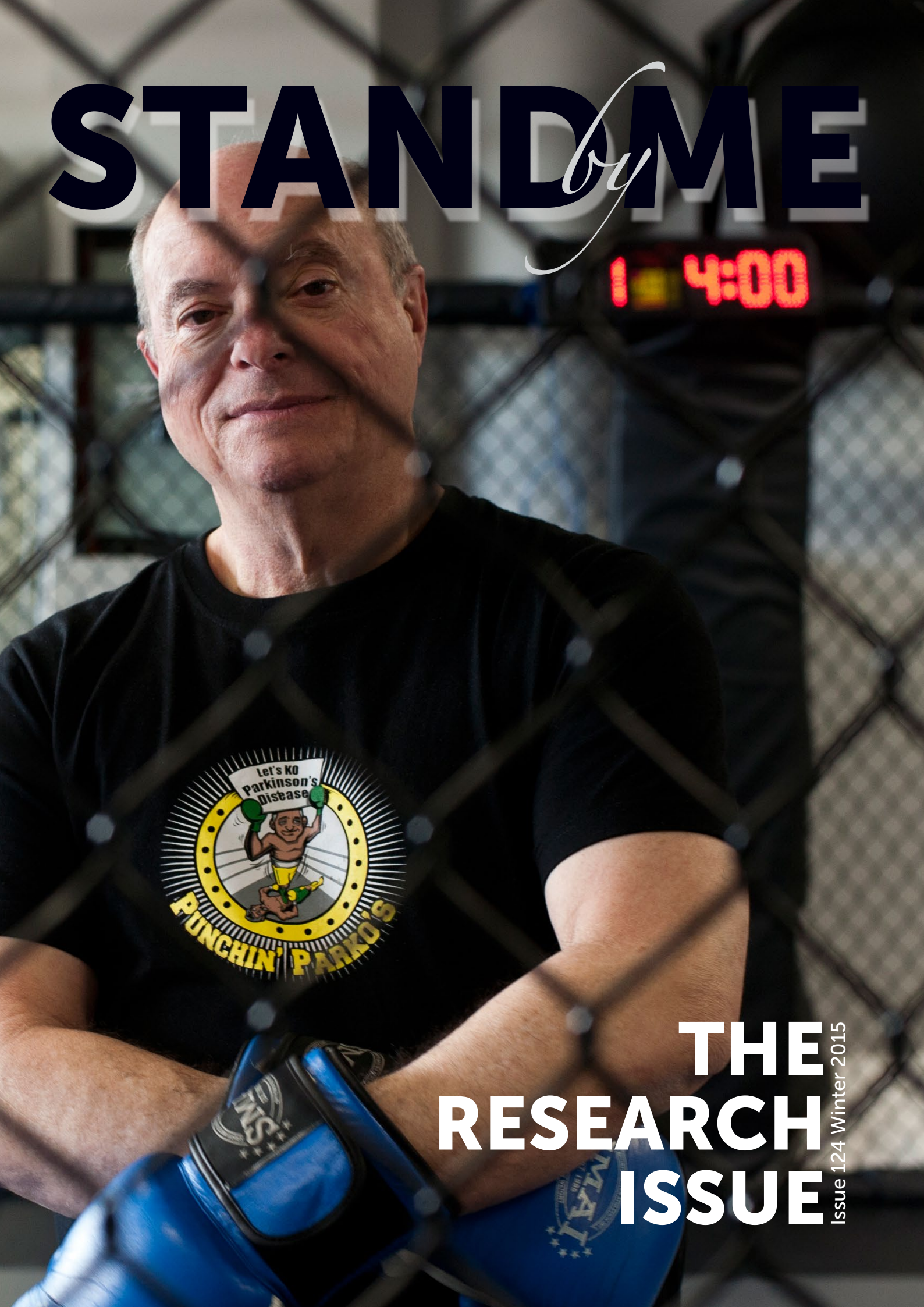
STAND by ME



THE RESEARCH ISSUE

Issue 124 Winter 2015

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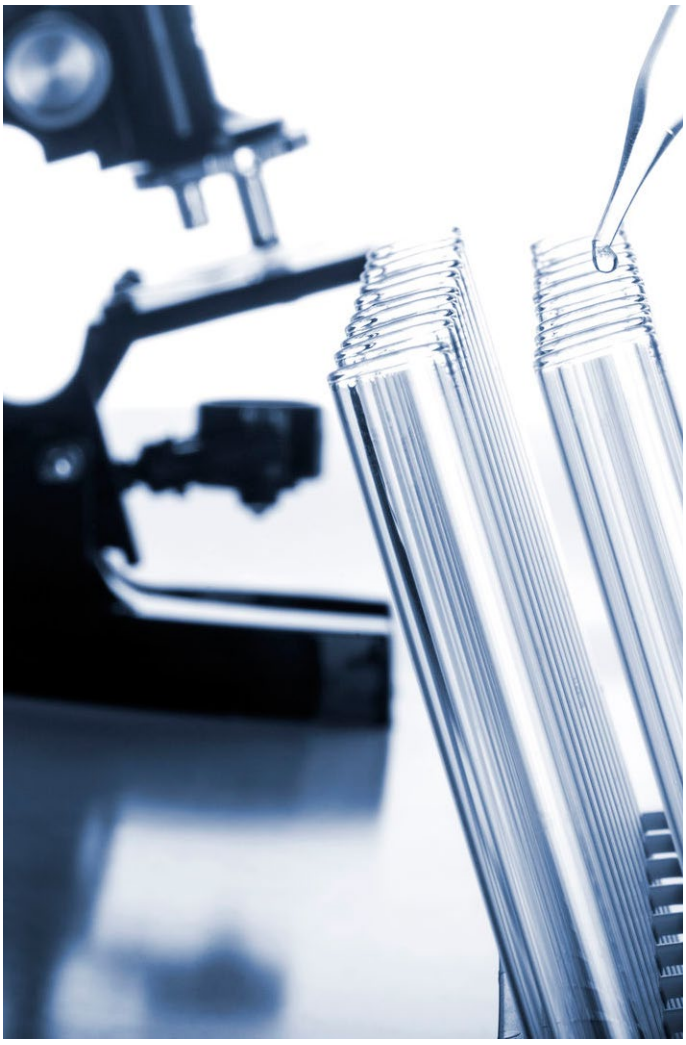

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IN THIS TOGETHER
parkinson's NSW

FROM THE CEO & PRESIDENT

Miriam Dixon

On 11 April 2015, World Parkinson's Day, we launched our new Unbuttoned campaign. This campaign is intended to draw wider public attention to Parkinson's, a disease that is widely overlooked. It is also intended to promote donations to the wider community

The campaign developed after discussions with international advertising company JWT which was so generous to provide pro bono creative development and execution to this important project. We were also assisted by producer and director David Jagoda.

On World Parkinson's Day we also launched our new website. I invite you to visit, if you have not already done so, to find the many helpful features. The website was designed and built pro bono by Surf Pacific, and we have Cromwell Property Group to thank for sponsoring the content.

I am delighted to advise that later this year we will be moving to new premises within the grounds of Macquarie Hospital in North Ryde, with assistance from the NSW Minister of Health and the local Health District including contribution to the fitout and a full rent subsidy.

I would like to welcome Laurie Grey onto the Board of Parkinson's NSW. Laurie was diagnosed with Parkinson's in 2011 and is replacing Sandra Elms as the Board's regional representative.

After 15 years with Parkinson's NSW, Chris Searles has sadly retired. On behalf of Parkinson's NSW I would like to wish her a wonderful retirement including more time with her husband Bruce and family.

