

Newsletter September 2021

Kia ora and welcome to our September newsletter.

With the South Island still in level 2 for the moment, most of our research remains suspended. Clinical trials and MRI scanning are underway and we can't wait to reach level 1 soon so we can return to all our other research assessments. In the meantime, this newsletter will share some great updates on staff and one of our star research participants, Marilyn.

Please help our lovely Dee

We all know someone who practically runs a business and rarely gets the recognition they deserve because it's just 'what they do'.

At NZBRI, Dee is our unsung hero. If you've ever visited our office then you've met the amazing Dee - she holds the place together and keeps it all running smoothly for our researchers as well as many of our participants.

Dee is a national finalist in the Canon Business Bestie competition and we need your help!



We'd really appreciate it if you could click on this LinkedIn post https://lnkd.in/gwPQnC8r then like and comment on the post. Every like and comment will help Dee. She's currently in second position with some amazing prizes available. Thank you!

NZBRI Financial Performance 2020

The 2020 financial year presented many challenges for NZBRI. The loss of revenue from fundraising events that were impacted by the Covid-19 pandemic, reduction in donation income, as well as disruption to our clinical research programme all contributed to an operating deficit for the year of nearly \$118,000.

Despite these challenges, we were able to invest nearly \$1.0 million into salaries for our dedicated research team. This year we are striving to exceed this amount by increasing the level of fundraising and donation income, both of which are critical to the ongoing sustainability of our research programmes.



Celebrating our 65th Research Thesis

We have great pleasure in announcing that NZBRI Neurotech research student, **Venkat Krishnamoorthy**, has successfully completed his PhD examination on his PhD project "Detection and Prediction of Microsleeps from EEG via Deep Learning". He will be formally awarded his PhD by the University of Otago in the next few weeks.

This brings the total number of completed NZBRI PhD and Master theses to a whopping **65 theses** over the past 17 years. This is a phenomenal amount of research and also shows how many promising, young, graduate students we train as researchers.



Marilyn's Story

Marilyn was constantly tired and frequently tripping over and stumbling. Then aged 58, she wasn't prepared for what would end up being a Parkinson's diagnosis.

Now 69, Marilyn's journey since her diagnosis has been one of change, adjustment and learning. "There's a bit of a sadness, knowing it's never going to go away," she says. Her Parkinson's has thankfully been progressing slowly. In the morning her movements are slow and she describes it as 'walking through treacle' and she has to sit down until it passes. "When everything slows down my face goes blank; it's a physical Parkinson's symptom," she says. "Making decisions is really difficult. I can't make up my mind what to answer, all the processes slow down."

"You grieve for the life that you're losing, now you have to think ahead," she says. "Where we've always been spontaneous, you can't just jump in the car without thinking twice. We have to make sure we've got

medication, and snacks to help if there's problems with the medication working."

For Marilyn, not being able to do everyday things can be the hardest. "I miss not being able to finish something because I am too tired," she says. "I used to move mountains in a day, and now I struggle with some of the simpler things like baking – it will take most of the day." But Marilyn tries to live her days with positivity and embraces what she can still do as she knows that will support her having a fulfilling life despite the challenges she faces.

"I find being physical, being out in the garden makes a difference for me," she says. "If I can get my hands in the dirt, I function a lot better."

Marilyn was also able to find a new partner after her diagnosis, something she didn't think would be possible. "It blows me away to think you can start a new relationship. It's the best decision I've ever made," she says. "I've been with Neville four years. We laugh every day, we're on the same page and our relationship is not hard work. He takes me as I am and we laugh a lot about some of the Parkinson's stuff."

She also takes pride in being part of New Zealand Brain Research Institute's Parkinson's Progression

Programme, something she values as helping her and that she knows will be important to others with this debilitating condition. "If you're going to have Parkinson's you may as well use it for something good. It brings a positive to it, instead of a negative," she says. "I enjoy doing the research, I feel like I'm being useful, everyone there is very caring, and I feel a part of something."

For Marilyn, she hopes the research will find answers and ultimately a cure. "I want to know what causes Parkinson's because until we know we're not going to change a lot," she says.

Until that time comes, she is grateful for the ongoing support of her friends, family and the continuing research at NZBRI; her advice to others living with the condition is to welcome what you can do. "Choose the friends you're comfortable with and socialise as much as you can, it will make you feel a lot more normal," she says. "Do the things you have always done for as long as you can attention the world abrinks too guidals."



Today is World Gratitude Day

At New Zealand Brain Research Institute we are grateful for many things, but especially Cas Van der Veer. Local businessman Cas provided a generous donation back in 2003 to establish the institute. We receive no direct government funding and rely on the continued generous support from the community through donations, bequests and fundraising events.

You can support us by donating on our website at www.nzbri.org/Donate/ or by clicking on the button below, or contact info@nzbri.org to discuss supporting our vital work in your will.

Donate Now

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Stay safe

Ngā mihi

The New Zealand Brain Research Institute Team







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