

NEWSLETTER

SPRING & SUMMER 2023/24



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

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WELCOME

A word from our CEO, Daniel McGowan



It's hard to believe that 2023 is fast drawing to a close, and I've no doubt that everyone is looking forward to a wonderful Kiwi summer shared with family and friends. It's also hard to believe that it's been just over a year since I joined the Cure Parkinson's NZ team — and what a wonderful year it's been!

Over the past few months we've seen many significant developments across the Trust from further research discoveries, to new Board members, multiple fundraising activities and fresh marketing campaigns, and I'm thrilled to be able to share more about our progress with you in this newsletter.

A personal highlight for me however, came via an invitation to attend the international linked clinical trials meeting, hosted by Cure Parkinson's at Cumberland Lodge, Windsor Great Park, in the UK. What a beautiful setting and what a privilege it was to be present among many of the world's leading authorities on Parkinson's disease therapies — more on that trip later.

I'd also like to take this opportunity to once again thank Bernie and Kaye and our amazing Board of Trustees, who through their dedication, expertise, passion and commitment continually help guide us on our mission, and provide true hope to the thousands of Kiwis living with Parkinson's.

And of course a very special thanks must go to you, our loyal supporters, volunteers, family and friends; your generosity through both donations and time allows us to envisage a world without Parkinson's as we know it — a world where clinical progression and neuronal loss after diagnosis are no longer inevitable. We won't rest until we have achieved this dream and rid the world of this awful disease.

We exist to find a cure for Parkinson's.

It's as simple as that.

A handwritten signature in black ink, appearing to read 'DMC', followed by a long, horizontal flourish.

BUILDING INTERNATIONAL CONNECTIONS I DANIEL MCGOWAN, CEO

It was an absolute privilege to be invited to attend the international linked clinical trials meeting this year, hosted by Cure Parkinson's at Cumberland Lodge, Windsor Great Park, in the UK. Over two days at the end of June I observed an assorted group of around 20 experts from the UK, US, Europe, and Australia share updates on a number of clinical trials already underway and debate the merits (or otherwise) of a portfolio of compounds for consideration for prioritisation into new trials. It was great to see the delegates in action assessing data from various models of the disease and human studies, in addition to mechanism of action and safety information, to determine which new compounds held the most promise as potential candidates for treating Parkinson's disease.

The meeting was a wonderful opportunity to spend time with those leading the charge in fundraising for a cure: from the brilliant team at Cure Parkinson's, who were so incredibly welcoming, to Clyde Campbell, founder of Shake it Up Australia Foundation, who has achieved remarkable success across the Tasman. It was also a great opportunity to meet with folk from the Michael J Fox Foundation for Parkinson's Research and Parkinson's UK and discuss our goals and the strength of NZ research over meals and drinks. What a strong, collaborative and welcoming international community!



BUILDING INTERNATIONAL CONNECTIONS II

DANIEL MCGOWAN, CEO

Following the iLCT meeting and some further meetings in London and Cambridge, the second leg of my trip took me to Barcelona, Spain for the 6th triennial World Parkinson's Congress - a meeting that brings together the world's top researchers, clinicians, companies, charitable organisations, people with Parkinson's, and their Care Partners. What a wonderful, inspiring, and highly motivating congress that was.

The congress was a fabulous chance to get up to speed on the latest in Parkinson's research from around the world and of course to develop further networks and relationships. It is especially gratifying to see how deeply the clinicians running clinical trials are listening to people with Parkinson's - about the symptoms that matter most to them; about aspects of study design; and about their hopes and fears for therapies.

It is exciting to see how different parts of the Parkinson's puzzle are now starting to fit together as the results of genetic research converge with those from neuropathology and cell biology studies. The key message is that there likely won't be a single cure for all, but rather, multiple targeted therapeutic approaches offered on the basis of a person's underlying disease biology.



OUR STORY

BERNIE CROSBY



“NO DREAM TOO BIG WAS THE SEED THAT MORPHED INTO A MAJOR OPERATION. WITH NO RESEARCH THERE CAN BE NO REMEDY. MY DREAM IS TO COMBINE WITH OVERSEAS RESEARCH CHARITIES TO FULFIL ASPIRATIONAL AND INSPIRATIONAL OBJECTIVES.”

