

# 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 sentence<sup>i</sup> and few patients are alive one year after diagnosis<sup>ii</sup>. The median survival for a person diagnosed with metastatic pancreatic cancer is three months<sup>iii</sup>. 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<sup>iv v</sup>. Consequently, by 2020, pancreatic cancer will be the second-greatest cause of death from cancer after breast cancer<sup>vi</sup>. While its incidence continues to increase<sup>vii</sup>, in the last 20 years there have been very few advances in treatment<sup>viii</sup>, 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<sup>ix</sup>. 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.

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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<sup>ix</sup>, explaining why the general course of action is palliation rather than treatment<sup>x</sup>.

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<sup>xi</sup>. It is therefore now time to devote attention to pancreatic cancer, the only cancer where survival rates are declining in both sexes<sup>iii</sup>.

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.

**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.

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