

20 Million Reasons to Discuss Life after Cancer:

Establishing a European Cancer Survivorship Day

On Tuesday, June 29th 2021, the European Cancer Patient Coalition (ECPC) hosted an online event entitled “20 Million Reasons to Discuss Life After Cancer: Establishing a European Survivorship Day”. Over 160 people registered for the event, which aimed to raise awareness of cancer survivorship issues in the EU and called for the formalisation of a European Survivorship Day.

What did our Speakers say?

Stella Kyriakides, European Commissioner for Health and Food Safety

1. Noted there is a need to promote social and economic measures to enable cancer survivors to get back to work, since employers usually don't know their exact needs.
2. “A European Survivorship Day is a good way to put a spotlight on policies for the rehabilitation of cancer patients.”
3. Added that the Commission intends to deliver on what the Beating Cancer Plan is designed to do, with plans to assess the legal situation in Member States and publish a report by the end of 2021.

MEP Cristian Silviu Buşoi (EPP, Romania), Chair of Challenge Cancer Parliamentary Intergroup

1. “The 20 million survivors in Europe are classified as a vulnerable population that requires medical and non-medical intervention.”
2. “The European Survivorship Day is a very important step to implement the targets of the EU Beating Cancer Plan.”
3. “There is a need to consider concrete measures at both an EU and national level for survivors to improve their situation in the coming years.”

MEP Romana Jerković (S&D, Croatia), Member of the Challenge Cancer Intergroup

1. “The European Parliament will continue standing up for cancer and cancer survivorship even though health is an area of national competence.”
2. Supported the establishment of a European Survivorship Day, adding it would be very important for raising awareness.
3. Stressed that cancer survivors are a vulnerable population that requires not only medical treatments, but also psychological and social support. Although post-therapy support does not cure the illness, for the patient it is as important as the treatment.
4. Hoped Member States and relevant institutions will take the opportunity to improve the lives of those who have suffered and who deserve to live without feeling excluded.

Dr. Roberta De Angelis, Senior Research Director for Cancer Epidemiology and Genetics, Istituto Superiore di Sanità

1. “Complete information on cancer survivors is not systemically available in Europe, meaning the number of ALL cancer survivors cannot be directly measured, it can only be estimated.”
2. Noted that the current joint action on cancer promotes the use and dissemination of indicators on complete cancer prevalence relying on the EURO CARE-6 dataset.
3. Called for increased epidemiological research to identify cancer survivors needs, especially for those with a limited quality of life, or with socio, economic or psychological long-term consequences.

Magali Mertens de Wilmars, Founder of Work&Cancer

1. Recognised the need for collective process and shared responsibility as issues can only be solved through collaboration and the involvement of managers in the workplace.
2. “Survivors are resilient and develop soft skills: better empathy, better sense of priority, better stress management. These qualities mean there is a lot of missed potential from employers.”
3. Highlighted that the public need to become aware of the problems that survivors are facing, including for instance the long-term side effects in order to understand why reasonable accommodations at work are important.

Barbara Wilson, Founder and Director of Working with Cancer

1. Stated that employers play the biggest role in the successful return to work for survivors but don't understand cancer in terms of its treatment or its emotional or physical impact, and, in addition, they don't know what best practice looks like.
2. “This requires a twofold approach: first through incentivising good practices promoted by the EU, and secondly by introducing employment legislation that treats cancer as a disability to protect workers from discrimination.”
3. Welcomed an anti-discrimination directive for cancer survivors and improved integration for them into the labour market, as well as a charter of rights for cancer patients. Also welcomed the intention to map national employment and social protection policies but hoped the latter does unduly delay the action that is needed.

Stephen Bevan, Head of HR Research Development, Institute for Employment Studies

1. “Policymakers and professionals don't always consider work as a primary outcome of treatment and care.”
2. Suggested that flexible working, enforcement of existing legal protections, creation of new legal protections, and the removal of barriers to receiving support are all necessary.
3. “We don't want just the successful return to work, but also progression opportunities for those who want them.”

Antonella Cardone, Director of the European Cancer Patient Coalition

1. “ECPC has started the process of calling on the European Commission and Parliament to establish the European Survivorship Day and has already received a positive feedback from all those who have been contacted.”
2. “So far, policy work on cancer has been mostly focused on prevention. It is now time to consider the whole cancer care pathway and break the silos between different stakeholders.”
3. Establishing a European Survivorship Day will provide a unique opportunity to set up trustful and fruitful relationships between all relevant stakeholders.

Prof. Dr. Mark Lawler, Professor of Digital Health, Faculty of Medicine, Queen's University Belfast and ECPC Scientific Committee Member

1. Highlighted that the establishment of a European Cancer Survivorship Day, first suggested by the Scientific Committee of the European Cancer Patient Coalition (ECPC), has become a key mission of ECPC and represents an opportunity to place a particular focus on the 20 million cancer survivors living with and beyond cancer in Europe”
2. “Ensuring that the 20 million cancer survivors in Europe live undiscriminated lives is a number one priority.”
3. “In this webinar, we provide crucial evidence that emphasises the absolute need for an effective and inclusive return to normal living for cancer survivors.”

What did we learn?

- That EU institutions and stakeholders support the establishment of a European Cancer Survivorship Day.
- The dissemination of good practice underpinned with social legislation to consider cancer as a disability are two key ways to support survivors in their return to work.
- Most speakers underlined the need for collaboration and shared responsibility across national and EU level to raise awareness of cancer survivors and implement new measures.

Our Audience

The webinar's audience was largely composed of patient advocates and representatives from non-governmental organizations, but also members of the European Parliament, as well as several national health authorities. It represents a tremendous achievement for ECPC 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.

Patients/ Patient Advocates		32%
Non-Governmental Organizations		18%
Industry		13%
Medical/ Research Society		13%
Policy Maker		8%
Others		16%