

# Foreword from the CEO

Pancare Foundation is taking on the challenge of improving the lives of people living with pancreatic and upper gastrointestinal cancers and their carers.

The survival rates for pancreatic and upper gastrointestinal cancers are grim. When someone is diagnosed with one of these cancers, their chances of being alive five years later is less than 20%.

Despite this, pancreatic and upper gastrointestinal cancers receive far less funding than cancers with five year survival rates of over 90%. Pancreatic and upper gastrointestinal cancers are the forgotten cancers.

With the right level of investment, substantial progress can be made to improve support for and survival rates of people living with these forgotten cancers. Pancare is well placed to help deliver this progress. In a short period of time, we have substantially increased the number of patients we support and made a real difference in the lives of people living with these cancers, along with their families and carers.

This strategy outlines our promise for progress over the next five years. It is our plan to ensure people living with pancreatic and upper gastrointestinal cancers are no longer forgotten.

With the right level of investment, substantial progress can be made to improve support and survival rates for people living with these forgotten cancers. **Doug Hawkins** Chief Executive Officer

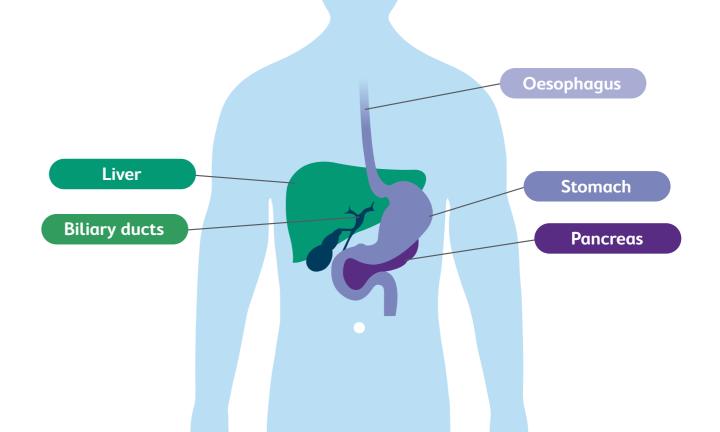
#### Front cover image:

In loving memory of Damien Woodruff, pictured with Pancare Foundation founder, Dr Mehrdad Nikfarjam.

# Understanding the challenge of upper gastrointestinal cancers

Upper gastrointestinal cancers are known as silent cancers as they are hard to detect in the early stages.

- Upper gastrointestinal cancer is a term for the group of cancers that affect the upper digestive system. The organs affected include the pancreas, liver, stomach, bile ducts and oesophagus.
- Each of these organs plays a vital role in digesting food and fluid, processing nutrients, absorbing energy, regulating blood sugars and filtering waste before passing through to the lower gastrointestinal tract.
- Pancreatic and upper gastrointestinal cancers often go undiagnosed in the early stages due to the presentation of vague symptoms such as nausea, pain in upper abdomen, loss of appetite, weight loss and tiredness.
- Once these cancers reach advanced stages, their spread to other organs means that any chance of curative surgery is effectively eliminated and survival is drastically reduced.

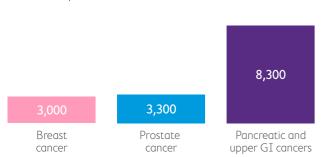


2 Pancare Foundation Strategic Plan 2020 - 2025 3

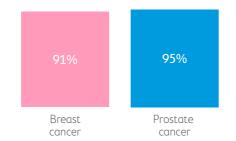
# Our challenge – Building the right support

More Australians die from pancreatic and upper gastrointestinal cancers than high profile cancers, and the prognosis is far worse...

