

# WPCC Member Engagement

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President & CEO, PanCAN*

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*WPCC Project Lead*



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CANCER COALITION<sup>SM</sup>

# Coalition Resources

# WPCC Budget

	<i>Actual 2018</i>	<i>Goal 2019</i>
<b>Total Sponsorship Support</b>	<b>\$430,000</b>	<b>\$510,000</b>
<b>Expenses</b>	<i>Actual 2018</i>	<i>Budget 2019</i>
Annual Meeting	\$225,727	\$218,554
WPCD	\$251,000	\$251,000
Coalition Consultant	\$30,000	\$30,000
Website Hosting, Analytics	\$1,688	\$1,688
Project Management (marketing, development, meeting planning, governance)	\$80,000	\$80,000
<b>Total Expenses</b>	<b>\$586,415</b>	<b>\$581,242</b>
<b>Net (PanCAN Donation)</b>	<b>\$(156,415)</b>	<b>\$(71,242)</b>

**THANK YOU  
TO OUR 2019  
SPONSORS**



# WPCC Resources



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- Celgene contributed \$250K in FY2019
- Celgene acquired by BMS, deal closing in 3<sup>rd</sup> quarter 2019
- Future funding from Celgene/BMS uncertain
- PanCAN's goal is to maintain coalition efforts at current level
- WPCC Steering Committee has brainstormed funding opportunities

# WPCC Budget

	<i>Goal 2019</i>	<i>Goal 2020</i>	<i>Goal 2020</i>
<b>Total Sponsorship Support</b>	<b>\$510,000</b>	<b>\$300,000</b>	<b>\$300,000</b>
<b>Expenses</b>	<i>Budget 2019</i>	<i>Budget 2020</i>	<i>Budget 2020</i>
Annual Meeting	\$218,554	\$218,554	\$0
WPCD	\$251,000	\$251,000	\$251,000
Coalition Consultant	\$30,000	\$30,000	\$30,000
Website Hosting, Analytics	\$1,688	\$1,688	\$1,688
Project Management (marketing, development, meeting planning, governance)	\$80,000	\$80,000	\$80,000
<b>Total Expenses</b>	<b>\$581,242</b>	<b>\$581,242</b>	<b>\$362,688</b>
<b>NET (PanCAN DONATION)</b>	<b>\$(71,242)</b>	<b>\$(281,242)</b>	<b>\$(62,688)</b>

SAVE THE DATE

# Annual Meeting 2020

*September 22 – 24, 2020*

*Los Angeles, CA*

# Stronger Together!

- Leverage each other's resources
- Share best practices
- Provide tools and resources
- Network to expand our communities



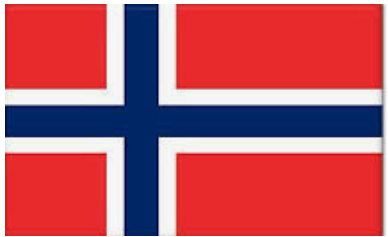
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# Member Engagement Examples



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## Pancreatic Cancer Network Norway + Argentina

- Provided support to a patient advocate and clinician in Argentina who wants to establish a pancreatic cancer specific patient advocacy group
- Practical advice and 'tips for success' based on their own experience in Norway
- This advice and being available to speak in person is hugely useful and appreciated!

# Member Engagement Examples



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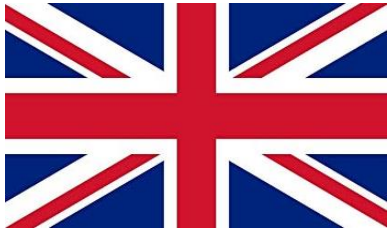
## Digestive Cancers Europe + EuropaColon Poland

- Patient advocates in Poland wanted to raise awareness
- The Coalition made connections between these patient advocates and Digestive Cancers Europe
- The result... a new, vibrant pancreatic cancer advocacy group operating in Poland -- EuropaColon Poland!