BERNIE CROSBY

In 2005, Bernie Crosby, ONZM, a prominent Waikato businessman, was sadly diagnosed with Parkinson’s disease. Five years later in 2010, Bernie and his wife Kaye were at a fundraising dinner in aid of Auckland’s School of Medicine, and Bernie found himself next to Dr Maurice Curtis of the University’s Centre for Brain Research (CBR) – a fortuitous meeting for both.

Dr Curtis (now Professor Curtis) demonstrated such an enormous amount of passion, conviction and energy in his pursuit of knowledge of the brain and its disorders, that Bernie, being an eternal optimist, decided they should raise money for the CBR to continue their work on Parkinson’s.

Bernie and Kaye established the Neuro Research Charitable Trust for this purpose in 2013, and they set a goal of raising \$1 million in 5 years.

Their Trust has continued to raise funds to support research at the CBR to the tune of \$2.3 million by the end of 2022. But in the face of this emerging pandemic, so much more needs to be done.

The Crosbys remain committed to ongoing fundraising to support research towards a cure for Parkinson’s, while the Trust they established has attracted several others with a personal connection to this awful disease, all committed to driving research towards a cure.

Only through further research can disease-modifying treatments to slow, stop or even reverse progression become a reality.

And that’s why we need YOU to join us on our mission.

THE BEST MINDS IN THE BUSINESS



Cure Parkinson's NZ is governed by a dedicated, passionate, and experienced Board of Trustees, all of whom bring considerable gravitas, wisdom, and valuable connections to the Trust. At the August fundraising event, CPNZ's Chairman Jon Tanner, shared an exciting announcement about the appointment of three new Board members, all of whom have a personal connection to Parkinson's. These new Trustees will now work closely with Jon, Kaye, Daniel, and the rest of the team on their heartfelt mission to find a cure.



DISTINGUISHED PROFESSOR SIR RICHARD FAULL, KNZM, ONZM
A 'giant' of New Zealand science, and a man whose name is synonymous with brain research both in New Zealand and on the world stage. He is the founder of the Centre for Brain Research, and a recipient of many accolades over his 50+ years of leadership in brain research, including the Royal Society Rutherford medal. He is widely recognised internationally for his work on neurodegenerative diseases and for the establishment of one of the best Human Brain Banks in the world.



ALEX PETERSON
Alex brings his own personal connection to Parkinson's and the Crosby family, and is also a wonderful fit for the new Board as he brings an immense amount of passion to our mission. Alex's connections, established through his very successful career in the financial sector, are absolutely invaluable as we continue to expand our reach across the Auckland region for additional funding and support of Parkinson's research.



MARISE WINTHROP
A Hamilton-based commercial lawyer and General Counsel at Livestock Improvement Corporation, along with being a Chartered Director, Marise now brings her stellar credentials to our Board. Her governance, financial, and legal skills combined with her deep passion for our mission and her own personal connection, makes her a tremendous asset to CPNZ.

PUTTING THE “FUN” INTO “FUNDRAISING”

WAIKATO FUNDRAISING DINNER & AUCTION

August 2023

Our Waikato Fundraising Dinner and Auction was an incredible evening raising nearly \$182,000 for Parkinson's disease research - a truly phenomenal outcome!

\$181,935.23

Massive thanks are due to all of the event sponsors, donors, bidders and supporters who made the evening such a success. We look forward to putting these funds to good use as we work toward a cure for this awful disease.

In particular, we would like to thank our wonderful MC Frankie Stevens; Brian King, auctioneer extraordinaire and his support crew; Montana Food and Events; Greenlea; New World Hillcrest; Caiger Charitable Trust; Wintec; JRD Advisory; Print House Ltd.; BNZ; and IT Partners.

Thanks also to the many generous donors of the wonderful auction items that helped us reach such a lofty total on the night... the support of the community is extremely touching.

Without the generous support of these individuals and companies, the evening would not have been anywhere near as successful. It is the generosity of such supporters that enable us to keep our costs low meaning that almost all of the funds raised will go to research!



PUTTING THE “FUN” INTO “FUNDRAISING”



AUCKLAND MARATHON

October 2023

While most of the country was watching the RWC final live, our small team of CPNZ athletes blitzed the bridge in blustery conditions to complete their courses at the 2023 Barfoot & Thompson Auckland Marathon.

