



PANCREATIC
CANCER EUROPE



AUGUST 2018 EDITION

WHO WE ARE/ HISTORY

Pancreatic Cancer Europe (PCE) is a platform composed of more than 40 European experts, academics, patients groups, clinical practitioners, journalists and policy makers. We are committed to raising awareness of pancreatic cancer with a view to optimising care for patients through earlier diagnosis, coordinated research and data collection for patients suffering from pancreatic cancer across Europe.

PCE was formed after a Call to Action launched by four Members of the European Parliament in July 2014, calling for the establishment of such a platform to address the main gaps surrounding this, forgotten yet serious terminal disease.

The platform is endorsed by key EU stakeholder organizations active in the field of cancer and gastroenterology. It also gathers multiple national patient groups and medical associations jointly collaborating for the prioritization of pancreatic cancer on the EU and national policy agendas.

The Platform is financially supported by several healthcare companies, and operates in full independence.¹

KEY EFFORTS AND ACHIEVEMENTS

2018

Focus on EU campaigning and on **developing national advocacy strategies**
Development of the Pancreatic Cancer heatmap and inequality report
Increased support to **pancreatic cancer research**

2017

January 2017 | Creation of a 4th work stream dedicated to research, headed up by Nuria Malats
June 2017 | Satellite session at the occasion of the ESMO GI Congress in Barcelona (Spain)

2016

ESTABLISHMENT
AS A NON-PROFIT
ASSOCIATION

April 2016 | Pancreatic Cancer Europe is established as a non-profit association in Belgium.
July 2016 | Pancreatic Cancer Europe's Administration Board gathers in person for the first time in Liverpool
November 2016 | First General Assembly meeting in Brussels, merger of the two work streams Awareness and Diagnosis; PCE awareness event in the European Parliament

2015

CONSOLIDATION
OF THE
PLATFORM

June 2015 | Platform meeting in Toledo (Spain) at the occasion of the 48th EPC Meeting, Baxalta (now part of Shire) officially joins the Platform as 2nd sponsor
Nov 2015 | 3rd Platform meeting in Brussels in the European Parliament, at the occasion of World Pancreatic Cancer Day (WPCD)
Nov 2015 | Launch of the Platform's website and of the social media campaign fightpancreaticcancer.eu
Nov 2015 | Translation and dissemination of the Platform brochures in 12 languages
Dec 2015 | Creation of a 4th work stream dedicated to national activities, headed up by the European Cancer Patient Coalition

2014

LAUNCH AND
BUILDING OF
THE PLATFORM

July 2014 | Call for action: Giving a voice to pancreatic cancer
Nov 2014 | Official launch and first meeting of the Platform in the European Parliament + Parliamentary awareness event on pancreatic cancer hosted by 2 Members of the European Parliament

¹ the 2018 sponsors of Pancreatic Cancer Europe are Celgene, Servier, Mylan and Terumo BCT.

GOVERNANCE

The four work streams of the platform are led by members of the platform coming from different national organizations, who constitute the administration board.

All decisions regarding the platform are taken collectively by platform members, each of them having an equal voice in the decisions regarding the platform's activities and orientations. PCE is an ASBL, registered in Brussels - Belgium, under the number ASBL n°656.553.804

Since 2016, the Platform is a formal entity.

ADMINISTRATION BOARD



PROF. ALFREDO CARRATO

Professor of Medical Oncology at Alcala University and Director of the Medical Oncology Department at Ramon y Cajal University Hospital in Madrid, Spain. He is presently serving as Director of the Ramon y Cajal Institute for Health Research IRYCIS.



ALI STUNT

Diagnosed in 2007, Ali Stunt is one of the few pancreatic cancer surviving patients. Saved by an early diagnosis of the disease, Ali is the Founder and Chief Executive of Pancreatic Cancer Action (UK), an association devoted to encourage early diagnosis for the illness.



EUROPEAN CANCER PATIENT COALITION (ECPC)

The European Cancer Patient Coalition is the voice of cancer patients in Europe. With over 400 members, the European Cancer Patient Coalition is Europe's largest umbrella cancer patients' association, covering all EU member states and many other European and non-European countries. The European Cancer Patient Coalition represents patients affected by all types of cancers, and was a founding member of Pancreatic Cancer Europe.



DR. NÚRIA MALATS

Head of the Genetic and Molecular Epidemiology Group at the Spanish National Cancer Research Centre (CNIO), Madrid, Spain. She is the chair of the EUPancreas COST Action. EUPancreas is a COST Action (BM1204) that aims to unite pancreas cancer research groups across Europe.

