

# ASPERT

Bulletin | Nov 2023



AOTEAROA AUSTRALIA PANCREATIC ENZYME REPLACEMENT THERAPY RESEARCH GROUP

## FROM THE PRINCIPAL INVESTIGATOR

AMANDA LANDERS



Tēnā koutou katoa,

ASPERT welcomes a number of research assistants to the team over the summer. Everyone is busy working on systematic literature reviews, setting up a patient-reported registry for the use of PERT in Aotearoa New Zealand and Australia, finishing manuscripts from previous work and setting up new protocols. We have also become a truly international research team with Dana Lewis (see spotlight) joining the team from the US. Dana is both an independent researcher and a consumer of PERT! Last week I attended the Australasian Gastro-intestinal Trials Group conference in my home town of Christchurch. I was able to have multiple conversations with other researchers about the benefits of PERT, and discuss new ideas for future work. It is exciting times!

I wish everyone a very Merry Christmas and a Happy New Year. It is so important to rest, rejuvenate, make new memories with loved ones, over this time. In 2024 we have more work to do for those with pancreatic cancer in all of our countries. See you early 2024!  
Meri Kirihimete

### IN THIS ISSUE

- Pancreatic Cancer Awareness Month
- Team spotlight: Dana Lewis
- PERT projects updates
- New team members
- AGITG conference
- Coming soon: patient reported registry
- ASPERT poster
- Contact us

## WORLD PANCREATIC CANCER AWARENESS MONTH

LOUISE DALY

November is World Pancreatic Cancer Awareness Month, an important time for many groups, including researchers and people with or affected by pancreatic cancer. For ASPERT, it cements and affirms our goal of every patient with pancreatic cancer having PERT available, as well as access to a dietitian. Many buildings around Aotearoa were lit up purple on November 16th to mark World Pancreatic Cancer Awareness Day. It is timely that this month aligns with many new and exciting projects that ASPERT has underway. With a very generous donation from the *Chalky Carr Trust*, we have been able to kickstart our patient reported registry project and focus group project, with more research assistants able to join the team to support these. We have also started a systematic literature review on the implementation of nutritional interventions in people with cancer- watch this space! To keep this momentum going, ASPERT has recently submitted a grant application in collaboration with CST.



## DANA LEWIS

LOUISE DALY

It is with great delight that we welcome Dana Lewis to the ASPERT team.



Dana Lewis is the creator and founder of the open source artificial pancreas system movement (OPenAPS), a passionate advocate for patient-centred/driven/designed research, as well as herself being a researcher, data scientist and app developer.

Dana first created a 'do it yourself' pancreas system back in 2013, developing a unique predictive algorithm, with personal experience using a continuous glucose monitor (CGM) herself. This led to the development of a hybrid closed-loop system, with Dana subsequently creating open source code and tools for people worldwide (OpenAPS).

As an independent and grant-funded researcher, Dana has a wealth of experience and skills to contribute to ASPERT. Alongside her extensive research including machine learning of diabetes and OpenAPS, she has also conducted research into pancreatic exocrine insufficiency. Her work includes the development of a iOS PERT app for people taking PERT.

It is with great excitement that we welcome Dana to the ASPERT team. Her research into PEI and PERT, alongside the diverse projects and people that she has worked alongside are a wonderful addition to ASPERT. We look forward to seeing the results of this new collaboration.

## PERT PROJECTS UPDATE

FONG FU

ASPERT has been busy with two research projects which will help improve PERT practices across Australia and New Zealand. Each of these projects aimed to explore the current state of PERT utilisation in these two countries, from both a patient and clinician perspective respectively. The paper looking from the patient's perspective has been completed and has been submitted for publishing while the clinician paper is under final revisions. Here is a sneak peak of what we found.

We found a lack of awareness of PERT among patients with pancreatic cancer, with around 30-40% of patients not having heard of PERT. This finding justifies our mission in promoting awareness of PERT so that patients are best informed of all available options and empowered when making treatment decisions.

For patients that were on PERT, most were not receiving it in agreement with current best practice guidelines. Current guidelines recommend a starting dose of two capsules with every meal and one with every snack as best practice. However, only 18% and 27% of the participants in NZ and AU reported receiving this advice, with a large variety of other recommendations given.

These results confirm our key belief that PERT is essential in improving the quality of life of patients with pancreatic cancer. PERT was reported by patients to greatly improve symptoms such as abdominal pain, bloating and diarrhoea.

Early findings from the study also show that approximately 70% of both NZ and AU clinicians are not aware of any PERT clinical guidelines. Without knowledge of the most up-to-date guidelines, clinicians may not be providing PERT effectively to patients and best improving their quality of life.

Australian clinicians only reported a low 69% for PERT prescription to those with unresectable pancreatic cancer, when this is one of the more susceptible populations to pancreatic enzyme insufficiency. PERT should be considered for all patients with pancreatic cancer.

## NEW TEAM MEMBERS

LOUISE DALY

2023 has brought about many exciting opportunities for ASPERT, with new projects up and running and papers soon to be published. An exciting update is that we have also expanded the Christchurch ASPERT team. We warmly welcome Dr Niamh Fanning, Jason Hart, Fong Fu and Sommah Tauwhare to ASPERT, who bring a wide range of experience including media communications, medical research and event organisation.

## AGITG CONFERENCE

LOUISE DALY

November 13-16th was the AGITG Annual Scientific Meeting, held in Christchurch, New Zealand. Amanda Landers represented the ASPERT poster, which covered the results of our PERT patient survey. We received some great questions and engagement.

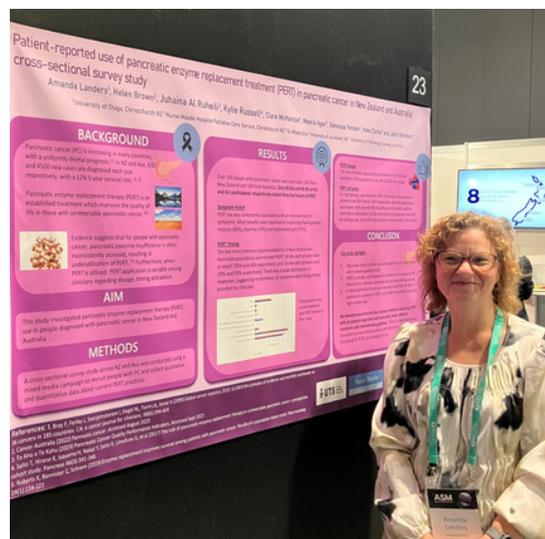
## COMING SOON: PATIENT REPORTED REGISTRY

LOUISE DALY

Work has begun developing a patient reported registry for people with pancreatic cancer, with a focus on PERT prescribing and utilisation. The aim of the registry is to monitor the effect of interventions from all ASPERT stakeholders into increasing awareness and use of PERT. The information will help guide ASPERT in the effectiveness of implementations and education.

## AGITG CONFERENCE

ASPERT'S PATIENT SURVEY POSTER



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