Grace Mayer pushed through the pain barrier to come home in 5 h 17 minutes in her first ever marathon, while 13-year-old Jack McGowan ran a quick 11-km coming home in 52 min (6 minutes ahead of his old man)!

There were lots of comments on the singlets and our cause, so we might have a larger team next year! It was also great to see our trustee Alex Peterson and his wife Shelley at the start of the 11-km!

Massive thanks again to Grace and Jack for raising both funds for (almost \$1600!) and awareness of Cure Parkinson's NZ! Thank you also to all who donated to their cause.

If you're planning to take part in any sort of endurance event or challenge over the next 12 months and would like to support Cure Parkinson's NZ while doing so, please get in touch at info@cureparkinsonsnz.org.nz

We'd love to add you to our team!

AN EMERGING PANDEMIC BUT WITH YOUR HELP WE CAN PROVIDE FUTURE HOPE FOR ALL KIWIS

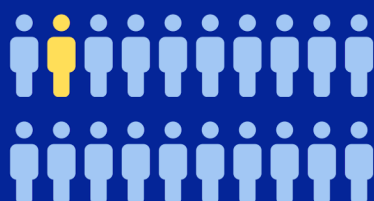
The number of people living with Parkinson's is growing exponentially. An ageing population alone does not account for this rise. Air pollution, metal production, certain industrial chemicals, and some synthetic pesticides are all linked to Parkinson's.*

Currently, Parkinson's affects at least 12,000 New Zealanders and approximately 10 million people worldwide. Prevalence has almost tripled since 1990 and is expected continue to increase exponentially.

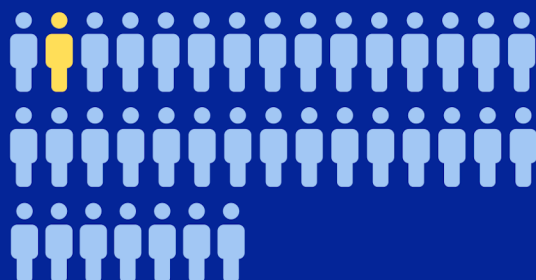
A RECENT SURVEY IN THE UK SHOWED THAT...



1 IN 3 ADULTS IN THE UK KNOW SOMEONE LIVING WITH
PARKINSON'S



1 IN 20 PEOPLE WITH PARKINSON'S DEVELOP
SYMPTOMS BEFORE THE AGE OF 50



1 IN 37 PEOPLE WITHIN THE UK ARE
PREDICTED TO RECEIVE A DIAGNOSIS
OF PARKINSON'S DURING THEIR
LIFETIME†

These statistics are likely paralleled in the New Zealand population.

This insidious disease places a significant burden on families, economies and health systems that will continue to increase unless we can find a way to stop or slow progression.

* <https://www.americanscientist.org/article/the-rise-of-parkinsons-disease>

† The Incidence and Prevalence of Parkinson's in the UK. Results from the Clinical Practice Research Datalink Reference Report (published Dec 2017) – Parkinson's UK

CURE PARKINSON'S NZ IS A VISIONARY CHARITABLE ORGANISATION, STEPPING UP THE BATTLE AGAINST PARKINSON'S DISEASE WITH GROUND-BREAKING RESEARCH AND AN UNWAVERING COMMITMENT TO FINDING A CURE.

OUR MESSAGE IS CLEAR.

"IT'S NOT A CASE OF IF, BUT A MATTER OF WHEN — TOGETHER WE CAN CURE PARKINSON'S DISEASE."



MY STORY

TONY EGAN



“LIVING WITH PARKINSON’S IS A BIT LIKE BEING A RACEHORSE WITH A HANDICAP...IT SLOWS YOU DOWN A BIT, BUT YOU CAN STILL BEAT THE ODDS...OR AT LEAST AVOID THE KNACKERS’ YARD IF YOU HANG IN THERE, HOWEVER IT’S PROBABLY BEST TO AVOID THE STEEPLE CHASE!”

