

CURE PARKINSON'S NZ

NEWSLETTER

Summer 2022/23



**CURE
PARKINSON'S NZ**
NO DREAM TOO BIG

Patron's message



Greetings everyone,

We are pleased to engage with you once again as we come into Christmas and re-energise with our NRCT community. We are excited to share our newsletter. In these wretched Covid times it has been hard to keep up with the latest strategies on science and well-being with floods of information a bit overwhelming at times! Jon and Daniel will inform you of upcoming news and events and we look forward to your support, while we continue to support research into finding a cure.

From myself, as with all fellow Parkinsonians, life does not remain static, and we are on a forever changing landscape. If you reflect on your status 12 months ago your body has lost some of its fine tuning over the preceding 12 months. In my case, I've lost approximately 90% of my vision adding to the list of cognitive dysfunctions to deal with. Regardless, I'm still very blessed and surrounded by enormous aroha. I count my blessings each and every day. I've come to the realisation of what is precious and what is pressing. So, to you all, I invite you to reflect on whanau with as much mihi as there is to enjoy and celebrate this Christmas.

Kaye and I wish you, and those near and dear to you, all the very best for the festive holiday season, and all the best for 2023.

Keep safe, happy, and well.

[No Dream Too Big](#)

Bernie
Founder & Patron



SAVE THE DATE

We are pleased to announce that we will be holding another fundraising dinner and auction in 2023! Further details on how to register and purchase tickets will be released in February via our new website and social media channels, but the date and venue are now confirmed. We hope you can join us at our 2023 Fundraising Dinner.

Thursday 17th August, 2023, at The Atrium,
Wintec House, Wintec, Hamilton

CHAIRMAN'S MESSAGE



2022 has been a big year for NRCT, as we developed our long-term thinking further.

We are now announcing our bold plans to transition to a national organisation, and with this, we welcome Daniel McGowan who commenced in October as our full-time CEO.

While we take great pride in our hugely successful fundraising efforts, which will not stop, we think we can do more. The dream is to find a cure for Parkinson's, and if we want to have an even bigger impact, we need to have a wider reach, we need to be national. Our first step and highest priority was to find a highly capable leader that brings a passion for what we are about. That we found Daniel, who is an uncannily perfect fit for the role, was amazing.

For some time, Michael Jackson, our founding Chair from 2013, had been indicating his wish to call time and step aside. With the change in strategy, it was timely for Michael to step down from the Trust, and for myself to be appointed a trustee and take on the Chair role. Michael will of course remain a great supporter of the Trust and we thank him for his generosity, wise counsel, and leadership over so many years.



I will continue to lead the fundraising committee, where Brian King, Jason Cowan, Ken Williamson, and Tony Egan, with support from Amanda Walker, continue to be the key drivers of our hugely successful fundraising events. The team are once again all fired up for our big fundraising dinner at **Wintec** on **17 August 2023**, from **6 pm**. Ryan Hamilton stepped off the fundraising committee this year, and leaves with our huge appreciation and gratitude for his contribution over many years, on top of all his other community commitments. We are always on the lookout for new members with new energy.

We continue to have a great relationship with the Centre for Brain Research led by Sir Professor Richard Faull and Professor Maurice Curtis, who continue to do amazing work in mapping the brain and seeking to understand more and more the early underlying symptoms of Parkinson's. Maurice's passion for researching Parkinson's only seems to get greater as each year passes, and we are excited by a significant new initiative he has recently put in front of us. We hope to share details of this with you in 2023, should we be in a position to support that.

Another major step forward in 2022 has been the developing of a relationship with Cure Parkinson's in the UK, and as a result of that, other international organisations who also have the same dream we do of "finding a cure for Parkinson's". What we have uncovered is any number of global initiatives, some of which we have an opportunity to collaborate on. We are very keen to build awareness within the NZ Parkinson's community of what is happening globally, as well as within NZ.

