

OCTOBER 16 > 18, 2022

PANCREATIC
CANCER
SYMPOSIUM

DOMAINE DU HAUT-CARRÉ,
UNIVERSITY OF BORDEAUX

WWW.PCS-AFRCF.COM

Welcome to my journey !

My name is Isabelle Chabrier, I live in Paris.
My cancer was discovered in 2019.

Let me share my journey as a patient, whose
world collapsed when the word « cancer »
was spoken ...

Personal context and symptoms

Healthy life : no tobacco or alcohol, no obesity, physically active

- Stomach pains when eating
- Back pains without reasons
- Weight loss



OCTOBER 16 > 18, 2022

PANCREATIC
CANCER
SYMPOSIUM

DOMAINE DU HAUT-CARRÉ,
UNIVERSITY OF BORDEAUX

WWW.PCS-AFRCF.COM

Diagnosis : locally advanced pancreatic cancer



Devastated
Disbeliever
Angry
Rejection

Treatment (part 1)

- Life expectancy unknown
- Surgery and/or radiotherapy impossible
- Medical suggestion : start Folfirinox
- Amazing efficiency

Treatment (part 2)

- Radiotherapy combined with Xeloda
- Excellent results
- Surgery is considered : Whipple procedure (July 2020)
- Enteral nutrition to fight malnutrition and dehydration
- Adjuvant chemos, Folfirinox

The hardest ...

- Diagnosis and fear of dying
- Few optimistic information
- Changes in physical appearance (thinness, partial loss hair, ...)
- No other patient to share experience with / discuss with
- After surgery : wich nutrition ?



What helped the most ...

- Attentive listening from the psychologist
- Being an active patient
- Being physically active
- Very close and confident relationship with the hospital teams, especially my physician
- Writing down my thoughts in a notebook

OCTOBER 16 > 18, 2022

PANCREATIC
CANCER
SYMPOSIUM

DOMAINE DU HAUT-CARRÉ,
UNIVERSITY OF BORDEAUX

WWW.PCS-AFRCF.COM

My book

L'Indigestion Journal intime de mon cancer du pancréas

Isabelle Chabrier

Editions de l'Harmattan, Janv. 2023

Personal website : <https://lindigestion.fr/>

L'Indigestion

Isabelle
Chabrier

Journal intime
de mon cancer
du pancréas



collection
Récits de Vie
Série Santé et Maladie

L'Harmattan

Today

- Rather good health but reduction in my physical abilities
- Regular medical follow-up (Ct scan, blood tests, liver monitoring, ...)
- Special care with nutrition
- Daily concerns about my health
- Hope

What may be improved

- Practical Q/A guide delivered to each new patient
- More communication about supportive care
- Patient's involvement in research
- Greater awareness by doctors of the need for exchanges between patients
- Systematic information and relationship set up with patient's associations



OCTOBER 16 > 18, 2022

PANCREATIC
CANCER
SYMPOSIUM

DOMAINE DU HAUT-CARRÉ,
UNIVERSITY OF BORDEAUX

WWW.PCS-AFRCF.COM

Patients' associations



is a European non-profit umbrella organisation of

nearly

40



national Member Organisations across Europe

We represent patients with digestive cancers



Colorectal



Gastric/Oesophageal



Pancreatic



Liver



Rare

Patient Co-Creation

- When patients are actively involved in helping create solutions for other patients.
- Patients work together with healthcare providers to make things that are useful for patients.
- This way, everyone trusts each other more because patients have a say in how things are made from the beginning.

Focus Groups

Surveys

Patient Advisory Boards and
Committees

One-to-one interviews

Feedback on documents

Communication and
dissemination of the results

Patient Co-Creation, benefits, trials

- Allows healthcare organisations to access valuable patient insights and incorporate them into their decision-making process.
- Tailor services to meet individual needs.
- Strengthen communication programs and improve communication strategies.
- Provide more effective and personalised services to patients.
- Build trust with the community by including the patient voice.

GUIDE.MRD
www.guidemrd-horizon.eu

Sagittarius

OCTOBER 16 > 18, 2022

PANCREATIC
CANCER
SYMPOSIUM
DOMAINE DU HAUT-CARRÉ,
UNIVERSITY OF BORDEAUX

P



French association focused on pancreas.

The major french association made up of patients and their families, in the field of pancreatic cancer

Founded in NANCY in 2016, by Philippe FRANCOIS-STEININGER



The association is supported

- ARCAD Foundation for digestive research.
- A Parisian **patient collective** supported by Pr HAMMEL from the APHP.
- The Institut for Cancerology of Lorraine, with Pr. Thierry CONROY
- Partnership agreements are in process
- Unicancer, Club Français of Pancréas and AFRCP

To make progress ...

Early detection of pancreatic cancer
Available resources to patients and research

To share the best cares and knowledge in treatment

Carry the voice of patients, families and loved ones

And represent patients in Ad-Hoc committees



Annual conferences : last one in September (Pr Cindy Neuzillet)

Efficient website : More than 20.800 visits for 2022, assistance with testimonials, responses to FAQ from patients and families

Social media : Instagram, Facebook (1 651 subscribers)

Local offices opening : Lille, Paris coming soon, other cities in project



Developping services of the association

Relay testimonies, books about pancreatic cancers

Establish local offices in collaboration with the main cancer center

Set up a Scientific Committee to provide answers to the most FAQ by patients and families.

Listening and support unit

Join in clinical trials and scientific research

Mobilizing new volunteers !

Through "Why get involved" awareness campaigns

Interest in developing the life of the Association

Organizing community events, building relationship media.

OCTOBER 16 > 18, 2022

PANCREATIC
CANCER
SYMPOSIUM

DOMAINE DU HAUT-CARRÉ,
UNIVERSITY OF BORDEAUX

WWW.PCS-AFRCF.COM



<https://www.espoir-pancreas.fr>



<https://digestivecancers.eu>



<https://>

contact@lindigestion.fr