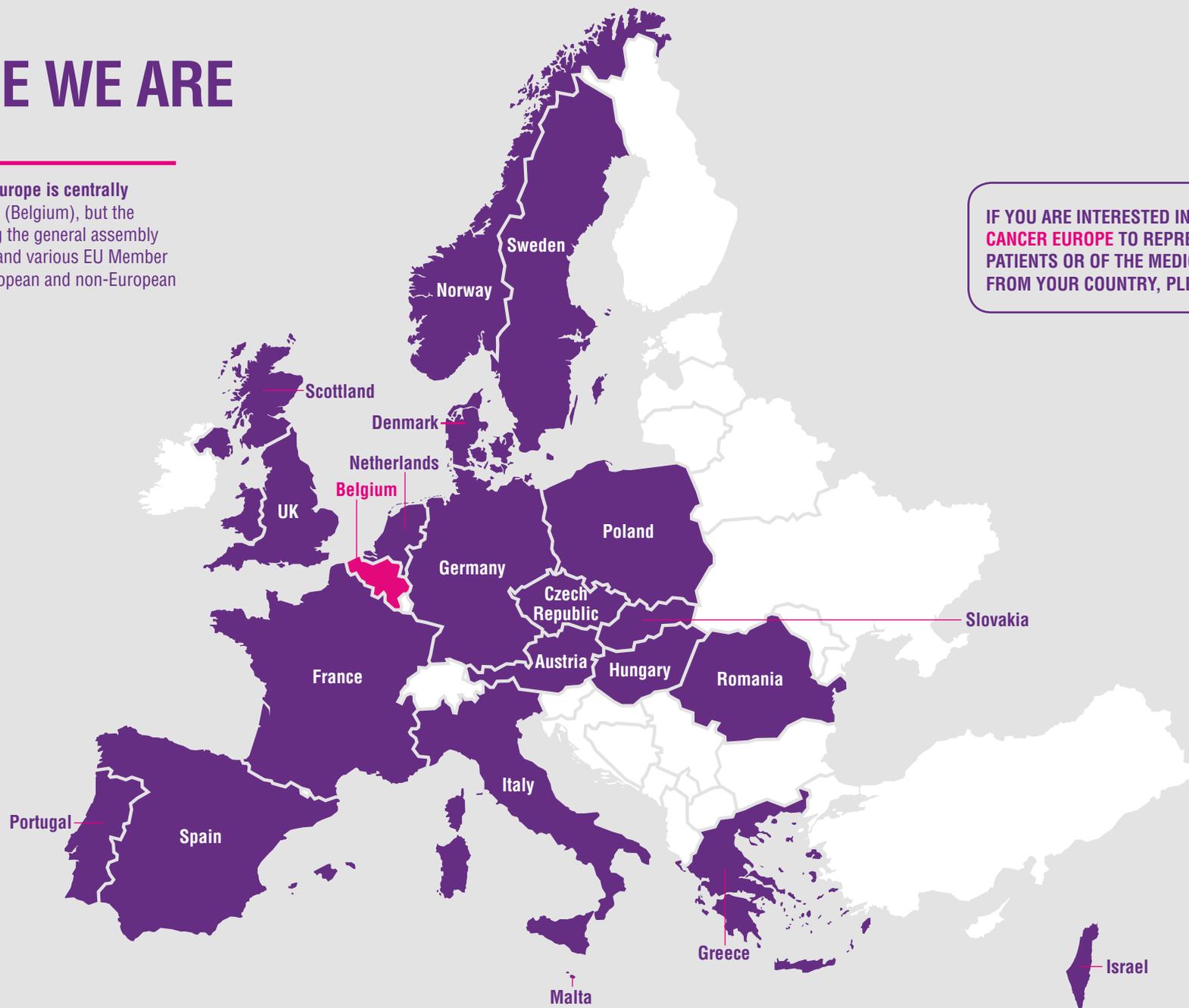


SORIN T. BARBU

Professor of Surgery, Chairman of the 4th Surgery Department and member in the Surgery Council at the "Iuliu Hatigeanu" University of Medicine & Pharmacy in Cluj-Napoca, Romania. He has been President of the Romanian Pancreatic Club since 2007 and is a member of the UEG Public Affairs Committee and of the European Pancreatic Club since 2002.

WHERE WE ARE

Pancreatic Cancer Europe is centrally managed in Brussels (Belgium), but the members composing the general assembly come from multiple and various EU Member States and other European and non-European countries.