More deaths occur as a result of pancreatic and upper gastrointestinal cancers each year than breast and prostate cancers combined <sup>1,2</sup>



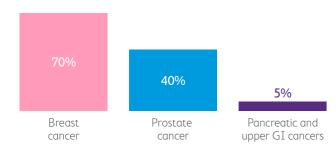
Pancreatic and upper gastrointestinal cancers have significantly lower five-year survival rates than breast and prostate cancers 1,2



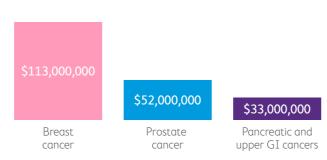
#### Pancreatic and upper GI cancers

#### ...yet support and funding are significantly lower.

Far fewer pancreatic and upper gastrointestinal cancer patients have received active support over the last 10 years than breast and prostate cancer patients <sup>3\*</sup>



Despite worse outcomes, pancreatic and upper gastrointestinal cancers received less research funding from 2012 to 2016 than breast and prostate cancers <sup>4</sup>



Source: <sup>1</sup>Australian Institute of Health and Welfare 2019. Cancer in Australia: an overview 2019. Cancer series. No 119. Cat. no. CAN 1 23. Canberra: AIHW. <sup>2</sup>Cancer Australia 2014. Cancer Research in Australia: an overview of funding to cancer research projects and research programs in Australia 2006 to 2011, Cancer Australia, Surry Hills, NSW. <sup>3</sup>Breast Cancer Network Australia, Prostate Cancer Foundation of Australia, Pancare data. <sup>4</sup>Parliament of Australia, 28 November 2017. 'Select Committee into Funding for Research into Cancers with Low Survival Rates Report'. www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Funding\_for\_Research\_into\_Cancers/FundingResearchCancers/Report

\*The definition of patient support may vary across not-for-profit cancer organisations. For example, active patient support in comparison to engagement with online platforms and/or educational content.

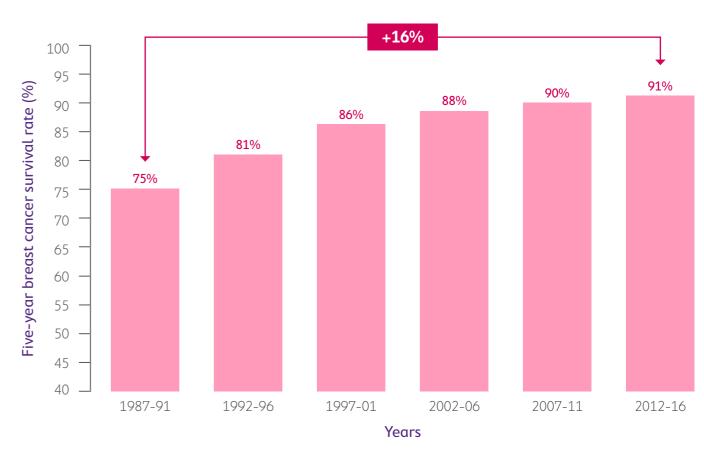
# There is hope, but progress takes time

Increases in survival rates for other cancers are correlated with significant investment and education over time. Sustained investment and research have delivered progress in breast cancer survival rates in the last 30 years.

In stark contrast, there has been little progress in pancreatic and upper gastrointestinal cancer survival rates over the past 40 years. Low investment and community awareness have contributed to a lack of early detection tests and only limited treatment options.

Pancare has been working for a decade to address this, and we are encouraged by the breast cancer story that shows the potential. We can make progress in pancreatic and upper gastrointestinal cancers with sustained investment and education over time.

#### The breast cancer five year survival rate has increased steadily since 1987<sup>4</sup>



Source: <sup>4</sup>Parliament of Australia, 28 November 2017. <sup>5</sup>Select Committee into Funding for Research into Cancers with Low Survival Rates Report'. www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Funding\_for\_Research\_into\_Cancers/FundingResearchCancers/Report

4 Pancare Foundation Strategic Plan 2020 - 2025 5

### Who we are

The Pancare Foundation is Australia's only national not-for-profit organisation dedicated to supporting patients with pancreatic and upper gastrointestinal cancers.

The Pancare Foundation works to save and improve lives of those affected by pancreatic and upper gastrointestinal cancers by supporting patients, raising awareness, and enabling research.

These cancers have some of the lowest survival rates of all cancers, yet they receive among the lowest amounts of funding and support.

Growth and progress over the last five years has meant we have been able to grow the number of patients we support. However, there is still more work to do to support more patients and improve the dismal survival rates.

