



One family's experience with Parkinson's disease and End of Life Choice

Robyn Evans, an avid supporter of AMRF, retells her family's experience in dealing with Parkinson's disease and being involved with research on assisted dying in New Zealand.

When Robyn Evans joined the Voluntary Euthanasia Society in 2011, little did she know that her younger son, Troy, born in 1974, would be one of the first people in New Zealand to choose assisted dying with The End of Life Choice Act 2019.

On 29 December 2021, Troy's life ended. He had survived leukaemia in 2009/2010 and while in remission from leukaemia in 2012, he was diagnosed with early onset Parkinson's disease. Robyn describes Troy as a fighter and someone who never gave up.

"My son was a highly respected Marine Pilot at Port of Tauranga and a new pilot boat, is being named the Troy Evans, in his memory. The words of one of the skippers who worked with Troy are so true of my boy: *"This vessel is so much more to us than just a boat. It's a reminder*



Troy Evans, Marine Pilot and Tugmaster that no matter how many times life knocks you down, you get up and get on with it, which is what Troy did, time and time again," Robyn shares.

Robyn wanted to share her version of the events leading to Troy's choice, a choice that she acknowledges is so completely personal and unique for every individual.

"I know Parkinson's is different for everyone and Troy had very few symptoms for several years. But by 2019, he had become increasingly unwell and he had Deep Brain

Stimulation Surgery [DBS] - actually two separate surgeries - electrodes inserted into the brain and a stimulator implanted into the chest," she reflects.

"This was very successful for a short time, but sadly as can be the case with some of these invasive treatments, he got infections, at first the chest stimulator was removed and replaced, but more infections resulted, and eventually the electrodes and second stimulator had to be removed.

continued on page 2

CANCER RESEARCH IN AUCKLAND

We are looking forward to presenting our next free online event, sharing with you the latest and greatest in medical research.

In August, we'll be featuring a cancer research webinar from two acclaimed researchers, Prof Peter Browett and A/Prof Nuala Helsby, focusing on understanding cancer and searching for cures, recently supported by donors like you.

To hear more about this event when details are finalised, please register your interest by emailing events@medicalresearch.org.nz or phone 09 923 1701

You can view our past events anytime — they are available to watch at your leisure on our website or search for our YouTube channel.



continued from page 1

ROBYN EVANS' STORY

"In early 2021 after other Parkinson's treatments [including apomorphine] were investigated, Troy had further DBS. Unfortunately this procedure didn't go well and Troy ended up with a brain bleed.

"By now Troy had difficulty walking and while the Parkinson's had affected his left side, he now had the added distress of the brain bleed affecting his right side.

"He was still working and his employer, Port of Tauranga, was very kind and accommodating. Then in early October Troy sustained a back injury which resulted in excruciating, relentless pain.

"Parkinson's can cause stenosis [narrowing] of the spine and this aggravated his condition. He was admitted to Tauranga Hospital where he stayed, apart from 9 days at home, until he died.

"His pain was barely relieved despite heavy medication," Robyn goes on.

"In November, it seemed the prognosis would be that Troy may never be able to go home to his wife and two young daughters and would never be relieved of the significant and unrelenting pain. He stopped eating and drinking, thinking he would die quite quickly but sadly this wasn't to be.

"Troy applied for assisted dying but because it was so new in New Zealand, there were delays. However it was eventually approved.

"He phoned me half an hour before he died as he didn't want me to be there. He was very lucid and he died very peacefully.

"Our brave 'Captain of the Ship' has now sailed into peaceful waters. But for assisted dying he would have had to go through elongated and wretched suffering in a hospital room and his death would have been so different," Robyn ends.

When Robyn was approached to be a participant in an AMRF funded research project, Experiences of Using the End of Life Choice Act, she was a very willing participant.

International studies have shown there can be significant emotional



Robyn and Troy Evans

and psychological effects for the health practitioners involved in assisted dying and the whānau and families of the person who has been assisted to die.

This, combined with the Act being so new in this country and the lack of any studies in a New Zealand context, led the University of Auckland's Associate Professor Gary Cheung, Department of Psychological Medicine, and Dr Rosemary Frey, School of Nursing to embark on this important project.

Both Dr Cheung and Dr Frey identified the critical need for ongoing transparency around an Act of this nature and to drive continuous improvements in practice. Without this research, they knew the opportunity would be lost to explore the collective experience, potential knowledge and services gaps, and the implications for the ongoing development of training and educational resources for health practitioners.

Robyn was one of the family participants interviewed for the project in late April this year and she

found the process both cathartic and interesting.

