NET News

NETwork!

Newsletter September 2015

About NETwork!

Project highlights

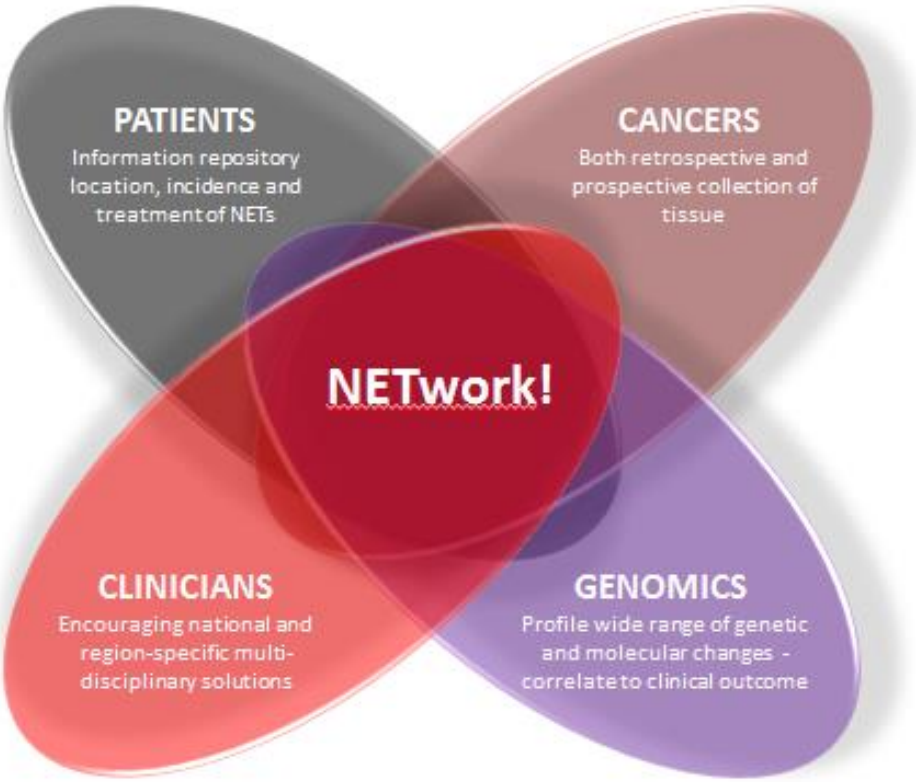
NETwork! Website now on line

NET registry now includes data on over 1700 patients

First meeting of the project Incidental Findings Committee convened

pNET tissue collection reaches 50 patients

Surgical tissue collection approved and ongoing in 5 DHBs



The NETwork! Project is a New Zealand wide alliance of cancer clinicians, endocrinologists and scientists who are working together to manage and study neuroendocrine tumours (NETs). By applying scientific expertise to clinical practice, the project aims to improve outcomes for patients with NETs.

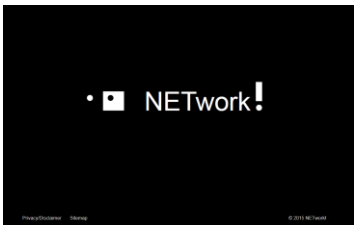
We have established a registry of all cases of NETs in New Zealand between 2008 and 2012, which to date has collected information on over 1700 patients. Alongside this, we are collecting samples of both new and retrospective cases of cancer on which we conduct in-depth genomic analysis.

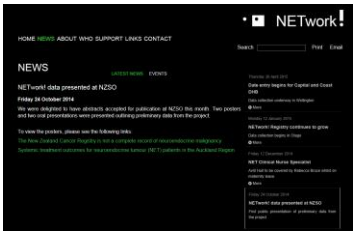
The NETwork project has been launched and is funded through generous philanthropic donations from individual New Zealanders.

These donations are administered through the Translational Medicine Trust, which is part of the University of Auckland School of Medicine Foundation.