# Member Engagement Examples



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## Pancreatic Cancer Action (UK) + Pancreatic Cancer Action Gibraltar

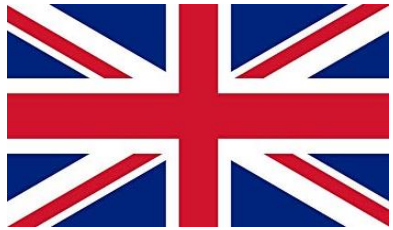


- PCA has generously shared awareness-raising resources with a number of WPCCC members, including Gibraltar
- PCA Gibraltar was able to use these resources effectively during their WPCCD 2018 campaign

# Member Engagement Examples



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## Pancreatic Cancer UK + Pancreatic Cancer South Africa



- These two members made a connection at an early WPCC meeting, and remained in touch afterwards
- PC UK provided PC SA with information and resources they could use on their website

**Any Other Exciting  
Member Sharing?**

# Strategic Planning

# Methodology



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- **Conducted 24 interviews** between June 14 – September 17, 2018:
  - 12 Coalition members:
    - *Steering Committee members, several WPCD Committee members, and other general members*
  - 4 pharma sponsors
  - 5 clinicians/researchers
  - 3 agency consultants
- **22 phone interviews**; 2 in-person
- **8 countries represented** – Australia, Argentina, Belgium, Canada, Italy, Sweden, UK, US

# Three Emerging Themes



# #1

## Drive earlier detection by increasing public and HCP awareness of pancreatic cancer



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1. Continue with WPCD and year-round awareness raising efforts
2. Engage and educate Healthcare Professionals:
  - General Practitioners/PCP

# #2

**Maintain a highly activated, engaged membership that is unified in vision and has clarity of purpose**

1. Continue with Face to Face Meeting
2. Pancreatic Cancer Research Brief



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# Sharing Research on Closed Facebook Group



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 **Clara Conway** shared a link.  
Admin · April 16 at 10:25 AM

Sharing links to two really interesting research projects on behalf of Pancreatic Cancer Network Norway. Both worth a read!  
<https://pancreas.w.uib.no/pancreatic-cancer/>  
<https://www.med.uio.no/.../pancreatic-cancer-biology-therape.../>



PANCREAS.W.UIB.NO  
**PANCREATIC CANCER :: Molecular pathology of pancreatic diseases**

 You and 3 others Seen by 25

 Like  Comment

 **Pancreatic Cancer UK** shared a link.  
April 16 at 6:34 AM

Hello, delighted to share our Pancreatic Cancer UK research program with our WPCC colleagues! <https://www.pancreaticcancer.org.uk/research/>

PANCREATICCANCER.ORG.UK   
**Research | Pancreatic Cancer UK**  
We fund world-leading research into pancreatic cancer through...

 You, Clara Conway and 2 others 1 Comment Seen by 27

 Like  Comment

 **Jenny Isaacson**  This is terrific. Thank you for sharing this valuable information.  
Like · Reply · 3d

 Write a comment...    

# Facebook Group and Pages



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World Pancreatic Cancer Coalition Members

WORLD PANCREATIC CANCER COALITION

17 people want to join this group

Clara Conway July 20  
One of our newer WPCC members would love a little help with their logo: does anyone have design tools/ expertise that they could share? Thanks!

WPCD

World Pancreatic Cancer Day @worldpancreaticcancerday

2017 WORLD PANCREATIC CANCER DAY

Demand Better For Patients. For Survival.

WORLD PANCREATIC CANCER DAY NOVEMBER 16

WORLD PANCREATIC CANCER DAY NOVEMBER 16

Every day, more than 1,000 people worldwide will be diagnosed with #pancreaticcancer and an estimated 955 will die from the disease. Awareness has to be an every day, every month priority if we are going to change those numbers. Start by sharing these symptoms with the name of someone you're honouring. #WPCD

World Pancreatic Cancer Coalition @worldpcc

2017 WORLD PANCREATIC CANCER DAY

Demand Better For Patients. For Survival.

WORLD PANCREATIC CANCER DAY NOVEMBER 16

WORLD PANCREATIC CANCER DAY NOVEMBER 16

Today thousands of people across the globe are coming together to fight #pancreaticcancer, the world's toughest cancer. Join us in showing your support by wearing purple and encouraging your loved ones to do so, too!

