



CHANGING THE COURSE OF  
HUMAN HEALTH THROUGH BOLD  
PURSUITS IN SCIENCE



**ImpactPANC** Award Program

*Susan Gorky, Sr. Director, Oncology Global Advocacy*  
*Vicki Amari, Director Corporate Communications, Oncology*



# ImpactPANC 2019 Theme



## ***“Supporting Doctor Patient Discussions in Pancreatic Cancer”***

- Open to **ALL** WPCCC members
- Designed to: Support the information needs and areas of consideration in the Doctor/Patient Discussions during a pancreatic cancer diagnosis and . . .
- . . have the potential to be adapted/replicated in other countries
- Five awards of \$20,000 USD each (or local equivalent) will be granted by Celgene



# ImpactPANC website has everything you need!



- Online application:
  - HOW does your organization intend to address the critical information that patients and their physicians should discuss?
  - WHO will your initiative impact?
  - WHAT impact will your initiative have?
  - HOW will you measure your program to know that you have been successful
  - How can your initiative be adapted and/or replicated in another country or shared as a best practice?

[www.impactpanc.com](http://www.impactpanc.com)

# ImpactPANC 2019 Application Timeline

***“Supporting Doctor Patient Discussions in Pancreatic Cancer”***

**June  
30<sup>th</sup>**

**Deadline to  
submit  
applications**

**Mid  
August**

**Winners To  
Be  
Contacted  
By Celgene**

# Pancreatic Cancer: It's Personal (USA)

**James Rolfe**

*President, Board of Directors  
Rolfe Pancreatic Cancer Foundation*

**Rachel Sheinkop**

*Vice President, Board of Directors  
Rolfe Pancreatic Cancer Foundation*



WORLD **PANCREATIC**  
CANCER COALITION<sup>SM</sup>



# Rolfe Pancreatic Cancer Foundation “It’s Personal” Campaign

Jim Rolfe, President, Board of Directors

Rachel Sheinkop, Vice President, Board of Directors

# About Rolfe Pancreatic Cancer Foundation



- ▶ Leading Midwest institution based in Chicago
- ▶ Founded in 1999 in honor of Michael Rolfe, who died of pancreatic cancer just two weeks after diagnosis

The Rolfe Pancreatic Cancer Foundation's mission is to serve as a catalyst for the early diagnosis and ultimate cure of pancreatic cancer.

# Our “It’s Personal” Campaign

- ▶ A two-pronged campaign that rolled out in May 2017

## Know Your Family

Downloadable  
worksheet to guide  
family medical  
history discussions

## Know Your Risk

Link to search by zip  
code to find a  
certified genetic  
counselor



# Year 1:

- ▶ Successfully drove media coverage of Know Your Family. Know Your Risk



- ▶ Drove online conversations with social media content and events



## Year 2 - Expanded our “It’s Personal” campaign to focus on:

- ▶ Driving direct clicks to [KnowMyRisk.org](https://www.knowmyrisk.org)
- ▶ Expanding the spokesperson panel to integrate more patient and advocate voices and tell more personal stories



Derek Faust



Roslyn Turner



Jessica Stoll,  
CGC



Aaron Colwell



Emily  
Eisenkramer

# Media Relations

- ▶ Continued driving messages with **editorial media** for stories and interviews
  - 180 million impressions for media hits across two years
  - New spokespersons shared first-hand experiences with Rolfe Foundation
  - Strategic outreach to regional media focused on Rolfe Foundation support services

From the community: Rolfe Pancreatic Cancer Foundation's Online Tools Help Drive Holiday Family Health Discussions



**Chicagoland-based Foundation's Tools Help Drive Holiday Family Health Discussions**

Tips for dealing with a bad diagnosis



Jim Rolfe Follow  
President of the board of directors for the Rolfe Pancreatic Cancer Foundation  
Jun 15 · 2 min read

**“Know Your Family, Know Your Risk” for Early Detection of Pancreatic Cancer**

Those who have had a family member diagnosed with pancreatic cancer understand: it's personal.



**Pancreatic cancer; Know your family, know your risk**



## CANCER SCREENING

Know your pancreatic cancer risk

Pancreatic cancer is one of the most deadly cancers, with a mere 20 percent 1-year survival rate and 7 percent 5-year survival rate.

Family history is a risk factor for this type of cancer. To learn more about your family history, visit the Rolfe Pancreatic Cancer Foundation at [www.KnowMyRisk.org](http://www.KnowMyRisk.org) to download a worksheet you can fill out as well as access other tools.

After filling out the worksheet, if you learn you have a history of pancreatic cancer in multiple family members, you should consider meeting with a genetic counselor to assess your level of risk and determine if additional cancer screening tests are necessary.

# Social Media

- ▶ Amped up social content to focus on the stories of our ambassadors

**Outnumbered**  
Real moms keepin' it real ●●● 3 to 1 ●



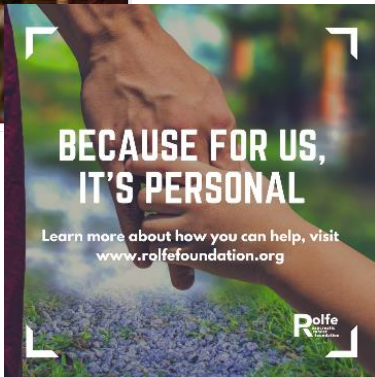
**Pancreatic Cancer and The Rolfe Foundation – Know Your Family. Know Your Risk**

**Hip Mama's Place**  
est. 2007

**Pancreatic Cancer: Know Your Family, Know Your Risk**

Rolfe Pancreatic Cancer Foundation  
Published by Hannah Cheney [P] · November 16 at 4:00 PM · 🌐  
Knowing your family history is so important! This Thanksgiving, make sure you are aware of your family background to understand if you are at risk for pancreatic cancer. Download our worksheet at [www.KnowMyRisk.org](http://www.KnowMyRisk.org) #RolfeFoundation

**Are you at risk for pancreatic cancer? Know your family to know your risk.**



Rolfe Pancreatic Cancer Foundation  
Published by Hannah Cheney [P] · November 14 at 7:00 PM · 🌐  
Show your passion by wearing purple tomorrow for #WorldPancreaticCancerAwarenessDay! Spread the word to friends and family!



**November 15 is World Pancreatic Cancer Day. Wear purple to show your support!**



**"The Rolfe Pancreatic Cancer Foundation put my family in contact with physicians, surgeons, researchers and geneticists throughout the country."**

-Emily Eisenkramer,  
Rolfe Foundation Advocate



**"The Rolfe Pancreatic Cancer Foundation was instrumental in helping my family navigate this difficult journey."**

- Emily Eisenkramer,  
Rolfe Foundation Advocate

# Facebook LIVE Series

- ▶ Hosted Facebook LIVE series to share patient and family stories during Pancreatic Cancer Awareness Month




FACEBOOK  
LIVE SERIES

**Derek Faust**  
Pancreatic Cancer Survivor  
and Rolfe Foundation  
Patient Navigator

Thursday, Nov. 29 | 12 p.m. CT

#PancreaticCancerAwarenessMonth



Rolfe Pancreatic Cancer Foundation



12:17

Know Your Family, Know Your Risk  
This Holiday Season



6:28

Our Mission: Early Detection and  
Prevention of Pancreatic Cancer



10:47

It's #PancreaticCancerAwarenessMonth



6:16

Here's What You Can Do to Help  
Early Detection



- 292,000 impressions
- 5,700 engagements
- 1,600 link clicks
- 10,600 video views

