

Official Newsletter of the New Zealand Brain Research Institute

Winter 2015 Edition

New Zealand Brain Research Institute

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From Michael's Desk

This week, Dr Death stalked the halls of the Institute.

A new volunteer in our research programme, he told me of his varied career, which included a period as a professional wrestler. His stage name had clearly been chosen to inspire fear in his opponents and awe in his audience. Still barrel-chested and strong, fortunately for me, he only wanted to engage in a battle of wits.

"When did your Parkinson's start?", I asked.

"Well, we don't really know, do we?", he countered.

Dr Death: 1, Dr MacAskill: nil. I had to be on my toes with this one, I thought, and quickly re-phrased the question.

"When did you first notice the symptoms of Parkinson's?"

Dr Death wouldn't let me be sloppy. We both knew that the disease starts long before the first movement symptoms become apparent, perhaps several decades before. The diagnosis is based primarily on abnormal movements. But prior to those diagnostic features, many other non-movement symptoms occur. They aren't unique to Parkinson's, however: things like gastrointestinal disturbances, loss of sense of smell, sleep difficulties, and mood changes. Both patients and their doctors will often naturally just attribute them to the ageing process. An influential theory explains this by saying that the disorder might actually originate in the gut rather than the brain. An abnormal protein then travels up the nerves controlling the muscles of the colon wall, eventually finding its way to the top of the spinal cord and then into the base of the brain. A second front advances from the olfactory bulbs in the nose, explaining any loss of smell. By the time a diagnosis is made, the disease has likely reached stage four of a six-stage process. At that point, patients will usually begin pharmaceutical treatment and experience substantial relief. This is just treating the symptoms, however. The changes in the brain are relentlessly progressing, and we don't currently have any way to reverse or even slow them. Although many teams across the world are working on this, realistically we are many years away from an effective treatment or cure for the underlying process.



For the time being, we still need to understand more about how the disease affects individuals.

So my session with Dr Death moved away from verbal questions and on to a physical examination. We came to the assessment of his balance (impaired postural reflexes are a significant milestone in the progression of the disease). I gave my standard instructions: "I'm going to pull firmly on your shoulders. You do whatever you need to do to maintain your balance." "I can't promise my old wrestling reflexes won't kick in", he said menacingly.

"OK", I replied with a grin, "You do anything, short of assaulting me, to keep your balance."

Although he was bigger and stronger me, I yanked firmly on his shoulders and managed to get him to tilt and sway for a moment. He quickly steadied himself, though, by taking a few steps backward. MacAskill 1, Death 1. An honourable draw there, but an points victory to him overall. I look forward to our re-match in two years time, when we will catch up with how Dr Death has been wrestling with Dr Parkinson.

Michael MacAskill, PhD

Research Director

We've Changed!

Alongside our parent organisation The Canterbury Medical Research Foundation, we have just rebranded our Institute with a new logo, which reflects the close bond between the two organisations and symbolizes what we do and where we do it.

Over the coming twelve months the group will be running a campaign to get our names out into the light and to educate the Canterbury community about the great research going on right in their own region. You will see the faces of our two patients profiled inside this issue, on billboards and in newspapers and online to promote the idea of giving to research far and wide. Look out for our new look on the streets of Christchurch.





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Media Stars – Patient Profiles: Sue Robinson and David Chua



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In this edition we want to profile two people who have gone out of their way to help us as we rebrand our organisation. David Chua and Sue Robinson are both patients of Professor Anderson's and both have Parkinson's Disease.

In late January, David and Sue both became models for a day, when they posed for publicity shots for the Canterbury Medical Research Foundation and Brain Research Institute, which will be used in our advertising and new branding over the coming year.

Sue's story is one of courage and a generous giving spirit. Sue is married with three boys ranging in age from 25 -37. The youngest of the boys has Duchenne Muscular Dystrophy and came to be adopted by Sue and her husband after they had him for a short period as respite carers. Sue tells us that despite expressing their interest in adopting early on with their son, they were unable to at the time as they were not legally married, so they got married specifically so they could!

Sue is a degree-qualified early childhood teacher, working in a senior role at a large centre at the time of her diagnosis, six years ago. She simply knew something was not right and in particular that she had lost her sense of taste. After her diagnosis, her employer, who was not at all supportive of her condition, made it impossible for her to stay in her job, despite Sue being able to still work at the time. Sue misses her work very much and remains very proud of her qualifications and is sad she can no longer use them.

Sue has lost 40kgs since her diagnosis and tells us that her grandchildren look at photos of her prior to the weight loss and do not recognise her! As well as managing her own condition and being the main carer for her son. Sue has been very active on the Muscular Dystrophy Board at local and national levels for many years and was a member of the National Board.

David Chua has had a wide variety of roles throughout his working life. Along the way he and his wife have also had three children and two grandchildren.