IF YOU ARE INTERESTED IN **JOINING PANCREATIC CANCER EUROPE** TO REPRESENT THE VOICE OF PATIENTS OR OF THE MEDICAL COMMUNITY FROM YOUR COUNTRY, PLEASE **CONTACT US!**

WHAT WE DO

Pancreatic cancer is currently the 4th cause of death by cancer in Europe, and is set to be 2nd by 2020, if no action is taken. It is the only cancer with a rising mortality in both sexes, and it also has the lowest survival rate of all cancers.

In spite of these alarming figures, pancreatic cancer is absent from most cancer control policies, either at EU or national level. Pancreatic cancer is often referred to as the “forgotten cancer”, which is one of the reasons why the platform has decided to make awareness raising one of its key priorities.

In order to push for the prioritization of pancreatic cancer on the policy agenda, the platform has engaged with a group of key supportive policy makers at European level.

We aim at bringing together relevant stakeholders to advocate for an improvement in the standard of care for patients with pancreatic cancer, by addressing the existing gaps related to the lack of awareness, diagnosis and data collection.

Spun off by a strong political will to address the devastating impact of pancreatic cancer, Pancreatic Cancer Europe aims at reversing the trend of lack of improvement in survival for pancreatic cancer by:

- Increasing pancreatic cancer research and political support
- Raising lay and medical awareness by developing awareness tools and campaigns
- Uniform collection of data relating to pancreatic cancer diagnosis and treatments across Europe
- Enabling a forum of exchange between national stakeholders

WHAT DO WE BRING?

Pancreatic Cancer lacks the usual level of awareness, even among some medical professionals, associated with such a killer disease. The diversity of the Platform membership, the cross section of stakeholders and their high level of engagement is resulting in speedy agreement among members especially on strategy and priorities.

Leveraging stakeholders’ experience in other cancers has allowed speedy consensus development and communication of best practice.

THE WORK OF PCE IS BASED ON 4 WORK STREAMS IMPLEMENTING THE ACTION PLAN OF THE PLATFORM



AWARENESS AND DIAGNOSIS

The Work Stream aims to raise of awareness of the disease itself and the challenges faced by patients.



REGISTRIES

The main objective of the Registries work stream is to fill the gap of the lack of organized data collection in pancreatic cancer across Europe, which would lead to a better understanding of the disease and development of more efficacious diagnosis strategies and personalised treatments.



NATIONAL SUPPORT

The National Support Work Stream gathers members from national organizations and is helping them to get the most from the platform’s materials and actions.



RESEARCH

The Research Work Stream promotes policies & research programmes that can advance medical science on pancreatic cancer and to help coordinate the pancreatic cancer research effort across Europe.

Since its creation in November 2014, Pancreatic Cancer Europe has been active in raising awareness of pancreatic cancer, in increasing its political prioritization, and in encouraging earlier diagnosis for pancreatic cancer.

We have developed several documents to help local groups and patients to learn more about the disease.



