



Fred Binns
Parkinson's Foundation

newsletter

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

AUTUMN 2018

'Fred's Walk' the Bay for Parkinson's



In recognition of World Parkinson's Day on 11 April, we are holding our annual 'Fred's Walk' on Sunday, 8 April. This event allows us to highlight the incidence of Parkinson's disease and to raise funds for much needed research. Registration is available online at www.fredbinns.org.au and will also be available on the day. Registration starts at 0930 and all walks will start at 1000.

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There will be walks varying in distance, catering for all fitness levels. We are planning to have all those walking to MONA to start 1st, followed by those going to the Montrose Bay High School and lastly, those doing the shorter walks. If you are intending to walk to MONA, please ensure that your level of fitness is suitable. We would like everyone back at the Pavilion by 1200 for the drawing of our raffle and spot prizes. You do need to be there to claim your prize!!

Last year we had amazing TV coverage and we are hopeful of the same again this year. Please make sure you 'don some purple' so we increase our impact in the media.

- 0930 Registration
- 0940 Welcome
Di Binns
- 0945 Parkinson's
Disease Research
at Menzies:
An update
from the lab
Anastasia Salter
- 1000 MONA walkers
Montrose BHS
walkers
DEC and
shorter walkers
- 1200 All walkers to
be back at the
Pavilion
- 1205 Drawing of raffle/
spot prizes
- 1215 Close
Di Binns



All Round Health and Community Care have recently moved to 71 Murray St.

Ange and David will be on hand again this year to talk about all the fabulous programs they offer, including mindfulness, the B.E.E.R and WOW programs. They also offer GP and dietary services and have a therapy dog named Theodore. There's something for everyone!



All Care Physio in Sandy Bay offer a range of services, including Pilates, Neurological Physiotherapy and assistance with balance, all beneficial for those with Parkinson's disease.

They will be at Fred's Walk again this year. Talk to their representative to find out how they can help you.

Big Henry's Food Van will be providing food this year. Richard and his team will have a great variety of things to choose from.



Glenn and his team from **Double Shot** will be making coffees and hot chocolates again this year. A hot drink may be just what you need to warm you up prior to the walk. Soft drinks will also be available.

Vicki Sauvage has been teaching **Tai Chi** in Hobart since approximately 2012.

For the last 2 years she has been teaching a fusion form of Sun Long Form, Qi gong exercises and Mindfulness practices which she calls Mind in Motion.

This is a VERY accessible programme and suits people of all physical ability.

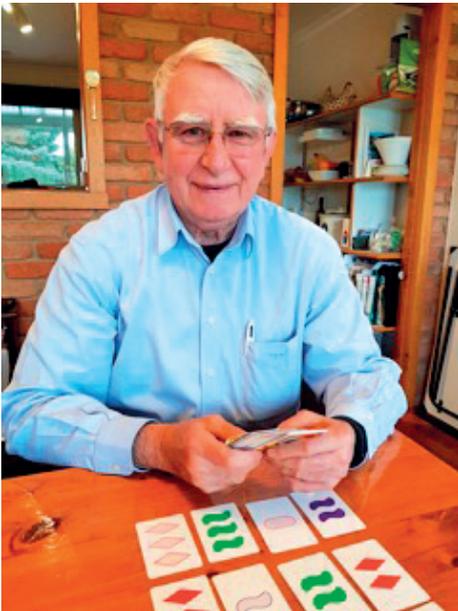
Robert and his team at **TWS Healthcare** stock a wide range of disabled assistance aids and understand and care about your needs. They will work with you and your therapists to find the most positive solution and out-come, for all ages.

Robert will be at Fred's Walk the Bay, 8 April, and will be happy to talk to you about his range of products.



Sisters Clare and Nik will be there doing **face painting**. Last year this appealed both to the young and the 'young at heart'!! Cost is \$3





“This is a kick in the guts!

(I've got Parkinson's Disease... what is Parkinson's Disease?)

Over a while (probably two years) I built up a litany of minor symptoms and physical irritations that of themselves were tolerable but when experienced altogether created a very unpleasant condition. Eventually my general demeanour was impacted, my sleep badly affected, I was in a state of deep fatigue and my mood so low I was seen by everyone who knew me to be quite unwell.

However, my wife thought otherwise and cajoled me to see our local GP. I'm glad I did and recall having a very emotional teary talk leading me to begrudgingly agree and accept his gentle caring advice that I really needed professional help. I was dispatched to a Parkinson's specialist. Even before I had sat down, he mentioned he was already largely convinced that I had Parkinson's disease. The external symptoms were manifest and to the practised eye of this very talented man, obvious!

I recall the voices in my head at the time saying things such as:

Is it terminal? What does degenerative truly mean? How long do I have? Will I be a burden on my family? What about my wife? Work? Social impacts? What happens as I deteriorate further? How long? Will it just keep getting worse?

