

Directors Report

This has been a busy and productive year at NZBRI. Two large grants from the Health Research Council have allowed us to substantially grow our team of research support staff in order to enable more ambitious projects. One of those projects is the Parkinson's Environment and Genes Study (PEGS). Led by Dr Toni Pitcher, PEGS will extend our research beyond Canterbury, creating a large sample from across the country. One thousand people, who either have Parkinson's or who do not, will give a comprehensive account of the risk factors that they have been exposed to across their lifespan. They'll also post back a saliva sample so we can examine the DNA profile associated with Parkinson's risk. They'll also have the fun of working through a booklet of 'scratch and sniff' tests. The loss of sense of smell is more than just a symptom of COVID – it's also one of the first signs of disorders like Parkinson's and Alzheimer's beginning to attack the brain. This project promises to improve our understanding of what may cause Parkinson's in a specifically New Zealand context. It will also allow us to involve more Māori and Pasifika, which we've struggled to do in Christchurch. We know that Parkinson's is much less common in these two groups, and Toni and her team are working to find out why.

In this newsletter you'll also read about NZBRI becoming a centre in the massive international Skyline trial by Roche. This aims to identify people who are at elevated risk of Alzheimer's and test a novel antibody that could actually prevent the disease from taking hold. For both Parkinson's and Alzheimer's, by the time people are diagnosed, a lot of irreversible damage has already occurred. For effective treatments or cures, we really need to begin that treatment before noticeable symptoms begin. After years of careful research, we are now in the position of being able to identify people who are in that 'Goldilocks' zone. This is an exciting period for clinical research, with reasonable hope that there may soon be effective options to prevent the onset of what are currently incurable diseases.

Best wishes,
Dr Michael MacAskill
Research Director

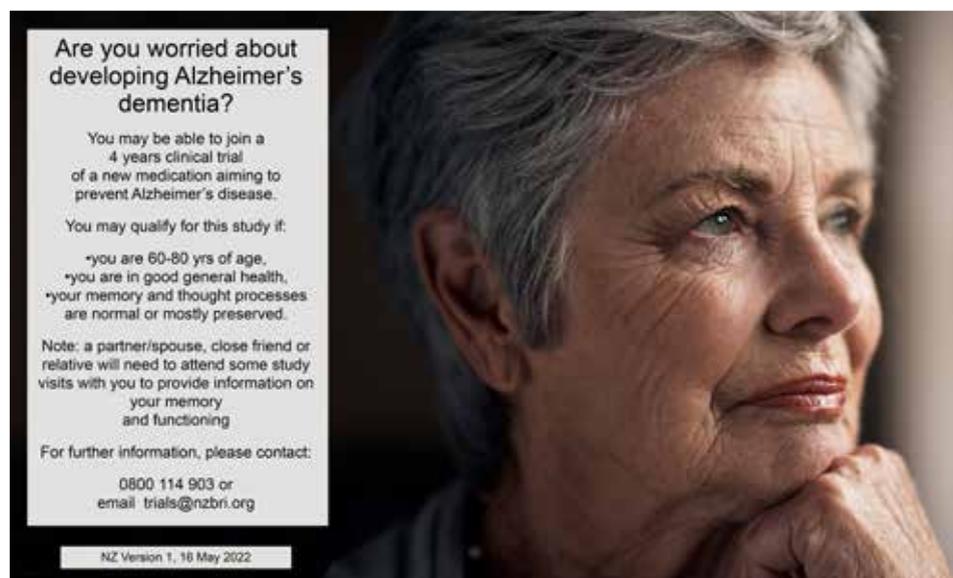


We are now recruiting for Alzheimer's Dementia Clinical Trial

We are now recruiting for the worldwide clinical trial of a new investigational treatment (gantenerumab) for people who are at risk for Alzheimer's Dementia.

Alzheimer's dementia is thought to be caused by a combination of factors which trigger brain changes, with the subsequent accumulation of amyloid protein outside the brain cells (neurones) and tau protein tangles inside brain cells. This ultimately leads to loss of brain cells and symptoms. Research shows that amyloid accumulation may start up to 20 years prior the start of clinical symptoms. This study is therefore looking at the effect of gantenerumab on people with normal cognition, but who are at risk of developing Alzheimer's dementia because they have increased level of amyloid in their brain. To be eligible for this study, participants have to be 60-80

years old, have normal cognition and have elevated level of amyloid protein in the brain; which can be evaluated by screening. To enquire about being part of the trial, please call 0800 114 903 or email trials@nzbri.org.