# Event Incorporation

- ▶ Began weaving our Know Your Family. Know Your Risk. messaging into communication about our events
- ▶ Increased marketing to drive more participation and awareness



## HIGHLAND PARK NEWS

Shout Out: Derek Faust, pancreatic cancer survivor

## DAILY NORTH SHORE

DASH for Early Pancreatic Cancer Detection



# Coming in 2019

- ▶ Continue to drive awareness of our Know Your Family. Know Your Risk. Resources
- ▶ Evolving to incorporate healthcare professionals as a core target audience
- ▶ Continue building awareness of the need for a early detection test, drive fundraising to support research and work with patients and families as they fight pancreatic cancer



**ANY  
QUESTIONS?**



# Pancreatic Cancer Awareness (UK)

**Lucy Constable**

*Marketing & Communications Manager,  
Pancreatic Cancer Action*



WORLD **PANCREATIC**  
CANCER COALITION<sup>SM</sup>



We save lives through early diagnosis

# About us

Our mission is to **improve survival rates** of pancreatic cancer by ensuring more people are **diagnosed early** and in time for surgery – currently the only potential for a cure – and **improve the quality of life** for patients.

*We are doing this by*

- Providing free resources and e-learning to **healthcare professionals**
- **Funding research** into early diagnosis
- Raising **public awareness** of the signs and symptoms
- Producing free, easy to understand, **patient information**
- **Campaigning** for more funding and better treatments options



# Our ImpactPANC project entry

Our entry outlined a campaign with a specific focus of raising awareness of the signs and symptoms of pancreatic cancer to improve early diagnosis.

**PANCREATIC  
CANCER  
AWARE.org**

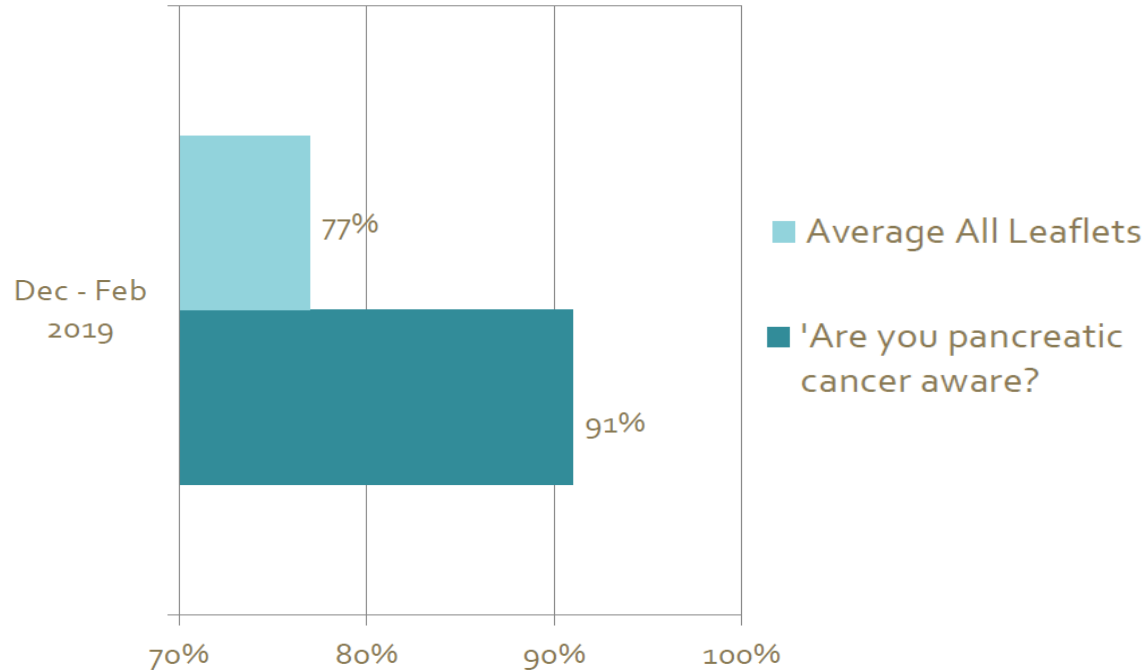


## Key aims:

- Highlight the poor prognosis and survival rates of pancreatic cancer
- Raise awareness of the signs, symptoms and risk factors of pancreatic cancer among the public
- Provide GPs with the tools to diagnose patients early and in time for surgery

# Key findings and impact

North West/South West GP campaign



Leaflet pick up rate for our campaign was 14% higher than the average across other leaflet campaigns in the same time period.

*"Excellent, I have never enjoyed reading a topic such as this one which was to the point and very much reflective of General Practice!" – GP*

*"I liked the poster so I took a leaflet as I know nothing about pancreatic cancer" – patient, 58*

*"It was a great campaign and it was fantastic to see people engage with the general public. Never before had I seen the symptoms so well laid out." - GP*



We save lives through early diagnosis

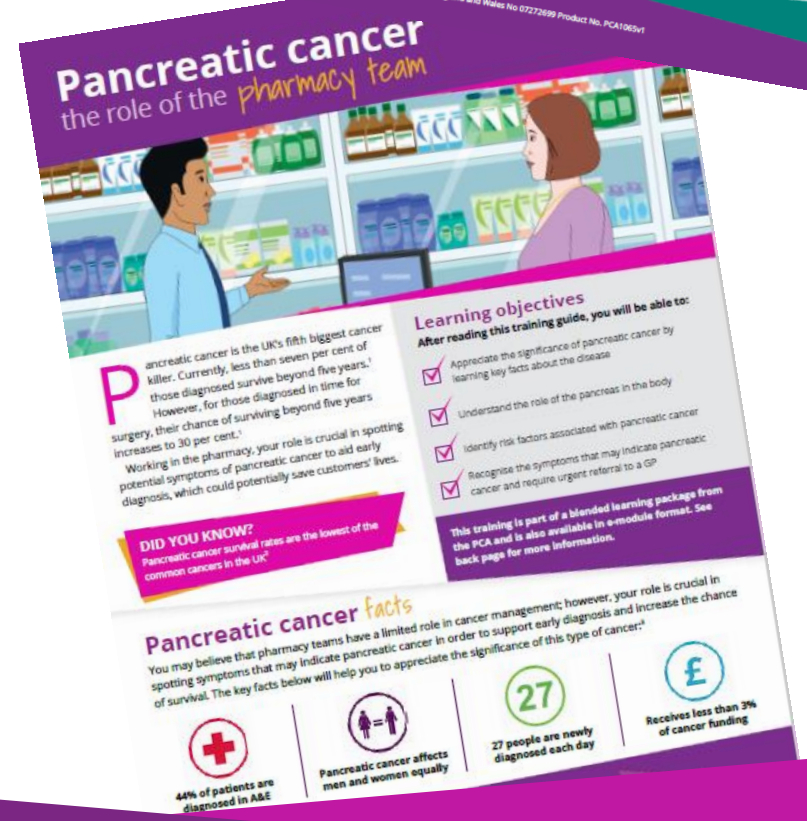
# What we have learnt

## Measurement and feedback

- Survey's including response cards with incentive
- Enough resources for more than one GP

## Updates

- Update module
- Re branding the resources depending on the audience
- Targeting pharmacists as well as GPs
- Specific symptom information depending on region