Yours in Parkinson's friendship,

Miriam Dixon
CEO

Andrew Whitton

This edition of Stand By Me is devoted to research and those projects which were awarded the Bendigo Bank Grants and Seed Grants.

It is pleasing to report that we recently presented cheques totalling $288K at our annual Research Presentation morning tea at NSW Parliament House in April.

Congratulations to the recipients:

A/Prof Colleen Canning
A/Prof Kay Double
Dr Nicolas Dzamko
Dr Dan Johnstone
Dr Jin Sun Park
Dr James M Shine
Dr Bryce Vissel

If you mention research, people immediately have a vision of finding the Holy Grail – a cure for Parkinson's Disease. The projects PNSW has invested its money in this year have more to do with reducing the impact of the symptoms of PD than finding a cure. Finding the cause and earlier diagnosis are some of the keys to unlocking the disease, but just as important is improving or maintaining the quality of life for PD sufferers.

Don't get me wrong, I would be first in a queue if there was a cure. And quite often a cure comes out of left field, so we never know when that might happen – I read an article in a recent edition of SMH's Good Weekend "that a virus behind the common cold has emerged as a potential destroyer of melanoma cells", we too could simply get lucky or let us hope that with the support that PNSW is providing that eventually one of the researchers finds a cure!

Andrew Whitton
President

PUNCHIN' PARKOS EXERCISE PROGRAM

Adrian Unger

There's a fight currently going on 24/7. You can't watch it on your TV sport's channel or at any arena. This fight is being fought in thousands of Australian homes, perhaps in a neighbour's house or even in yours. Up to now, it's been one-sided, but, at last, there is hope for the under-dog.

In one corner stands the current, undefeated, but despised champion in the world, Parkinson's Disease (PD). The hopeful contender, the Punchin' Parko (PP), stands in the opposite corner knowing they cannot win the war (not yet) but can and will win many battles in the years to come. The new secret weapon they have is the Punchin' Parko's Exercise Program (PPEP).

People with Parkinson's now have a choice – remain frustrated and angry with the poor cards they have been dealt and resign themselves to a life where independence is gradually taken away (i.e. do nothing and accept their lot in life) or fight back with PPEP.

PPEP EXPLAINED

- An intense, non-contact activity based on the training exercises of amateur and professional boxers
- The focus is on improving balance, mobility, breathing, voice, co-ordination, footwork, speed, power, reaction time, gait and posture.
- It is evidence based. Current scientific and medical research shows that any exercise may help neuro-degenerative diseases but the more complex, forced and repetitive the exercise is, and the more effort one puts in, the more improvement one will see.
- Of sixty sports examined in detail, boxing was found to be the most difficult and tough sport to master and gave the quickest and most sustainable results.
- And it's FUN.

Anyone with PD of any age (20 – 90+) can join. You can start at any stage, but optimally, the sooner after diagnosis the better. After receiving medical clearance, each potential PP is graded 1,2,3 or 4 depending on the degree of disability. Exercises are tailored according to grade.

Currently, two sessions of 90 minutes duration are offered to each participant each week. Every session has a suitably qualified and experienced coach, assistant coach and volunteers to assist. The maximum number is 10 - 12 participants per session.

All sessions are held at VT1 Academy of Martial Arts in Chatswood NSW. There is level access from the carpark with no steps to negotiate. Disabled toilet facilities are on same level.

As the program grows, we intend to train suitable people throughout Australia in our methods so that they can offer the program at their local facility.

Why not take a sneak preview of what we do with a few videos we have made. Just put Punchin' Parkos into YouTube or Vimeo and you will find them.

Like to join? Know somebody who might benefit from such a program?

Contact me on 0416 2123 19 or 02 9416 2123 and if I'm not there, leave a message.