The research design of the NETwork! Project has been peer reviewed and is informed by a Scientific Advisory Committee made up of eminent NZ and overseas clinicians and researchers.

NETwork! Website now on line





We are very pleased to announce that our dedicated project website is now up and running. We will use the website to better communicate with our research partners around New Zealand, and keep them up to date with the overall progress of the project. In addition, we have committed to keeping patients connected with the outcomes of our project. The website is a great way to do this, and will also include published results as they become available.

Descriptions of the project included on the website are also provided in Te Reo. Dr David Jansen has helped us with the intricate task of translating some of the technical explanations of our project. David is Ngāti Raukawa and a qualified medical practitioner. His main focus is on running clinical teaching and Te Reo programmes throughout New Zealand and in 2006 he produced a phrase book of Māori medical terms.

Our website can be found at www.network.ac.nz

Engagement with Key Stakeholders

Consultation with advisors who offer a Māori perspective has emphasised the concept of "reciprocity". As researchers, when we are given tissue, we are also given the responsibility to use it appropriately, and to reciprocate responsibly. How this is achieved exactly needs to be examined further, but the minimum is an expectation to be informed about the research and outcomes. We also need to ensure that participants share in any benefits that arise from the project, as part of an ongoing relationship that begins with participation.

Throughout the set up and now as the project moves forward, we continue to engage and take advice from key stakeholders.

We are influenced by the generous advice provided by Māori leaders in the area of tissue banking and genomic analysis. We have a genuine drive to ensure that this project respects tikanga Māori, includes participation of Māori patients and researchers / clinicians and responds to advice from Māori leaders and experts. We hope that consultation will help us to recognize both what we are doing correctly and where we inadvertently fall short. We are optimistic that this engagement can assist this project to address, rather than perpetuate, NZ health disparities. This consultation is an ongoing process .

We are also fortunate to have involvement of a wide range of stakeholders in our various project groups and advisory boards. Some of the key individuals with whom we have engaged are profiled on our website.

We have also engaged closely with the NZ patient support group for Neuroendocrine Cancer, the UNICORN Foundation. We are extremely grateful for the support and feedback from patients. You can find out more about the Unicorn Foundation here.

Dealing with Incidental Genomic Findings

"As part of the ethics approval for this project, we have committed to establishing an Incidental Findings Advisory Committee. This committee will be asked to give independent and objective advice as to whether, on balance, reporting information identified in our research to the patient via their physician, would be of benefit to the patient and / or the patient's whānau / family."

Our analysis will include very deep genomic analysis of NETs. The samples we analyse are donated by patients undergoing surgery for their cancer. Each person's cancer is then analysed alongside their normal genetic profile, so we can better understand their disease.

The genomic study is an early investigation and not designed to change the clinical management of participants who have donated tissue. However, it is sometimes the case that genomic data may reveal unexpected information that could either directly impact ongoing clinical care, or could have implications for their whānau / family. In such circumstances, we have committed to feed back clinically relevant information to these participants if they have asked to receive this information when they joined the project.

The decision to provide this information to participants is usually not straight forward. There are technical and scientific considerations and clinical interpretation is needed to decide if this information in truly reliable and important. To help us with this we have set up an independent Incidental Findings Committee.

This committee will provide impartial and objective advice as to whether, on balance, reporting information identified about an individual participant is based on sufficient data veracity and is justified clinically – in other words, is passing on this information likely to help the patient.

When the committee determines that the research finding might be clinically meaningful, we will feed back the information to the participant's clinician, who will be able to evaluate the meaning of this information in the clinical context of that individual. The participant's clinician would communicate this information to their patient, depending on her/his own clinical judgment. We expect the clinician will consider the option of genetic counselling and will consider follow-up of incidental findings with diagnostic-grade tests in an accredited laboratory if required. Any decisions to alter clinical treatments based on the incidental findings and follow-up testing would be made by the clinician responsible for the patient in consultation with the patient, independent of the research project.

We expect this committee will also advise us on changes to project design in order to maximize benefits and minimize risks for participants as both the project and NZ's ethical landscape evolves.