The 10 Warning Signs of Pancreatic Cancer

Pancreatic Cancer: Improve early detection for a better cure

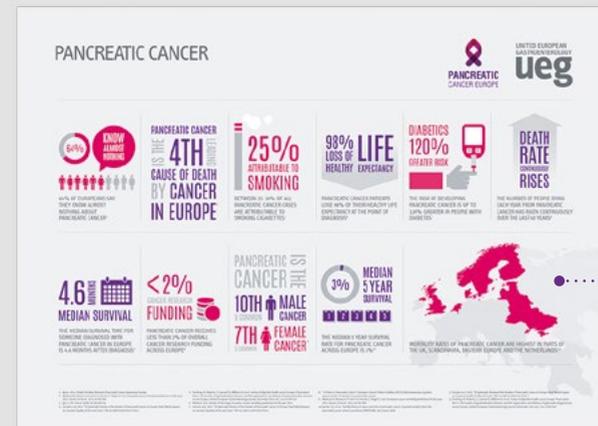


10 things you need to know about Pancreatic Cancer



PCE Microsite

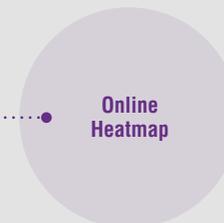
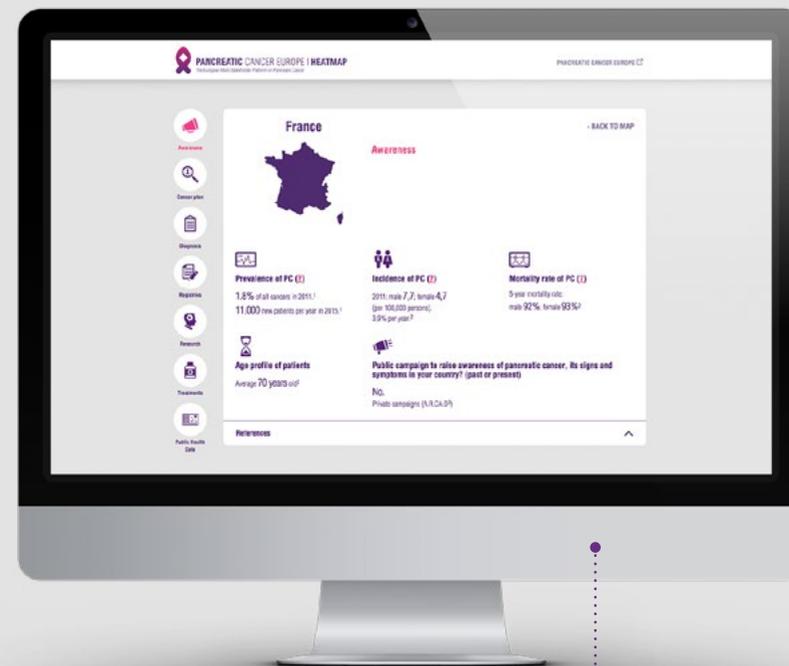
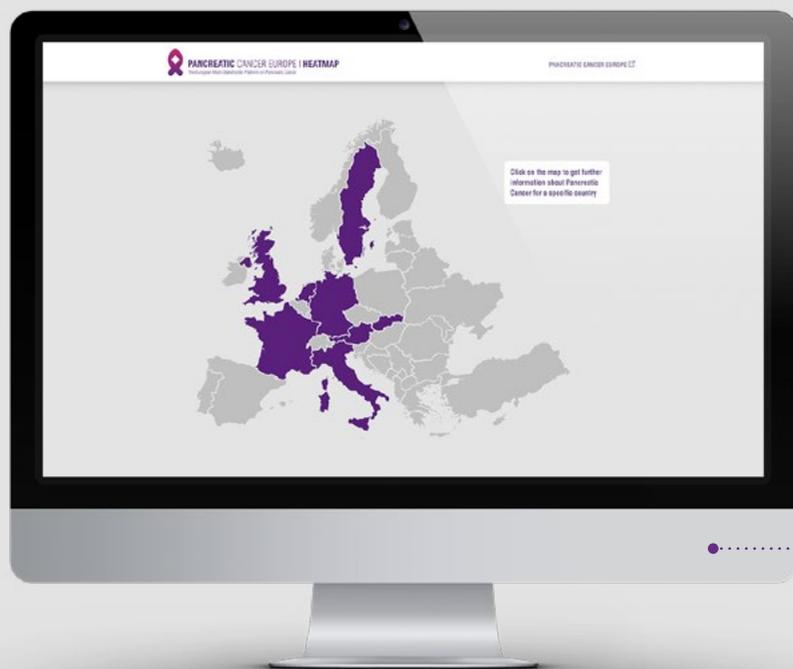
At the occasion of World Pancreatic Cancer Day 2016, UEG and PCE have jointly developed a video to raise awareness of pancreatic cancer and its symptoms, and an infographic on the disease



Infographic on the disease

Conceived as a powerful tool to compare the situation of pancreatic cancer patients' in each European country, the heatmap provides information on awareness, national policies, diagnosis, research...

We are always looking for more data and information to enrich the heatmap. Should you want to add some data for your country, please contact directly the Secretariat.



CONTACT US

Are you patient group?

An academic?

A physician?

A healthcare company?

Are you willing and able to contribute to our goal of improving care for patients with pancreatic cancer?

JOIN US NOW !

Contact the PCE Secretariat at
actionpancreaticcancer@outlook.com

PCE secretariat, Rue Guimard 10
1040 Brussels
Belgium
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The secretariat of the platform is managed by a Brussels-based consultancy, RPP Healthcare (RPP Group), which organizes teleconferences and meetings of the platform, coordinates the elaboration of the platform's documents and websites, as well as external contacts and communications between the platform and advocacy or political partners.

FOR MORE INFORMATION



www.pancreaticcancereurope.eu
www.fightpancreaticcancer.eu



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