"The doctor who interviewed me was a wonderful woman. She was so empathetic, listened to me, took her time and is obviously very knowledgeable. I left the interview feeling I had been able to contribute to a really essential piece of research and she helped me to further understand the outcomes they were hoping to achieve, which will be so beneficial for all those involved with assisted dying in the years to come," explains Robyn.

"After the interview, I was able to meet up with Sue Brewster, Executive Director of AMRF, who introduced me to Dr Peter Freestone, an incredibly talented researcher who has received AMRF funding over the last ten years to study Parkinson's disease.

"His latest project is exploring less invasive techniques to help treat the symptoms of Parkinson's and seeing the optogenetic device that Peter and his team are working on, a tiny light no bigger than the top of a pen nib that can be inserted into the brain, gives me great hope for the future for people with Parkinson's disease.

"While I know there is still no cure for Parkinson's, knowing there is research like this and the End of Life Choice study happening right now reinforces all of the reasons I support the AMRF and have left them a bequest in my will.

"I want to give hope to others who might walk down a similar road we walked with Troy but have a different outcome," says Robyn.



The pilot boat 'Troy Evans' built by Hart Marine (Victoria, Australia) for Port of Tauranga. Hart Marine. 2023-03-01. Launch day for our latest 17.3m Pilot Boat [Facebook status update]. Retrieved from <https://www.facebook.com/photo/?fbid=51879187377018&set=pcb.518791947104044>

Want to know about leaving a bequest in your will? Ask us how.

FELLOWSHIP ENABLES GROUND-BREAKING NEUROSCIENCE RESEARCH AND ACADEMIC CAREER

Dr Brigid Ryan, Department of Anatomy & Medical Imaging at The University of Auckland, was awarded an Edith C. Coan Postdoctoral Fellowship through AMRF in 2018.

The two year fellowship was like striking gold for Brigid, allowing her to continue working on a ground-breaking study with a New Zealand family – a family with a mutant gene that meant they had a 50/50 chance of getting early-onset dementia.

“FTDGeNZ is a unique, long-term study of a NZ family with genetic dementia, established in 2015, with the aim of identifying the very early changes that are happening before people develop the symptoms of dementia,” says Brigid.

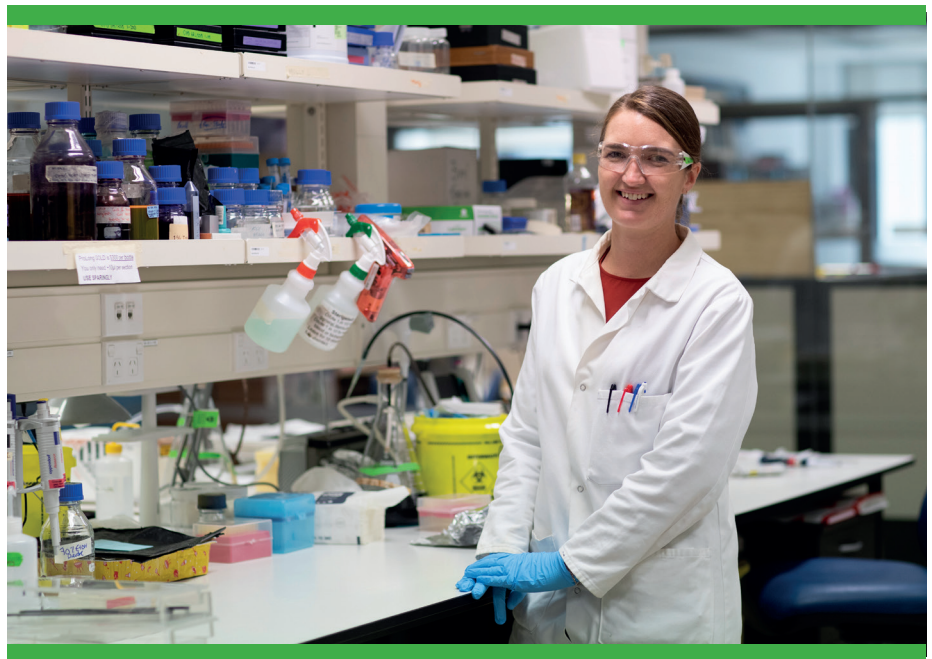
“Receiving the fellowship from AMRF meant so much as it allowed me to be wholly engaged with this body of research and work closely with the family to identify any neuropsychological, biological or sensory changes that were early indicators of the development of the disease.

“The ultimate aim is for earlier detection of dementia and being able to provide more effective treatments before the disease has progressed. With a study of this nature, our major challenge is it takes years to collect and analyse the data and then translate into meaningful interventions.”