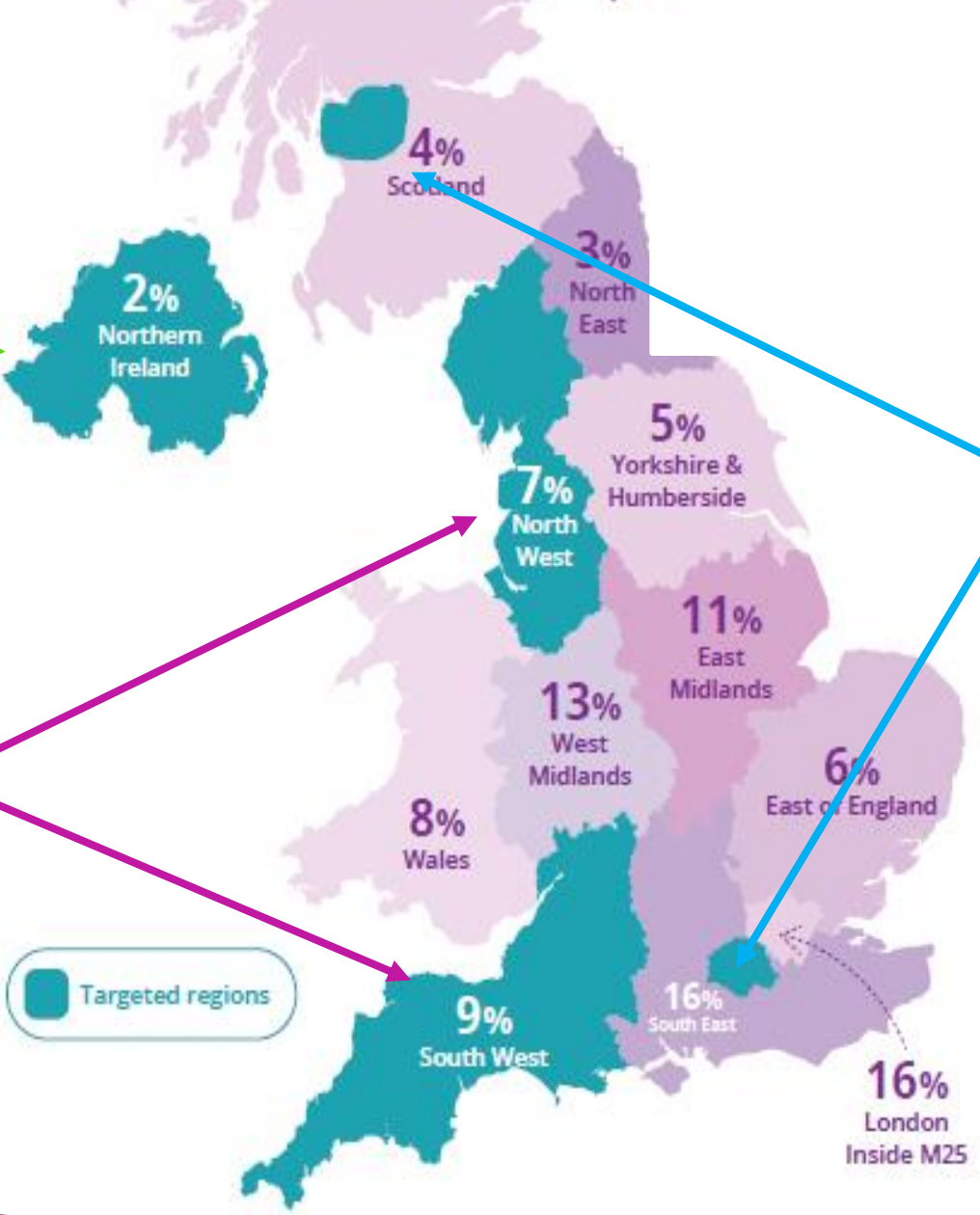
We save lives through early diagnosis

# Update on the project

June 2019

Dec – Feb 2018

November 2017



We save lives through early diagnosis

# Update on the project

What next?

Northern Ireland

JUST **2%**  
OF PEOPLE KNOW  
A LOT ABOUT  
PANCREATIC CANCER



THE SUPPORT OF  
NIPanC WILL MAKE OUR  
CAMPAIGN MORE  
SUCCESSFUL THAN EVER

ALMOST **250**  
DEATHS FROM PANCREATIC  
CANCER PER YEAR

PROJECTED ANNUAL CHANGE  
IN NUMBER OF CASES BY 2020  
**MEN: +29%**  
**WOMEN: +34%**

HCP awareness

**142**  
GP SURGERIES

WILL RECEIVE OUR **RESOURCE PACKS**  
TO HELP WITH DIAGNOSIS AND MANAGEMENT  
OF PATIENTS WITH PANCREATIC CANCER.



**538**  
PHARMACIES

WILL RECEIVE OUR **RESOURCE PACKS**  
ACROSS NORTHERN IRELAND.



Public

advertising: bus stops, highstreets and roadsides

- Pharmacy bags
- Newspapers
- Posters and leaflets in GP surgeries
- Side of buses



We save lives through early diagnosis



# Thank you!



@LuConstable



Lucy Constable



@OfficialPCA



@Pancreatic Cancer Action



@PancreaticCancerAction

t: 0303 040 1770

e: [enquiries@panact.org](mailto:enquiries@panact.org)

w: [www.panact.org](http://www.panact.org)

# Increase Early Detection in Pancreatic Cancer (Portugal)

**Vitor Neves**

*EuropaColon*



WORLD **PANCREATIC**  
CANCER COALITION<sup>SM</sup>



# Increase Early Detection in Pancreatic Cancer Disease



europacolón  
portugal

APOIO AO DOENTE  
COM CANCRO DIGESTIVO

Vitor Neves  
WPCC 2019 - 8, 9 May / Miami

# Member




I3S/Ipatimup – Etich Comission

# Who we are

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[Europacolón Portugal](#) - Patient Association for Digestive Cancer was created in 2006.

Major goals:

- Encourage preventive attitudes
  - Promote support and improve the quality of life of Digestive Cancer Patients, Families and Caregivers
  - Press government to improve quality life conditions of the Portuguese Health System (SNS)
- 



Membro Fundador da:



Membro da:



## Projectos Vencedores:

### 1. EuropaColon Portugal: Increase Early Detection in Pancreatic Cancer Disease (Portugal)



### 2. Rolfe Pancreatic Cancer Foundation: Pancreatic Cancer: It's Personal (USA)



### 3. KEFI of Athens Association of Cancer Patients 'PANCare': A web application for elevating awareness and for supporting pancreatic cancer patients and their families (Greece)



### 4. Pancreatic Cancer Action: Pancreatic Cancer Awareness (UK)



### 5. Instituto Oncoguia: Pancreatic Cancer: With Awareness, There is Hope (Brazil)



2017 ImpactPanc Awards



# Pancreatic Cancer

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The way to decrease the incidence of Pancreatic Cancer in Portugal:

- Raising awareness to citizens and family doctors
- 

# Increase Early Detection in Pancreatic Cancer Disease

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The project have an impact nationwide, involving the majority of Family Doctors in all health centers throughout the country.

In Portugal, the healthcare system is divided into 5 regions (North, Centre, Lisbon, Alentejo and Algarve).

Each of these regions is divided into 74 groups do health care, which each include several health centres.





# Increase Early Detection in Pancreatic Cancer Disease

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We propose to implement an experimental study directly to Family physicians, 5 GP's of each one, in health centers belonging to the totality of the different health center groups in Portugal.

# Increase Early Detection in Pancreatic Cancer Disease

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This project aims to reinforce the awareness raise among general practitioners so that they can take concerted action on an individual basis, in order to raise awareness about the disease, increase early diagnosis and focus on prevention.