Our priorities heading into 2023 include:

- adding new trustees to our board to reflect that we are now a national organisation and to expose us to new networks
- to establish ourselves as part of a global consortium of organizations with a shared goal
- to refresh our brand and identity and build a community with a clear mission and vision
- to engage more with the research community and be proactive in driving research toward new treatments
- to add new major donors and funders (as always)!

Jon Tanner
Chairman



CEO'S MESSAGE



Nau mai, haere mai ki te panui raumati! Ngā mihi o te Kirihimete!

Welcome to this summer newsletter! Christmas greetings!

It is a wonderful privilege and an honour to have joined NRCT as CEO just a couple of months ago, and I fully embrace the challenge that lies ahead: to fuel research toward a cure for Parkinson's. Talk about a moonshot mission—what could be better than that?! In this sense, a 'cure' means any combination of therapies that can stop, slow, or reverse the progression of Parkinson's disease. Thus, it will mean different things to different people, and we define that in slightly more concrete terms in a short piece later in this newsletter. One thing that stands out though is the complete absence of therapies that can modify the natural course of disease; available therapies can only temporarily relieve symptoms. With Parkinson's disease being the fastest-growing neurological condition in the world, and with the number of sufferers expected to double by 2040, our mission is now more urgent than ever.

This appointment is, for me, a continuation of a journey that began 25 years ago. After watching my grandmother's decline owing to Parkinson's, over many years, I transitioned my field of study from marine biology to molecular neuroscience, joining the lab of Professor Richard Faull in the Anatomy Department at the University of Auckland's School of Medicine, where I completed my PhD studying Huntington's disease. A year or so later, a young Maurice Curtis joined the lab. With a fair bit of water under the bridge in between, as a postdoctoral researcher in Cambridge, UK (which included work on Parkinson's models), as an academic journal editor at Nature Publishing Group in London, and after 16 years in executive and board roles at a Japanese medical science communications and strategy consulting firm, I was yearning for a deeper purpose at just the right time.

One thing that has stood out for me since joining is the calibre of the people connected to NRCT. The esteem in which Bernie, Kaye and Jon, in particular, are held, is palpable, and the willingness of those in the philanthropic space I have met with so far, to offer advice and ideas, speaks to a shared desire to change the world for the better. Having a feeling of 'these are really good people' was a key factor in my decision to make the jump. It is clear to me that we have a strong group of supporters already, and while we plan to grow this group exponentially in the years ahead, I do very much look forward to meeting as many of the hard-core NRCT supporters as I can at our Hamilton-based fundraising dinner in August 2023.

There will be a number of exciting changes and initiatives ahead, and some of these you can see already in this newsletter, including a new 'operating name' and logo as well as a refreshed style. While the legal entity will remain the same, our strategic partnership with Cure Parkinson's in the UK, and their sanctioning of the name change, means we can go forward with a strong and very clear brand identity ready to capture hearts and



minds as we raise funds for our cause. We expect our new website and social media channels to be going live by early February, so watch this space! There will be many more events to support, from endurance challenges like the Coast-to-Coast multisport event in February, which the indomitable Rob Spear and Sam Paterson are undertaking to raise funds for NRCT (see the Events piece at the end of this newsletter), to boardroom lunches and gala dinners, including the one in August. There will be many more ways to support us in 2023!

While we have only just begun to establish strategic partnerships with similar organisations globally, to engage with researchers about the latest findings and priorities for research, and to add to the potential income streams to reduce our reliance on the annual 'sugar hit' of a single event, fundamental to all of these activities is the building a local community of people connected in some way to our mission. To this end, expect to see more regular e-mail updates and newsletters, and a website that will be updated regularly. We hope you will regularly visit our website and follow us on social media channels once those go live, and that you will share these with anyone with a connection to Parkinson's. With >12,000 New Zealanders with this awful disease, and with many family members and friends associated with each one, we hope to connect them all to Cure Parkinson's NZ and our vision of a world without Parkinson's disease.

Stay well and have a joyous and safe Christmas and New Year period.

Nāku iti nei, nā Daniel
(Humbly yours, Daniel)



WHAT WILL A “CURE” FOR PARKINSON’S LOOK LIKE ANYWAY?

