

Giving a Voice to Pancreatic Cancer

A CALL TO ACTION

Pancreatic cancer is currently a death sentence

Today, a diagnosis of pancreatic cancer is generally associated with a death sentenceⁱ and few patients are alive one year after diagnosisⁱⁱ. The median survival for a person diagnosed with metastatic pancreatic cancer is three monthsⁱⁱⁱ. Worryingly, as the incidence of pancreatic cancer increases with age, it is expected to become even more prevalent in the coming decades as the European population ages^{iv v}. Consequently, by 2020, pancreatic cancer will be the second-greatest cause of death from cancer after breast cancer^{vi}. While its incidence continues to increase^{vii}, in the last 20 years there have been very few advances in treatment^{viii}, making pancreatic cancer a largely neglected disease.

There is an urgent need to provide solutions for patients with pancreatic cancer, a deadly disease that leaves patients, their families and healthcare professionals with very little hope.

A variety of factors contributes to increasing mortality rates

Most European countries do not use cancer registries to collect outcome data on the treatment of pancreatic cancer patients^{ix}. This lack of data collection therefore hampers physicians and researchers' efforts to better understand the disease. It also results in a lack of shared experience amongst scientists, something that has been shown to improve diagnosis and the effectiveness of treatment in other cancers.

The increasing mortality rates relate to late diagnosis, generally after the cancer has spread to other organs, which elicits a reaction of resignation and hopelessness in healthcare professionals^x, explaining why the general course of action is palliation rather than treatment^x.

Furthermore, the high and sudden death rates of people with pancreatic cancer mean that only very few survivors are able to share their experience, which also explains the lack of patients' organisations devoted to pancreatic cancer. Without a strong unified voice, the fight against pancreatic cancer is failing to receive the attention it deserves.

Paving the way for improved care and increased hope

Since 1980, there has been a significant improvement in the death rates of the most prevalent cancers in the European Union, such as breast, cervical, colorectal and lung cancer. Political leadership has proven vital in helping society tackle cancer. European initiatives aiming to address the burden of cancer have significantly influenced policies, awareness programmes and improvement of patient care across Member States. It is proven that a strong, holistic, political commitment to act can have tremendous impact on health issues^{xi}. It is therefore now time to devote attention to pancreatic cancer, the only cancer where survival rates are declining in both sexes^{xii}.

The European Union has a fundamental role to play in the fight against pancreatic cancer: it is time for EU institutions, Members of the European Parliament and national ministries to support European citizens affected by pancreatic cancer, and trigger real change in research, treatment and care.

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We call on European institutions and EU Member States to take immediate action to reverse pancreatic cancer death rates trend by:

1. Ensuring pancreatic cancer is included in key European initiatives aiming at fighting cancer, such as the Member States-led 2014-2017 Cancer Control Joint Action (CANCON), the Expert Group on Cancer Control and the EU Network for Cancer Registries hosted by the Joint Research Centre, in view of:
 - Increasing research to better understand the mechanisms and basic biology of pancreatic cancer;
 - Improving systematic data collection through setting up and maintaining disease registries to increase knowledge of the disease and inform treatment decisions;
 - Identifying appropriate tools and methods to promote earlier diagnosis to provide patients with timely and appropriate care, and therefore improved health outcomes;
 - Providing widespread education programmes to reduce the time from diagnosis to treatment and increase prevention initiatives;
 - Improving the standard of care from purely palliation to active treatment where appropriate.
2. Ensuring that Member States include pancreatic cancer in their national cancer plans and in their health awareness programmes
3. Encouraging the creation of a European pancreatic cancer multi-stakeholder platform, including patient representatives, academia, clinicians, policy-makers and industry with an interest in pancreatic cancer:
 - To help maximise European policy initiatives in view of the dramatic rise in pancreatic cancer mortality rates across Europe;
 - To increase awareness at European and national levels around the need to significantly improve the standard of care for patients with pancreatic cancer.

Philippe De Backer
ALDE, Belgium

Ivo Belet
EPP, Belgium

Soledad Cabezón Ruiz
S&D, Spain

Ashley Fox
ECR, UK

Brian Hayes
ALDE, Ireland

Roberta Metsola
EPP, Malta

Piernicola Pedicini
EFDD, Italy

Pavel Poc
S&D, Czech Republic

Antonio Tajani
EPP, Italy

Françoise Grossetête
EPP, France

Brando Benifei
S&D, Italy

Nessa Childers
S&D, Ireland

Elisabetta Gardini
EPP, Italy

Andrey Kovatchev
EPP, Bulgaria

Louis Michel
ALDE, Belgium

Alojz Peterle
EPP, Slovenia

Anne Sander
EPP, France

Claudiu Ciprian Tănăsescu
S&D, Romania

Philippe Juvin
EPP, France

Biljana Borzan
S&D, Croatia

Anneliese Dodds
S&D, UK

Juan Carlos Girauta Vidal
ALDE, Spain

Cécile Kashetu Kyenge
S&D, Italy

Liadh Ní Riada
GUE/ NGL, Ireland

Bolesław Grzegorz Piecha
ECR, Poland

Alfred Sant
S&D, Malta

Derek Vaughan
S&D, UK

Daciana Octavia Sârbu
S&D, Romania

Cristian-Silviu Buşoi
EPP, Romania

Frank Engel
EPP, Luxembourg

Marian Harkin
ALDE, Ireland

Jérôme Lavrilleux
EPP, France

Demetris Papadakis
S&D, Cyprus

Sirpa Pietikäinen
EPP, Finland

Bart Staes
Greens/ EFA, Belgium

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