# Increase Early Detection in Pancreatic Cancer Disease

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The project will be evaluated by analysing the GP's participation in the project between the data base of the **2 surveys**, that will show the degree of awareness and the implementation early detection actions already made in this moment by the GP's.

The results and National Action Plan are sent to the Ministry of Health and the Europacolon will propose to this Ministry measures to solve the problems encountered and will follow up.

# together

*We can change the future of Pancreatic Cancer!*

## DEMAND BETTER | DEMAND MORE!



# 2018 ImpactPanc Award Updates



# Celgene 2018 ImpactPANC Awards



WORLD **PANCREATIC**  
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## **Support4Caregivers (Canada)**

*Stefanie Condon-Oldreive, Founder/Director, Craig's Cause Pancreatic Cancer Society*

## **Pancreatic Cancer Patient Navigation (Trinidad & Tobago)**

*Natalie Sabga, Director & Lisa Ghany, Operations Consultant, John E. Sabga Foundation for Pancreatic Cancer*

## **Break 4 You (Austria)**

*Michaela Hartenstein, President & CEO, Selbsthilfegruppe Pankreaskarzinom (Support Pancreatic Cancer)*

## **Empowering Caregivers of Pancreatic Cancer Patients for Enhanced Patient Outcomes (Cyprus)**

*Miranda Chrysostomou, Gastrointestinal Cancers Group 'Althea' Officer, The Cyprus Association of Cancer Patients and Friends (PASYKAF)*

## **No Caregiver Left Behind (Australia)**

*Tami McMahon, Director, Fundraising & Development, Panccare Foundation*

# Support4Caregivers (Canada)

**Stefanie Condon-Oldreive**

*Founder/Director,*

*Craig's Cause Pancreatic Cancer Society*



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# Craig's Cause Pancreatic Cancer Society

## - History -



- ❖ Grassroots organization
- ❖ Started in 2006, after Craig Condon passed away from pancreatic cancer, 8 weeks after diagnosis.
- ❖ No organization in Canada that offered awareness, education, support and research programming.
- ❖ Patients and Family reaching out after “Googling”
- ❖ Craig's Cause was formed
- ❖ Incorporated in 2007
- ❖ Charitable status in 2012
- ❖ Partnerships have been instrumental





# Craig's Cause Pancreatic Cancer

## -Four Pillars-

### Awareness

- ❖ National commercial and national media campaigns
- ❖ Proclamations across the country
- ❖ National signature events
- ❖ Tackle Pancreatic Cancer

### Education

- ❖ Brochures, Books and DVD's
- ❖ Information sessions for medical staff, patients
- ❖ Healthcare Outreach Program with PCCF
- ❖ Support4Caregiver Program
- ❖ Eastern Canada Pancreatic Cancer Symposium

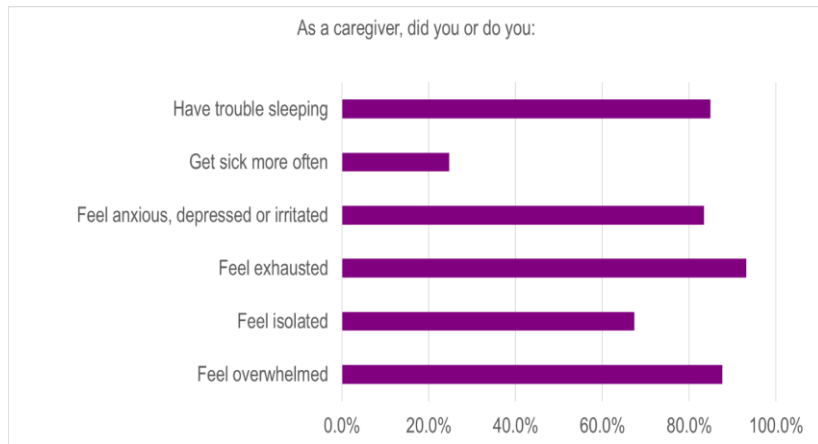
### Support

- ❖ Support4Caregivers
- ❖ Ask a Doctor Program
- ❖ Patient Support Grants
- ❖ Toll free phone number

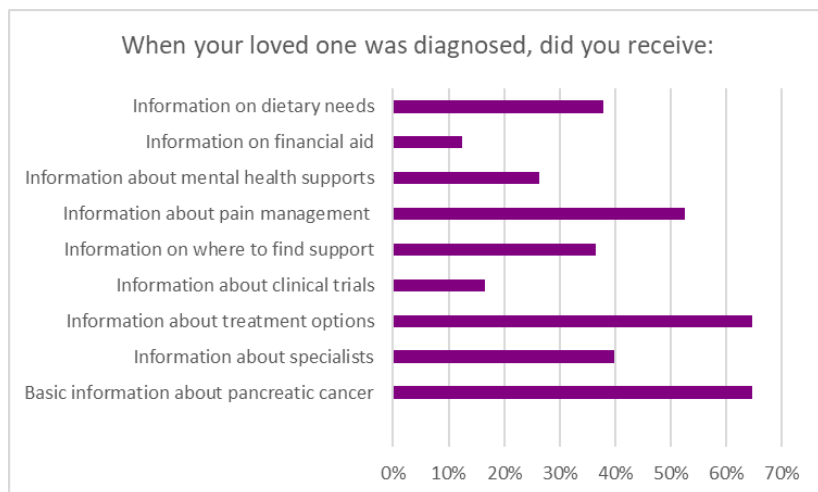
### Research

- ❖ Over \$3 million dollar in research funding
- ❖ Research Collaborations
  - Beatrice Hunter Research Institute
  - PCCF
  - Canadian Cancer Society
  - New Brunswick Research Foundation
  - Dalhousie Research Institute

# Support4Caregivers - Unmet Needs -



In 2018, 101 pancreatic cancer patient caregivers from across Canada (all provinces and territories except for Nunavut) responded to our survey designed to uncover gaps in caregiver support.



The responses and comments revealed that the creation of an interactive, on-line video support series would be welcomed in the caregiver community due to the immense toll on the caregiver. The survey identified specific areas where support was needed.

# Support4Caregivers - Objectives-

Support4Caregivers was designed to address the needs identified by caregivers.

Steps taken include:

- The creation of an on-line, monthly, interactive video series offering caregivers the opportunity to connect and to share personal stories and experiences.
- Choosing session topics which will allow caregivers to receive support in specific areas, as requested by the caregivers, and facilitated by professionals.
- The creation of **www.support4caregivers.ca** where caregivers can watch past sessions and register for upcoming sessions, and where information is provided that is difficult to access.



# Support4Caregivers - Measure and Impact -



**SUPPORT4CAREGIVERS**

SUPPORT YOU NEED, FROM THE COMFORT OF HOME

*confidential & interactive online support group,  
facilitated by professionals experienced in the cancer journey*

FOR MORE INFO ▼  
Click here  
Spaces are limited

The banner features an illustration of five diverse people of various ages and ethnicities holding hands in a line. Below the illustration is a purple bar with the text 'SUPPORT YOU NEED, FROM THE COMFORT OF HOME'. Underneath that is a smaller purple bar with the text 'FOR MORE INFO ▼' and a button that says 'Click here' and 'Spaces are limited'. To the left of the button is a laptop icon with hands typing, and to the right is the logo of the Pancreatic Cancer Society, which is a purple ribbon with a white flower in the center and the text 'PANCREATIC CANCER SOCIETY' around it.