At present, there are no disease-modifying drugs approved for patients. All of the currently prescribed medications (and approved surgical interventions) treat the symptoms only and do nothing to halt disease progression. However, there are a number of potentially disease-modifying treatments currently in clinical trials, at various stages of clinical development, with results emerging all the time and some highly anticipated results expected over the next few years.

We will be regularly sharing research updates and news via our website, newsletters, and social media channels, so please subscribe to these to stay abreast of developments!

A “cure” for Parkinson’s disease will likely be a combination of different treatments for people at different stages of the Parkinson’s disease process, and even for those who do not (yet) have it. Indeed, different therapeutic strategies can be applied in different circumstances.

Preventing the development of Parkinson’s disease through removal/mitigation of environmental factors (e.g., banning the herbicide paraquat, which has been linked to Parkinson’s disease, or protecting against head knocks) and lifestyle interventions like regular exercise and coffee drinking has the potential to reduce the incidence of new cases of Parkinson’s disease. Although strictly not therapies or treatments, such interventions in people without Parkinson’s fall into the category of healthy brain ageing strategies. Indeed, coffee drinking is strongly associated with a reduced risk of Parkinson’s disease, while exercise has been shown to improve motor symptoms in patients with early-stage Parkinson’s in addition to its effect on healthy brain ageing.

For those already diagnosed, there are three different types of treatment that collectively might comprise a ‘cure’:

- A disease halting treatment that stops progression;
- A neuroprotective agent that protects the remaining cells; and
- A cell replacement therapy that can potentially replace what has been lost.

STAGE	PRE-PD	PRODROMAL PD	EARLY-STAGE PD	LATE-STAGE PD
Disease severity				
Strategy	Prevention	Stop or slow progression		Reverse the damage
Therapeutic strategies (non-exhaustive)	<ul style="list-style-type: none"> Exercise Mediterranean diet Time-restricted feeding Caloric restriction Supplements 	<ul style="list-style-type: none"> α-synuclein clearance & replacement α-synuclein aggregation prevention 	<ul style="list-style-type: none"> Neurotrophic factors* Stem cell transplants Neuroprotection 	

Therapeutic strategies for Parkinson’s disease by state and severity

**Delivered directly or via gene therapy*



The good news is: significant progress is currently being made in clinical studies across all three types of “cure”.

Therapies that can slow or stop progression of disease will add years of ‘health-span’ and improve quality of life in those with prodromal (a medical term for the period when the earliest signs and symptoms are observed) or early-stage Parkinson’s. Professor Curtis’s current work (see later in this newsletter) can potentially help us identify these people sooner, while some of the therapies being tested in clinical trials at the moment, including a number of agents that target the protein alpha-synuclein, which plays a key role in the development of Parkinson’s, have the potential to slow or stop progression. Such agents, if successfully found to stop (or slow) the disease from progressing, can help us protect the remaining vulnerable neurons in the brain that are key to controlling movement.

For those with mid- to advanced-stage disease, there has already been significant loss of neurons, so therapies for these patients need to compensate for this loss, either through cell replacement (via transplantation) or by providing additional support to the remaining neurons (e.g., via delivery of GDNF or other “neurotrophic factors”). Most likely, it will be a combination of these approaches that provides success.

A number of groups are currently investigating stem cell transplants (one new trial of this approach is now getting underway in the UK and Sweden) and delivery of neurotrophins to the brain. Neurotrophins are basically neuroprotective agents that support neuronal survival and function; these provide a nurturing environment for cell replacement therapies to succeed. One big step forward in the latest studies of neurotrophins is the use of viral vectors to deliver these supportive factors to the brain—far less invasive than the approaches (e.g., via implanted catheter) used in previous trials.

There is unlikely to be a ‘silver bullet’ therapy that will fit everyone; what is required is a personalised approach that focuses on individual needs (depending on where people are in the disease course). The goal is to get the right treatment to the right person at the right time to stop, slow or reverse the natural course of Parkinson’s.



