# **ASPERT**

### Bulletin | April 2023



AOTEAROA AUSTRALIA PANCREATIC ENZYME REPLACEMENT THERAPY RESEARCH GROUP

## FROM THE PRINCIPAL INVESTIGATOR

AMANDA LANDERS



We are excited to be on the brink of establishing our new direction in terms of research in the area of pancreatic cancer and PERT. With the results in from the patient population study, and the clinician survey, we can now clearly see the gaps and challenges for all the different stakeholders. We will let you all know the outcome of our research planning day. ASPERT is starting to make connections with people from all over the world who are also passionate about nutrition, PERT, and improving the lives of people with pancreatic cancer. Consumers, clinicians and advocacy groups have reached out from the US, Canada and the UK hoping to collaborate with our team. Helen Brown, one of our founding members, continues to be asked to educate general practitioners all over Aotearoa New Zealand about PERT use. ASPERT team members and the Australasian Gastrointestinal Trials Group have a meeting in May to discuss some collaborative work. Please remember to reach out if you have ideas or questions about the work we do. The patient information pamphlet can be downloaded from the website and utilised for patients and their families. If you can think of any other resources you would like please let us know.

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## PERT PLANNING DAY

LOUISE DALY

Our PERT planning day in Christchurch is fast approaching, with over 13 people coming together to discuss all things PERT. This will be the first time many of the ASPERT team have come together in person, since the beginning of the COVID-19 pandemic. It will be a fantastic opportunity to develop new plans and goals for ASPERT, reflecting upon the preliminary outcomes of our patient and clinician surveys. We look forward to meeting with both new and familiar faces, utilising the different strengths and backgrounds of our group. We hope to share the outcomes of this planning day in due course, so stay tuned!







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## **CONSUMER GROUPS**

LOUISE DALY

ASPERT is fortunate to work with, and receive the support of many Pancreatic Cancer consumer groups. These ties are important for our goals, through engaging with people who are living pancreatic cancer and understanding what is important for them. They provide a key link between consumers, researchers and clinicians, and we will continue to strengthen these bonds through collaboration and research.

### PCANZ- Pancreatic Cancer Aotearoa/ New Zealand

Founded and led by Briony
O'Farrell, PCANZ started as a
Facebook Support group for those
affected by Pancreatic Cancer, and
has developed into providing
support, education, awareness and
fundraising towards eradicating
Pancreatic Cancer. The Gut Cancer
Foundation is the charity partner
of PCANZ.

## New Zealand Gut Cancer Foundation

Led by Executive Officer Liam Willis, the NZGCF had a team of professionals that are dedicated towards improving outcomes and creating positive change for gut cancers, including pancreatic cancers. Their work includes funding research, raising awareness and supporting patients and Whānau affected by gut cancers.

### **PanKind**

Pankind is the Australian
Pancreatic Cancer Foundation, an organisation dedicated to improving the outcomes for Australian's impacted by pancreatic cancer. Their mission is to triple the pancreatic cancer survival rate by 20230, improving the quality of life for those impacted by the disease and. They are involved in research, advocacy, increasing awareness and resource creation for patients and carers.

## MEETING WITH GCF

LOUISE DALY

Last month, Amanda and I were able to meet with Liam Willis, the Executive Officer of the New Zealand Gut Cancer Foundation. It has been great to be able to continue our collaboration with the GCF, since the successful PERT webinar last year. These positive ties help us to further engage with patients and whanau affected by pancreatic cancer, especially given the GCF links with other support services and funding streams. Research delivery, with subsequent implementation and dissemination (a focus of our planning day) succeeds with support from many fronts, including groups such as the GCF. We look forward to seeing this collaboration grow, combining and utilising the different strengths ASPERT and the GCF have.

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## PERT IN OTHER COUNTRIES

#### LOUISE DALY

Mr Keith Roberts is a consultant Hepatobiliary, pancreatic and liver transplant surgeon at the University Hospitals, Birmingham. He had conducted research into pancreatic cancer in the UK, including in the use of PERT. He was part of a retrospective population based observational cohort study among patients diagnosed with pancreatic ductal adenocarcinoma (PDAC) in the UK, with all cause mortality compared between patients who had received PERT vs those who had not.

Among the 4554 patients with PDAC included, 21.7% (987) had received PERT, compared to 78.3% (3567) who had not. 807 of these patients who had received PERT were then matched to 807 non-PERT-treated controls. Unadjusted median survival was greater in the PERT group (274 vs 140 days; p<0.001). PERT-treated patients had greater median survivals in both the chemotherapy and non-chemotherapy treated subgroups. Adjusted outcomes showed that median survival time was 262% greater in PERT treated cases compared to matched, non-PERT-treated controls (STR 2.62, CI 2.27-3.02). This pattern was consistent across clinically relevant subgroups.

This survival benefit amongst PERT treated patients is clinically significant and concordant with research that ASPERT has conducted. Patients on PERT who received no chemotherapy or surgery had an improved survival, which shows that PERT alone can benefit patients separately to established therapies for PDAC. Most patients (>80%) with PDAC have un-resectable disease, with PERT benefitting both this group, and those who are receiving other treatments.

Whilst there are limitations to cohort studies compared to RCTs, it is clear that the association between PERT use and increased survival is not incidental. Lack of ethical equipoise restricts the ability to conduct large randomised controlled trials in the use of PERT, however this and other population based studies have shown improved survival with PERT. With more evidence coming forward about the poor prescribing of PERT for patients with PDAC, further work is required to understand why this is, and what further evidence is required to illustrate PERT's benefit.

Roberts K, et al. Enzyme replacement improves survival among patients with pancreatic cancer: Results of a population. based study. Pancreatology. 2019:19:114-121.

## ANZAC DAY

At the going down of the sun and in the morning, we will remember them.

Lest we forget



## WE'RE ON SOCIAL MEDIA!

ASPERT has Twitter, Facebook and Instagram profiles! Follow us to keep up to date with all things.

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FACEBOOK: <u>@aspertstudy</u>
INSTAGRAM: <u>@aspertstudy</u>
LINKEDIN: @aspertAus/NZ



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