“

**Is it terminal?
What does
degenerative truly
mean? How long
do I have?**

Selfishly, what about me?! (All those things I have to do, or I enjoy ... must they stop; what about my plans for the future ... there is so much I have yet to do – do I now get locked away, or must I follow a medical regime that will dominate my life? Grrrrrr! Loss of freedom)

This is scary... Fear! (I am afraid. Fear of the unknown, fear of everything to come)

Far out, I don't want to be old! (but I am! See... I am now visiting aged care specialists, in aged care areas of hospitals and medical centres, treated as an aged person, the culture of this world is focussed on diseases of the aged as are the rooms etc.)”

Diagnosed with Parkinson's disease, I was already at the end of my tether and to think that there was worse to come was all but unbearable. Contrary to the advice of my specialist I truly felt there was no hope for the future!

He was right, I was wrong!

I was so wrong. Immediately I was diagnosed I was put on medication. And straight away my symptoms diminished – I started to feel better. I was sent to the physios who helped me improve through specially targeted exercise programs. More recently I have been undertaking training in 'mindfulness' and learning about the benefits of neuroplasticity.

I am enjoying life again and my family and friends remark on the improvement – it's wonderful.

I feel blessed to be here in Hobart under the watchful eye and expert supervision of a well-directed and coordinated team of Tassie health professionals – Doctors, Nurses, Physios, Speech Therapists, Occupational Therapists and Psychologists.

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I hold out great hope of more to come through the benefits of research if only we can marshal the resources to help those looking for the cause, seeking new treatment options and hunting for a cure. I am encouraged by the world leading research activities undertaken here in Hobart at the Menzies Research Institute and feel sure that with appropriate funding they can help me too.

This where the Fred Binns Foundation comes in. The Foundation seeks to raise money so that PhD students and research programs can be funded.

I have it all!

Practitioners, carers, supporters *and* research centres – I now see that here in Tasmania we have it all... even our own fund-raising foundation... I am mentally and physically so much better than I was, and I have tremendous hope for the future.



A message from Di

I hope everyone has enjoyed our great summer – we are hoping the nice weather will prevail until 8 April for Fred’s Walk the Bay. This event is held on a day close to 11 April, which is World Parkinson’s Day.

You will find all the details in this newsletter and on our website at www.fredbinns.org.au. It is a great family day, and at the same time you are supporting a worthy cause. Kids on scooters and bikes and dogs are welcome to attend. Don’t forget to ‘don some purple’. Online registration is \$12, children are free. On the day registration is \$15.

My thanks to Kim for sharing his story in this edition. Many people like Kim are devastated when they are diagnosed, while for others there is a sense of relief at finally getting a diagnosis. I’m heartened by all the articles appearing about ‘eminent tests’ being available, hopefully a test for Parkinson’s disease is not too far away.

I look forward to seeing many of you at Fred’s Walk the Bay on 8 April.

TCE concerns

As the readership of this newsletter would know, the cause or causes of Parkinson’s disease remain mysterious. However, for some years there has been concern for a possible role of neurotoxic industrial solvents particularly trichloroethylene (TCE) which for many years has been used for degreasing and dry cleaning.

Because of TCE’s well known damaging toxic effects on body systems other than the brain, particularly on the liver and reproduction, it has been phased out of general use. Nonetheless, some workers by virtue of the nature of their work may have been exposed to high levels for years or even decades.

Because of these concerns, a detailed scientific review was carried out in 2013 by a group from John Moores University of Liverpool, England, and concluded that “there is no consistent



evidence from either the toxicological or epidemiologic perspective that any specific solvent or class of solvents is a cause of PD”. Despite this, the Australian Navy through the Department of Veterans’ Affairs recently agreed (January 2018) that heavy exposure to TCE is a cause of Parkinson’s disease and

accepted a claim to that effect from a Navy veteran of 36 years, Keith E. Bailey. Mr Bailey believed he was the first Australian veteran to have such a claim approved. A New Zealand Navy veteran also successfully won compensation in December 2017. Clearly further research is required.

Testing tears could lead to cheap and effective Parkinson’s disease screening



Researchers analysing the tears of Parkinson’s patients and non-affected adults found that patients with the disease had five times the level of alpha-synuclein, the protein molecule that forms toxic clumps and causes nerve damage, than the healthy patients.

The study’s author, Dr Mark Lew, from the Keck School of Medicine at the University of Southern California believe

their research is the first to show that tears may be a reliable, inexpensive and non-invasive biological marker of Parkinson’s disease”.

Although further research is required, this could prove to be a cheap way to screen patients for Parkinson’s disease, allowing earlier diagnosis and, potentially, treatment that can delay the disease.