This program has been developed for caregivers and will be evaluated by caregivers.

Each monthly session will be recorded. The number of registrants, along with their evaluation of the session, will provide valuable insight into the success of the program.

Respondents will answer evaluation questions with various scales. There will also be open-ended questions that will encourage input about current session and future sessions

Online presence will also be monitored and reported on.

[support4caregivers.ca](http://support4caregivers.ca)



# Pancreatic Cancer Patient Navigation (Trinidad & Tobago)

**Natalie Sabga**

*Director,  
John E. Sabga Foundation for Pancreatic Cancer*

**Lisa Ghany**

*Operations Consultant,  
John E. Sabga Foundation for Pancreatic Cancer*



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CANCER COALITION<sup>SM</sup>



**JOHN E. SABGA**  
foundation for pancreatic cancer

Patient Navigation &  
caregiver  
support  
Program





**JOHN E. SABGA**  
foundation for pancreatic cancer

Patient Navigation &  
caregiver  
support  
Program

## Who We Are

The foundation honors **John Edmond Sabga** who died at the age of 56 in January 2017 after a valiant 10-month battle with Pancreatic cancer

The **JESF** initial focus is accelerating the race for an early detection test for Pancreatic cancer to ultimately aid in finding a cure

Our primary activity is to support this initiative through funding a Clinical Trial in collaboration with TGEN "The Trinidad Trial - The Final Assault"







**JOHN E. SABGA**  
foundation for pancreatic cancer

# Patient Navigation & Caregiver Support Program

## Who We Are

Our secondary activity is patient Support through a collaboration with CCRI that offers a **Patient Navigation Service.**

Ongoing Patient support through the **JESF** call in line and Facebook page along with quarterly Group support meetings

The **JESF** other activities include Pancreatic cancer education and awareness in collaboration with WPCC with a focus on early detection

**JOHN E. SABGA**  
foundation for pancreatic cancer

About Us

## Our World Our Fight

Join us in our worldwide quest to find a cure and protect future generations from pancreatic cancer.

[DONATE NOW](#)

**WHAT IS THE PANCREAS?**  
The pancreas is an approximately 6 long gland shaped like a long, flat fan and located deep in the belly.  
Although the pancreas is unnoticed in day-to-day life, it is a key part of the digestive system and is responsible for controlling our blood sugar.

**WHAT CAUSES PANCREATIC CANCER?**  
Biliary pain, Nausea, Weight loss, Dark stool, Jaundice

**PANCREATIC CANCER SYMPTOMS**

**OUR WORLD. OUR FIGHT.**

**JOHN E. SABGA**  
foundation for pancreatic cancer

**OUR WORLD. OUR FIGHT.**

**PROUDLY**  
a partner of the American Cancer Society

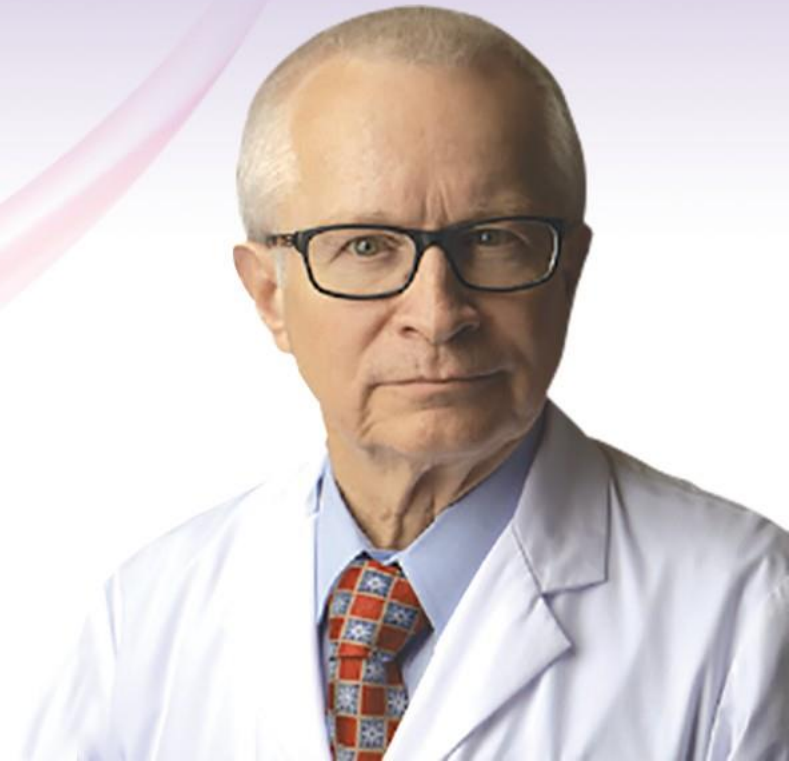
**Republic Bank**

## Key Activities

Public Education and Awareness - Coordination of public seminars annually in partnership with local healthcare and non-governmental organizations for patients and care givers and the general public

Capacity-building for clinical providers - Established the Distinguished Lecture series with the first featuring Dr. Daniel Von Hoff (TGen). Follow up workshops every six months

John E. Sabga Clinical Trial for Pancreatic Cancer Raise \$1M (U.S) to fund trial



## Situational Analysis in Trinidad & Tobago

In Trinidad and Tobago (T&T), a country approximately the size of Dallas, Texas (U.S.), the annual pancreatic cancer mortality rate per 100,000 people is 6.7; this represents a 545% increase since 1990

More alarming, T&T has a pancreatic cancer mortality rate 31.4% higher than its Caribbean neighbors, ranking top five in all of North America. This can be compared with statistics in the United States where pancreatic cancer will kill 10.9 per 100,000 people





**JOHN E. SABGA**  
foundation for pancreatic cancer

Patient Navigation &  
caregiver  
support  
Program

# Patient Navigation & Support Program in collaboration with CCRI

Primary audience is made up of Pancreatic Cancer Patients, Care Givers, Families and immediate support personnel

Secondary audience is the General Public and the extended medical support personnel



# Patient Navigation & Support Program in collaboration with CCRI

## Objectives include:

- To provide a forum for caregivers and patients to meet and discuss their challenges and to provide trained professionals that would educate and provide support for the caregivers
- To develop a referral pathway to identify PanC patients upon diagnosis



# Patient Navigation & Support Program in collaboration with CCRI

## Objectives include:

- To develop key program characteristics and strategies for continuous training
- To develop a comprehensive list of service providers to meet patient needs





**JOHN E. SABGA**  
foundation for pancreatic cancer

Patient Navigation &  
Caregiver  
Support  
Program

## Evaluation and ROI

### JESF patient and Care givers support group:

- Attendance records from workshops
- Attendee survey and feedback from meetings
- Referrals to other medical professionals and feedback on outcomes





## Evaluation and ROI

**CCRI quarterly reports are produced on the following:**

- Number of patients navigated and amount of time and contact
- Barriers identified, resolved and unresolved
- Patient satisfaction with the service
- Assessment of challenges and strategies for improvement







**JOHN E. SABGA**  
foundation for pancreatic cancer

*“Be a rainbow  
in someone  
else’s cloud  
-Maya Angelou”*

Patient Navigation &  
caregiver  
support  
Program

# Break 4 You (Austria)

**Michaela Hartenstein**

*President & CEO, Selbsthilfegruppe*

*Pankreaskarzinom (Support Pancreatic Cancer)*



WORLD **PANCREATIC**  
CANCER COALITION<sup>SM</sup>

A close-up photograph of two hands, palms up, holding a purple awareness ribbon. The ribbon is tied in a loop and is the central focus of the image. The background is a soft, out-of-focus light color. The text is overlaid on the image.

