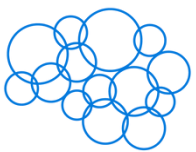


CURE PARKINSON'S NZ

NEWSLETTER AUTUMN 2023



CURE
PARKINSON'S NZ
NO DREAM TOO BIG



Welcome to our Autumn 2023 newsletter, coming to you during international Parkinson's Awareness Month, April!

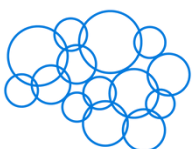
It has been a busy but productive first few months of the year with some clear highlights worth mentioning. It was great to be able to get to Christchurch in February to support Rob Spear and Sam Paterson on their Coast to Coast journey, which ultimately raised \$13,000 for Cure Parkinson's NZ—a fantastic effort! It was also heartening to visit the fabulous BrainTree wellness centre there (we need one of these in every region!) and to spend some time with neurologist Professor Tim Anderson and Parkinson's researcher Dr Christina Buchanan, discussing their research.

Another highlight was seeing our new website and social media channels go live with new subscribers and followers coming in, some in response to our printed flyers. On that note, we welcome all of our new supporters and we look forward to taking you along on our mission to find a cure.

Finally, what a wonderful job our fundraising committee have done bringing in auction items and selling tables for our Waikato-based fundraiser in August, which is now fully subscribed. Really looking forward to meeting many of our supporters at that event, which is shaping up to be an incredible night!

Ngā mihi nui, mā te wā,

Daniel McGowan
Chief Executive Officer



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BIOMARKER BREAKTHROUGH NEWS FROM MJFF

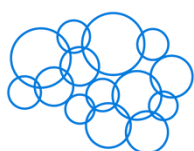
Many of you will have seen the news of a “biomarker breakthrough” from the Michael J. Fox Foundation, but you may be wondering what this really means for people with Parkinson’s. A biomarker (short for “biological marker”) is essentially just a measurable indicator of biological state—it can be a molecule like blood glucose or cholesterol, or a measurement like heart rate or blood pressure.

The biomarker described in a new publication this month is basically a test of the aggregation propensity of a key molecule in Parkinson’s (called alpha-synuclein) within study participants’ cerebrospinal fluid (CSF). If a person’s CSF alpha-synuclein was shown to have a propensity to aggregate, they were highly likely to have Parkinson’s disease.

Excitingly, the researchers found not only that their biomarker could distinguish people with Parkinson’s from healthy controls,

but also that it could identify most (nearly 90%) of the prodromal participants (people with early signs and symptoms who had not yet been diagnosed), especially those those with loss of smell as an early symptom. There were also some interesting differences in biomarker results in different subgroups of participants with Parkinson’s (with different underlying causes), which will help inform which therapies might work best in which people.

This biomarker will therefore enable accurate biochemical diagnosis of very early-stage Parkinson’s disease, matching of potential treatments to the individuals most likely to benefit from them, and better tracking of treatment outcomes (improvements with treatment), all of which will aid in clinical trial design and getting new beneficial therapies approved for people living with Parkinson’s. Exciting times ahead!



Read more at

cureparkinsonsnz.org.nz/news/

COAST TO COAST 2023



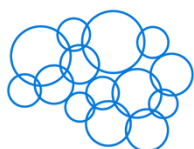
SUPPORTERS RAISE FUNDS FOR PARKINSON'S RESEARCH

We are hugely grateful to two of our supporters, Rob Spear and Sam Paterson, who raised \$13,000 for Parkinson's research through their generous sponsors of their Coast to Coast challenge in February. When we first caught up with them at the end of last year, after a training run over Goat Pass, they were worried they might have bitten off more than they could chew. But they were committed and giving up was never an option. Training continued in earnest through January, working off the Christmas excesses, and they hit the start line in Kumara on the wild West Coast on Feb 10 feeling nervous, but ready. Things didn't quite go to plan with Rob getting cramps in both legs on the first stage, but they soldiered on, working together to get up and over Goat Pass on a stunning day. Their support crew helped and pushed them along at transitions, which must have kept spirits high as they kept going despite some kayak capsizes, a near collision with

a massive rock, and a head wind on the bike leg into Christchurch on the 11th. It was great to see them come around the corner into the final straight at New Brighton Beach with their beautiful families and supporters cheering them along. Rob later said the highlight for him was "running up that sand bank [to the finish line] with our girls".

