21 OCTOBER 2026

Event Report

UNIVERSITY FOUNDATION, RUE D'EGMONT 11, BRUSSELS

Ending Discrimination Against Cancer Survivors

The Right to be Forgotten as a Human Right

*THIS EVENT WAS RECOGNISED AS AN **ASSOCIATED EVENT OF THE IRISH PRESIDENCY** OF THE COUNCIL OF THE EUROPEAN UNION 2026*



CO-CHAIRED BY

Prof. Françoise Meunier

Founder, Ending Discrimination Against Cancer Survivors

Prof. Mark Lawler

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Master of Ceremony: Lutz Dommel, CEO, RPP Group; Partner, Paritee

With the support from Fonds Cancer (FOCA)

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Ending discrimination against cancer survivors

In collaboration with
Irish Cancer Society

AT A GLANCE

A right that should not depend on your postcode

On 21 October 2026, survivors, patient advocates, clinicians, epidemiologists, legal experts and policymakers met in Brussels for the High-Level Conference **The Right to be Forgotten as a Human Right**, an Associated Event of the Irish Presidency of the Council of the EU. Organised by the Ending Discrimination Against Cancer Survivors initiative (EDACS) with the Irish Cancer Society and the support of Fonds Cancer (FOCA), it brought together nearly 30 speakers from 11 countries. The full programme is available on the conference page.

Two years after the first conference under the Belgian Presidency asked that a person cured of cancer **"should not pay twice"**, the room celebrated real progress: Ireland's statutory Right to Be Forgotten had entered into force just six days earlier, while Malta's adoption of its law brought the number of EU Member States that had legislated for the right to 11. Momentum is also building in Germany, Luxembourg and Czechia. Yet protection remains uneven, varying by country, financial product and waiting period.

11 MS	5 yrs	~30	-85%
+ Monaco & Andorra with a legal right to be forgotten	after treatment without relapse: the standard called for	speakers from 11 countries	premiums for the first Irish survivors using the law

KEY TAKEAWAYS

01

Human Rights, not compassion

When data show a survivor's risk matches the general population, financial rules must follow.

02

Survivors shape the rules

Discrimination reaches far beyond mortgages: insurance, jobs, civil service, child adoption.

03

A law is only the start

Monitoring, appeal mechanisms and awareness matter as much as adoption.

04

Codes are not rights nor binding

Voluntary industry codes are insufficient, only legislation gives certainty.

05

Rules and practices must follow progress of medicine

Evidence-based reference grids allow shorter periods for good-prognosis cancers.

06

One European standard

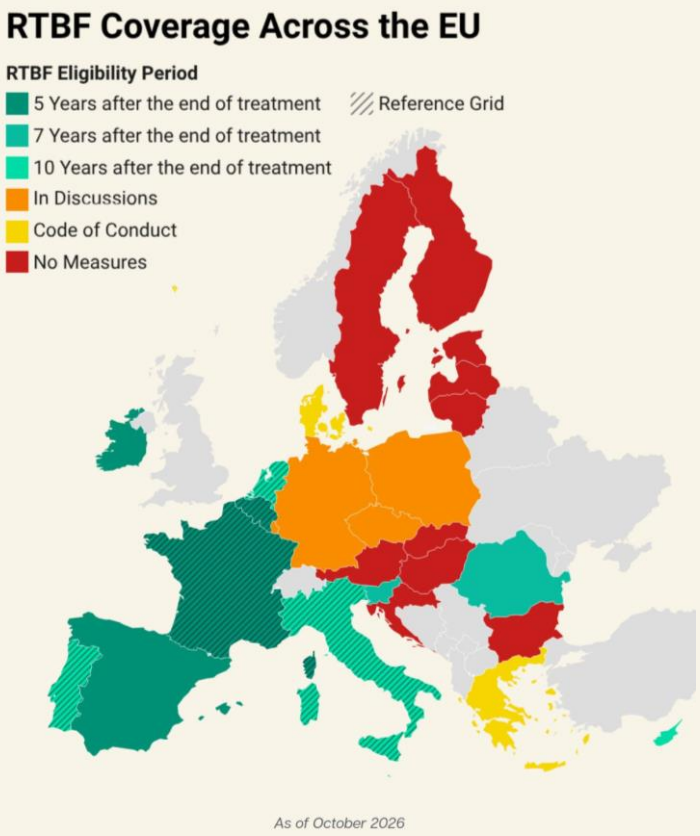
A binding EU framework built on a standard five years rule after the end of treatment without relapse.