Are you worried about developing Alzheimer's dementia?

You may be able to join a 4 years clinical trial of a new medication aiming to prevent Alzheimer's disease.

You may qualify for this study if:

- *you are 60-80 yrs of age.
- *you are in good general health.
- *your memory and thought processes are normal or mostly preserved.

Note: a partner/spouse, close friend or relative will need to attend some study visits with you to provide information on your memory and functioning

For further information, please contact:

0800 114 903 or
email trials@nzbri.org

NZ Version 1, 16 May 2022

What is a Clinical Trial?

The FDA defines clinical trials as “voluntary research studies conducted in people and designed to answer specific questions about the safety or effectiveness of drugs, vaccines, other therapies, or new ways of using existing treatments”. The recent Covid-19 vaccination trials have brought clinical trials to the attention of everyone.

After being developed and tested in a laboratory, a new medication is then tested on humans through different phases, from phase I to phase IV (as illustrated). From preclinical testing to post marketing phase, the development of a new medication takes decades; it requires deep financial pockets and a huge level of organisation and worldwide collaboration. The FDA estimates that the development of one new medication may cost up to US \$15 billion. It is truly a massive mammoth task. Ultimately, the conduct and success of a clinical trial depends on the participation of patient volunteers.

In New Zealand, clinical trials are vetted by the Health and Disability Ethics Committees (HDEC) and Medsafe who both review carefully the trial submission and any documents associated with it. No trials can start until all those regulatory authorities are satisfied by the trial design and rationale, that it is safe, and that adequate staffing and insurance are in place. Importantly, the Ethics Committee makes sure that participants’ rights are respected.

Professor Tim Anderson has been running neurological clinical trials for 30 years, and for the last 18 years these have been based here at NZBRI. Study coordinator Laura Paermentier started working in 2009, with Kyla Horne and Chris Tyler joining the small team last year. We mainly undertake clinical trials for Parkinson’s and Huntington’s disease, with the occasional trial for epilepsy, cervical dystonia (torticollis), essential tremor, and more recently other neurodegenerative diseases such as MSA (multiple system atrophy) and MND/FTD (motor neuron disease and frontotemporal dementia). Clinical trials have become