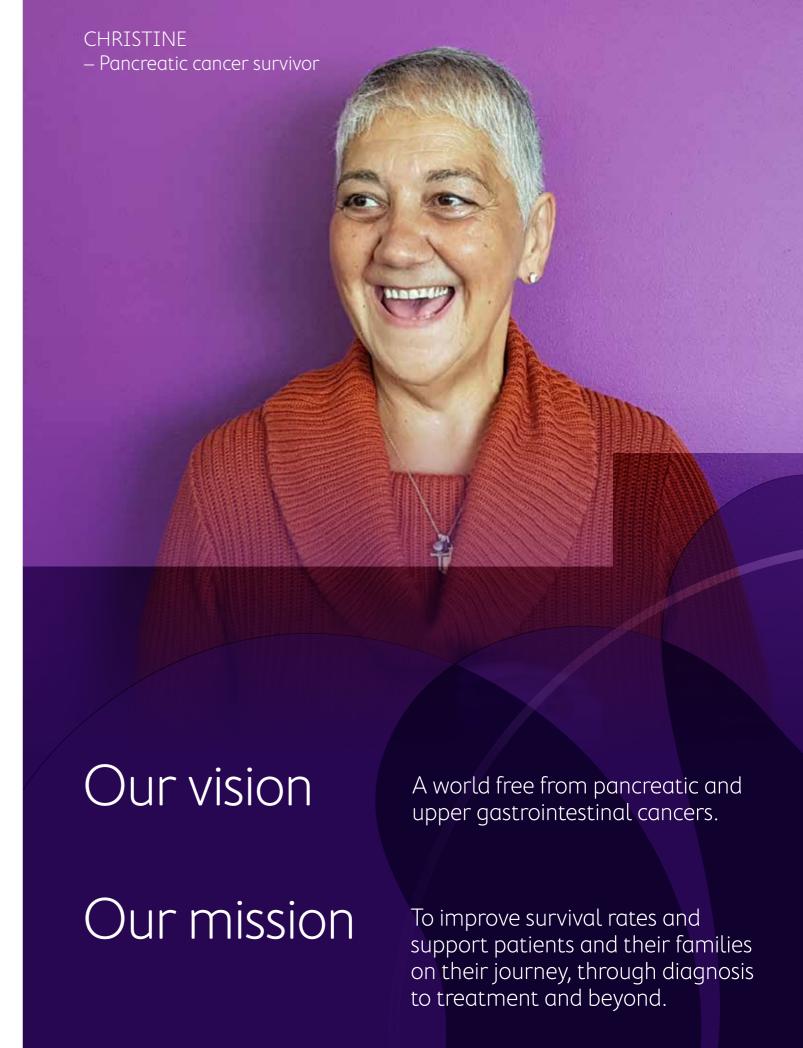
As we reflect on our past and boldly chart our course for the next five years, we remain dedicated to our vision of a world free from pancreatic and upper qastrointestinal cancers.

The number of patients and carers actively supported by Pancare has increased year-on-year as a result of increased funding and additional FTE.



The amount of total funding Pancare receives for education, research investment and patient and carer support has increased over the last five years.





#### PANCARE'S PLAN ON A PAGE Dramatically improving survival and support

#### Vision

A world free from pancreatic and upper gastrointestinal cancers.

#### Mission

To improve survival rates and support patients and their families on their journey, through diagnosis to treatment and beyond.

#### Key Challenge

Fewer than 20% of people with pancreatic and upper gastrointestinal cancers survive for five years, compared with over 90% of those with breast and prostate cancers.

In 2019, Pancare had the capacity and resources to actively support only 5% of people diagnosed with pancreatic and upper gastrointestinal cancers.

#### **Strategic Priorities**



Tell all Australians about the challenge facing pancreatic and upper gastrointestinal cancers.

Five-year success measure: Double education activities on pancreatic and upper gastrointestinal cancers.



Support more Australians diagnosed with pancreatic and upper gastrointestinal cancers.

Five-year success measure: Actively support 20% of patients and carers affected by pancreatic and upper gastrointestinal cancers.



Double the survival rates of all Australians diagnosed with pancreatic and upper gastrointestinal cancers through research.

Five-year success measure: Invest in research that contributes to an average 40% five-year survival rate across pancreatic and upper gastrointestinal cancers.

#### **Enablers**



Design and discover innovative ways of meeting the challenge in everything we do.

Five year success measure: RACE Innovation Lab accounts for 25% of the revenue portfolio.