WHERE EUROPE STANDS

11 Member States + Monaco & Andorra, but still a patchwork

Since France legislated in 2016, **11 EU Member States plus Monaco and Andorra** have adopted a legal right to be forgotten, Ireland and Malta being the latest. But the existence of a law does not mean equal protection: national systems differ on **waiting periods**, cancers covered, childhood cancers, reference grids and the **financial products** concerned.

At EU level, the **Consumer Credit Directive** (to be applied from 20 November 2026) is a first step, but it excludes mortgages and allows periods of up to 15 years – an excessively long time for cancer survivors to face continued financial discrimination.



Right to be forgotten coverage across the EU, as of October 2026. Source: EDACS. More on national and EU developments on the EDACS website.

INTRODUCTORY REMARKS · SETTING THE AMBITION FOR THE DAY

Five years, and not a day more

Prof. Françoise Meunier, Founder, EDACS • Prof. Mark Lawler, Queen's University Belfast • Master of Ceremony: Lutz Dommel, CEO, RPP Group

Welcoming nearly 30 speakers, **Lutz Dommel** framed the day as one journey, starting with the people it is all about: survivors. For co-chair **Prof. Françoise Meunier**, the conviction has not changed since her first commitment to this cause in 2014: once an oncologist says a patient is cured, banks and insurers should adapt. Five years after the end of treatment without relapse, or sooner where evidence allows, a past cancer should no longer

compromise access to **any financial product** in any EU country. *"This is not a favour. This is not about compassion. It is about dignity, equality and non-discrimination."*

Ireland shows what evidence can achieve. Faced with a proposed seven-year period, **Prof. Mark Lawler** and the Irish Cancer Society brought international benchmarking data to the Minister, indicating that, five years after successful treatment, cancer survivors faced a comparable level of risk to the general population. When the Minister saw the hard evidence, he agreed to and implemented the five-year benchmark. On the law's first day, monthly mortgage protection premiums for the first two cancer survivors fell from **€451 to €75** and from **€270 to €35**, a drop of about 85%. Prof. Lawler's advice: *"Never be satisfied until you get what you want."*



Figure 1. Prof. Mark Lawler and Prof. Doctor Françoise Meunier opening the conference

SESSION I · LIVING BEYOND CANCER: SURVIVOR EXPERIENCES AND THE REALITY OF FINANCIAL DISCRIMINATION

A past diagnosis should not be a life sentence

Moderator: Kinga Wójtowicz, RPP Group • Jacqueline Daly (IE) • Magali Mertens de Wilmars (BE) • Izabela Chełkowska-Klasa (PL) • Miriam Vogt (DE) • Dr. Stefan Schmidt (DE) • Antonella Cardone, Cancer Patients Europe

Five testimonies from four countries showed the same pattern: treatment ends, but the diagnosis keeps returning in every application for loans or mortgages. In Ireland, mortgage protection was so expensive for **Jacqueline Daly** and her husband, both survivors, that they turned to their savings and their credit union. Welcoming Ireland's new law, she stressed it covers mortgage protection only: *"Your home should be yours, your future should be yours, and your past should not hold you back forever."*

Even in Belgium, with one of Europe's strongest laws, **Magali Mertens de Wilmars** received dozens of pages of sensitive medical questions 14 years after her diagnosis, including questions on how the health of the child she was carrying at the time of the application. She sent the law back with her answers. *"We cannot be second-class citizens."* In Poland, which still has no law, **Izabela Chełkowska-Klasa** saw her family refused a housing loan after her husband's cancer, and was **dismissed** the moment she was diagnosed herself: *"The right to be forgotten is not a privilege. It's an absolute necessity."*

Germany has no law yet either, but momentum is growing. Cancer-free since 2010, **Miriam Vogt** was offered life insurance at more than twice her husband's premium and settled for cover against accidental death only: *"A person's future after cancer should not depend on luck."* More than 20 years after childhood sarcoma, **Dr. Stefan Schmidt** was refused occupational disability insurance by some 20 insurers, and his path to a professorship is threatened by a civil service health check: *"I demand that I can finally reach the finish line."*

Across all these stories, **Antonella Cardone** of Cancer Patients Europe (CPE) highlighted the limitations of voluntary industry commitments, recalling CPE's concerns regarding the proposed ten-year waiting period during discussions on an EU code of conduct. She emphasized the importance of binding legislative protections to ensure that cancer survivors can effectively exercise their rights. From the floor, a professor urged the medical profession to take up the cause (*"We don't treat cancer, we treat people"*), and a survivor called for concrete stories to reach European citizens. Closing the panel, Lutz Dommel called on everyone to challenge discriminatory practices wherever they meet them: *"We will never have perfect laws, perfect rules, even if we strive for them. But it is our own obligation and responsibility to fight for a better world."*

Following their testimonies, **Professor Lawler** led a standing ovation, praising the courage and determination of the panelists in the face of unacceptable discrimination.