TONY EGAN

Tony Egan is the Managing Director of Greenlea Premier Meats, a highly successful family-owned business producing and exporting premium quality New Zealand beef, lamb and venison. He is also a shareholder of Greenlea and was part of the initiative to establish The Greenlea Foundation Trust. At Cure Parkinson’s NZ, we are incredibly lucky and grateful that the Greenlea Foundation Trust is an active and significant supporter of our mission, but the connection is more than just financial, it’s also personal, as Tony himself is living with the disease.

At our August Fundraising Dinner and Auction, Daniel invited Tony to sit on the Q&A discussion panel and share his views on living with Parkinson’s. His light-hearted yet heart-warming approach was both entertaining and factual and we’re grateful to share a snippet with you here.

Daniel:

I wonder if you could perhaps start by telling us about how Parkinson’s disease has changed your life... the day-to-day things that have had an impact on your quality of life.

Tony:

Parkinson’s has certainly made me more versatile... I can drag my leg around behind me or do Kung Fu kicks in my sleep... As Bernie says: ‘No dream is too big!’ And there are advantages... people insist on bringing me a cup of tea these days, and everyone stands up when I carry my cup around the lunchroom – such respect – clearly they see me as a mover and a shaker. It pays to remember that there are always people worse off than me...for instance my friend is dyslexic – he confided in me recently that he’s being trying to get a 96er for 25 years!

MY STORY

TONY EGAN

Daniel:

As you know, CPNZ is keen to fund preclinical and clinical research that can lead to promising new drug therapies that can stop or slow progression. What would it mean to you to have treatments like this available here in NZ?

Tony:

Optimism is the cure for many things... Parkinson's is the fastest growing neurological condition in the world with 10 million people signed up and more joining us every day. And while it is certainly a great way to meet interesting people, at this rate I run the risk of having too many friends, especially if we must line up for medication.

I figure that if a Kiwi can climb Mount Everest, then we can knock this bastard off as well, and clinical trials are a big part of that ambition. Bernie and Kaye have shown us that no mountain is too big if we believe it is possible.

Thanks to the good work of the Centre for Brain Research, New Zealand is no sleepy backwater. Cure Parkinson's NZ has also evolved further with your appointment; with you at the helm, we can make an even bigger difference both in New Zealand and on the world stage.

Daniel:

We are hugely grateful to you and your extended family at Greenlea for your Trust's support of Cure Parkinson's NZ and our mission - do you have any messages for Kiwis about why they should get in behind Cure Parkinson's NZ and help us achieve our mission?

Tony:

The Greenlea Foundation is proud to be an active and significant supporter of Cure Parkinson's NZ, not just tonight but through our annual gifting each December.

It may be a bit late to stop some of us walking into walls...but we can shine a light for future generations here tonight...with our collective support.

NEW KNOWLEDGE & NEW DISCOVERIES

RESEARCH UPDATE



A cure for Parkinson's is on the horizon. It will likely require advancements in three key areas: earlier diagnosis, objective markers of disease progression, and drugs and therapies that can stop or slow progression. Recent advances have been made in all three of these areas, including in Aotearoa New Zealand, but more work is needed.

Kiwis are known for their innovative spirit and creative 'solutioneering'. New Zealand is home to some world-class researchers, with the University of Auckland's Centre for Brain Research team having achieved numerous world firsts. And, thanks to the close and meaningful relationships the team has built with the families of kiwis affected by neurological disorders, we have a world-class human brain bank fuelling exceptional neurological research and progress.

Made possible by the generous donations of our supporters, grants from the Cure Parkinson's NZ to the University of Auckland's Centre for Brain Research have led to several research breakthroughs bringing us closer to a cure for Parkinson's, including:



The world's first 3D reconstruction of the human olfactory system, which is affected early in the course of Parkinson's disease, leading to a loss of smell.



The world's first findings of typical Parkinson's pathology in the olfactory mucosa of people with Parkinson's disease, creating opportunities for earlier diagnosis.