Adrian Unger
PPEP Facilitator

WORLD PARKINSON'S DAY

celebrated with $288,000 awarded for research projects

Clare Audet, Parkinson's NSW Marketing Director

L to R: A/Prof Kay Double, A/Prof Simon Lewis, A/Prof Colleen Canning Dr Dan Johnstone, Dr Nicholas Dzamko, Dr Jin Sung Park

On April 11, Parkinson's NSW hosted a morning tea at State Parliament to award over $288,000 in research grants to seven innovative projects. The Hon Victor Dominello MP, Minister for Innovation and Andrew Whitton, Parkinson's NSW President presented the awards to the successful recipients.

Over 80 people were in attendance, including; researchers, PNSW members, people with Parkinson's and some of our support group members. After a short project overview from each recipient, attendees mixed informally with the researchers to learn more about their work.

The $288,000 project funding has gone towards research that, if successfully developed, will aid in finding a cure for Parkinson's and help those living with the disease improve their quality of life. The recipients were chosen by the Parkinson's NSW independent judging panel and cover the most innovative research in biological/non-clinical and clinical/psychosocial research. Specifically, the highly competitive grants explore areas such as; new drug treatments, non-drug treatments, familial Parkinson's, uptake and adherence to exercise programs, brain cell death and new treatments for hallucinations.

Parkinson's NSW is committed to supporting research and has awarded over $1 million in research grants over the past eight years. These grants were made possible by the fundraising and events undertaken by Parkinson's NSW and sponsorship by Bendigo Bank.

The grant recipients include

Dr James Macquarie Shine, *Brain & Mind Research Institute, The University of Sydney*
A study of 100 people with Parkinson's, using EEG to detect and predict the brain activation pattern that may allow for new treatments to be developed.

Dr Bryce Vissel, *Garvan Institute, The University of New South Wales*
Research into the potential neuroprotective effect of UBP310 and investigate the role of KARs in a PD model.

A/Prof Colleen Canning, *The University of Sydney*
A study to be conducted of 300 people with Parkinson's to determine the attributes that most influence uptake and adherence of exercise programs.

A/Prof Kay Double, *The University of Sydney*
Investigation into why Superoxide dismutase (SOD1) protein is aggregating in Parkinson's disease and if the aggregation is concentrated in brain regions of cell loss.

Dr Dan Johnstone, *The University of Sydney*
Research into three non-drug interventions – dietary saffron, near infrared light (NIr) and remote ischaemic conditioning in reducing the pathology and signs of Parkinson's disease.

Dr Nicolas Dzamko, *Neuroscience Research Australia, The University of New South Wales.*
Research to determine if UPS35, a protein that regulates receptor trafficking and is genetically implicated in PD, contributes to the uptake of alpha-synucleins.

Dr Jin Sung-Park, *Kolling Institute of Medical Research, The University of Sydney*
This project will attempt to provide a basis for developing therapies to treat mitochondrial dysfunction through identifying the proteins interacting with Nix (a selective autophagy receptor) during mitophagy.

BENDIGO BANK GRANT

Identifying an electroencephalographic signature to predict and prevent visual hallucinations in Parkinson's disease

Dr James Shine

Classically, Parkinson's disease has been viewed almost exclusively as a disorder of impaired movement. When people think of someone that they know with Parkinson's disease, they imagine someone with a resting tremor, who is unable to move around freely due to stiffness and slowness.

However, a range of other symptoms also commonly affect people with Parkinson's disease; and those disorders are not due simply to dysfunction of the motor systems of the brain. Importantly, the mechanisms responsible for these 'non-motor' symptoms are poorly understood, and as such, there are currently very few effective ways to treat these symptoms.

One such symptom is visual hallucinations, which occur when someone "sees something that isn't there". These symptoms are remarkably common in Parkinson's disease, particularly in the latter stages of the condition, and understandably, can cause a great deal of emotional stress and suffering for those individuals affected by the symptom, as well as those that care for them.