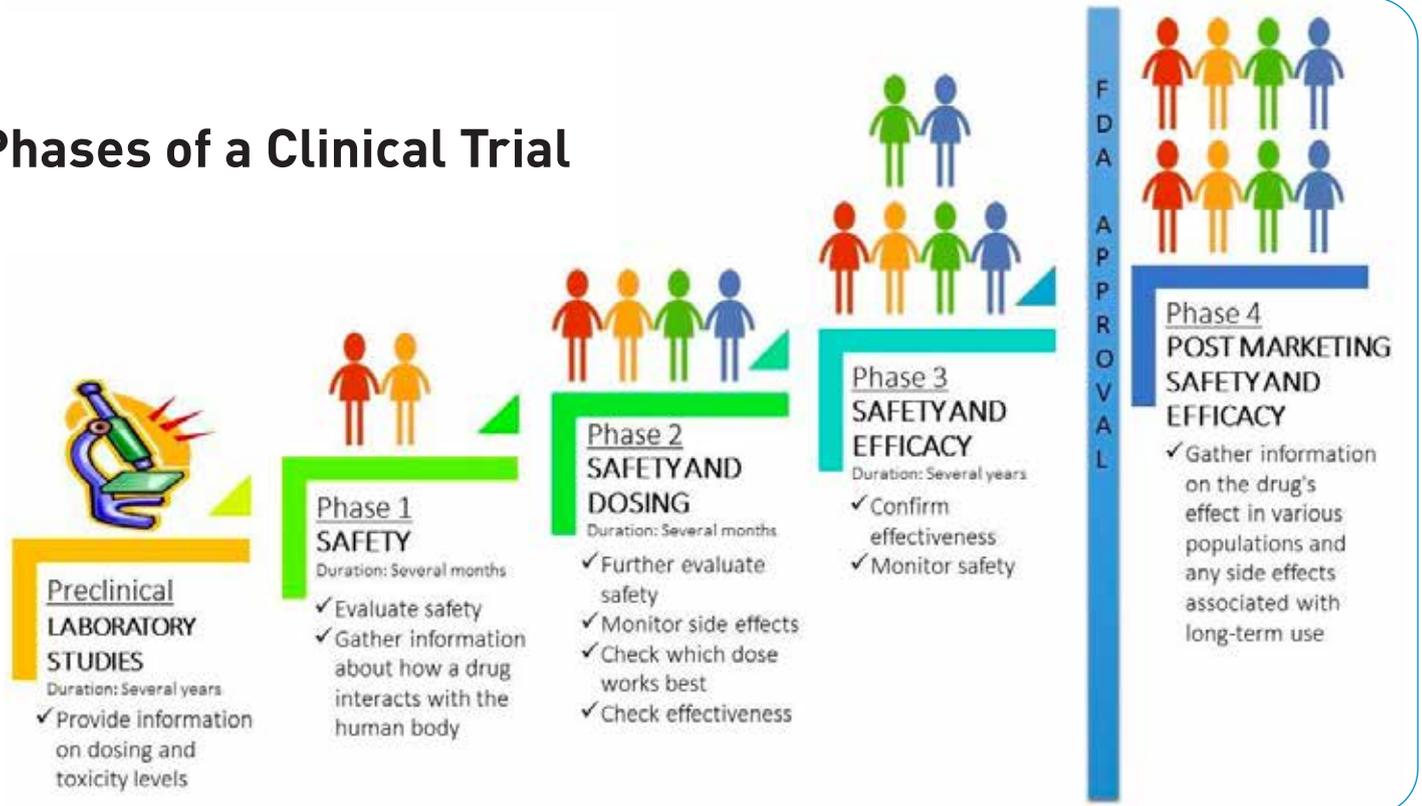
more and more labour-intensive over the years, with an increasing number of study assessments, collection and processing of blood or other biological samples, and the use of smart phone and wearable devices/sensors to gather a massive amount of information. The demand for clinical trials to be done in New Zealand has increased because, unlike many other countries, we stayed ‘open for business’ through much of the Covid 19 pandemic. This has been the reason for expanding our small but expert and dedicated team.

Over the years, many wonderful volunteers have selflessly offered time and effort to our clinical trials. Taking part in a trial requires diligence, openness, perseverance, and a sense of humour which has been evident from all our participants. Not all clinical trials will lead to a new drug becoming available on the market, but useful knowledge is always gained. Although many clinical trials ‘fail’, either due to a lack of efficacy, futility (where the benefits do not outweigh the negatives), or a flaw in the trial design, and this outcome is extremely disappointing to all involved, lessons are learned and lead to new and better future studies.

Professor Anderson and team have contributed to a number of successful clinical trials that have resulted in a new drug making it to market and available to people with Parkinson’s. These include Sinemet CR, Ropinirole, Cabergoline, Tolcapone, Rotigotine transdermal patches, Duodopa (delivery of liquid levodopa directly into the small intestine), Safinamide, and Droxidopa (for the treatment of low blood pressure). Other successful treatments in which the NZBRI was involved are anti-epileptic treatments (intranasal Midazolam intranasal and Topiramate), and Natalizumab, a very helpful treatment for multiple sclerosis. Clinical trials are an important facet of our work and at NZBRI and Prof. Anderson and the team wish to express their grateful thanks to all our patients who have – and will in the future – put their hands up to participate in them.



