

ASPERT

Bulletin | March 2022



AOTEAROA AUSTRALIA PANCREATIC ENZYME REPLACEMENT THERAPY RESEARCH GROUP

FROM THE PRINCIPAL INVESTIGATOR

AMANDA LANDERS



Kia ora (hello) everyone.

In our first bulletin for 2022, the ASPERT team will outline what we have achieved in the last few months and outline plans for the coming few years. The Aotearoa and Australia PERT survey has been open for 4 months. We have achieved 80% of the estimated goal of 100 responses in New Zealand and surveys continue to trickle in. In Australia, it has been harder to reach the target population. We have plans in place to keep going for longer than 6 months if necessary. If you have any ideas as to how we may get our message to the community, please let us know. In the next few months we will be putting together the PERT clinician survey, to potentially open this mid-year. We have teamed up with University of Auckland Masters Student Sophie Hooke to progress this work collaboratively. The short-term goal is to have information on the use of PERT from both the patient and clinician perspectives by the end of 2022.

If you or your organisation would like further resources on the PERT studies please let us know here at ASPERT.

Ngā mihi, Amanda

IN THIS ISSUE

Impacts of research so far

Team news

NZSO Conference

We're on Social Media!

Contact us

IMPACTS OF RESEARCH SO FAR

CHARLOTTE CAHILL

The New Zealand and Australian surveys have now been open for four months. They have been promoted using social media, radio, google and newspaper adverts. This has resulted in some very touching messages from members of the public and those who have filled in the survey. Several responses have highlighted how life changing PERT has been for them. People have reported an increased in their well being as well as resolution of symptoms like abdominal pain and diarrhoea. This is a driving force for us to continue our research, as the results have the potential to make a drastic impact worldwide.



TEAM NEWS

JUHAINA AL RUHEILI



Kia Ora! My name is Juhaina Al Ruheili, I am one of the Aotearoa New Zealand ASPERT team members.

Hailing from the land of Frankincense, Oman, I came to New Zealand in 2009 just as I started my medical degree at the University of Auckland (UoA). I graduated with a Bachelor of Medicine and Bachelor of Surgery (MBChB) in 2015. Following on, I gained my early clinical experience in Waikato before moving to Wellington in 2020. Working at Waikato Hospice in 2018 sparked my interest in palliative medicine. It's then that I had that light-bulb moment that I had found my tribe!

Last year, I had the pleasure of working at Southland Hospice for six months, where I gained more experience in palliative medicine. Currently I am in my final year of General Practice training (GPEP3) as well as working as a registrar at Te Omanga Hospice, in Wellington. During this time I have grown my passion for palliative medicine and I aspire to join Palliative Medicine Advance Training next year (RACP). I am passionate about holistic integrative medicine and growing the research and evidence in palliative medicine.

I am so grateful to have this opportunity to be part of the ASPERT team to provide education and improve the care for patients with pancreatic cancer.

Outside of medicine, I enjoy tramping in Aotearoa's beautiful outdoors with my husband, as well as roller skating, where I try to stay safe from falling. My friends enjoy my cooking, and they call me the queen of indoor plants! Kia tau te rangimarie (peace be with you) and stay safe!

NZSO CONFERENCE

In January the New Zealand Society of Oncology held their conference. This was due to be held in Rotorua, but due to COVID restrictions it was changed to a virtual event. The ASPERT team submitted a poster titled "Food, aroha and hope in the face of advanced pancreatic cancer". The poster focused on 4 key themes.

1. The problem
 - Many with pancreatic cancer suffer from pancreatic exocrine insufficiency (PEI) and its debilitating symptoms.
2. The solution
 - PEI can be treated with PERT
3. The evidence
 - Literature has demonstrated PERT improves survival, weight loss, symptoms and weight loss.
4. The way forward
 - Our Australasian study asking people with pancreatic cancer about PERT.

Food, aroha and hope in the face of advanced pancreatic cancer

What is the impact of enzyme replacement: A systematic review

Amanda Landers 1, Clare McKenzie 2 & Helen Brown 2

1 University of Otago, Christchurch NZ 2 Nurse Maude Hospice Palliative Care Service, Christchurch NZ



The problem

People diagnosed with **pancreatic cancer** face...

- Dismal prognosis,
- Decreased quality of life
- Symptoms (1)
 - **Pancreatic exocrine insufficiency (PEI)**

PEI leads to

- Decreased enzyme production
- **Abdominal pain**
- **Diarrhoea**
- **Significant weight loss** (2)



The solution

PEI can be treated!

With pancreatic enzyme replacement therapy (PERT)

PERT

- Improves fat, protein and carbohydrate digestion.
- Has positive effects on **quality of life** (1)



The evidence

12 studies were included in the literature review. Four themes arose

- PERT education
- Efficacy of PERT
- Patient experience
- Lack of awareness

Evidence in literature demonstrates that PERT...

- **improves weight loss**
- **symptoms**
- **relationship to food**
- **survival**



The way forward

- **Research funding**
- Collaborative research network spanning Australia and New Zealand (**ASPERT**)
- Enhance community engagement.
- **New Australasian study asking people with pancreatic cancer about PERT** (see study pamphlet)

TEAM NEWS

VANESSA YENSON



Greetings from Oz!

I am the Research Assistant Writer at Cancer Symptom Trials, located at the University of Technology Sydney. My role within the ASPERT team is to provide writing support, which includes grant applications, protocol writing, and ethics applications. I am enjoying being a part of a dynamic, productive, and dedicated team, their genuine enthusiasm to make a difference for those living with a pancreatic diagnosis spurs me to truly do my best. Professionally, I have a couple of Bachelor degrees in Health Science and Biomedical Science, through The University of Sydney and the University of Technology Sydney, respectively. I have nine years' experience in benchwork science, with a PhD in Immunology (Sydney University) and was a Postdoctoral Scientist at the University of California, Davis. My decision to return to Australia stemmed from the fact my research seemed to be getting further and further away from the patient. Since 2014, I have been working in clinical trials in various capacities – with experience in Contract Research Organisations and Medical Device companies assisting in Regulatory Affairs and Feasibility, as well as a Clinical Research Associate travelling to hospitals around the country to monitor clinical trials. This involved ensuring the safety, rights, and confidentiality of patients; adherence to the protocol and ICH-GCP[1] guidelines; and verifying the collected data to guarantee accurate analysis and meaningful results.

On a personal note, I am a leukaemia survivor and will celebrate 23 years in remission this October. I was the first adult in Australia to receive a bone marrow transplant from cord blood (the stem cell-rich blood collected from the umbilical cord after birth) and have worked to improve the lives of others through medical research. I have just started my part-time Masters degree in Creative Writing, which has been a humbling experience. It is something I have dabbled in for so long, but the theory and literary techniques are so very different to the world of science and research that I am used to. Here's to stepping outside one's comfort zone and diving straight in!

[1] International Conference on Harmonisation – Good Clinical Practice

WE'RE ON SOCIAL MEDIA!

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

TWITTER [@aspertstudy](https://twitter.com/aspertstudy)

FACEBOOK: [@aspertstudy](https://www.facebook.com/aspertstudy)

INSTAGRAM: [@aspertstudy](https://www.instagram.com/aspertstudy)



Subscribe or find out more by email to Amanda Landers

E: aspert@otago.ac.nz

W: uts.edu.au/aspert