**Break4You**

*ImpactPANC Award 2018*

**Selbsthilfegruppe Pankreaskarzinom**

Support Group Pancreatic Cancer – AUSTRIA

Michaela Hartenstein

# Who we are and what we do...



Selbsthilfegruppe  
Pankreaskarzinom



2016

Exchange

Information



Awareness

Support



WP  
CD



# Break4You - Overview

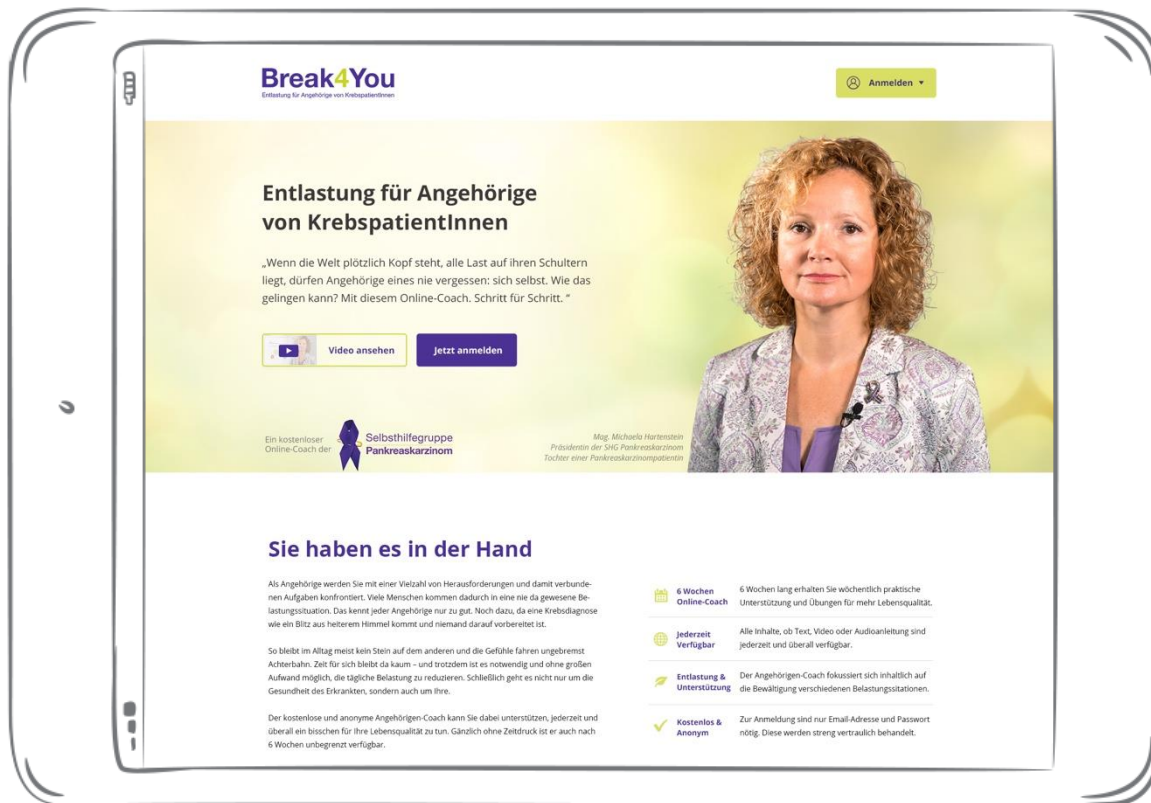
## Online Coach for Family Caregivers



- **Current situation:** Being a family caregiver is an emotionally stressful job dealing with difficult life circumstances. The care and well-being of the cancerpatient is in the center of their mind, while the sense of own welfare and needs is pushed aside.
- **Unmet need:** „Only when you **care for yourself**, you are able to care for someone else“
- **Objectives and aims of „Break4You“:**
  - IMPROVE quality of life of family caregivers
  - DEVELOP self-awareness and LISTEN to own needs
  - STRENGTHEN self-confidence of caregivers
  - IMPLEMENT an easy and diverting mindfulness-training in daily routine

# Break4You – Key Features

## Online Coach for Family Caregivers



### Approach:

During the 6-week-program participants will learn to **identify different types of emotional stress** (such as helplessness and fear, excessive demands, grief and depression, ect.) and **gain insights into different relaxation techniques** to better cope with them.

A qualified psychologist will be available for **individual coaching calls on demand.**

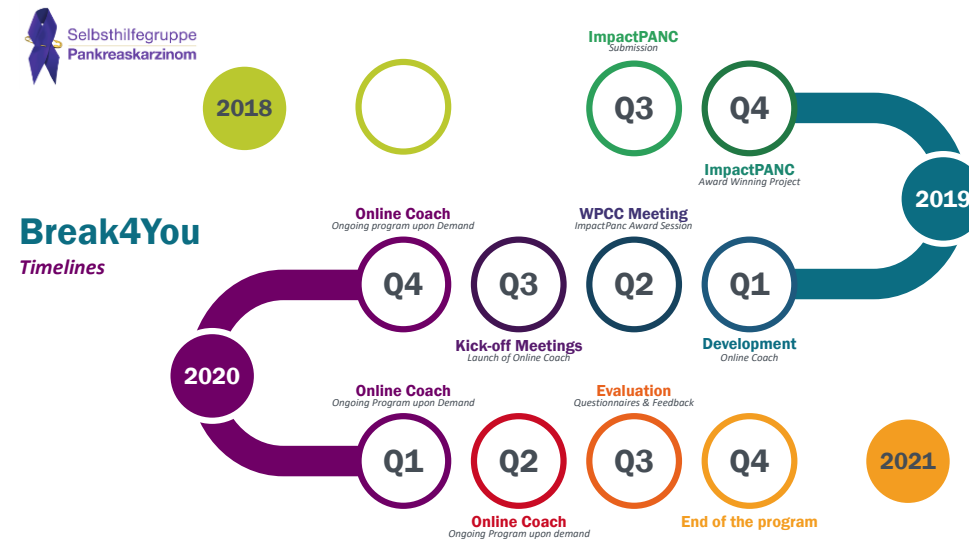
# Break4You – Metrics & Timelines

## Online Coach for Family Caregivers



### Metrics & Timelines:

- **Self-assessment** of current stress-level and health at baseline and after completion of the online program.
- **Number of calls** at expert support line.
- **Qualitative feedback** from participants during individual coaching calls.



# Break4You – Outcome & Challenges

## Online Coach for Family Caregivers



### Projected Outcome

- Participants of the program will perceive excessive demands earlier and will be able to avoid them.
  - Better awareness, interpretation and regulation of emotions
  - Increased perception of own needs
  - Higher stress-resistance and faster recovery
  - Focus on the here and now

### Projected Challenges

- Limited time available for training program and exercises
- Bad conscience of family caregivers to focus on their own needs





A close-up photograph of two hands, palms up, holding a purple awareness ribbon. The ribbon is tied in a loop and is the central focus of the image. The hands are light-skinned and appear to be of a woman. The background is a soft, out-of-focus light gray. The overall tone is warm and caring.