**Facebook Closed Group**  
<https://www.facebook.com/groups/worldpcc/>

**WPCD Facebook Page**  
<https://www.facebook.com/worldpancreaticcancerday>

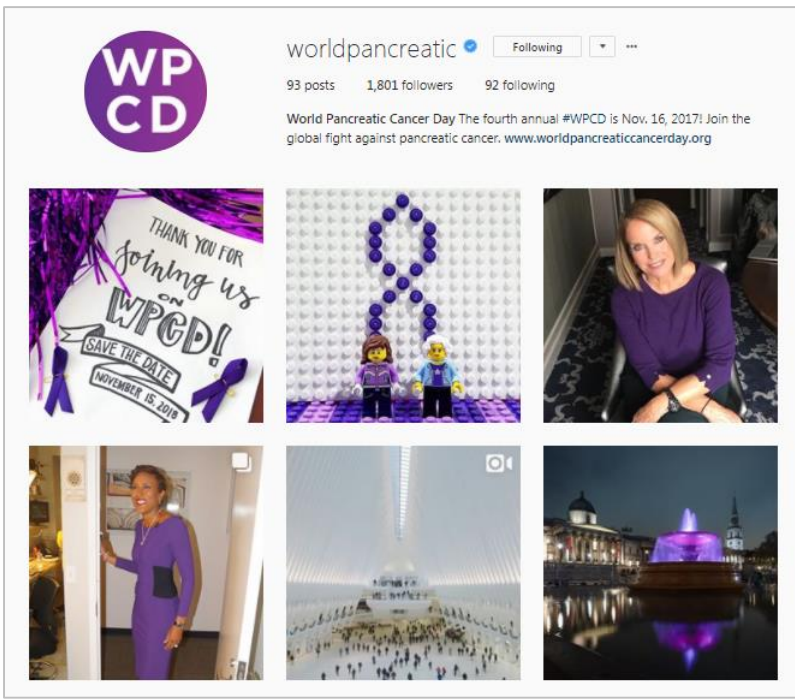
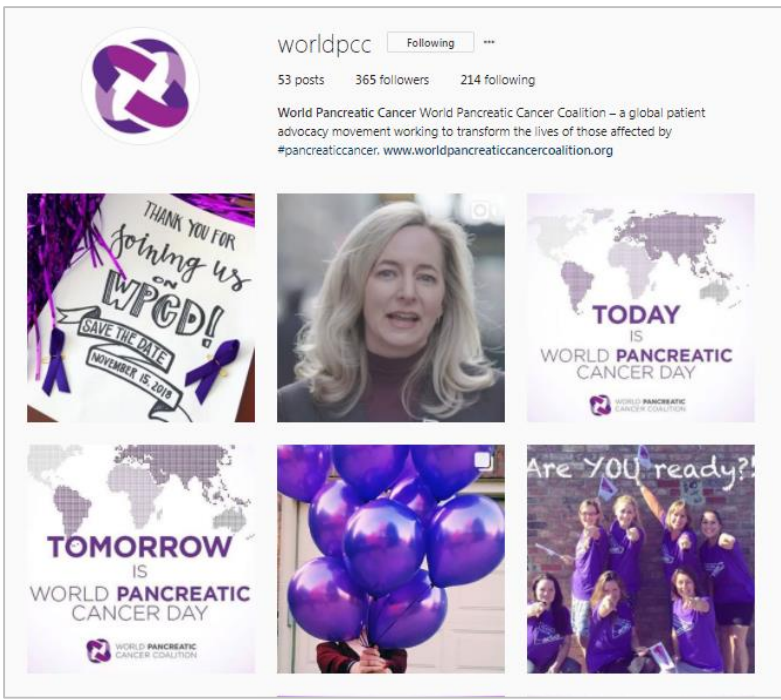
**WPCC Facebook Page**  
<https://www.facebook.com/worldpcc>



# Social Media



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**Twitter**

@worldpcc and @worldpancreatic

**Instagram**

@worldpcc and @worldpancreatic

# #2

**Maintain a highly activated, engaged membership that is unified in vision and has clarity of purpose**



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CANCER COALITION<sup>SM</sup>

1. Continue with Face to Face Meeting
2. Pancreatic Cancer Research Brief
3. Pancreatic Cancer Key Messages
4. Deepen Alliances/Networks among Members

# #3

## Strengthen the WPCCC evaluation framework so that we can measure the overall impact of the Coalition



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1. Expand on the WPCCC mission with supporting statements

# Expand on the WPCCC Mission with Supporting Statements



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CANCER COALITION

ABOUT US

MEMBERS

INITIATIVES



## ABOUT US

Through global collaboration, raising awareness of pancreatic cancer and coming together we strengthen all our member organizations.

By sharing best practices and leveraging expertise, we strengthen our collective impact and the impact of individual member organizations that will drive transformational change.

We have a globally diverse membership that is highly engaged and unified in its vision and purpose. Members have access to universal tools and resources for World Pancreatic Cancer Day and throughout the year. We speak with a unified voice by using consistent data and information to provide the public with accurate and up-to-date messages about pancreatic cancer. We meet face-to-face annually to share knowledge, expertise and best practices.

## Global Impact

Global collaboration amplifies our impact on pancreatic cancer to save lives. Through our annual World Pancreatic Cancer Day campaign and raise awareness about the symptoms and risk factors of pancreatic cancer to drive earlier detection.