Our congratulations and thanks go out to Rob and Sam for not only completing this huge undertaking, but for raising much-needed charitable funds along the way. Looking ahead to next year's race Rob did say "never again"! I wonder if he's maybe changed his mind!

If you would like to complete an endurance event or challenge of some other kind with Cure Parkinson's NZ as your nominated charity, please get in touch at info@cureparkinsonsnz.org.nz.



GLOBAL PARTNERS

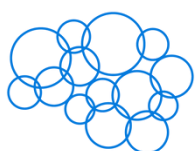
Parkinson's affects people of all colours, on all continents and of almost all ages. The explosion in the number of people with Parkinson's (doubling in the last 25 years and expected to double in the next 10-15) has been referred to as a coming pandemic. This is a global problem, not only a NZ one. It is therefore fantastic to be working with global partners toward a cure for this awful disease. By working together strategically and collaboratively we can get the greatest bang for buck. After all, it doesn't matter where a cure comes from as long as it benefits all.



Cure Parkinson's, a charity registered in the UK, 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. We are grateful for the invitation to join this group and look forward to working with the team there toward our shared goal.



Shake It Up Australia Foundation have had some phenomenal success to date, raising A\$22M for Parkinson's research in just 12 years. They have also fostered a highly fruitful relationship with The Michael J. Fox Foundation. We would love to emulate some of that success here in Aotearoa New Zealand, and are grateful to them for the knowledge and insights they have shared to date.



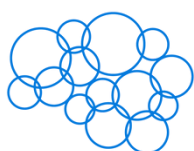
NEW ADDITION TO OUR FUNDRAISING COMMITTEE

Our volunteer fundraising committee does tremendous work behind the scenes to make sure events like the upcoming one in August not only happen, but are incredibly successful in terms of both funds raised for Parkinson's research and the lasting memories of good times left in the minds of those attending. We have been fortunate to benefit from the tireless efforts of Brian King, Ken Williamson and Jason Cowan over many years as they hustle for auction items, sell tables, and procure pro bono support to make these events so successful.

In February this year it was great to welcome Kathy Wilson onto our fundraising committee. Kathy brings a professional background in banking and insurance, as well as extensive networks, and has already proven herself invaluable as she has gone about twisting arms. Kathy also has her own personal experience of Parkinson's disease, providing her with the motivation to do something that can make a genuine difference for those suffering from this awful disease.

Kathy recalls clearly the evening she first met Bernie in 2006: when she asked him which lady in the room was his wife he answered "only the best looking woman in the room!" He later became her "go to" person about Parkinson's, when newly diagnosed. Bernie told her "Welcome to the club. You are one of the lucky ones—there aren't many of us!"

We welcome Kathy to the team and thank her for her drive and commitment to our cause!



SOUNDS 2 SOUNDS BIKE-PACK



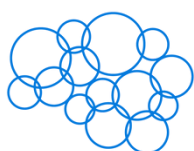
One of our long-term supporters, Mike Havill, spent most of March completing the self-supported Sounds 2 Sounds bike tour, a 1500-km bike-packing route from Queen Charlotte Sound to Milford Sound. This route is open to cyclists for most of the year, but there is an annual event that starts on March 1 each year.



Making it potentially more challenging for Mike than for most is the fact that he has Parkinson's disease (diagnosed in 2012). Of course, exercise is one of the best things for people with Parkinson's to do, and what better way to get it than on a bike taking in some of this country's impressive scenery along the way?



Many of you will recall that Mike completed a ride from Cape Reinga to Bluff in 2020, raising funds for Neuro Research Charitable Trust and Parkinson's NZ. Of this latest challenge Mike said that the route was "all terrain" on sealed roads (25%), gravel roads, trails and tracks, via Marlborough, Molesworth, Hanmer, Rakaia Gorge, Geraldine, Tekapo, Lake Ohau, Omarama, Otago Rail Trail, Lake Dunstan Trail, Nevis Valley, Mossburn, and Te Anau to Milford.





Mike completed this challenge in an incredible 22 days, including 20 days of riding and only two rest days. His longest day was 130 km, while the shortest was 20 km from the Homer hut to Milford via the Homer tunnel. In total, Mike covered 1570 km with 16,700 m (!!!) of climbing. On two of the days, there were 25 river crossings each day.