In work conducted at the Parkinson's Disease Research Clinic at the Brain and Mind Research Institute under the supervision of Dr Simon Lewis, we have recently begun to make progress in understanding the brain mechanisms that are responsible for causing someone to suffer from hallucinations. Based on the results of a series of functional brain imaging experiments, we have been able to conclusively demonstrate that hallucinations occur when individuals are unable to effectively direct their attention to outside world. This then allows their imagination to 'fill in the blanks', somewhat like dreaming while they are awake.

Now that we have a good idea about what is causing hallucinations, our aim is to create new treatments that can potentially remove hallucinations before they occur. In our study that was recently funded by Parkinson's NSW, we will use another brain imaging technology - electroencephalography or EEG – to measure brain waves in real-time. We will leverage our burgeoning understanding of the brain mechanisms underlying hallucinations, we can focus on the key rhythmic brain rhythm abnormalities that predispose people to hallucinate.

By analysing these signals using sophisticated pattern recognition algorithms, we hope to be able to detect hallucinations before they occur. The establishment of the predictive signature of hallucinations in real-time will allow for the development of wearable devices that monitor a patient's brain activity providing real-time feedback to an individual about the likelihood that a hallucination is about to occur.

BENDIGO BANK GRANT

Dr Bryce Vissel

The motor symptoms of Parkinson's disease develop when approximately 70% of the dopamine-producing cells are damaged. These nerve cells play a critical role in smooth, purposeful movement and their loss results in the classic signs of Parkinson's: tremors, rigidity, and trouble walking and moving.

Despite decades of research, the exact cause of why cells die in Parkinson's disease remains to be understood and a treatment that is successful at halting the progression of the disease is yet to be discovered. Doctors Bryce Vissel and Sandy Stayte from the Garvan Institute of Medical Research will now be one step closer to discovering a potential new therapeutic approach with promise for slowing dopamine neuron cell death in Parkinson's, with the award of the 2015 Bendigo Bank Parkinson's Research Grant from Parkinson's NSW.

The research being conducted by Doctors Vissel and Stayte will investigate if a prototype drug is able to protect against the death of dopamine-producing cells in the brain in two different mouse models of Parkinson's disease. This is a key first step for developing this drug for use in humans to halt the progression of the disease.

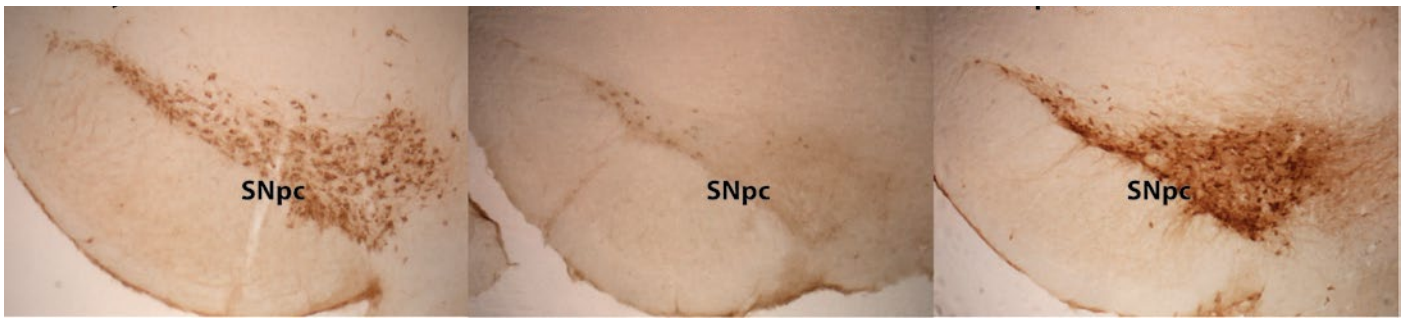
The prototype drug being investigated by the researchers targets kainate receptors, signalling molecules that function within the glutamate system, an important excitatory or "go" system of the brain. The researchers aim to administer the drug directly into the brains of mice using a "minipump" delivery system and determine if this is able to increase the number of surviving dopamine cells in mice that have been rendered Parkinsonian. The researchers believe that by blocking kainate receptors, the drug will be able to reduce the excitatory effect of glutamate and thus provide an environment in the brain in which dopamine cells can survive, rather than die.