# **Break4You**

**Only when you care for yourself,**

**you are able to care for someone else!**

# Back-up



**Break4You**  
Entlastung in schwierigen und herausfordernden Situationen

Wochen: 1 2 3 4 5 6 7 8 **MEIN PROFIL**

**Woche 1**

Willkommen in Woche 1

- Sie sind nicht alleine ✓
- Emotionale und physische Belastung
- Auf sich selbst achten
- Entlastungsübungen

### Konfliktsituation

#### Gefühle annehmen lernen

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„Hin und wieder finde ich die Zeit, um mal wieder etwas für mich zu machen, z.B. mich mit Freundinnen treffen. Aber ich kann diese Momente nicht mehr richtig genießen.“

weiter >

LEKTION ABHAKEN

**Break4You**  
Entlastung in schwierigen und herausfordernden Situationen

Wochen: 1 2 3 4 5 6 7 8 **MEIN PROFIL**

**Woche 1**

Willkommen in Woche 1

- Sie sind nicht alleine ✓
- Emotionale und physische Belastung
- Auf sich selbst achten
- Entlastungsübungen

### Entspannungsübung

#### Die Stressreaktion kontrollieren

Das nächste Mal wenn Sie merken, dass Ihr Körper in Alarmbereitschaft versetzt wird, nutzen Sie eine der folgenden Übungen, um die Stressreaktion einzubremsen.

Starten Sie die Übung, sobald Sie die typischen Stressreaktionen bemerken. Diese Übungen entspannen den sogenannten Vagusnerv, der dadurch die „Kampf oder Flucht“ Stressreaktion abschalten kann.

Die folgenden Übungen brauchen nur 90 Sekunden Ihrer Zeit, wirken aber sehr entspannend. Wählen Sie eine der folgenden Übungen, dann haben Sie jederzeit eine wirksame Übung zur Hand:

- Atmen Sie ruhig und zählen Sie bis 90
- Zählen Sie von 90 rückwärts und atmen Sie ruhig
- Stehen Sie auf und gehen Sie herum während Sie ruhig atmen
- Umarmen Sie jemanden für 90 Sekunden
- Halten Sie jemandes Hand für 90 Sekunden
- Achten Sie auf darauf wie Ihr Körper Ihren Stuhl berührt

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**1 Achten Sie auf Ihre eigenen Bedürfnisse**

# Empowering Caregivers of Pancreatic Cancer Patients for Enhanced Patient Outcomes (Cyprus)

**Miranda Chrysostomou**

*Gastrointestinal Cancers Group 'Althea' Officer,  
The Cyprus Association of Cancer Patients and  
Friends (PASUKAF)*



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althea  
Gastrointestinal  
Cancers Group  

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learn • act • prevent



2018 ImpactPanc award for  
innovation

Cyprus

# ‘PASYKAF’ - The Cyprus Association for Cancer Patients and friends

PASYKAF was founded in 1986 by a group of cancer patients, their families and friends who in pursuit of their mission have established services tailored to satisfy the patients’ needs.

Today, a non-profit organization dedicated to eliminating cancer through cancer prevention and early diagnosis and improving the quality of life of cancer patients and their families through education, awareness, advocacy and service. Every year, the multidisciplinary team of PASYKAF provides its services to more than 6,000 patients and their families.

All services and support programs listed below are available across Cyprus free of charge.

- Home Nursing Care
- Psychology and Social support
- Physiotherapy
- Lymphedema service
- Post Mastectomy support
- Awareness service
- Gastrointestinal cancers group
- Advocacy for patients’ rights
- Transport service

# Empowering Caregivers of Pancreatic cancer patients for Enhanced Patient Outcomes

- Records show 80 new cases of pancreatic cancer in Cyprus every year out of which 80% are diagnosed when the disease has metastasized and difficult to be treated. The pancreatic cancer patient and the caregiver are faced with a daunting reality. Psychosocial support is of paramount importance for both, from the moment of diagnosis throughout the pancreatic cancer journey up to rehabilitation and/or bereavement.
- This initiative will focus on evolving psychological support within group settings for pancreatic caregivers, due to the emerged need.
- Additionally, over 80% of pancreatic cancer patients report weight loss when diagnosed and suffer of malnutrition due to physiologically-induced anorexia, malabsorption and increased caloric requirements. Oncology Nutrition Expert Services are not available by the Cyprus NHS yet, except for a limited provision in one Oncology Centre and the private sector.

# Project Objectives

## ✓ Developing Psychosocial Caregiver Support Group Programs

- Existent one-to-one support to be complemented with group support for caregivers and patients, during and post therapies, to enable individuals to share personal experiences, feelings and coping strategies.
- Existent Bereavement Support Groups aiming to provide information and psychological (cognitive behavioral) tools to individuals who have experienced the loss of a loved one to pancreatic cancer.
- Caregiver workshops

## ✓ Introducing Expert Nutritional Guidance

An Oncology Nutrition Expert will:

- Access and consult pancreatic cancer patients and train caregivers
- Provide practical guidance regarding nutritional problems
- Redress symptoms and address caregivers' and patients' needs

# Implementation

- The patient referral system from the Oncology Centre, private hospitals and clinics and public hospitals to PASYKAF has been running for several years. PASYKAF's social workers team is the first to receive the patients' referral from his/her doctor asking to be offered one of PASYKAF's free of charge services (this includes psychosocial support, home nursing/palliative care, physiotherapy, transportation and rehabilitation). In addition to the doctors' request, PASYKAF's social worker will assess the patient's and caregiver's overall needs and forward the patient details to the desired service/health care team.
- Doctors will be informed by this additional service by post or by personal meeting and asked to refer pancreatic patients once a diagnosis has been given and at the earliest possible. If the doctor does not request for the patient to be given nutrition advice then our social worker will assess the patient's needs and will forward the patient to our service if needed.
- Oncology Nutrition Expert Guidance is not yet considered to be one of PASYKAF's services as it is only administered to pancreatic patients and caregivers at this point, and for this reason is not included on the referral form but doctors will be informed about this service and so will PASYKAF staff. All pancreatic patients referrals will be forwarded to Oncology Nutrition Expert Guidance and Psychosocial support team for assessment.



# Outcomes

Caregivers will be provided with:

- The necessary tools to administer the best possible care to patients including advice on dietary requirements, treatment schedules and practical day-to-day routine.
- Help to restore mental, physical and psychological balance throughout their joint journey
- Secure optimum quality of life with the reliable support network of PASYKAF.
- Confidence and empowerment

Pancreatic cancer patients

- Concerns about post-operative nutritional care will be addressed for each patient with a personalized nutritional plan.
- Nutritional support and consultation by the Nutrition Expert will help minimize symptoms such as loss of appetite, nausea and vomiting, control weight loss.
- Home stay decision during the end of life stage will be enhanced.

This initiative may long term:

- Influence and encourage support groups to flourish
- Oncology Expert Nutrition Guidance to gain its relative space among the oncology health professional team.
- National Health System may adopt this initiative as a standard procedure
- Introduce best practices for nutritional screening to be performed at the time of the diagnosis, not later.



# Project's Impact & Timeline

- ✓ The project is set to start in May 2019 and run for the next 12 months.
  
