



newsletter

What's been happening to raise awareness of, and support research into, Parkinson's disease

SPRING 2018



My journey with parkinson's disease

by Barry Jones (written June 2018)

It was about January 2017 sitting in the consultation room with my eye surgeon, about to sign the 'authority to operate' form that I happened to mention that my ability to sign in my usual way had deteriorated in the last couple of years from a full signature to a 'BJ' that diminished in a wavy line. His comment was "you should see your Doctor a.s.a.p. as you could have Parkinson's?"

In April 2017 it was confirmed that I had the beginnings of Parkinson's Disease (PD) and my GP prescribed the lowest dose of MADOPAR (Levodopa). At that time, I was presenting with symptoms such as weakness in the legs, right leg calf muscle shaking partly uncontrolled, similarly the right arm as well although the arm tremors were minimal. Speech was marginally affected to sometimes a slight slur. My ability to smell was also affected. This situation was rather deflating to say the least.

"So where to from here?" Some research was required to better understand what PD was and what I could do to minimise the long-term effect of the disease as there is no cure at this time. With some help I opened up the State of Victoria website for Parkinson's Disease which appeared to be more authentic than others. Recommendations to assist with management of the disease was exercise, diet and symptom management. At this early stage I acquired an exercise bike which seemed to be a good beginning to exercise development.

The internet also had a site depicting a form of exercise for the stimulation and retraining of the brain. This system is called PD Warriors, designed here in Australia and available locally in Tasmania. This system of exercise

combines simple, easy movement often combining two movements together to exercise and stimulate co-ordination. I joined up in the November of 2017, the sessions being for one hour on a weekly basis.

About this time, a few weeks prior to joining PD warriors, I suffered a severe attack of sciatica, not realising that this condition is or can be associated with Parkinson's Disease.

I had suffered deferred pain in the toes of the right foot in the previous couple of years, at the time it was diagnosed as originating from the sciatic nerve. This condition had now developed into a very painful episode lasting some weeks.

Earlier I mentioned about a slight impediment in my speech which was picked up by the PD Warriors Physiotherapist. She referred me to the Speech Pathologist who gave me some exercises to strengthen the vocal chords over a period of weeks. It was also noted that my lung capacity was below par so another referral was organised, to a Respiratory Physiotherapist to strengthen lung capacity.

All these Medical Services are part of the Launceston General Hospital and of course supported by Medicare.

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The differential vulnerability of cell types in Parkinson's disease

Alpha-synuclein is the main protein found in Lewy bodies, which are the pathological hallmark of degeneration in the Parkinson's disease brain. Whilst it is unclear what causes changes to alpha-synuclein and how this eventually leads to the formation of pathological Lewy bodies, current theories propose that abnormal conditions within the brain may initiate early changes to alpha-synuclein, such as misfolding of the protein's structure, which can result in its aggregation.

The brain is a complex network made up of many different cell types. In Parkinson's disease there is evidence that specific types of nerve cells are more vulnerable to toxic Lewy bodies. In particular, dopaminergic neurons in a region of the midbrain called the substantia nigra are characteristically affected in Parkinson's disease. The degeneration of these cells has a distinct

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Most of these treatments were in place and ongoing prior to my first appointment with a Consulting PD specialist, based at the Royal Hobart Hospital (who travels to the North and North West of the State). The initial appointment was in January 2018 with a follow up in June 2018. At this consultation there was no sign of symptoms worsening therefore no need to change medication strength which was all very positive. The specialist commented that the condition appeared somewhat mild and slower in development.

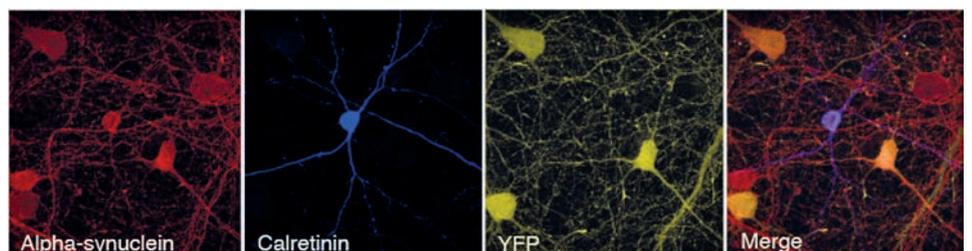


influence on Parkinson's symptoms due to the depletion of the neurotransmitter dopamine (eg. Tremor). However, why these nerve cells are specifically vulnerable is poorly understood.

My research employs a variety of experimental techniques to further investigate the vulnerability and resilience of different cellular populations within the brain to alpha-synuclein changes. One technique involves growing nerve cells sourced from the brains of mice and using these cells as a model to learn more about the disease processes occurring in Parkinson's disease. The nerve cells are grown in a dish to replicate the connections and conditions of a brain, which we can then challenge with a range of different treatments to probe how alpha-synuclein responds. The mice used artificially express Yellow Fluorescent Protein (or YFP) in specific cells in the

brain. The expression of this fluorescent protein aids in the identification of a particular type of excitatory nerve cell that enables communication between cellular networks. Additionally, I use a technique to fluorescently label specific cellular proteins in order to visualise alpha-synuclein, as well as a population of nerve cells that natively express a protein called Calretinin. Calretinin is a calcium binding protein that is specific to a type of nerve cell which is able to inhibit cellular communication within the brain. These approaches enable me to investigate the vulnerability of different cell types and the causes of pathological changes to alpha-synuclein simultaneously. Learning more about the cause and mechanisms of Parkinson's disease will help us to design effective and targeted therapeutics.