Raise more funds from a more diverse range of sources to invest in the future.

Five year success measure: On average, 25% year-on-year growth in revenue over the next five years.



Foster mutually beneficial partnerships to improve research and patient support.

Five year success measure: Five new mutually beneficial partnerships established.

#### Actions for Pancare to achieve the five-year strategy

#### **Actions**

#### Tell all Australians about the challenge facing pancreatic and upper gastrointestinal cancers.

- Develop and deploy a targeted marketing and communications
- Leverage and recruit influential Ambassadors.
- Educate the community, patients and carers.
- Engage with government.
- Challenge the funding status quo.

#### **Support more Australians** diagnosed with pancreatic and upper gastrointestinal cancers.

- Establish a patient-centric culture.
- Develop an engaged referral network of cancer care specialists.
- Diversify delivery channels, migrating to majority online service delivery within three
- Develop regular patient and carer awareness campaigns.
- Develop a clearly articulated approach to case notes.
- Establish a best practice approach to intellectual property and resource development.

#### Double the survival rate of Australians diagnosed with pancreatic and upper gastrointestinal cancers through research.

- Contribute to the discovery of novel and specialised treatments and therapies.
- Develop personalised medicine strategies.
- Contribute to improved screening.
- Ensure patient care is informed by best practice.
- Support future leaders.
- Support clinical trials.

#### Design and discover innovative ways of meeting the challenge in everything we do.

- Establish the RACE Innovation
- Develop a highly efficient, streamlined and digitally enabled operation.
- Build a formal innovation capability that underpins our culture, operation and future viability.

Enablers

- Build a high performance culture and highly accountable delivery-based management
- Deliver sound governance practices.

#### Raise more funds from a more diverse range of sources to invest in the future.

- Develop new and innovative partnership models, including open-ended and multifaceted programs.
- Develop a donor-centric culture.
- Diversify our fundraising product offering.
- Diversify and grow ourdonor
- Focus on donor retention and promotion of regular, longterm giving.
- Take a long-term view to fundraising.
- Establish a culture of ethical fundraising.

#### Foster mutually beneficial partnerships to improve research and patient support.

- Build an engaged network of clinical and allied health alliances that promote Pancare's support and services for patients living with upper gastrointestinal cancers.
- Enhance existing relationships on programs and partnerships that align with Pancare's strategic goals.
- Rapidly accelerate the development of new partnerships to meet strategic goals in program development.

8 Pancare Foundation Strategic Plan 2020 - 2025

# Tell all Australians about the challenge facing pancreatic and upper gastrointestinal cancers

Pancreatic and upper gastrointestinal cancers have some of the worst survival rates all of cancers, yet receive little funding and attention.

Almost everyone diagnosed with pancreatic or upper gastrointestinal cancer dies from their cancer. Five-year survival rates for pancreatic cancer have remained below 10% for decades, and the story is similar for the other upper gastrointestinal cancers. Despite this, these cancers receive far less funding than some of the higher profile cancers.

The high profile cancers show what is possible.
Breast and prostate cancers have five-year survival rates of over 90%but this was not always the case.
Increased attention on these cancers in recent decades has led to increased funding, which has delivered improvements in diagnosis and treatment.
These cancers are a success story, and now it's time for pancreatic and upper gastrointestinal cancers to shift the dial.

# We want to significantly increase government and community awareness of these cancers.

Pancare aims to raise awareness of the prevalence and dire statistics of pancreatic and upper gastrointestinal cancers, as well as the funding shortfall. Without appropriate funding, patients cannot be fully supported and survival rates will not improve.

Key actions to achieve the strategic priority



Develop and deploy a targeted marketing plan to increase awareness of pancreatic and upper gastrointestinal cancers and bring attention to the criticality of early detection and funding.



Leverage and recruit influential Ambassadors to

promote pancreatic and upper gastrointestinal cancers and attend events and fundraisers.