Professor Maurice Curtis and Sir Professor Richard Faull inspect a brain.



Impact



An important measure of the success of any charitable organisation is the impact that donations actually make. In our case, this translates into the outcomes of research we have funded, and more bluntly, the question “How much closer to a cure does this bring us?”.

In 2019, NRCT made a commitment to fund Professor Curtis’s research with \$300,000 over 3 years (to August 2022). The supported work focused on understanding the neuroanatomy of the olfactory system in unaffected and Parkinson’s-affected individuals, and the fruits of that work are now being written up for publication for sharing with the global Parkinson’s research community. Why the olfactory system? Loss of smell is one of the very early signs of Parkinson’s disease, and the identification of an early-stage Parkinson’s disease-related process in the olfactory system could lead to much earlier diagnosis, most importantly, before significant loss of neurons in the brain. With early diagnosis comes an opportunity for early treatment that could stop the spread, and thus, prevention of progression.

As a result of the funding and support from NRCT, Professor Curtis and his team will soon reveal a world-first, three-dimensional reconstruction of the human olfactory system. Further, they show Parkinson’s-related pathology in the lining of the nose in patients, another world first. Their on-going work will examine biopsied cells from newly diagnosed Parkinson’s patients and their live-in partners to test new drugs with the potential to block this pathology—in short, to identify patients at a very early stage of the disease and stop the progression of disease before it affects the vulnerable neurons required for movement in the brain.

Professor Curtis and his group are also investigating a number of promising drug candidates at present. One of these has shown promise for treating the hallucinations and psychosis that can occur in late-stage Parkinson’s, currently a huge unmet clinical need because the drugs normally used to treat these sorts of symptoms counteract the standard Parkinson’s meds. So, all in all, Professor Curtis and his group have made some significant advances potentially benefitting patients at both ends of the disease spectrum.

Finally, we are pleased to announce that we recently approved funding of \$329,998 for a further three years to ensure the continuity of this excellent work. This funding will provide a salary and working expenses for the postdoctoral scientist Dr Victoria Low (pictured above) to continue the work on the olfactory system in Parkinson’s patients and controls. We look forward to bringing you updates on further progress via our website and social media channels.



STRATEGIC PARTNERSHIPS

CURE PARKINSON'S (UK)



We are thrilled to announce that we have established a meaningful, collaborative, strategic partnership with Cure Parkinson's, the operating name of The Cure Parkinson's Trust, a charity registered in the UK. Cure Parkinson's share our vision of a world without Parkinson's and are key drivers of international collaborations and funding of clinical trials that have the potential to slow, stop or reverse the progression of Parkinson's. They established and continue to lead the International Linked Clinical Trials (iLCT) programme, a drug-repurposing initiative that prioritizes promising drugs for testing in clinical trials. The problem of Parkinson's disease is truly a global one and the solution will come from strategic and collaborative coordination of global efforts to find a cure.

This partnership brings us into a global collective of organisations singularly and tirelessly focused on finding a cure for this insidious disease. Through it, we have the opportunity to multiply our own funds and leverage matched funding from partner organisations to accelerate clinical research and the process of getting new drugs approved for patients with Parkinson's. The partnership with Cure Parkinson's was a key first step in our rebranding, and we are hugely grateful to the fabulous team there for their welcoming enthusiasm in graciously allowing us to adopt our new name, Cure Parkinson's NZ.

As part of this strategic partnership and in collaboration with other global partners of Cure Parkinson's, we presently have an opportunity to co-fund a phase 3 clinical trial (the last stage of clinical development before a product is approved for use in the community) of a potential disease-modifying treatment centred at University College London. Importantly, any funds provided by Cure Parkinson's NZ would effectively be quadrupled, owing to matched funding from partner organisations! This is the power of a strategic global network. We are on the look-out for a major donor (or a consortium of major donors) that can help us underwrite this important clinical trial and ensure it gets underway in 2023. Please get in touch for a confidential conversation if you would like to learn more about this opportunity.