Phases of a Clinical Trial

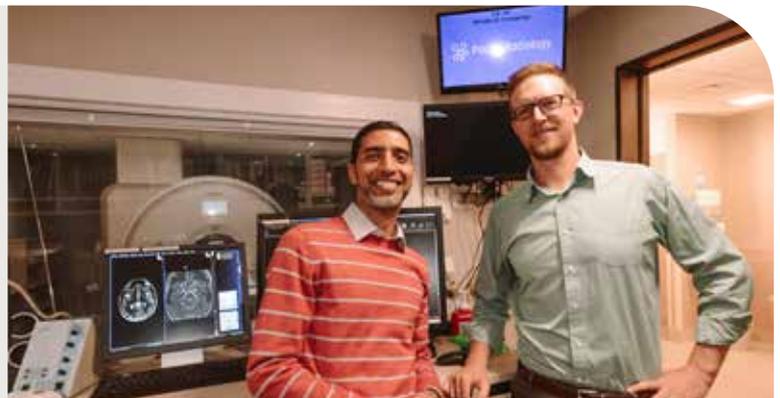


Picture: MDS foundation

Our Sincere Appreciation to Our Supporters

Our new Corporate Partner – Pacific Radiology

Pacific Radiology and NZBRI have a 14-year history of working together to improve health outcomes for New Zealanders. This year, Pacific Radiology specialists in medical imaging, diagnostic and interventional services, have made their commitment to this even stronger by becoming our inaugural Corporate Partner, supporting our Imaging Research Programme. We are extremely thankful to them for joining us in a partnership and for the impact it will have to NZBRI and our work.



A Tech Boost from Verizon Connect

Verizon Connect have donated four computer servers to us, which will greatly assist us in our work. The Christchurch startup Telogis, which created a successful telematics business in vehicle, GPS, route, traffic and other data, combined with others in 2016 to form Verizon Connect. Verizon has a strong focus on virtual data, meaning their physical servers became less important to their operations. Rather than wasting what could still be used, they gifted the technology to local groups including Orana Park, the YMCA, Christchurch Men's Shed and ourselves.



Special thanks to family donors

Our sincere thanks are extended to Dr Roy Wade for his significant bequest to our brain research and to the JT Turner Trust for their recent donation.

We are also grateful to Bill and Noela Scurr. Bill was a volunteer in our Parkinson's research for 18 years; their gift was given on his passing. Thank you both for your long-standing support and our thoughts are with your family.

Christchurch Neurotechnology Research Programme at NZBRI

Four of our Neurotechnology PhD students recently received their doctorates. We're proud of their work and achievement, but sad to see them go. We will remain in regular contact with them, focused on pursuit of further publications from their research. The students are Dr Russ Buckley, Dr Venkat Krishnamoorthy, Dr Uma Venkatasubramanian and Dr Mohammed Zaky (pictured).

All four used advanced mathematical analyses of brain activity, revealed through either EEG measures of electrical brain waves, or MRI scans of blood flow in the brain. All examined 'micro-sleeps', or lapses of attention – brief moments where our brain stops paying attention to the world. These aren't usually a problem, but put us at particular risk of accidents while driving.



Congratulations Dr Le Heron!

Congratulations to Dr Campbell Le Heron who was awarded a research grant from Canterbury Medical Research Foundation. Apathy (loss of motivation) is commonly experienced by people with Huntington's disease (HD) but remains poorly understood. Dr Le Heron's team will study people with HD in Canterbury and Auckland using novel behavioural tasks to determine whether apathy is caused by disruption of normal brain decision-making processes. By combining these insights with analyses of international HD datasets – which researchers and patients in Canterbury have

been contributing to for the last eight years – they will deepen understanding of how apathy evolves in relation to other aspects of HD. This will open two new avenues for improving clinical management. Firstly, it will pave the way for treatments that specifically target apathy itself, thereby improving quality of life for patients. Secondly, the combined understanding of what causes apathy and its trajectory over time will provide an important step towards an apathy-based behavioural 'biomarker', which could guide management in clinical settings and provide a reliable outcome measure in clinical trials.

Study Participants Wanted

We are looking for people *at risk of or with early Huntington's disease* as well as *control volunteers without Huntington's disease*, to participate in a new study. The study is investigating a framework for understanding apathy – known as effort-based decision-making. The study will investigate how people with Huntington's – with and without apathy – make these types of decisions. Participation involves a 2.5 hour visit at NZBRI, where you will fill out questionnaires about your mood, memory and thinking as well as your quality of life. You will also perform computerised decision-making tasks (no computer skills needed). One year later we will repeat everything to see if there are any changes over time. Each participant will receive a \$20 petrol voucher, and an additional small cash pay-out for the choices you make during the computerised decision-making tasks.

