEGACy project: New study on gastric cancer

Can stomach cancer be inherited? Does the use of the refrigerator to preserve food lowers the risk of stomach cancer? Participate in this study to help us to determine awareness levels of the risk factors and warning signs in the general population associated with gastric cancer. The questionnaire is available in English, Spanish.
EU Parliamentary Intergroup Challenge Cancer hosted a public event “EU Joint Action on Rare Cancers (JARC) recommendations towards implementing the Rare Cancer Agenda 2030” on Wednesday 24th February 2021. Following the launch of the EU’s Beating Cancer Plan, the event was a timely opportunity to discuss the implementation of the Rare Cancer Agenda 2030 in the EU.

The shortcoming of the European Reference Networks is the lack of awareness among patients and, as a result, the lack of access to the benefits offered by these networks because access is strictly linked to hospitals. The activity of the ERNs is currently hampered by the lack financial support for infrastructure. Mainly ERN’s implementation at national level and their accessibility for patients was the main objective of the debate.

Please click here to read the press release

Watch again our webinar “14 Million Reasons to Discuss Life after Cancer: Implementing the Right to be Forgotten across Europe”
This online event on cancer survivorship that took place on Friday 19th February 2021 focused on the implementation of the Right to be Forgotten, a right which can help ensure that former cancer patients no longer suffer from financial discrimination for financial services such as getting loans and mortgages following the end of their treatment. The online event provided a platform for key stakeholders to collaborate on identifying the right path for the implementation of this right across Europe.

You can read the report of the event here.
The White Paper calls for **increased access to cancer biomarker testing**, to identify those who will benefit most from precision cancer medicines.

Advances in biomarker testing are having a transformative impact on cancer care, but Europe will have to overcome significant barriers in the equitable access and quality of these tests to realise their full potential, concludes an important new study released by the International Quality Network for Pathology (IQN Path), the European Cancer Patient Coalition (ECPC) and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

The study presents the results of research conducted in 2020 to assess the availability, quality and reimbursement of biomarker tests in the EU27 and the United Kingdom, identify country-specific shortcomings, and develop policy recommendations to improve equitable access to and quality of biomarker testing across Europe.

Please click here to read the press release
"I feel healthy, why should I be tested?" The European Association of Urology (EAU) has prepared a page with relevant and valuable information on prostate-specific antigen (PSA) testing. Would you like to know more? Keep reading here!

Prostate cancer shows no clear symptoms and men are normally not aware it has developed unless it is far advanced. If the disease is not discovered and diagnosed in its early stages, men can develop symptoms such as bone pain. For that reason, **early detection is aimed at finding this asymptomatic cancer in an early stage where it can still be cured** and stopped from moving to an advanced stage.
Like prostate cancer, **Multiple Myeloma** is a cancer that poses an under-recognized risk to those same populations at high risk from breast, colo-rectal, and prostate cancers. Listen to the **interview with Drs. Irene Ghobrial and Karen Winkfield**! If you are interested, you can watch more videos about it [here](#).

Please contact the PROMISE Study research team at the Dana Farber Cancer Institute through their website [www.promisestudy.org](http://www.promisestudy.org) or by email at [promisestudy@partners.org](mailto:promisestudy@partners.org) if you have any questions or are interested in participating in the study.

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**What's coming up**

**Cancer Won't Wait: Building Resilience in Cancer Screening and Diagnostics in Europe based on Lessons from the Pandemic**

The webinar **“Cancer Won't Wait: Building Resilience in Cancer Screening and Diagnosis in Europe based on Lessons from the Pandemic”** will take place on **Tuesday 11th March 2021 from 15:00 to 16:00 (CET)**.

The ongoing impact of COVID-19 on health services across Europe has led to significant reductions in cancer screening, testing and diagnosis. Delays in diagnosis are impacting cancer treatment and survival and are likely to continue for years to come. Responses to the pandemic have differed within individual countries and for specific tumour groups, with some countries responding exceptionally well under the circumstances. Emerging from the clamor are examples of best practices that provide the basis for further discussion.

**Online event 'Integrative Oncology' the holistic approach to cancer care**
The European Parliament event “Integrative Oncology – the holistic approach to cancer care” will take place on Wednesday 17 March 16.00-18.00 CET. If you have any questions about the holistic approach of cancer treatment you don’t want to miss out this opportunity. Listen to and speak with leading experts and members of the European Parliament.

The registration deadline is 16 March 2021 17.00 CET and it needs to be done through this link. After registration, you will receive the link to the livestream of the event. Join and take part in the discussion!

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**ECPC recommends**

- Did you know that early detected prostate cancer can be easily cured without significant side-effects and at a rather low price. ECPC, Europa Uomo and EAU have created a factsheet and a diagram focused on early detection. Have a look at it!

- **What matters most to lung cancer patients?** PREFER project looks at how and when it is best to perform and include patient preferences in decision making during the medical product life cycle. Several publications have been issued that may be of interest to you!
  - Patient Preferences in Rare Diseases: A Qualitative Study in Neuromuscular Disorders to Inform a Quantitative Preference Study
  - What Matters Most to Lung Cancer Patients? A Qualitative Study in Italy and Belgium to Investigate Patient Preferences

- A free massive open online course (MOOC) “Introducing co-creation and design methodologies for policy-makers” has been developed. It is time to start transforming policymaking! Participants will learn the basics on how to collaborate directly with citizens to build better policies. The videos will be available in English,
Members' corner

Please, share with us your news and activities so we can include them in the next newsletter

New ECPC members