



# European Cancer Patient Coalition

## Special Newsletter focused on the Right to Be Forgotten

Provide your feedback on an anonymous survey on the financial impact of a cancer diagnosis



**The Netherlands Cancer Institute is developing patient research on the financial effects of a cancer diagnosis.** This Institute, in collaboration with the German DKFZ Heidelberg, would like to learn more about the financial effects of a cancer diagnosis and how (former) cancer patients feel about this additional burden. The survey is anonymous, and the results are intended to help improve future cancer care.

Please provide your feedback [here](#) (The survey is available in all EU languages)



## Implementing the Right to Be Forgotten across Europe

We are pleased to announce that **the Right to Be Forgotten has been approved in Portugal and it will be implemented by January 2022.**

On 14th May, two Portuguese parties - the Socialist Party and the People, Animals and Nature Party- presented two law projects. On the same day, the parliament voted for one of the two proposals. Since then, the law-making was ongoing undertaking discussions with the relevant stakeholders, including cancer patient's organisations and the Portuguese doctors' association. Finally, on the 22nd October, the Portuguese Parliament voted and approved it.

The final version of the law approved is available [here](#) (in Portuguese).

By January 2022, **Portugal will become the 5th country to ensure cancer survivors access to financial instruments. One step towards the implementation of the Right to Be Forgotten across Europe.**

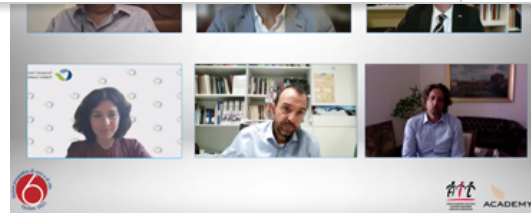
Watch the [video from Acreditar](#) (Association of Parents and Friends of Children with cancer)

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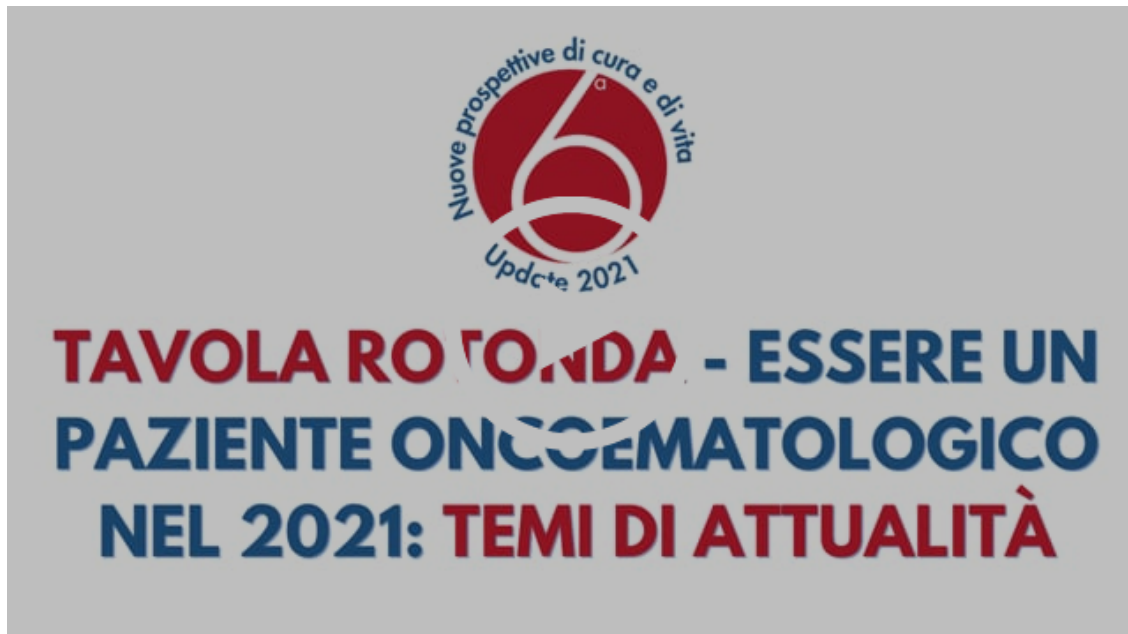
**AIL- Gruppo pazienti has launched a proposal for a working group on the implementation of the Right to Be Forgotten in Italy**

**During the Sixth National Conference "The**

against [Leukemia](#), [Lymphomas](#) and [Myeloma](#), the Right to Be Forgotten for cancer survivors was introduced as a policy topic in a panel attended by MEP Alessandra Moretti, Grazia Scocca (ECPC Legal Specialist) and other relevant Italian experts.



On the same occasion, the results from a survey addressed to haematological patients were presented. Data showed that around 13% of them experienced issues in access to financial services and around 65% declared to be in favour of a law on the Right to Be Forgotten in Italy.



Watch the recording of the event (in italian)

The Sub-group on Cancer under the Steering Group on Health Promotion Disease Prevention and Management of Non-Communicable Diseases discussed the issue about the Right to Be Forgotten



On the 23rd September, the **Sub-group on Cancer under the Steering Group on Health Promotion Disease Prevention and Management of Non-Communicable Diseases** discussed the issue about the **Right to Be Forgotten** in the context of fair access to financial services for cancer survivors.

[The meeting report](#) announced a study activity will be conducted to assess the situation in the **EU Member States** and also a **stakeholder consultation** to heard from broader audiences regarding the need for EU-level action to ensure equitable access of cancer survivors to financial products. These activities will take place in November 2021 with a final report delivery date scheduled for February 2022.

**The Right to Be Forgotten debated in the ESMO 2021 Patient Advocacy Track**



15:10 - 16:10 The burden of cancer: Cancer's financial toxicity and the right to be forgotten



**The burden of cancer: cancer's financial toxicity and the Right to Be Forgotten was the main topic of the first panel of the ESMO 2021 Patient Advocacy Track.**

Grazia Scocca (ECPC Legal specialist) contributed to the discussion with an overview on the Right to Be Forgotten, the content of the project and the role played by the European Union.



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