

There is Life after Cancer:

Putting an End to the

Discrimination



On Tuesday 9 June 2020, the European Cancer Patient Coalition (ECPC) hosted an online event entitled **"There is Life after Cancer: Putting an End to the Discrimination"**. Over 180 people registered for this event dedicated to raising awareness of cancer survivorship issues in the European Union (EU), the success of this event led to participants calling for the formalisation of a **European Cancer Survivors Day**.

What did our Speakers say?

Ms. Antonella Cardone, *ECPC Director*

1. "Survivorship is a unique and ongoing experience; different for each person and those close to them."
2. "Despite the rising number of cancer survivors, almost all EU countries lack adequate policies to ensure rehabilitation and smooth reintegration of cancer survivors into social and professional life."
3. "Raising awareness of the challenges cancer survivors face will always be at the core of ECPC's list of priorities."

Doctor Françoise Meunier, *Chair of the Cancer Survivorship Committee, EACS*

1. "There are more than 12 million cancer survivors in the EU and many, without any medical justification whatsoever, are being turned away or imposed excessive premiums by insurance providers when they seek financial services."
2. "The EU has the competence to address the Right to be Forgotten which falls under the provisions of the Single Market and Consumer Protection Policy. It is our duty to ensure the Right to be Forgotten so that cancer patients never again have to pay twice for their disease."
3. "The Right to be Forgotten is only one of the many challenges cancer survivors must face; it is high-time to launch a formal and consistent celebration of survivorship in Europe."

Doctor Grazia Scocca, *ECPC*

1. "The Right to be Forgotten has already been recognised in France, Belgium and Luxembourg; the good news for an EU approach to overcoming this challenge is that these three initiatives have a lot of commonalities."
2. "The recognition of the Rights to be Forgotten ensures more transparency and equity in practices related to access to financial instruments, it plays a key role in empowering cancer survivors."
3. "The Dutch government is working on implementing the Right to be Forgotten in their national system, their proposal is also inspired by existing provisions in France, Belgium and Luxembourg."

Professor Mark Lawler, *Queen's University Belfast*

1. "In the past, the focus has been on cancer diagnosis and cancer treatment; cancer survivors were not adequately recognised."
2. "The European Cancer Patient Bill of Rights and ECPC's Europe of Disparity in Cancer Care provided evidence of the discrimination which exists for cancer survivors."
3. "We have to develop cancer survivorship research and take a nuanced view of the challenges people living beyond cancer face; whether they are financial, social or psychological."

Ms. Janette Rawlinson, *Patient Advocate*

1. "One of the key issues cancer survivors must overcome is the need to pick up their lives after their cancer treatment."
2. "When it comes to cancer survivors, we need to find out what makes them tick. We need to focus on what matters to them as opposed to what is the matter with them."
3. "Cancer survivors are an asset; in no other area would we abandon such a valuable resource in the way that we do for cancer patients. Policy makers must take a broad perspective to cancer survivorship and develop appropriate policies."

MEP Petra De Sutter, *Vice-Chair of the MEPs Against Cancer Group*

1. "Europe's Beating Cancer Plan will be announced by the end of the year 2020 and will take a holistic approach to cancer and focus on every aspect of cancer care; cancer survivorship is of course important part of the Plan."
2. "We can dream of a harmonised approach to the Right to be Forgotten, but more coordination between Member States would already be a huge step forward. People should enjoy the freedom of moving from one country to the next and taking their rights with them across EU borders."
3. "Members of the European Parliament will make sure that the topic of cancer survivorship will take its place at the top of the European agenda."

MEP Tomislav Sokol, *Member of the MEPs Against Cancer Group*

1. "When we speak about the Right to be Forgotten, we must consider its implications on the Internal Market. This is the strongest area of competence for the European Union and provides a path for regulating this discrimination."
2. "Discrimination against cancer survivors in countries of central and eastern Europe is a persistent issue given that these Member States have yet to adopt the appropriate legislation."
3. "We need to raise awareness of the Right to be Forgotten within the various European institutions and continue to organise events such as this webinar."

What did we learn?

- MEP De Sutter and MEP Sokol underlined their support for cancer survivorship issues and their commitment to addressing the Right to be Forgotten within Europe's Beating Cancer Plan and the Cancer Mission.
- The European Commission is analysing national legislation regarding the Right to be Forgotten and it has confirmed that this challenge will be addressed within Europe's Beating Cancer Plan.
- ECPC and Dr. Françoise Meunier called for the formalisation a European Cancer Survivors Day and the organisation of an annual event dedicated to cancer survivorship.

Our Audience

The webinar's audience was largely composed of patient advocates and industry representatives, but also members of the European Commission and the European Parliament, as well as several national health authorities. It represents a tremendous achievement for ECPC and Dr. Meunier which would not have been possible without the support of the European Commissioner for Health and Food Safety, Ms. Stella Kyriakides, and devoted policymakers within the European Parliament.