At the time of his diagnosis with Parkinson's David was a chef at Twiggers. The first sign that something was going wrong for him occurred seven years ago with the loss of his sense of smell (a real challenge for a chef) and he noticed that he was finding writing a lot more difficult, with his handwriting becoming a lot smaller than usual. He has been under the care of Prof Anderson for some time now.

David is very happy that he can use a computer to write now so his handwriting is no longer an issue. He has considered the Parkinson's as a new chapter in his life and he and his wife have a great attitude to living with his condition.

Welcome to Dee



A big welcome to the team, to Dee Brocherie – our new Receptionist / Administrator at the NZBRI. Dee's originally from Clapham, London.

She has 28 years experience in Administration and customer service and four of those were as the Fundraising Assistant to the Alzheimer's Disease Society in London. She then moved to the National Health Service where she undertook various administrative and business manager roles in ever-changing departments. After accepting voluntary redundancy in 2006, her family emigrated to NZ and settled in Kaiapoi.

She has two fabulous children; Nicole who is 14 and Thomas who is 7. In her spare time she likes to read, spend as much time as she can acting silly with her children, and catching up on the English soaps!

Researcher Profile – Dr Sridhar Alla



Dr Sridhar Alla is a Research Fellow at the New Zealand Brain Research Institute, University of Otago, Christchurch. He has special interests in neurological research, in particular neuro-epidemiology and understanding the natural history of multiple sclerosis.

Dr Alla is a rehabilitation therapist with experience in undertaking multiple sclerosis disability assessments. He is the research coordinator of the Multiple Sclerosis Research Group and was the investigator of the recently concluded New Zealand national Multiple Sclerosis Incidence Study.

Dr Alla is currently involved in the five year follow-up of recently diagnosed multiple sclerosis cases investigating the factors associated with onset and progression of the disease. His aim is to build a comprehensive research program to improve the quality of life and overall care of the persons with multiple sclerosis by identifying environmental and genetic factors associated with the risk and progression of the disease.

His research position is supported by the "grant for salary support" funded by the Multiple Sclerosis Society of New Zealand and the New Zealand Brain Research Institute.

Out and About!

The team at the NZBRI have certainly got out and about in the past few months with stands at local supermarkets and in Merivale Mall to celebrate "International Brain Week"

We're always pleased to have the opportunity to educate the community about what we do and give people the chance to sign up as research participants!

Pictured here Dr Michael MacAskill and his team showcased "The Amazing Brain" at a local supermarket, and researchers Siobhan Lockie and Amy Wang talk to the public at our stand in Merivale.





Fundraising News

Our busy fundraising month kicked off on the 5th March, hosting the inaugural "Riccarton Park Twilight Charity Race Day" with special thanks to the Canterbury Jockey Club and the Hickman family. Many used the opportunity to treat their staff and clients to an entertaining evening out whilst supporting a great cause. We raised \$10,000 and were able to rollout our new branding to the public and gain a wider audience.



We celebrated "International Brain Awareness Week" with the NZBRI staff and students hosting an information stand at Merivale Mall. It was very well received and the team is already looking at fun and interactive ways to educate the public about

what is being achieved at the Institute. They also held a collection and sold Professor Ivan Donaldson's book, with proceeds going to NZBRI. (still available for purchase at **www.nzbri.org**)

On the 19th March, at Rydges Latimer Christchurch, the sold out "Great Brain Teaser" trivia evening was held. This fun and interactive evening provide plenty of challenges and laughs for all. Taylor Shaw Solicitors had a convincing win and took home an awesome prize worth \$800 thanks to the Christchurch Casino. Followed close behind were Harmans and Lane Neave. Professor Steve Weaver's University of Canterbury team, including Ross Hutton (both Board members); and the team from NZBRI both collected prizes for being in the top 8 out of 31 teams. \$7,000 was raised and it was heart-warming to see so many new businesses becoming corporate supporters. By popular demand, we will be hosting this event annually. You will have to be in quick to secure your table!

Mark your diaries for the Friends of the NZBRI fundraiser at the Court Theatre on Wednesday 30th September. MAMIL, "Middle Age Man in Lycra", features Mark Hadlow as Bryan Cook, a property developer who has made his fortune building leaky homes. When things start to fall apart, he joins a mens' cycle group to relieve stress. Along the way he makes some startling discoveries in various cracks and crevices. Tickets are \$60pp, available by emailing **gabrielletasman@xtra.co.nz**

We'd like to thank some businesses that went the extra mile to support our March events; Rydges Latimer Christchurch, Christchurch Casino, Multi-Media, Skope Industries, Rendezvous Hotel, GE Capital, Wanaka Selection Holiday Homes, The Moorings Wanaka, Sheffield South Island Ltd, Ryman Healthcare and Alpine Resort Wanaka.

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