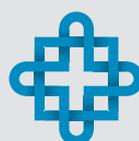
You are eligible to take part in the study if you:

- Are aged 30 – 65 years
- Don't have any neurological or psychiatric conditions (other than Huntington's)
- Live in Christchurch or don't mind traveling to Christchurch

Contact Dr Kyla-Louise Horne

kyla.horne@nzbri.org; 03 928 1497

or Lee-Anne Morris leeanne.morris@nzbri.org if you would like more information or want to be involved



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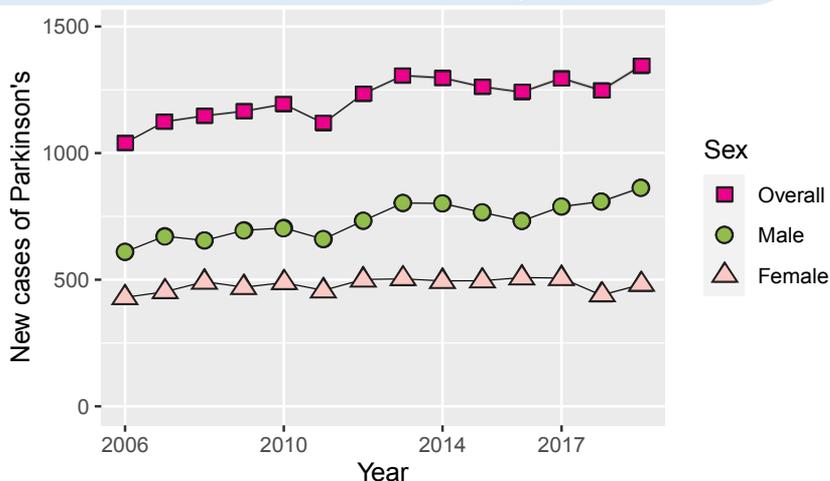
Parkinson's in New Zealand Today

Epidemiology is the study of the number and distribution of people with a particular condition. Over the past eight years the epidemiology of Parkinson's has been a focus of NZBRI researchers Drs Toni Pitcher and Daniel Myall. They now have 14-years of data allowing for the number of people with Parkinson's to be studied. This data helps to identify and understand potential risk or protective factors. It can also narrow down future research areas. From the data our researchers have been able to show the nationwide trends in the incidence (number of new cases per year) and prevalence (total number of people living with the disorder).

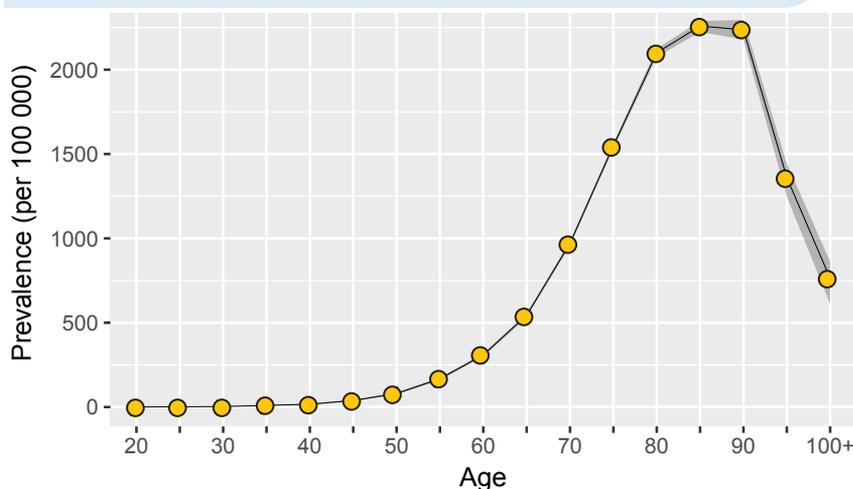
While these statistics tell us about the number of people with Parkinson's, further research is required to understand the factors that contribute to the development of Parkinson's in New Zealand. This will be a key focus of NZBRI-based research over the next three years.

The epidemiology team have been awarded a grant from the Health Research Council of New Zealand to study the risk factors for Parkinson's. They will collect detailed data on occupational exposures, wider environmental exposures, lifestyle factors and genetic factors. This will be the first systematic study of Parkinson's risk factors in New Zealand. The study will involve 500 people with Parkinson's and 500 controls and will involve online surveys and video calling to collect data from people across the country.