Figure 2. Kinga Wójtowicz, Jacqueline Daly, Magali Mertens de Wilmars, Izabela Chełkowska-Klasa, Miriam Vogt, Dr Stefan Schmidt, Antonella Cardone

SESSION II · FROM COMMITMENT TO ADVANCING THE RIGHT TO BE FORGOTTEN ACROSS EUROPE: NATIONAL PERSPECTIVES

From law on paper to protection in practice

Moderator: Kinga Wójtowicz • Hugo Soares, AICIB (PT) • Emma Harte, Irish Cancer Society (IE) • Dr. Gabriele Calaminus, University Hospital Bonn (DE) • Prof. Dr. Inken Hilgendorf, Jena University Hospital (DE) • Pavel Trcka, HOP – Cancer Patients Voice (CZ) • Video message from Poland

A law does not reach patients automatically. Adopted in 2021, Portugal's law then stalled for almost three years until patient and consumer groups filed a **formal complaint** against the State; the framework was only completed in April 2026, now extended to HIV, diabetes and hepatitis, as well as loans for commercial and professional purposes. *"How does this get to patients? Well, in Portugal, it gets slowly,"* said **Hugo Soares**, calling for permanent rather than volunteer-based **monitoring**.



Figure 3. Kinga Wójtowicz, Hugo Soares, Emma Harte, Prof. Dr. Inken Hilgendorf, Dr. Gabriele Calaminus, Pavel Trcka

Ireland's more than five-year campaign offers a playbook, shared by **Emma Harte**: put **lived experience** at the centre, compile the evidence-base, build cross-party consensus, engage the media, and pivot when needed, as when industry launched a seven-year voluntary code in 2023. Five years is now law.

In Germany, the medical case is clear. **Dr. Gabriele Calaminus** distinguished **cure from care**: follow-up for potential late effects is not a continuing risk from the original cancer, and German data show survivors use health services like everyone else. *"Cure is cure from the original cancer."* Politically, **Prof. Dr. Inken Hilgendorf** traced the campaign from a 2023 survey to resolutions by the Bundestag in April and the Bundesrat on 16 October 2026; implementation is still pending. Quoting Goethe: *"Enough words have been exchanged; let me finally see some action."*

In Czechia, parliamentary approval on 21 October marked progress towards a **seven-year Right to be Forgotten**, covering insurance linked to non-housing consumer credit under the EU Consumer Credit Directive, but excluding mortgages. An existing insurers' grid will continue to apply alongside the new framework. For Pavel Trčka, **"legislation provides certainty"**, a guarantee that voluntary commitments alone cannot offer. A video message by Piotr Rutkowski from Poland described an insurers' offer of 10 years (five for paediatric cases) and a joint call by ombudsmen and oncology bodies for five. Closing the session,

Prof. Meunier urged countries **not to reinvent the wheel**, especially when France and Belgium have shown it works without jeopardizing insurers financial sustainability.

FROM EVIDENCE TO FAIRER RULES: CANCER INEQUALITIES FACTS & FIGURES

The data are clear: more and more survivors are cured

Caroline Berchet, OECD • Dr. Luigino Dal Maso, CRO Aviano, IRCCS National Cancer Institute (IT)

Inequalities run along the whole cancer pathway. With **2.7 million** new cases in the EU in 2024, mortality is falling, but men in Latvia die of cancer at almost twice the rate of men in Sweden, and screening participation remains below half for colorectal cancer. A diagnosis also cuts the likelihood of employment by **14%** on average, the gap being widest in Central and Eastern Europe. For **Caroline Berchet**, *"prevention policies are developing, but we need to target the most vulnerable."*

Cure can be measured. Across Italy, more than **85%** of people living after a cancer diagnosis, seven in eight, have the same life expectancy as the general population, rising to 93% five years after diagnosis. For testicular, thyroid and early-stage melanoma, breast and colorectal cancers, and Hodgkin lymphoma, "time to cure" is under three years. *"Insurance must not exclude nor penalize these people,"* concluded **Dr. Luigino Dal Maso**. Dr. Dal Maso also mentioned the possibility to take into account data from diagnosis while laws count from the end of treatment.