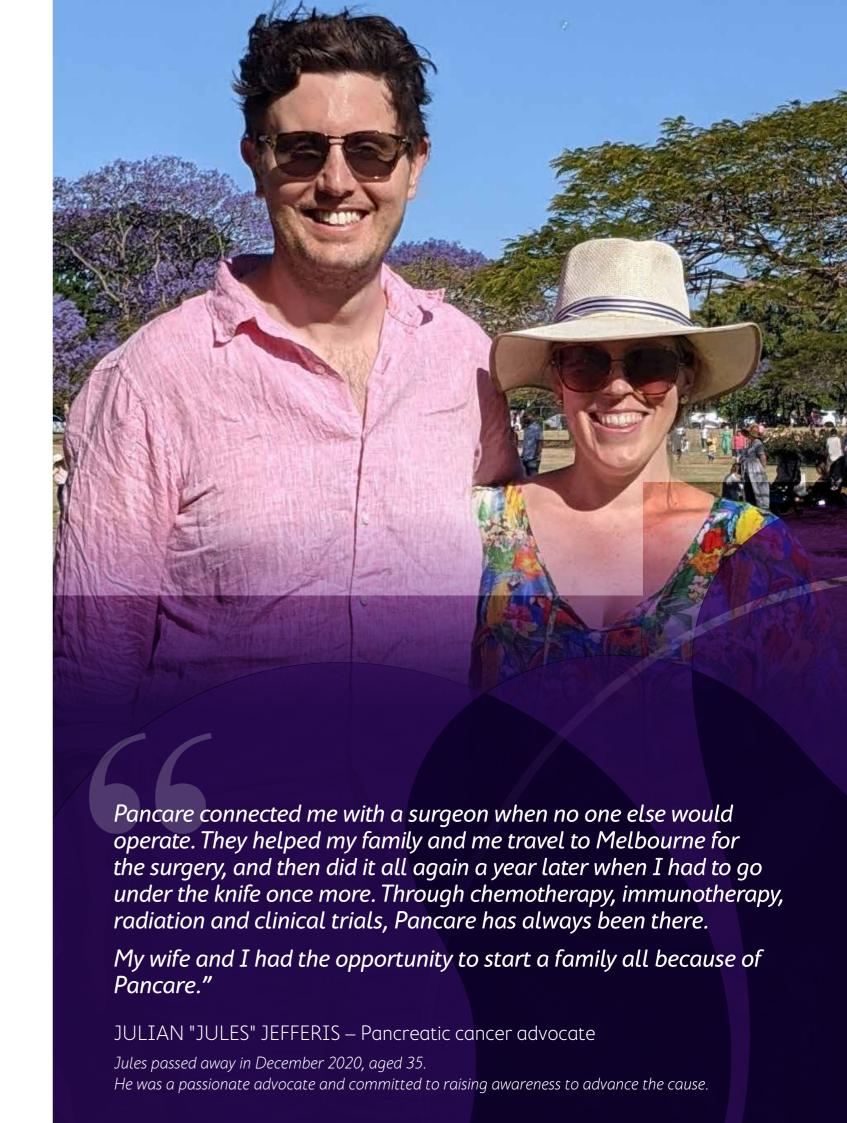
**Educate the community, patients and carers** to promote support for patients and carers of these cancers.