The researchers already have promising results that show that their prototype drug has a potent neuroprotective effect in mouse models of Parkinson's. In fact, mice that received the drug had approximately 85% of their dopamine neurons survive, compared to approximately only 40% in animals that did not receive the drug.

Doctors Vissel and Stayte will now be using the Research Grant provided by Parkinson's NSW to begin the initial investigations into the mechanisms of the drug's effect to understand better exactly how it works in the brain. The researchers aim to achieve this by administering the prototype drug to mice that have been genetically modified to have certain kainate receptor subunits "deleted". The researchers are hoping this will allow them to determine which subunits are required for the neuroprotective action of the drug.

Until now, almost all treatments for Parkinson's disease have focused on attempting to replace the dopamine that is lost. However, this treatment strategy is unable to halt/slow the progressive nature of the disease. With the support of Parkinson's NSW, Doctors Vissel and Stayte hope that their research will provide the first steps for the development of a novel drug that will significantly protect against dopamine cell death and furthermore will be critical in achieving prestigious funding from the National Health and Medical Research Council in the future.

Healthy Brain | Cell Loss in Parkinson's Disease | Therapeutic Treatment



BENDIGO BANK GRANT

Deciding to start exercising and to continue exercising: considering the preferences of people with Parkinson's disease.

A/Prof Colleen Canning (Faculty of Health Sciences, The University of Sydney), Dr Serene Paul (George Institute for Global Health), Prof Cathie Sherrington (George Institute for Global Health), Prof Kirsten Howard (Institute for Choice, University of South Australia) (top to bottom)

There is an expanding evidence-base supporting the benefits of exercise for people with Parkinson's disease (PD) by improving motor symptoms, balance, mobility and quality of life, and preventing falls. Despite this evidence, people with PD are less active than the general older population and their physical activity levels progressively decline. A core principle of patient-centred healthcare for people with PD is the need for healthcare systems to offer interventions that are not only effective, but that also have high-likelihood of being adopted by people with PD. However, there is no research available identifying the features of exercise programs that would enhance adoption of evidence-based exercise programs.

The discrete choice experiment is a methodology used in health economics to understand participant preferences for health care programs. The method is based on the idea that a healthcare program can be described by a number of attributes, which can vary. We will conduct a discrete choice experiment to identify the preferences of people with PD for specific attributes of exercise programs that are likely to influence adherence and uptake. The discrete choice experiment is administered as a survey. We will survey 300 people living with PD and will determine, from the perspective of the person with PD, the attributes of exercise programs that most influence decisions to start exercise and to continue exercising.

Participants will make a series of choices between alternative exercise programs. The attributes for each program will include: cost, transport, travel time, type of exercise, frequency of exercise, exercise time per session and expected benefit. Each attribute is defined by multiple levels (eg, for the cost attribute, the levels range from $0 per week to $60 per week). Participants will be presented with up to 10 choice sets of two alternative programs, where one program represents the status quo (the exercise the participant is currently undertaking, including no exercise) and the other program represents a hypothetical new program where levels of each attribute are systematically varied.

Table 1 shows an example of a choice scenario from the feasibility study.

The survey will be offered in two modes: as an online survey and as a paper-based survey for those potential participants who do not have access to the internet or who are not comfortable completing the online version. The results of this study will inform decisions about how to best deliver evidence-based exercise programs that account for preferences of people with PD and thus maximise uptake and adherence.

The team would like to thank Parkinson's NSW for the recently awarded research grant allowing this work to proceed, and for their previous research grants which have hugely contributed to the development of the evidence-base for exercise in Parkinson's disease.

