



Fred Binns
Parkinson's Foundation

newsletter

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

WINTER 2018

A remarkable success



This year's Walk the Bay was a remarkable success, despite the brisk and damp weather. With approximately 170 people in attendance, through registration fees, donations and raffle ticket purchases we were able to raise a significant amount of money for Parkinson's research in Tasmania.

Held along the Montrose foreshore, the 2018 Walk the Bay was held on 8 April and offered participants the option of three walks of 1km, 3km, or 7.6km, and as usual there was a number of information and product stands, as well as food and coffee, available.

This year's World Parkinson's Day was 11 April, and with the expert assistance of our MC, Tim Cox, we were able to raise both money and awareness for the cause, which affects more than 2,500 Tasmanians and around 6.3 million people worldwide.

Our thanks to Alderman Gaye Richardson, representing the Glenorchy Lord Mayor, for starting the walkers off, and to Mr Andrew Wilkie for his assistance in drawing of the raffle.

We would like to sincerely thank our supporters, including those who donated prizes, our stall holders and of course this year's participants.

It is only through your support that we are able to continue to achieve our aims by raising money and supporting Parkinson's research.

Bright side to the diagnosis of Parkinson's disease

According to a recent article in the *British Medical Journal* (BMJ 2018;360:k1146), patients with Parkinson's disease may have greater artistic abilities. This claim is based on clinical observations both in newly diagnosed PD patients who have discovered unexpected novel talents, and in established artists who claim to have observed "newly enriched artistic skills" and greater productiveness.

It's not clear whether this bright side to the diagnosis of PD is due to the disease itself, the drugs used to treat it or a combination. It is noted that some patients with brain diseases other than PD (such as dementia) are already known to have enhanced creativity without the use of drugs, with lack of inhibition in some cases a possible explanation. On the other hand, antiparkinsonian drugs are claimed in some circumstances to boost pre-existing creativity or even awake novel artistic skills. Whatever the reason, this observation should encourage PD patients to explore their possible newly acquired or newly enhanced artistic capabilities, described as a "gift" by the paper's author.



Penny and Parkinsons Disease

In spring 2010 my husband Bob and I were caretaking for three months and doing conservation work on Deal Island, a remote island in northern Bass Strait. During this period, I noticed a range of symptoms and was diagnosed as having Parkinson's Disease in 2011.

The symptoms seemed to appear suddenly - but looking back, I now recognise that some had been affecting me for a long time - perhaps for a few years.

During the period that we were on the island I suddenly found that I couldn't clean my teeth as usual. Doing up shoelaces and buttons became difficult. I felt weak and suddenly found I couldn't do things like kneading the bread. I wasn't strong enough to use the secateurs, nor pull out the weeds. I had trouble walking, particularly downhill.

I felt nervous and shaky. It became hard to do more than one activity at a time. Talking whilst walking for instance and writing while talking or listening. It is difficult to accurately take down a list or instruction. Organisation at any level from cooking a three-course meal to making a food list for a working bee of 8 people for 2 weeks became increasingly difficult.

All of these symptoms lessened when we came home, and I was able to ignore them for a time. My daughters in law though recognised that something was wrong, and a work colleague noticed

that my handwriting had become very small. My GP at first wasn't convinced that what I was experiencing was significant either, but the neurologist recognised PD immediately.

I was referred to specialist Frank Nicklason and in turn to a range of other support people, all of whom assist me.

I now keep most of the symptoms under control with Parkinson medication, participate in exercise classes specially designed for Parkinson people, do a weekly Pilates class, and walk and swim regularly. I am experimenting with infrared light therapy, and feel it helps.

With the help of Bob's and my families I have been able to continue to enjoy a fairly active life.

Over the last 8 years I have enjoyed several overseas trips and 4wd camping trips in remote areas of Australia. I see a lot of my 4 grandchildren (aged 3 to 7).

I continue my involvement with conservation, including a 14-day working bee back on Deal Island working on weed management and revegetation in February this year.

At home my current projects include restoring a couple of chairs, redecorating our newly completed bathroom - laundry upgrade, and gardening when I have time.

But with patience and some adjustment I continue to lead a busy and fulfilling life.

Anastasia Salter

Research update
22/5/2018



My research focuses on a protein called alpha-synuclein, which is a characteristic feature of Parkinson's disease brain pathology. I aim to understand the initial changes to alpha-synuclein that eventually lead to Parkinson's disease, as well as why specific cells in the brain are vulnerable to these changes.

My experiments utilizing brain cells from mice have indicated that calcium, which is important for communication between brain cells, may be involved in the development of pathology.

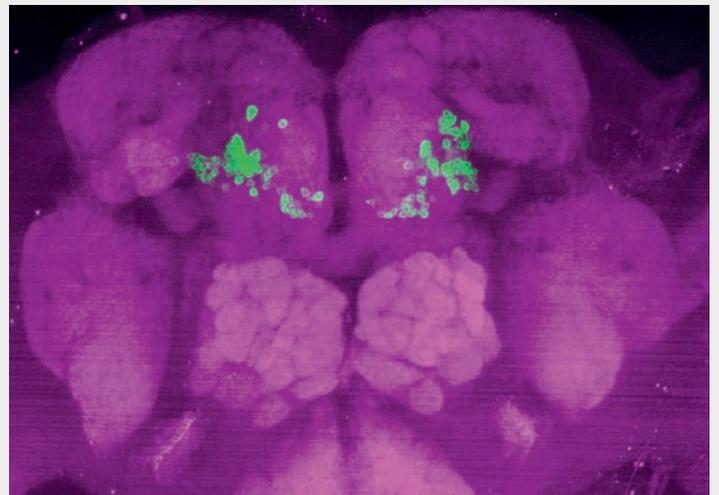
I am currently learning new techniques in the lab to further investigate initial pathological changes in Parkinson's disease, and I have also received samples of brain tissue from Parkinson's disease cases. This brain tissue is a valuable resource that will allow me to investigate the features of some brain cells that render them vulnerable to Parkinson's disease pathology and increase our understanding of the processes leading to Parkinson's disease at the cellular level.