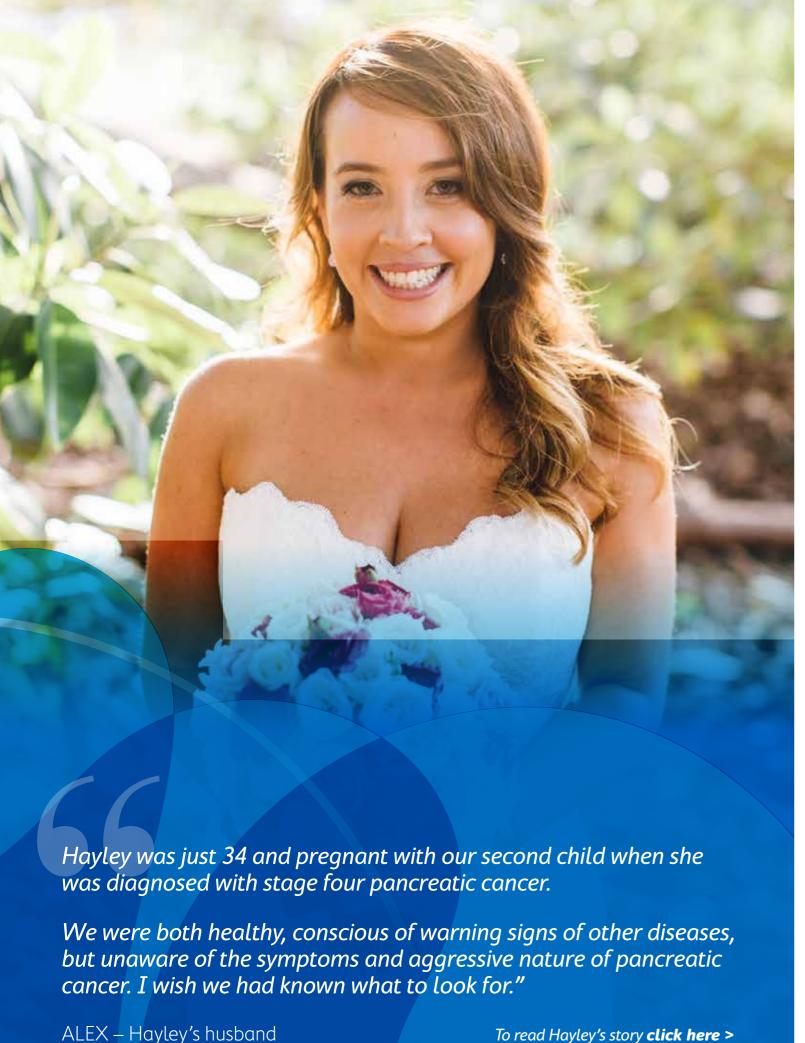


**Engage with government** to draw a greater healthcare focus on these cancers



Challenge the funding status quo to raise the community's awareness of the lack of funding provided for fighting these cancers in comparison to the funding provided for fighting breast and prostate cancers.





Support more Australians diagnosed with pancreatic and upper gastrointestinal cancers

#### Only 5% of Australians diagnosed with pancreatic cancer are supported by Pancare, and this must change.

We are aiming to actively support 20% of Australians diagnosed with pancreatic and all upper gastrointestinal cancers by 2025. This requires significant organisational growth as we currently support around 120 patients a year. If we achieve our goal, we will be supporting on average 2,300 patients annually.

#### Our patient support services help improve the quality of life for patients, carers and families.

Our patient support services ensure patients, carers and their families are supported through their journey. We help address physical, psychological, social and emotional needs. We also provide information on pancreatic and upper gastrointestinal cancers and treatment options and connect patients with medical professionals.

Our current initiatives include:

- Pansupport an online hub for information, education and services for patients, carers and families affected by upper GI cancers
- A specialist pancreatic and upper GI cancer nurse
- Specialist patient and carer support groups
- Patient support days
- Financial and psycho-social support services
- One-on-one advice and case management.

#### Key actions to achieve the strategic priority



Establish a patient-centric culture to ensure patients and carers are at the heart of everything we do.



Develop an engaged referral network of cancer care specialists to encourage an organic referral pathway and position Pancare as 'top of

mind' for patient services and support.



Diversify delivery channels, migrating to majority online service **delivery within three years** to allow patients and carers equitable access to information at a time and in a way that



Develop regular patient and carer awareness campaigns targeting identified 'pain points' in the patient journey.



Develop a clearly articulated **approach to case notes** to ensure the insights we capture inform patient service development, grant and funding submissions and marketing



Establish best practice approach to IP and resource development

including a rigorous and robust review and approval process to ensure our information is accurate.

## Double the survival rate of Australians diagnosed with these cancers through research

#### Existing drugs and treatments for these cancers often only provide small benefits in terms of survival outcomes

While we have seen new therapies provide families with more time together, there has not been any dramatically significant advances in survival rates for decades. We remain committed to delivering new and specialised treatments that will improve the quality of life for patients and their families. We will focus on improving early detection and supporting clinical trials to reduce the number of deaths as a result of these cancers and one day seek a cure.

Our survival rates will be some of the best in the world.

Pancare works with world leading researchers and people affected by pancreatic and upper gastrointestinal cancers to fund research that will transform and save lives.

We are investing \$5 million into our research program over the next five years to contribute to doubling survival rates for these cancers.

Our research approach will focus on:

- improving early detection
- supporting clinical trials that will seek to identify a cure
- understanding best practice patient support.