Figure 4. Caroline Berchet, Lutz Dommel, and Luigino Dal Maso

KEYNOTE SPEECH

Enforceability matters: Ireland's road to a statutory right

Robert Troy TD, Minister of State at the Department of Finance (IE)

A voluntary code, introduced in Ireland in 2023, proved the protection works, but "a voluntary arrangement does not create a statutory right". Signed into law on 15 July 2026 and in force since 15 October 2026, Ireland's new Act is a **right to disregard** once the conditions are met, qualifying cancer history cannot be used to refuse cover or raise premiums. The Government went beyond the code, based on the provided evidence, cutting the benchmark from **seven to five years** and raising cover to **€650,000**, reviewed every five years. Sharing that he lost two siblings to cancer, **Minister Robert Troy** urged participants to respond to the European Commission's targeted consultation.

> *"When it comes to human rights, enforceability matters."* — **Minister Robert Troy**

FOUR LESSONS FROM IRELAND

1

Survivors at the heart

Five years means around 140 more survivors a year can access mortgage protection.

2

Grounded in evidence

The voluntary code tested protection; the data and the experience of other Member States showed the way.

3

Cooperation matters

Survivors, cancer professionals, actuaries, insurers and officials around one table.

4

Designed to evolve

Monitor, review and update as medicine and housing markets change.



Figure 5. Minister Robert Troy, Minister of State at the Department of Finance, Ireland

THE UK EXPERIENCE

Righting a wrong across the four nations

Survivors in ten Member States and now Ireland are protected, but not in Northern Ireland, Scotland, Wales or England, where there is neither a law nor a code. With Cancer Focus Northern Ireland, cross-party support at Stormont and new YouGov evidence, **Prof. Mark Lawler and Cancer Focus Northern Ireland** will launch a UK-wide campaign at Westminster, focusing not only on adults but also highlighting the lifelong impact on children cured of cancer. *"There is life after cancer, let's make it the best life possible, without fear of financial discrimination."*



Figure 6. Prof. Mark Lawler

SESSION III · THE RIGHT TO BE FORGOTTEN AS A HUMAN RIGHT: ENDING DISCRIMINATION AGAINST CANCER SURVIVORS

Not compassion, but dignity, equality and proportionality

Moderator: Prof. Françoise Tulkens, former Vice-President, European Court of Human Rights • Prof. Isabelle Rorive, ULB Equality Law Clinic (slides presented in her absence) • Dr. Grazia Scocca, legal researcher • Prof. Florence Caeymaex, ULiège

Opening the roundtable, **Prof. Françoise Tulkens** welcomed a day that began with survivors, because *"human rights should be concrete and effective"*, and preferred "ending discrimination" to the more ambiguous term "right to be forgotten". **Prof. Isabelle Rorive** set out through her slides that medical information can be accurate and initially relevant, yet

become **disproportionate** over time: *"the legal relevance cannot be presumed to continue forever."* Not every difference is discrimination; it must pursue a legitimate aim, be objectively justified and **proportionate**. Her Equality Law Clinic proposes bringing the issue to the **European Committee of Social Rights of the Council of Europe (Strasbourg)**.

What happens when society keeps defining someone by a past illness? Drawing on philosopher Claire Marin, **Prof. Florence Caeymaex** described "healthism", a system in which lives seen as damaged are devalued, and defended *"the right to be oneself instead of being merely a diabetes, a psychosis, a cancer."*

Drawing on an overview of 11 existing national initiatives, **Dr. Grazia Scocca** highlighted the risk of fragmentation arising from diverging national approaches, whereby people with the same cancer history may enjoy different levels of protection depending on their country and the financial product concerned, creating "**an inequality within inequalities**". She stressed the need for a European framework built around **three priorities**: common minimum standards; enforceable protection, including effective complaints mechanisms and safeguards against indirect questions; and extending protection beyond mortgages, including to employment.

Discussion focused on remedies. A case before the **European Court of Human Rights** is possible but slow, while the **Social Charter route** can take around two years. A survivor and advocate, dismissed after her diagnosis, asked whether focusing on mortgages is fair to those excluded from work; the panel agreed the right to be forgotten is one **proven tool** in a wider puzzle, and that specific problems need specific solutions requiring dedicated legislative approaches.



