

#### 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







# 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 efficency



# 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



### My book

L'Indigestion

Journal intime

de mon cancer du pancréas

Isabelle Chabrier

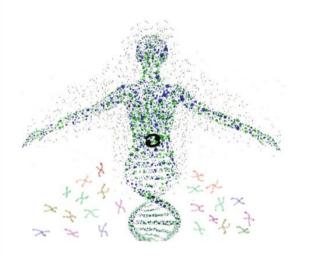
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#### L'Indigestion

lsabelle Chabrier

Journal intime de mon cancer du pancréas











# 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





### Patients' associations





is a European non-profit umbrella organisation of



national Member Organisations across Europe

We represent patients with digestive cancers





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.



**Sagittarius** 







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

Etablish 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.









https://www.espoirpancreas.fr



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