- ✓ Psychosocial Caregiver Support Group & Expert Nutritional Guidance Programs output and impact will be assessed by:
  - Completion of appraisal forms anonymously
  - Caregiver Quality of Life questionnaire to highlight their needs, emotional, psychological or physical.
  - Caregiver workshops will give more recognition on their role and provide documentation on how the caregivers' needs should be measured in order for us to help solve several of the problems faced.
  - PASYKAF's database system named 'DITIS' will be used for record keeping of patients' personal data and history.
  - Portable device for Bioelectric Impedance Analysis will be used to capture body composition data (body fat, visceral fat, muscle mass, muscle quality, total body water, bone mass, physique rating, basal metabolic rate, daily caloric intake, body mass index). This will be recorded on a separate database system under each patient's personal file.
  - Patient's personal file will also include: record of advice and support given to caregiver at each session, clinical examination details and weight records.
  - Malnutrition Universal Screening Tool (MUST)
  - Telephone communication/assistance with PASYKAF's officers will be available for pancreatic cancer caregivers/patients for any concerns or additional information needed.

# No Caregiver Left Behind (Australia)

**Tami McMahon**

*Director,  
Fundraising & Development, Pancare Foundation*



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# No Caregiver Left Behind

Meeting the needs of all caregivers  
Australia wide – a feasibility study



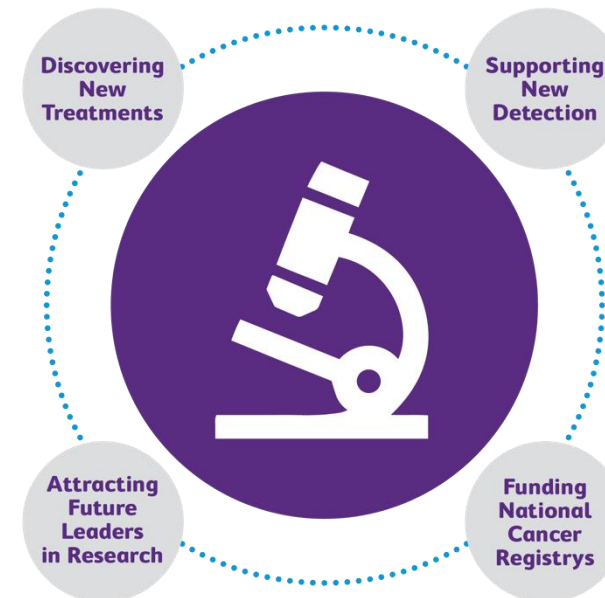
# What we do

**We're committed to delivering patient support services and to funding research that will have a direct impact on increasing survival rates for pancreatic and upper GI cancers.**

Delivering equitable access to our services that meet the needs of patients – no matter where they live.



Support research that has the best chance to improve survival and outcomes of pancreatic cancer.



# No caregiver left behind

**Conduct a feasibility study to understand the needs of carers and what services they may want.**

## Project objectives:

- ⑥ To gain an understanding of the unique needs of caregivers and tailor a program to better meet these needs in a way that is accessible to any caregiver, no matter where they live.
- ⑥ To gain an understanding of worldwide best practice and develop a roadmap for bringing a best practice program to the Australian caregiver landscape.



# Methodology

**Bring together a project team to conduct research and define services.**

**Project team are from Queensland and Western Australia. Queensland University of Technology will work with the team on measurements and impact.**

## Three main stages:

- ⑥ Conduct research and define services.
- ⑥ Develop recommendations and service offerings.
- ⑥ Develop final report and recommendations.



# Results and conclusion

**Detailed understanding of the varying types of caregiver roles and their unique needs including but not limited to consideration of the stages of the caregiver journey, gender, age, geographical location and the use of technology.**

## Project measurements and impact:

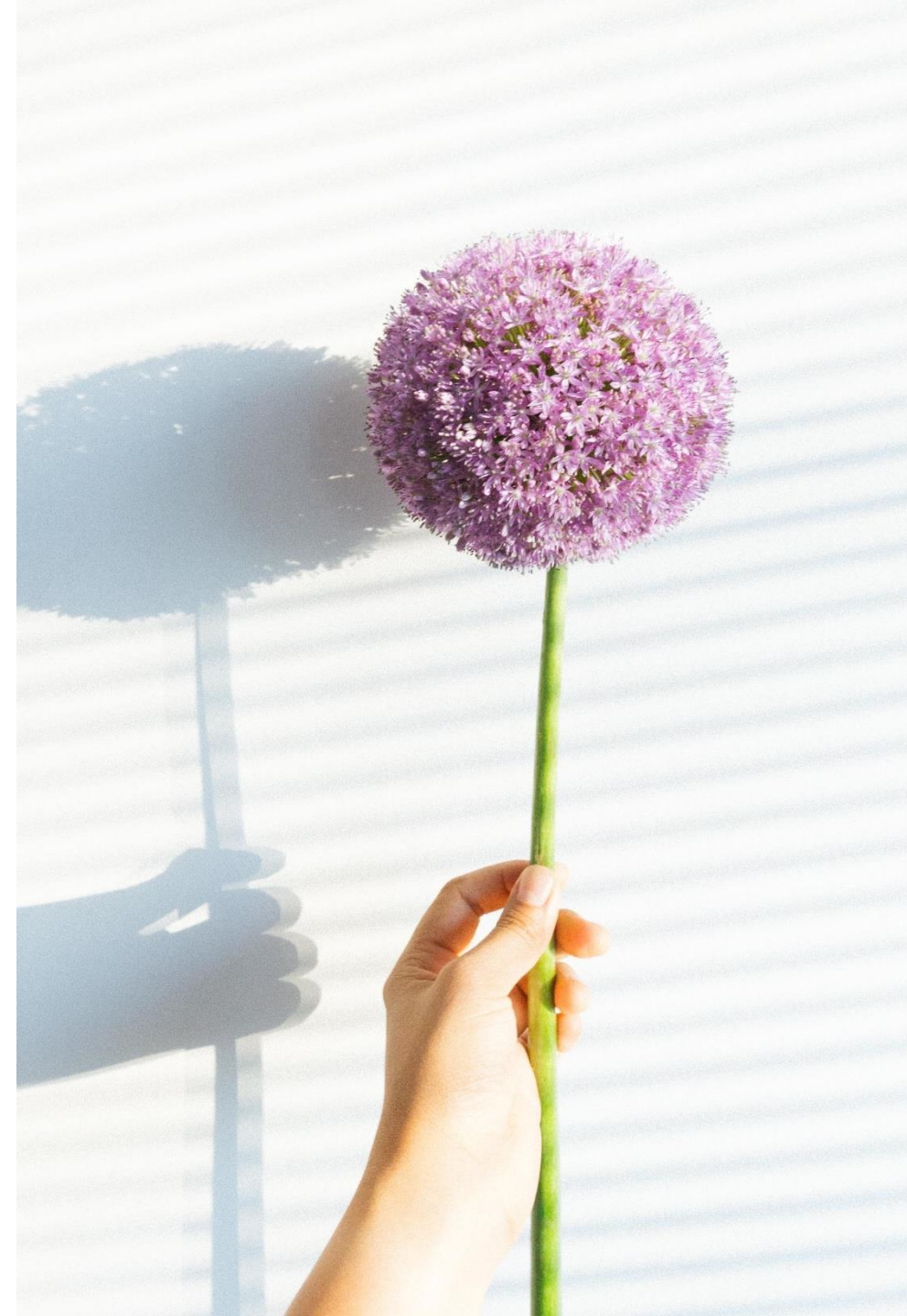
- ⑥ Caregiver priorities and needs and their views on what would assist
- ⑥ Evaluation of current services using indicators relevant to and developed with caregivers
- ⑥ Taking technology, cost-effectiveness, social return-on-investment and caregiver benefit into account
- ⑥ Delivering caregiver support for the future





# Thank you to Celgene ImpactPANC Award

Our commitment to be a leading voice for pancreatic patients  
and carers is unwavering.





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