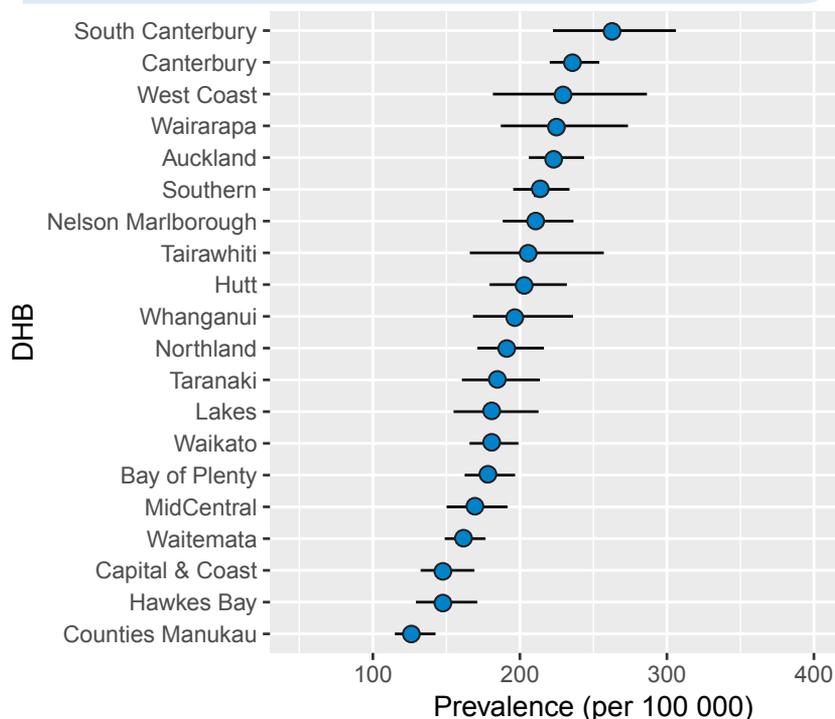
Results – Number of new people with Parkinson's each year



Results – Prevalence by age



Results – Prevalence by region



Want to Learn More about our Research? Come Along to Brain Health Matters



BRAIN HEALTH MATTERS

1 in FIVE New Zealanders live with a neurological condition.

Come and join us to hear the latest research
on the brain - from experts here in Canterbury.

Registration essential.



**FREE
PUBLIC
EVENT**

Proudly presented by:



**New Zealand
Brain Research
Institute**



**TE PAPA
HAUORA**
The future of health

In association with:

**Canterbury District Health Board
University of Canterbury,
and the University of Otago.**

Hear the latest research on

- Using Artificial Intelligence in the assessment of Parkinson's disease
- Measuring health outcomes in New Zealanders with multiple sclerosis,
- How swallowing changes with ageing
- The latest statistics and research on Parkinson's around NZ, and
- Ground breaking clinical trials for people at risk of Alzheimer's dementia

When: Wednesday 13th July

Time: 5.30pm - 7.00pm

Refreshments from 5pm,

Talks start at 5.30pm

Where: 276 Antique Street

Register at nzbri.org/event

Raising funds for neurological research in Canterbury

MUSIC MEETS ART

Saturday 13th August 7pm

This is a must-see event for lovers of fine wine, art and music!

- Popular opera and musical theatre performed by local Canterbury singers with guest artist, James Harrison
- An Art Auction featuring some of Canterbury's most talented artists.

Tickets are \$79 and include wine, nibbles, entertainment and a chance to own a beautiful piece of art. Purchase tickets at www.nzbri.org/events

Supporting brain research into conditions such as Alzheimer's, dementia and Parkinson's.



Friends of the
**New Zealand
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Support our Work

Neurological conditions affect one-in-five New Zealanders. With your support, we can do more to lessen the effect of brain conditions and work towards understanding how and why they occur so we can ultimately find cures. Our research and education is vital and we welcome you to join with us in our journey so that together we can make a real difference in human lives and our communities. We have a number of ways in which you can become a supporter; please email traci.stanbury@nzbri.org or call us today on **03-595-6800**.



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