Anastasia Salter



Mouse nerve cells are used as a model to investigate the pathological changes underlying Parkinson's disease.

Di has been spreading the word!

In the past few weeks Di enjoyed speaking to community groups about Parkinson's disease and the role of the Fred Binns Parkinson's Foundation in promoting and funding related research. The first was with the 'Glenorchy Wellbeing Club' on 14 June and more recently with the 'Glenorchy School for Seniors' on the 18 July.

Di spoke with obvious commitment and compassion about Parkinson's disease and its symptoms, of the relative lack of community awareness and understanding, the hopes of determining a cause and the importance of research to finding a cure. Using her personal story of life with her much loved husband Dr 'Fred' Binns (Fred suffered with Parkinson's for several years before succumbing to related illness) Di gently and with great good humour captured the audiences' attention and won their support. Di was able to explain the variability of the way that Parkinson's disease presents to individuals and spoke of the most prevalent symptoms; importantly she encouraged people who had, or even suspected they may have, any of the symptoms to visit their GP and seek professional advice so that they might be diagnosed as early as possible in order to receive appropriate treatment.

Di had the moral support of Kim Pitt with both presentations; he spoke briefly about his own experiences and reinforced Di's central message i.e. understanding enough about the disease to be aware when to seek professional advice and of course as early as possible.



Di and Kim with Guila Kelly, Chairperson, and Maureen Costello, Program Co-Ordinator for the Glenorchy School for Seniors

Both Di and Kim concluded by explaining the importance of raising money to fund Parkinson's research and the way that the 'Foundation' has been able to raise and provide funds for doctoral studies at the Menzies Institute here in Hobart.

Happily, the response from everyone was of genuine interest and it was heartening to receive generous feedback complimenting Di for her initiative and the effectiveness of her tireless work to promote and fund Parkinson's research.



In June I attended the Scholarships Morning Tea, which was held to thank organisations and individuals who support research students. It was great to be able to meet up with not only our PhD student Ana, but also to talk to other students and donors.

Professor Tracey Dickson spoke about her life-changing circumstances due to having been supported by means of a scholarship and current student, Ishanka Munugoda, spoke about what a great difference having a scholarship makes to his life. Born in Colombo, Sri Lanka he graduated as a Physiotherapist from the University of Colombo. He started his PhD at Menzies in 2015, identifying lifestyle risk factors for Osteoarthritis in Tasmanian Older-Adults. Ishanka is in receipt of the Ashdown Family Scholarship. Graeme Lynch, CEO Heart Foundation Tasmania also spoke about the Heart Foundation's commitment to ongoing research.

“ It was a great honour to represent all our donors and/or supporters as it is you that has made it possible for us to support Ana's passion for research into Parkinson's disease.



A message from Di

This will be my last newsletter as I step aside from the Managing Director role. The last few years have been 'a labour of love' for the Foundation named after a man who brought much love and laughter to my life.

I would like to take this opportunity to thank everyone who has supported Fred's Foundation in various ways, be it through donations, volunteering, contributing to our newsletter and/or supporting our events. My thanks to Nathaniel for his guidance. I still intend to be involved, but at a less stressful level. I will certainly be at our Bunnings Barbecue on 27 October, come and say hello.

Thank you Di

After four years at the helm of the Fred Binns Parkinson's Foundation, founder Di Binns has decided to hang up her Managing Director's hat to spend more time with her family.

Fred Binns Parkinson's Foundation began as a passion of Di and Dr Cliff Kelland in the months after Di's husband's death in 2013. The Foundation was established to raise funds for research into Parkinson disease.

Since its inception Di has worked tirelessly, developing the foundation from an idea into an organisation. Since the inaugural Fred's Walk the Bay 3 years ago, Di, along with a team of dedicated volunteers, has seen approximately 200 people attend the walk each year, raising funds and awareness for Parkinson's research. Under Di's leadership the Foundation has also sponsored a PhD student at Menzies Research Institute and continuing to grow in support from the community of people touched by Parkinson's.

Di will continue to work with the Foundation in an advisory (and much more relaxed) role, assisting with events,



Pictured are Nathaniel Garvin centre with Andrew Hudson left and Kim Pitt right.

fundraising and any other activities that she can turn her skills to, while the foundation's management will be handled by a team of three people, who each bring a diversity of skills to the role.

Di has done an amazing job in guiding the activities of the Foundation, playing a key role in developing relationships with volunteers and

research organisations and building the profile of the Foundation within the Tasmanian community. Her efforts will be impossible to match.

Thank you Di for the incredible work you have done. We wish you all the very best in this next chapter of your life.

Nathaniel Garvin

Bunnings' Sausage Sizzle Fundraiser



Saturday 27 October

Are you planning on working around the house or in the garden at Royal Hobart Show time this year? Will that entail a visit to Bunnings?

Our application to Bunnings to hold a sausage sizzle has been successful! So, we'll be cheerfully barbecuing sausages and onions and selling soft drinks at Glenorchy on Saturday, 27 October. We'll be ready to serve at 9.00 am and will be in action until 4.00 pm.

What a great way to support the efforts of our small band of Fred Binns Parkinson's Foundation volunteers to raise funds for research until a cure for the disease is found. The Foundation has already made a grant for three years to the Menzies Institute for a post graduate student to research the disease. Our volunteer committee aims to continue supporting this effort and to raise awareness of Parkinson's Disease. We would love you to help us raise funds for a cause close to our hearts, while you enjoy a tasty snag.