Owen and his team investigate Parkinson's

My name is Owen Marshall. I moved to Hobart in 2016 after working at Cambridge University in the UK for four years, where I was investigating how the brain develops in early life. The Menzies Institute is particularly strong in neuroscience research, and I'm very fortunate to be working here amongst so many talented researchers and in such a beautiful city.

My lab and I have recently started investigating the causes of Parkinson's disease and the means through which the disease spreads within the brain. We are creating new models of the disease in the vinegar fly (*Drosophila melanogaster*), a common and extensively studied genetic model organism that is also found natively around compost bins all over Tasmania. Flies have a much shorter lifespan than mammals and develop the symptoms of Parkinson's disease within a few weeks, allowing us to investigate the changes that occur during disease progression much faster than if we were working in conventional mouse or rat models.

In particular, we are looking at how changes in the packaging of DNA (or "epigenetics") within disease-affected brain cells may influence the onset and spread of the disease. We are currently characterising the different forms of DNA packaging that control the particular brain cells that are affected in Parkinson's, and we will go on to ask how these change during ageing and disease. Understanding these changes in packaging will allow us to identify new genes involved in the disease, and investigate strategies to potentially restore normal brain cell function.



Dopaminergic neurons (coloured green) in the adult fly brain.



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A message from Di

On 8 April, the day of Fred's Walk the Bay, it felt as if winter had arrived early. But to our delight and surprise, we were pleased to see so many of you rug up for the conditions and join us for a walk around Montrose Bay. My thanks to all our volunteers who did a great job ensuring the day went smoothly and to Nathaniel Garvin for organising great media coverage. Fred's Walk was well supported by ABC Radio, The Mercury, WIN and Southern Cross, all helping to increase the awareness of PD.

Our major prize, provided jointly by Robert from Tasmanian Wheelchair Specialists and Piermont was won by Bob Tyson. Penny, (see story page 2) won a bottle of Gin, kindly donated by Knocklofty Gin and the Pennicott Cruise was won by one of our volunteers, Kim Pitt, who also has PD. Thank you to everyone who has contributed to this newsletter, I hope you enjoy reading.

PICTURED ABOVE RIGHT: Bob Tyson, winner of the TWS / Piermont prize.



PIERMONT

FREYCINET COAST TASMANIA

Living with Parkinson's

Ken Kirkby, Professor of Psychiatry at the University of Tasmania provides some hints on living with Parkinson's from his own diary:

Parkinson's disease imposes physical constraints, depending on the nature and severity of the symptoms. With the right support and some imagination it may still be still possible to enjoy activity based holidays, and it can be all the more special when you do. Last year my wife, Stacy, and I went to Raja Ampat, an archipelago of islands on the equator in Papua, Indonesia, on an eleven day sea kayaking adventure run by a very professional local operator with modern equipment.

When booking we apprised the operator of my needs, which they were pleased to address. The trip usually has one guide. We hired an extra guide to paddle in the back of a two-seater kayak with me (I can paddle but it doesn't produce much power!) and Stacy paddled a

single-seater, four others made up the six clients paddling. We wore the usual sea kayaking regalia including lifejackets. The trip was around 140km, circumnavigating a large island, mostly national park with stunning rainforest to the water. There were fringing coral reefs and islets in abundance with a myriad of sea creatures and spectacular coral formations. I wore a diving inflatable buoyancy vest, kept on the surface, and was accompanied in the water by a guide on the daily skin diving sessions. Nights were spent in 'homestays', palm-thatched huts on the coconut palm fringed foreshore or on stilts over the water. There were no waves other than chop on several windy days The water was high 20s, the air low 30s, and we swam or dipped to cool off numerous times each day. We slept on matted floors on foam mattresses under mosquito nets but since the islands are old upturned reefs with no surface water and November was not monsoon season there were no mosquitos!

Nothing dried in the humidity. The food was predictable but healthy - fish, rice and some green fronds - for breakfast, lunch and dinner. The hardest part of the trip for me was peeling off my

clinging wet shirt at the homestays, this generally required a helping hand. The guides helped me rise out of the kayak and in fitting the spray deck. They also had melodious voices and often broke into singing Melanesian and Indonesian melodies, which was delightful.

As you can gather the trip was magnificent. This style of travel is not for everyone; an alternative in Raja Ampat are wooden-ship based tours with air conditioned cabins and attentive staff, kayaking and diving from the ship base each day. I took two sets of medication, kept separately in case one got lost. Kayaking and diving are not without risk. We had past experience of both and we were careful to take necessary precautions, as described. Adventures and activity based holidays come in all shapes and sizes. With eighteen years of personal experience with Parkinson's disease as my constant companion I cater for 'both of us' when planning the next trip! The arrangements were also optimal for myself and Stacy whose idea of fun does not include paddling both of us, though on some past trips we have invited a son along to provide the extra paddle power instead of a guide.



ABOVE L-R: Me looking over myriad islands; Life is a beach; Paddling along, the guide doing conspicuously more!; Lunch on a tidal sand bar.