

The right to be forgotten for cancer survivors

Prof. Françoise Meunier

- I am delighted to join you today and attend a meeting of the BECA Committee whose work I am sure will lead to the development of many productive initiatives in the field of cancer and lead to the further protection of European cancer patients, survivors, and their families.
- I am Professor Françoise Meunier and, for more than 45 years, I have dedicated my professional life to improving the survival and quality of life of cancer patients. Thanks to the tremendous progress of medicine and research in the last decades, our society has witnessed a tremendous decrease in cancer-related mortality, and we have successfully ensured that cancer is no longer a death sentence.
- Since 2014, I have dedicated the last part of my professional activities to cancer survivorship issues. Lately, my efforts have been devoted to the development and implementation of an EU approach to the Right to be Forgotten.
- Nowadays, there are more than 14 million cancer survivors in the EU. This means that more and more citizens survive cancer and look to resume their lives and take part in socio-economical activities.
- For former patients, financial discrimination remains a true obstacle that we have to overcome as they look to restore their quality of life following the end of their treatment. Today, cancer survivors across Europe are facing numerous challenges such as the psychological impact of their treatments, workplace marginalisation and limited access to financial services such as mortgages and loans. For former patients, financial discrimination remains a true obstacle that we have to overcome. I am often led to wonder why cancer survivors have to pay twice for their disease, once because of their condition which is followed by a second penalisation following the end of their treatment.
- An encouraging point is that solutions and legal frameworks have been developed in a number of European countries. Laws on the Right to be Forgotten have been implemented in France, Belgium, Luxembourg and more recently the Netherlands.

The good news for a European approach to the Right to be Forgotten is that these national initiatives have a lot of communalities and largely implement the same principles. Of course, these laws have their national specificities, but they are

united in that they allow cancer survivors to contract life insurances or other financial instruments such as mortgages and loans, acquire property and launch new professional projects without fear of their cancer being used against them.

- Broadly speaking, these initiatives ensure access to financial instruments to former cancer patients 10 years after the end of their treatment provided that there have been no relapse. In some of the listed countries, this term is reduced to 5 years in the case of paediatric cancers.
- Moreover, these national measures include relevant derogations for a number of cancers with a better prognosis. This list is regularly updated and ensures reduced terms to enjoy the Right to be Forgotten for cancer survivors.
- Seeing these achievements take place at the national level, I turn to the EU and its extensive legacy when it comes to the development of initiatives which can positively impact cancer patients with the hope that the Right to be Forgotten may be replicated more broadly in order to provide more equal access to financial services for all cancer survivors across Europe.
- The MEP Group Against Cancer, the Beating Cancer Plan and the Cancer Mission are strong examples of the EU's added value and each have considered the specific issue of the Right to be Forgotten. For this reason, I am delighted to attend a meeting of the BECA Committee to discuss this issue in yet another setting. I would also like to take a moment and extend my gratitude to MEP Tomislav Sokol for nominating me to join you today.
- Despite the principle of subsidiarity in health, the EU provides a number of legal bases for EU action on health but also on social inclusion, equality, and consumer rights and their protection in the internal market.
- The EU is adept at eliminating national barriers through a joint approach in order to provide its citizens a better quality of life. With the number of cancer survivors increasing daily, I believe survivorship issues should become fully integrated in the EU's intent to provide the highest level of protection of health and consumers rights in order to eliminate all physical, economic, and social barriers former cancer patients must overcome.
- The Right to be Forgotten has now gained significant momentum in the EU and the Beating Cancer Plan's roadmap's inclusion of the Right to be Forgotten represented a tremendous outcome for this campaign.

- Not only that, but the Interim report published by the Cancer Mission also recognised the importance of the Right to be Forgotten to counteract discrimination and ensure equality, for cancer survivors. Recently, we also saw the Parliamentary Assembly of the Council of Europe endorse a report on these issues inviting parties to implement patient protection systems and the “Right to be Forgotten”.
- Europe has been, can and should continue to play a key role in the promotion of a better life for cancer patients. Through the Right to be Forgotten for cancer survivors, EU efforts could significantly impact long-term research and the collection of data on cancer survivorship in Europe, as well as improve coordination between the national cancer registries of EU Member states and empower cancer patients, survivors, and their families in beating cancer.
- The increased consideration for the Right to Be forgotten has been particularly encouraging for cancer patients, survivors and the organisations who represent them and I wish to mention here also the recently Code of Cancer Practice developed by ECCO and I believe it is high time for the EU to tackle this long-standing issue which is linked to the protection of European’s consumer rights.
- As a conclusion, I would like to highlight the following key aspects as the means to developing a long-term strategy to promote social inclusion, wellbeing and to ensure that cancer survivors never again have to pay twice for being diagnosed.

These recommendations include:

1. The need to common standards on the Right to be Forgotten under provisions of the TFEU on the Consumer Protection Policy. In particular, this includes the fragmented national practices of creditworthiness assessment to ensure equal access to credit to cancer survivors. For that, articles 114.3 and 169 provide the legal foundation for this intervention as it states that Consumer Protection will take into account scientific facts and contribute to protecting the economic interests of consumers.
2. The implementation of a European legislative initiative able to ensure common legal frameworks among EU Countries and among cancer patients in Europe to avoid discrimination and support more equal access to social rights for patients and cancer survivors.
3. Increased support for multidisciplinary research on cancer survivorship, the improvement of infrastructure and databases to collect long-term data on cancer survivorship through initiatives such as the Beating Cancer Plan and the Cancer Mission.

4. Finally, I would also call for the formalisation of an EU Cancer Survivorship day which every year could be used to raise awareness of the problems cancer survivors must overcome.

- Before closing my statement, I am pleased to announce that we will be organising an online event on the Right to be Forgotten “*14 Million reasons to discuss life after cancer: implementing the Right to be Forgotten across Europe*”. This event, hosted by MEP Manuel Pizarro, MEP Tilly Metz and MEP Tomislav Sokol, will look to bring a number of international stakeholders and institutional figures together in an attempt to identify the right mechanisms for the implementation of the Right to be Forgotten in the EU. The day of the event will be made available to public soon. I would take this opportunity and extend the invitation to all MEPs who wish to join and circulate information to this event following this meeting.