#### Key actions to achieve the strategic priority



Contribute to the discovery of novel and specialised **treatments and therapies** to treat locally advanced and metastatic disease and reduce cancer recurrence.



Develop personalised medicine **strategies** through new approaches to better manage patients' health and target therapies to best manage each patient's unique disease profile.



#### Contribute to improved screening to enable early detection

through identifying biomarkers and developing early detection screening protocols for the general population, as well as those at high risk.



Ensure patient care is informed by best practice to ensure support provided meets the needs of patients and families.

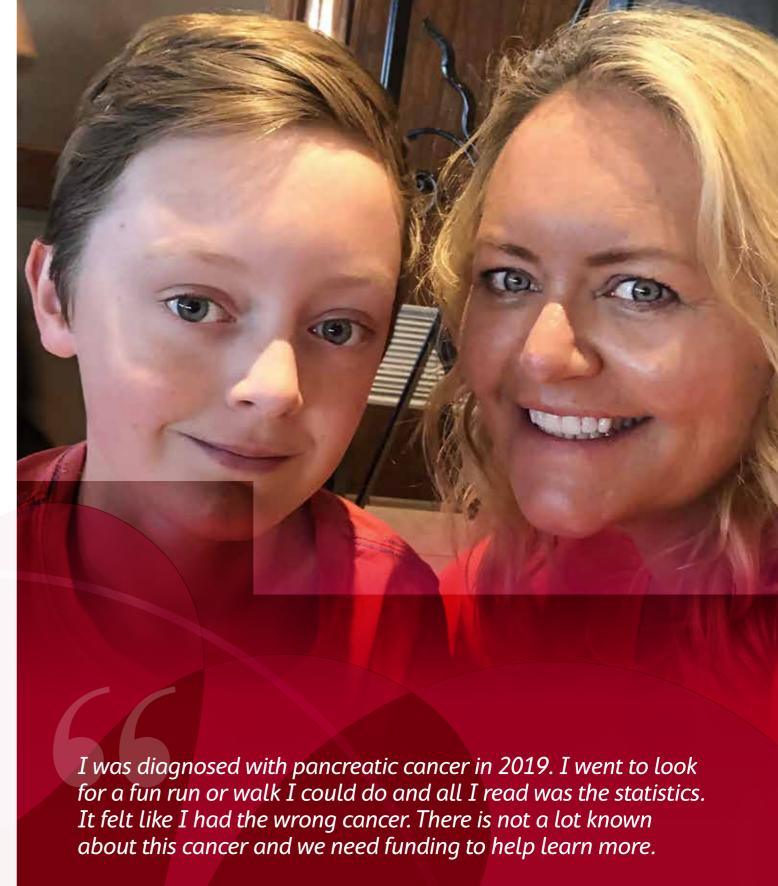


#### **Support future leaders** to attract the best and brightest to

the field of pancreatic and upper aastrointestinal cancer research.



**Support Clinical Trials** to increase accrual of patients into welldesigned clinical trials to test novel treatments and therapies.



It is important for me to have quality time with my son he is my everything. He is the reason I made it through every day of my chemo. I want to inspire others to keep fighting because I will not give up."

HELEN – Pancreatic cancer survivor

To watch Helen's story click here >

### Enablers to our strategy

Our strategy is underpinned by three enablers that help us achieve our vision and mission:



Design and discover innovative ways of meeting the challenge in everything we do, from the research we fund, the people we assist, to the way we operate our business



Raise more funds, from a more diverse range of sources to invest in the future and remain sustainable and viable



Foster mutually beneficial partnerships to improve research and patient support to improve research, raise awareness and support more patients

### Design and discover innovative ways of meeting the challenge in everything we do



We will find new innovative ways of meeting the challenge, from the research we fund, the people we assist, to the way we operate our business.

We strive to be innovative, embed good governance practices, process and be people driven to create a high performing culture and team delivering high quality outcomes. We have developed a formal and highly structured innovation model to underpin the diversification and scale of Pancare's Fundraising Program. We believe the way to enhance innovation is to collaborate with a global panel of innovation experts from a range of organisations. The program will be live in 2021.