The first meeting of our Incidental Findings Committee occurred on Friday 3rd July. We are very grateful to the members of this committee for so generously sharing their expertise and advice with us for this project.

The Committee members bring a range of expertise including clinical medicine, science, ethics and consumer perspectives and also represent a range of cultural perspectives. The members of this committee are profiled on our website:

Associate Professor Vernon Harvey (Auckland Hospital);
Dr George Laking (Auckland Hospital);
Mr Richman Wee (University of Otago);
Mr Maui Hudson (University of Waikato);
Ms Jo Fitzpatrick (Independent Consumer Advocate)
Professor Anthony Reeve (University of Otago);
Mr Phillip Shepherd, Secretary to the Committee (University of Auckland).

The Genomics of Pancreatic NETs

"This research aims to perform detailed genomic profiling on Neuroendocrine Tumours (NET) in order to further understand the underlying biology behind the development of the disease, and from this, to develop improved diagnostic and therapeutic modalities to benefit NET patients."

The first phase of genomic work to come out of the NETwork! Programme is a multi-faceted analysis of pancreatic neuroendocrine tumours (pNETs).

In a major undertaking we have conducted a deep, multi-modal genomic analysis of 50 pNETs. This has included analysis of gene mutations and amplifications and deletions using whole genome sequencing of DNA and RNA. We have also used 1,000x depth re-sequencing of over 500 genes of interest.

We are indebted to the patients that have participated in this study and donated their tumours. We are also indebted to those that have helped us to collect this incredibly precious tissue, including Helen Morrin at the Christchurch Tissue Bank, staff at the Auckland Regional Tissue Bank and collaborating surgeons, interventional radiologists and research nurses . At the time of writing contributors include John McCall, Tom Elliott, John Woodfield and Fran Munro (Dunedin), Peter Johnston, Adam Bartlett, Siraj Rajaratnam, Grant Beban, Sanjay Pandanaboyana, John Windsor, Arend Merrie, Brendan Buckley, Colette Kennedy and the wider Interventional Radiology Team (Auckland), Mike Hulme-Moir, Jonathan Koea, Mike Rodgers, Stephen Allpress and Sherry Nesbit (Waitemata), Richard Babor, Andrew MacCormack, Susan Bigby, Matthew Clark and the Interventional Radiology Team (Middlemore), Saxon Connor, Bridget Robinson, Helen Morrin and Gavin Harris (Canterbury), Win Meyer-Rochow (Waikato) and Jeremy Rossaak (Bay of Plenty).

In addition, key to the success of this project is our ongoing collaboration with pathologists. The input of pathologists has allowed us to also collect, under careful and strict ethical approval, archived tissue from patients identified through the NETwork! Registry, which is enabling us to significantly increase the tumours included in our study. These pathologists are listed on our website.

We are currently working on completing the deep genomic analysis of pNETs, alongside a review of how these genomic data correlate with pathological features.

We are aiming to complete this first phase of the analysis before the end of the year.

By combining traditional genomic analysis with mathematical network inference we already have significant new insights into the mutational landscape of these tumours, their segmental losses and gains of DNA and their networks of mRNA expression, miRNA expression and DNA methylation patterns. As part of this genomics work we have enjoyed collaborating with international experts in tumour analysis.

Getting Involved

Contact Information
If you would like to contact us, please contact the Kate Parker, NETwork! Project Manager in the first instance:

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We are initiating a study to find markers of NETs that can be found in a simple blood test. This study will recruit patients with and without NETs. We will test the hypothesis that molecular markers that indicate the presence of a NET are detectable in easily-collected samples such as blood or saliva. This could help in the development of improved diagnostic tools for NETs.

Tissue collection for all types of NETs is continuing. If you know of a patient that is due to undergo a biopsy or resection for a NET who would like to be included in our research, please contact us – we will do the rest.

Please keep an eye on the project website which will be regularly updated with project progress and feel free to contact us if you have any questions or comments. Thank you so much for your interest in and support of NETwork!