Figure 7. Prof. Françoise Tulkens, Prof. Florence Caeymaex, and Dr Grazia Scocca

SESSION IV · BEST PRACTICES: FROM ADOPTION TO IMPLEMENTATION

What makes a law work: evidence, awareness and follow-up

Moderator: Kinga Wójtowicz • Dr. Iris Pauporté, La Ligue contre le cancer (FR) • Prof. Maëlle de Ville de Goyet, Cliniques universitaires Saint-Luc (BE) • Dr. Irina Odnoletkova, KCE (BE) • Delia Nicoară, Oncology Institute Prof. Dr. Ion Chiricuță (RO) • Dr. Corinne Gail De Gabriele (MT) • Dr. Amanda Spiteri Grech, former MP (MT)

France needed 25 years, from the 2001 Belorgey convention to AERAS and the 2015 agreement signed by President Hollande, to reach today's **five years** after treatment, with hormone therapy and immunotherapy not counted. *"If there is not a law, nothing can be done,"* said **Dr. Iris Pauporté**. La Ligue's helpline still collects cases, now to cover **treatment-related sequelae**.

With some 85% of children now cured, half a million Europeans are childhood cancer survivors. Late effects are not recurrence, and a historical diagnosis does not describe a person's risk, argued **Prof. Maëlle de Ville de Goyet**, whose follow-up clinic informs young survivors of their rights: *"It is our responsibility as physicians to inform our patients."* Belgium keeps its rules up to date with evidence: KCE studies cut waiting periods for early breast cancer and support **no waiting period** for over 90% *of thyroid cancer patients*. For **Dr. Irina Odnoletkova**, the strength of the model *"is in transparency and very broad stakeholder involvement."*

In Romania, the seven-year law is *"adopted, not implemented,"* slowed by political instability, a shrinking workforce and the absence of follow-up systems; **Delia Nicoară** asked who will fund the patient organisations filling the gaps. Malta shows how quickly things can move. Cured of lymphoma at 12, **Dr. Corinne Gail De Gabriele** helped draft the new law: five years for those diagnosed before 25, ten otherwise, shorter lists set yearly, and a board deciding within a week. *"Let's not have to fight any more levels."* **Dr. Amanda Spiteri Grech** launched a public consultation and plans a foundation once the law applies from 1 January 2027: *"Cancer is part of the past and shouldn't define us."*

Questions from the floor highlighted what is still missing: data on how many survivors actually use the law, awareness among patients and physicians, and information for citizens **before** they fall ill, through schools, digital tools and the European Health Data Space.



Figure 8. Dr Iris Pauporté, Dr Irina Odnoletkova, Prof. Maëlle de Ville de Goyet, Delia Nicoară; Dr Corinne Gail, and Dr. Amanda Spiteri Grech

FINAL REFLECTIONS & CLOSING REMARKS

Towards one European standard

Moderator: Kinga Wójtowicz, RPP Group • Closing: Prof. Françoise Meunier and Prof. Mark Lawler

The ball is moving, with **11 Member States + Monaco & Andorra** now protecting survivors by law, yet protection still depends on where survivors live and which product they need. Summing up, **Kinga Wójtowicz** recalled that medical data and progress must be followed by policy action, and that a code of conduct *"does not guarantee your statutory rights."* **Prof. Mark Lawler** will take the conference's messages back to Minister Troy before the Irish Presidency ends on 31 December 2026 and proposed an EU project to collect the missing data. "Evidence, not opinion, is the key – the data do not lie".

> *"Cancer patients should not pay twice. Today we say it again, louder; we wish equal access to insurance for all EU cancer survivors."* — **Prof. Françoise Meunier**

POLICY PRIORITIES OF THE INITIATIVE

1

A binding EU framework

No penalty for a past cancer after a medically justified five years, shorter where evidence allows.

2

Stronger national laws

While EU action is pending, adopt or strengthen national laws on a five-year timeline.

3

The European Social Charter

Use Council of Europe mechanisms to treat these barriers as a social rights issue.

NEXT STEPS

- Pursue the three policy priorities with the EU institutions, building on the Irish Presidency and the Commission's targeted consultation.
- Support adoption in Germany, Poland and the UK, implementation in Romania, Malta and Czechia, and monitoring in Ireland and Portugal.
- Close the data gap on uptake and impact and raise awareness among survivors and healthcare professionals in all EU Member States.



Figure 9. Speakers of the 2026 High-Level Conference

Thank you to Minister Robert Troy, the Irish Cancer Society, Fonds Cancer (FOCA), RPP Group, the University Foundation, all speakers and moderators, and above all the survivors who shared their stories.

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