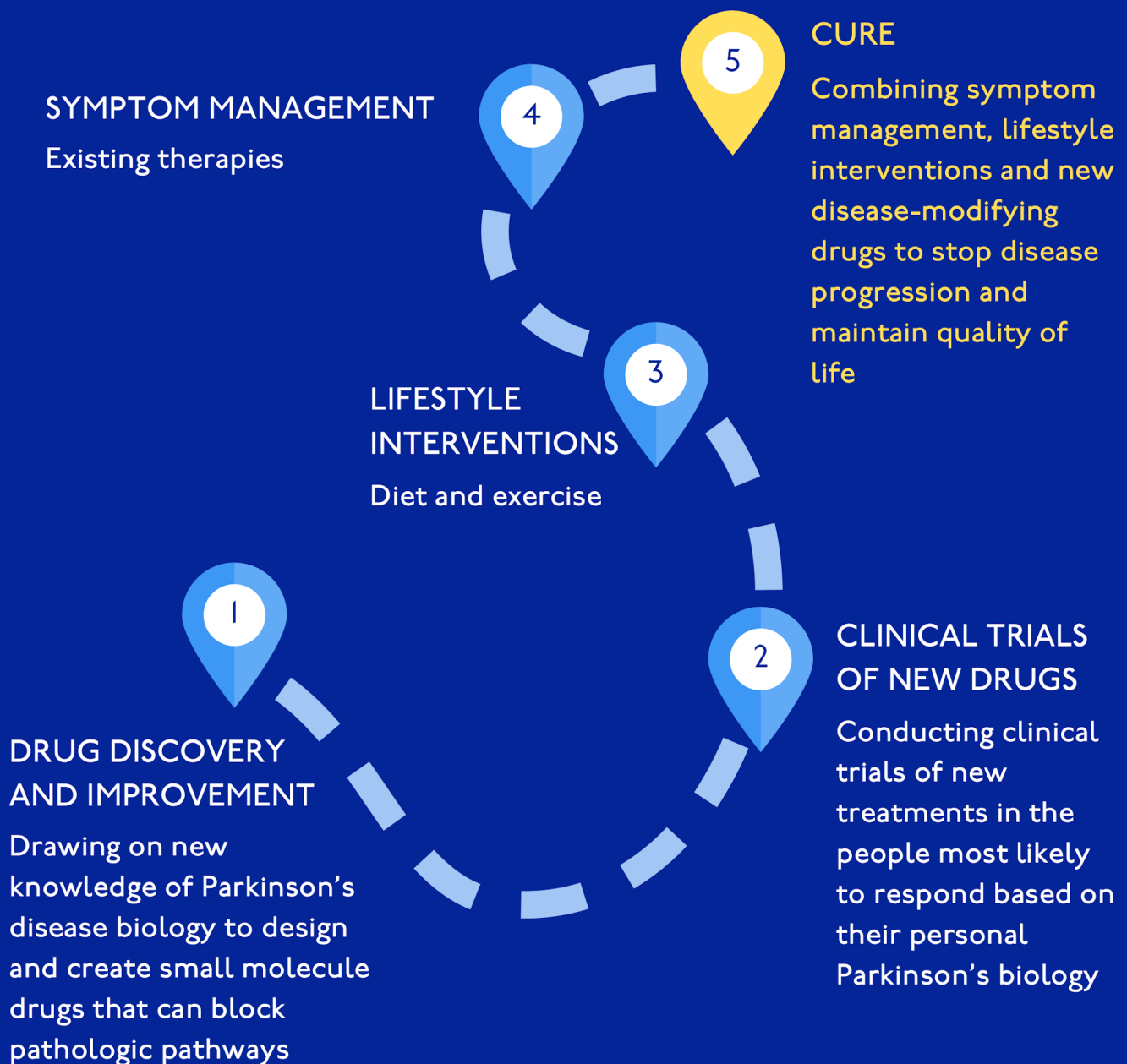


The successful isolation and lasting culture of cells from nose biopsies of people with Parkinson's and their live-in partners for testing new drugs in the laboratory.

NEW KNOWLEDGE & NEW DISCOVERIES RESEARCH UPDATE



This is an exciting time for our donors, volunteers and Trustees to be directly involved in bringing the first-ever disease-modifying drugs for Parkinson's to patients. Further research and clinical trials are urgently needed to get treatments into the hands of patients, but if we work together, you too can become part of history.





CURE PARKINSON'S NZ

NO DREAM TOO BIG



A 'CLICK AND SHARE' FROM YOU CAN
REALLY HELP OUR TEAM & OUR MISSION

PLEASE FOLLOW US ON SOCIAL MEDIA
[@cureparkinsonsnz](#)



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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.