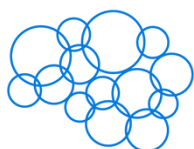


Mike said: "I met a lot of great people along the way and enjoyed the amazing scenery. You get a different perspective touring on a bike. On days 1 & 2, I spent over 11 hours per day actively riding. It was very challenging (hills, difficult gravel and wind and weather)."



Whilst he didn't want the added pressure of fundraising this time around, Mike did want to do this to raise awareness of Parkinson's. "Riding with Parkinson's, I needed to ride with patience and some caution, walking some of the steep uphill and downhill sections. I upped my medication when I felt it was needed."

Our huge congratulations to Mike on this impressive undertaking!



CLINICAL TRIALS



FUNDING OPPORTUNITY

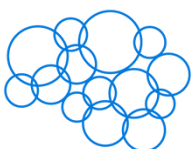
In our last newsletter we mentioned that we had an opportunity to co-fund a multicentre phase 3 clinical trial together with our partners Cure Parkinson's. This is an exciting and much needed trial with the potential to have a major impact. The good news is that this trial has recently gotten underway. However, there is still a £1M hole in the trial budget that will need to be plugged in the next few years. What makes this trial so interesting (and eagerly awaited)? The intervention, ambroxol, an expectorant that has been used for 50 years to treat coughs, is safe, well tolerated, low cost, and easily accessible. It also has the potential to stop or slow Parkinson's disease progression through the stabilizing of an enzyme called GCase, and in turn, supporting the removal of misfolded proteins and other cellular rubbish (which are known to clog up important cellular systems in Parkinson's disease).

The phase 2 ambroxol trial results, which were published in 2020,

were highly promising—higher levels of the protein alpha-synuclein (which adopts a misfolded state in Parkinson's leading to cellular dysfunction) were observed in cerebrospinal fluid (CSF) samples from participants who took ambroxol, indicating improved "trash clearance". They also had improved movement symptoms! Phase 3 trials are generally the last phase of testing before data are submitted to regulatory authorities (like the FDA) for approval to release a new drug onto the market. The phase 3 trial of ambroxol is large and involves multiple centres—the results will provide definitive evidence (one way or the other) on whether ambroxol can modify disease progress in Parkinson's. It is also one of only six phase 3 trials worldwide currently testing potentially disease-modifying therapies for Parkinson's.

Read more at
cureparkinsonsnz.org.nz/news/

For a discrete conversation about how you can help, contact us at
info@cureparkinsonsnz.org.nz.





CURE PARKINSON'S NZ

NO DREAM TOO BIG

Funding research since 2013



We are here for a cure, a world without Parkinson's disease

MISSION

We exist to shape and fuel research leading to treatments that can slow, stop or reverse the progression of this insidious disease through local fundraising and global collaborative engagement.

WHY?

- Parkinson's disease is the fastest growing neurological condition in the world
- Parkinson's affects >12,000 New Zealanders and >10 million people worldwide
- Prevalence is expected to double in the next 10-15 years
- Parkinson's affects people of all ages, but becomes more common with age, affecting ~1% of all people aged ≥60 years

The research required to get promising treatments to the clinic is expensive. But the cost to patients, their families, healthcare systems, and economies of not doing this research is much much more.

WHO?

Cure Parkinson's NZ is led by an experienced management team supported by a dedicated Board of Trustees, an international Scientific Advisory Council, and a volunteer fundraising committee. Learn more about our team at www.cureparkinsonsnz.org.nz.

IMPACT

From 2013-2022, as Neuro Research Charitable Trust, we granted \$2.3M to the Centre for Brain Research, University of Auckland, supporting ground-breaking research on brain diseases.

With a new name and leadership from 2023, and a clear purpose to shape and fuel research leading to a cure for Parkinson's, we expect to amplify our impact as part of a global group of organizations with a shared mission.

**We need your help to deliver our vision of a world without Parkinson's.
Please get in touch today to learn how you can help make this a reality.**

Phone +6421-02140403

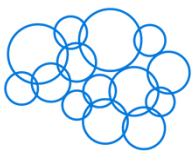
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Cure Parkinson's NZ is the operating name of the Neuro Research Charitable Trust, a charity registered in New Zealand (Registration number CC49200) and a separate legal entity to Cure Parkinson's (the operating name of The Cure Parkinson's Trust, a 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.