GLOBETROTTING POST-COVID



In November, our new CEO Daniel had the opportunity to meet with Cure Parkinson's Board Member Lyndsey Isaacs. Lyndsey runs a busy private acupuncture practice in London but is also actively involved in the governance and strategic direction of Cure Parkinson's, working closely with the management team there.

Lyndsey has a long-term connection with New Zealand and several close friends here, so it was a great opportunity to meet in person when she made the trip over for a 60th birthday celebration. Over coffees and a sushi lunch, Daniel and Lyndsey spent a few hours discussing their personal stories and connections to Parkinson's disease, the present therapeutic landscape, and the global network of organisations sharing a common vision of a world without Parkinson's disease. This was a wonderful way to cement the new relationship between our organisations and align on strategic objectives.

Lyndsey's late husband Tom was one of the founders and a former President of The Cure Parkinson's Trust. His struggles with Parkinson's disease and participation in the Bristol GDNF trial were beautifully documented in a two-part BBC documentary titled "The Parkinson's Drug Trial: A Miracle Cure?". Tom's drive and infectious spirit was key to the success of Cure Parkinson's as a force for fundraising. The meeting with Lyndsey certainly provided lots of motivation, ideas and inspiration for Cure Parkinson's NZ to take into 2023!



ANNOUNCEMENTS

Fundraising dinner

After a year of taking stock during 2022, with a change of Chairman, addition of a CEO to take us forward, and a clear strategy and single-minded objective for the years ahead, we are pleased to announce that we will be holding another fundraising dinner and auction in 2023! Further details on how to register and purchase tickets (tables of 10 will be \$2200) will be released in February via our website and social media channels, but the date and venue are now confirmed. We hope you can join us at our 2023 Fundraising Dinner.

Thursday 17th August 2023, from 6 pm

The Atrium, Wintec House, Wintec Hamilton.

New Website

At the time of writing, we are designing and constructing a new website through which we aim to engage with our community of supporters in more meaningful ways. We hope to go live with this in February 2023 at www.cureparkinsonsnz.org.nz... Watch this space!

Social media

In 2023 Cure Parkinson's NZ will, for the first time, engage with followers via multiple social media channels. We plan to build a community of supporters, donors, champions, and any other interested parties to share in our journey toward a world without Parkinson's. We will use these and a revamped website to share news, research updates and opportunities for fundraising as we pursue our mission of fuelling research leading to a cure.





SUPPORT FROM GREENLEA FOUNDATION TRUST

We are thrilled to be the recipients of a new \$100,000 donation toward our mission from the Greenlea Foundation Trust. We are hugely appreciative of their generous support over the last few years and this new donation helps immensely toward the continued support of Professor Curtis's work on the human olfactory system and its involvement in the earliest stages of Parkinson's disease.



EVENTS

Please get in behind the legends Rob Spear and Sam Paterson as they line up to compete in the two-day tandem team category of the Coast to Coast, on Feb 10/11, 2023. These amazing guys are pushing themselves well outside their comfort zone to raise funds to help save lives. They have set themselves a target of \$30,000 raised, half of which will go to Neuro Research Charitable Trust (the other very deserving beneficiary is the Canterbury West Coast Air Rescue Trust, which raises funds for the essential helicopter rescue service operating in Canterbury/West Coast). Please give generously via their [givealittle](#) page and show them your support. We will bring you a story about their epic undertaking in our next newsletter.

WISHING EVERYONE A MERI KIRIHIMETE AND LOOKING FORWARD TO DELIVERING FURTHER UPDATES AND HAVING YOUR SUPPORT IN 2023!



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Cure Parkinson's NZ is the operating name of the Neuro Research Charitable Trust, a charity registered in New Zealand (Registration number CC49200) and a separate legal entity to Cure Parkinson's (the operating name of The Cure Parkinson's Trust, a charity registered in the UK). Cure Parkinson's NZ collaborates strategically with Cure Parkinson's on their International Linked Clinical Trials (iLCT) programme of clinical and pre-clinical research to identify, test, trial and make publicly available a cure (and/or cures) for Parkinson's disease.