Recognising the immense value of this longitudinal study, Kelliher Charitable Trust provided a one year extension to Brigid’s fellowship, enabling Brigid and her team to begin analysis of their first three-year dataset.

“Our results showed real promise as there appeared to be very early changes in language, cognition, and the sense of smell. Unfortunately, our analyses of blood-based biomarkers was delayed due to the Covid lockdown, but these analyses are underway.”

In 2022, the baseline results of the study were published (Ryan, O’Mara Baker et al. 2022) and presented at the pre-eminent international conference in France, The International Society for Frontotemporal Dementia Conference.



Dr Brigid Ryan

“The ultimate aim is for earlier detection of dementia and being able to provide more effective treatments before the disease has progressed. With a study of this nature, our major challenge is it takes years to collect and analyse the data and then translate into meaningful interventions.”

“Without any doubt, the funding through AMRF has been critical to my career development as a neuroscientist,” Bridget states.

“As a direct result of this research funding and salary support, I have been able to establish myself internationally in the field of early dementia detection. This, in turn, led to a permanent academic position at the University of Auckland as a Senior Lecturer in the Department of Anatomy and Medical Imaging.

“Securing this role and establishing an independent programme of

research, which will include the continuation of the FTDGeNZ study, would not have been possible without this funding support.

“I cannot thank AMRF and the Kelliher Charitable Trust enough – they are providing more than just funding, they are providing hope for the future – the future of mid-career researchers like myself and the future of all those who will be impacted by dementia in years to come.”

Meet our new Board VPs

"It is an immense privilege to represent AMRF as Co-Vice President. I am passionate about the Foundation supporting incredibly talented researchers, where the outcomes of their work has a direct positive impact on the health New Zealanders." - Dr Anna King

Our volunteer Board of Trustees provides critical governance to ensure AMRF meets the ever-increasing range of legislative and charitable requirements. Their wide-ranging skill set, professional expertise, and steadfast focus on strategic priorities is the backbone of our ongoing achievement of the AMRF mission.

In 2021, we welcomed new Board members Dr Anna King and Katie Noble. In 2023, we're so pleased to welcome them to their new roles as co-Vice Presidents of the AMRF Board of Trustees.

Dr Anna King is a clinical nurse, with over a decade of experience in academic research and lecturing at The University of Auckland. Her expertise includes clinical skills teaching and older person's health and she has published widely in the field of gerontology. As Chair of the Goodfellow Foundation, Anna

supports the Goodfellow Unit's educational and development programmes for primary healthcare professionals. She is Portfolio Manager within the Population Health Strategy Team at ProCare, an Auckland Primary Healthcare Organisation (PHO).

Katie Noble is the Managing Director of Allied Medical Limited, a key provider of assistive technology and rehabilitation equipment to New Zealand. She has been active in a number of organisations through the disability sector and currently is also on the Board of YES Disability and is also a Life Member of Muscular Dystrophy New Zealand.

With significant past experience in the NGO sector, she has been a Trustee of Make A Wish New Zealand and was the Chairperson for the Lotteries Grants Board for both the Auckland region and the America's Cup. She brings to our



Dr Anna King



Katie Noble

board leadership, marketing and fundraising experience – and a passion for improving the lives of all New Zealanders.



Tell us now!
What do you think of this newsletter?



Subscribe
to receive this & more via e-mail



Connect
with us on social media



Donate now
securely online or via your banking app

amrf@medicalresearch.org.nz

Charity Registration: CC22674



AMRF account
02-0160-0012991-00

Thanks to **bluestar**  for sponsorship of design & printing costs.

Choose your favourite way to donate.

Supporting medical researchers has never been easier. Whether you choose to donate by credit card or via internet banking, everything can be done easily over the phone, in person or online with us or directly with your financial institution to AMRF account number 02-0160-0012991-00.

And don't forget the tax benefits: individuals can claim a 33.33% tax credit for all donations over \$5 to an approved charitable organisation such as AMRF. Corporate donations are also welcome and are tax deductible.

100% of your donation supports medical research. None of your donation is ever used for administration costs or overheads. Your donation goes directly towards supporting researchers and their critical work.

Need assistance?

To talk to us about the best way for you to make your charitable donation of any size, big or small, please contact us by phoning 09 923 1701 or e-mail amrf@medicalresearch.org.nz.

AMRF | PO Box 110139 | Auckland Hospital | Auckland 1148 | Phone 09 923 1701

Charity Commission#: CC22674

100%
OF YOUR DONATION
DIRECTLY SUPPORTS
*Medical
Research*

Become a member — join at www.medicalresearch.org.nz