# #3

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

1. Expand on the WPCCC mission with supporting statements
2. Develop a formal evaluation framework with metrics for all initiatives:
  - WPCCD Campaign
  - Annual Meeting

# WPCC ANNUAL MEETING 2019 - EVALUATION

## WPCC ANNUAL MEETING 2019 - EVALUATION

Thank you for attending the WPCC Annual meeting 2019. We greatly appreciate your feedback on the meeting. Please take a few minutes to complete this survey and help us to make our future Annual Meetings more useful and enjoyable.

OK

1. The meeting program (e.g. meeting structure, discussion topics and format of sessions and workshops) helped WPCC members learn and exchange ideas.

Strongly agree

Disagree

Agree

Strongly disagree

Neither agree nor disagree



# #3

## Strengthen the WPCC evaluation framework so that we can measure the overall impact of the Coalition



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CANCER COALITION<sup>SM</sup>

1. Expand on the WPCC mission with supporting statements
2. Develop a formal evaluation framework with metrics for all initiatives:
  - WPCD Campaign
  - Annual Meeting
  - Surveys of WPCC Members

# World Pancreatic Cancer Coalition Annual Meeting – Workshop Topics

1. Please rank how interested you would be in attending a workshop on the following topics. 1 being the workshop that you would be most interested in attending - 5 being the workshop that you would be least interested in attending.

⋮	<input type="text"/>	<b>Social media training:</b> this workshop will take members through World Pancreatic Cancer Day Campaign social media assets (from 2018). It will provide a practical demonstration on making the most of your digital campaign materials and tools.
⋮	<input type="text"/>	<b>Media skills training:</b> This workshop will build on last year's media skills session. It will provide member's more opportunity to develop and practice their media skills, including on-camera interviews.
⋮	<input type="text"/>	<b>Supporting pancreatic cancer patients, families and care-givers:</b> This workshop will showcase examples of services provided by WPCC member organizations that offer patients, families and care-givers emotional and practical support.
⋮	<input type="text"/>	<b>Organizing and running a succesful event:</b> This workshop will showcase 2 events (1 fundraising and 1 non-fundraising) currently run by WPCC member organizations. It will focus on practical steps including event planning, setting budgets, event marketing and evaluation.
⋮	<input type="text"/>	<b>Understanding clinical trials:</b> This workshop will provide an overview of clinical trials, including terminology, the different types of clinical trials, trial design and phases and how to find information about trials that are underway.

# #3

## Strengthen the WPCC evaluation framework so that we can measure the overall impact of the Coalition



WORLD PANCREATIC  
CANCER COALITION™

1. Expand on the WPCC mission with supporting statements
2. Develop a formal evaluation framework with metrics for all initiatives:
  - WPCD Campaign
  - Annual Meeting
  - Surveys of WPCC Members
  - Collaborations

# World Pancreatic Cancer Coalition Annual Meeting Participant List

The Biltmore Hotel | Coral Gables, Florida | May 7 – 9, 2019



ABOUT US

MEMBERS

INITIATIVES



Directory PDF:

Download



Support for people living with and affected by the disease.

- Opportunities
- Raising Awareness
- Support
- Fundraising Events
- Training

## USA



- Alliance of Families Fighting Pancreatic Cancer
- CodePurple: A Suzanne Wright Foundation
- Bella Lisa Pancreatic Cancer Foundation
- Dawn Hill Fight Foundation
- Declare HOPE
- Destroy Pancreatic Cancer
- Elvin Howard, Sr. Pancreatic Cancer Advocacy Foundation
- Fondazione Nadia Valsecchi
- My Everest Association
- Oltrelaricerca