#### Supporting actions:



- Establish the RACE Innovation Lab.
- Leverage global expertise.
- Develop a highly efficient, streamlined and digitally enabled operation.
- Build a formal innovation capability that underpins our culture, operation and future viability.
- Build high performance culture and highly accountable delivery-based management model.
- Deliver sound governance practices.

## Raise more funds from a more diverse range of sources to invest in the future

We will diversify funding and passive income streams, from new and existing sources, to ensure the sustainability of Pancare.

We have built our influence over almost a decade. however much of our support still comes from event and community fundraising. Our challenge is to establish a donor centric culture. This will help us build sustainable and viable sources of funding through partnerships and innovative approaches.

We receive funds from generous individuals and organise flagship events each year; Festival of Sports, Walk for Hope in each capital city, and a Day at the Races. These events are firmly established on the calendar; however, they can be affected by events outside our control (such as the COVID-19 pandemic).

#### Supporting actions:



- Develop new and innovative partnership models, including open-ended and multifaceted programs.
- Develop a donor centric culture focused on learning about and understanding our donors, building relationships, offering choice and recognising their support appropriately.
- Diversify the fundraising product offering to prevent the risks of relying on one revenue stream and protect ourselves from a downturn.
- Diversify and grow the donor base to reduce reliance on a small group of core donors and to build support from new and existing communities who are interested in the broader fundraising products offered.
- Focus on donor retention and the promotion of regular, long-term giving.
- Take a long term view to fundraising through building relationships with major donors and the establishment of a Gifts in Wills program to seek long-term and sustainable return.
- Establish a culture of ethical fundraising that involves the Board, staff and volunteers.



# Foster mutually beneficial partnerships to improve research and patient support

# We will foster strong partnerships to ensure sustainability, longevity and growth towards our goal.

Establishing long term partnerships can deliver sustainable funding and increase our public profile. We will look to actively build and strengthen partnerships to ensure that our services are meeting our strategic goals.

In order to ensure and maintain productive relationships, we apply the following principles to our partnerships:

- Mutually beneficial
- Scalable
- Multifaceted programs
- Passive revenue
- Values aligned.

#### Supporting actions:



• Enhance existing relationships on programs and partnerships that align to Pancare's strategic goals.

upper gastrointestinal cancers.

 Rapidly accelerate the development of new partnerships to meet strategic goals in program development.

### Measures of success

We will track our progress over the next five years.

# Tell all Australians about the challenge facing pancreatic and upper gastrointestinal cancers.

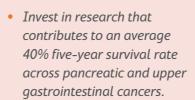
- Double education activities on pancreatic and upper gastrointestinal cancers.
- 20% increase in views on websites and social media platforms.
- Be recognised as the leading authority and resource centre on pancreatic and upper gastrointestinal cancers in Australia.

# Support more Australians diagnosed with pancreatic and upper gastrointestinal cancers.



- Actively support 20% of patients and carers impacted by upper gastrointestinal cancers.
- Reduce the number of days between diagnosis and first contact with Pancare to less than 90 days.
- Develop digitally accessible support groups, specific to patients, carers and cancers across the suite of upper gastrointestinal cancers we represent.

#### Double the survival rate through research.





- Invest \$5 million into research program by 2025.
- Define and develop a rigorous and transparent research investment strategy.

#### Design and discover innovative ways of meeting the challenge in everything we do.

- RACE Innovation Lab initiatives account for 25% of the revenue portfolio.
- RACE Innovation Lab to develop, commercialise and launch three new revenue generating initiatives per annum.
- The RACE Innovation Lab initiatives are well placed to account for 50% of the revenue portfolio by year 10.



#### Raise more funds from a more diverse range of sources to invest in the future.

- On average, 25% year on year growth in revenue.
- Deliver 10% more strategic and commercial partnerships that provide regular revenue.
- 20% of revenue in the portfolio to be derived from new, strategic partnerships or initiatives.



# Foster mutually beneficial partnerships to improve research and patient support.



- Five new mutually beneficial partnerships are established.
- An engaged network of 20 clinical and allied health alliances that promote Pancare's services.
- Network of clinical and allied health alliance meet quarterly to discuss Pancare's patient support and advocacy services.

18 Pancare Foundation Strategic Plan 2020 - 2025 Pancare Foundation Strategic Plan 2020 - 2025





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