## WPCC Members

Contact Name	Organization	Contact Email
Ann E. Goldberg	Kenner Family Research Fund/USA	agoldberg@kennerfamilyresearchfund.org
Ann Walsh	Lustgarten Foundation/USA	awalsh@lustgarten.org
Anna Murphy	Florida Pancreas Cancer Coalition, Inc./USA	ann@flpcc.org
Audrey Kurlan-Marcy	Pancreatic Cancer Alliance/USA	audreykm@townisp.com
Barabara Foley	Ron Foley Pancreatic Cancer Foundation/USA	barbara@ronsrn.org
Barbara Kenner, PhD	Kenner Family Research Fund/USA	drbkenner@kennerfamilyresearchfund.org
Bertha Howard	Elvin Howard, Sr. Pancreatic Cancer Advocacy Foundation/USA	drsizer@judahliiongroup.com
Blair Stewig	EuropaColon Poland/Poland	blair.stewig@gmail.com
Charlotte Borge-Andersen	Pancreaskreft Nettverk Norge(PKNN)/Norway	lotte.ba@icloud.com
Christina Parrish	The Purple Iris Foundation/USA	cparrish@purpleirisfoundation.com
Cindy Gavin	Let's Win! Pancreatic Cancer Foundation/USA	cindy@letswinpc.org
Colleen M. Schelde	Pankreascancer Natverket Denmark (Pancreatic Cancer Network Denmark)/Denmark	cschelde@yahoo.com
Daniel Goulburn	#PurpleOurWorld/Australia	danielgoulburn@gmail.com
Diana Jupp	Pancreatic Cancer UK/UK	diana.jupp@pancreaticcancer.org.uk
Diane Tonelli	Pancreatic Cancer Alliance/USA	dtonelli@hotmail.com
Dino Verrelli	Project Purple/USA	dino@projectpurple.org
Elvin Howard, Jr.	Elvin Howard, Sr. Pancreatic Cancer Advocacy Foundation/USA	drsizer@judahliiongroup.com
Eva Backman	PALEMA/Sweden	backmaneva@yahoo.com
Federica Valsecchi, PhD	Fondazione Nadia Valsecchi/Italy	fondazionevalsecchi@gmail.com
Fiona Brown	Pancreatic Cancer Scotland/UK	fbrown@pancanscot.org
Jacie V. Scott	Declare HOPE/USA	jacie@wedecclarehope.org
Jasmine Sanders	Declare HOPE/USA	info@wedecclarehope.org
Jennifer Loughran	Ron Foley Pancreatic Cancer Foundation/USA	jennifer@ronsrn.org
Jessica Abelsohn	#PurpleOurWorld/Australia	info@purpleourworld.com
Jessica Macdonald	Pancreatic Cancer Canada/Canada	jmacdonald@pccf.ca
Jim Rolfe	Rolfe Pancreatic Cancer Foundation/USA	jrolfe427@gmail.com
Julie Fleshman, JD, MBA	Pancreatic Cancer Action Network/USA	jfleshman@pancan.org
Kate Elliott	Craig's Cause Pancreatic Cancer Society/Canada	kate@craigscouse.ca
Kate Howarth	Pancreatic Cancer Awareness Gibraltar/UK	kate.howarth@cancerrelief.gi
Kendra Haywood	Alliance of Families Fighting Pancreatic Cancer (AFFPC)/USA	kendra@affpc.org
Kerri Kaplan	Lustgarten Foundation/USA	kkaplan@lustgarten.org
Kerry Irvine	Northern Ireland Pancreatic Cancer/UK	info@nipanc.org
Kerry McKean Kelly	Kelly's Heroes/USA	kmckeankelly@msn.com
Kimberly Stoll-French	National Pancreatic Cancer Foundation/USA	kimberly@npcf.us
Kristjan Porm	Avner Pancreatic Cancer Foundation/Australia	kristjan@avnersfoundation.org.au
Laura Beaupre, RN, BSN, OCN	J's Run/USA	l.beaupre@yahoo.com
Laura Loggia	Pancreatic Cancer Cure Foundation (PCCF)/USA	lauraloggia211@gmail.com

(continued on back)

World Pancreatic Cancer Coalition Members

Closed group

- About
- Discussion
- Chats
- Members
- Events
- Videos
- Photos
- Files



June 2018



July 2018



August 2018



September 2018



October 2018



November 2018



November 16, 2018



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Genova, Italy – World Pancreatic Cancer Day 2018

# Newsletter



From left, back  
Cancer Research



The v

MEMBER  
CANCER



MEMBER  
NATIONAL



**CARRERAS**  
Y no sólo la tuy  
4 NOV 2018  
11 NOV 2018  
[www.carreras.org](http://www.carreras.org)

MEMBER  
CANCER



WPCD: 5 T

A BEAUTIFUL PURPLE WORLD

Proud member of



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

Proud supporter of



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



# WPCC Project Lead



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

Clara MacKay

[Clara@worldpancreaticcancercoalition.com](mailto:Clara@worldpancreaticcancercoalition.com)



**SUPER  
POWERS**

# Small Group Discussions



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# Small Group Discussions

List with three columns:

**ORGANIZATION**

**SUPER POWER**

**GAP**

# Report Outs

# Small Group Discussions #2



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## Table Discussion Topics

Tables 3, 4, 5, and 7: Fundraising & Resources

Tables 1, 8, and 9: Patient Advocacy

Tables 2, 6, 10 and 11: Supporting Patients



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## Table Discussion

- What's working well in this area at your organization?
- What are the challenges?
- How might members at the table partner?