Table 1	Old exercise program	New exercise program
Out of pocket cost per exercise session	$0	$20
Transportation to get to the exercise venue	I don't need to use transport	I use my own transport
Travel time	None	15 minutes each way
Type of exercise	Nothing	Balance and strengthening exercises
Frequency of exercise per week	0 times per week	3 times per week
Time per day spent on exercise session	0 minutes/session	60 minutes/session
Ability to safely perform everyday mobility tasks, including standing up and sitting down, walking indoors and outdoors	No change	Increased by 10%

SEED GRANTS

A new type of protein aggregate in the Parkinson's disease brain

A/ Prof Kay Double, Brain and Mind Research Institute, The University of Sydney &
Dr Dominic Hare, University of Technology, Sydney

The abnormal accumulation of proteins is a ubiquitous feature of many diseases of the brain, including Parkinson's disease.

In the Parkinson's disease brain the accumulation of the protein alpha-synuclein into clumps called Lewy bodies is believed to contribute to brain cell death, but these protein aggregates are also seen in many brain areas where cells do not die.

Recently we identified a new type of protein aggregate in the brain in Parkinson's disease. This new aggregate type does not contain alpha-synuclein but instead contains another protein called superoxide dismutase 1 or SOD1. We showed that SOD1 aggregates are only found in brain regions where the cells die in Parkinson's disease. Similar aggregates of SOD1 protein result in nerve cell death is another degenerative disorder called amyotrophic lateral sclerosis, a type of motor neuron disease. We believe that the abnormal aggregation of SOD1 protein may also contribute to brain cell death in Parkinson's disease.

In this project we will investigate how SOD1 accumulates in the brain in Parkinson's disease and if these newly identified aggregates are similar to SOD1 aggregates in other brain diseases. This work will increase our understanding of how brain cells are damaged in Parkinson's disease. Using this knowledge we can develop new treatments to block pathways leading to brain cell damage to slow the progression of Parkinson's disease.

Our project involves a collaboration between neuroscientists and analytical chemists to answer basic questions about why specific brain cells die in the Parkinson's disease brain. It also contributes to the training of two young Parkinson's disease researchers at the University of Sydney, PhD student Benjamin Trist and Honours student Sian Genoud.

SEED GRANTS

Common Pathways in Neruoprotection: understanding mechanisms of three neuroprotectants in a model of Parkinson's disease

Dr Dan Johnstone

How do you prevent a disease when the cause is unknown? This is a big problem facing scientists as they pursue new treatments for Parkinson's disease.

While research in the last few decades has led to considerable advances in our understanding of PD and the development of treatments (e.g. dopamine replacement therapy, deep brain stimulation) that address signs and symptoms, there is still no treatment to slow or halt the underlying disease process. Without knowing the exact cause of PD, it is difficult to design a targeted therapy; this opens the door for the trial of more generic approaches to protecting the brain.

My colleagues and I work in the area of 'neuroprotection' – a term used to describe ways to protect the brain against a range of insults or diseases. To achieve this we take advantage of the fact that the human body has evolved a remarkable ability to protect and repair itself – this is true of the brain as well as other organs. The problem is that, with our current lifestyle, a lot of these protective systems within the cells of our brains lie dormant. The good news is that with the right intervention, we believe we can stimulate these systems to become more active, helping protect us against brain diseases such as PD. In addition, these self-protective mechanisms appear to be effective against a range of diseases; we don't have to define the cause first.

For several years we have been using animal models of PD to trial different interventions. We have now developed a short-list of approaches that are effective in improving movement and reducing damage to cells in the brain. What really excites us about these interventions is that they are not drug treatments; they are safe, have no known side effects, are non-invasive and involve no pain, are relatively cheap and could potentially be used in the comfort of a patient's home. The main question we now have to answer is exactly how these treatments work, and whether combining two or more could provide even better protection of the brain than each individually.

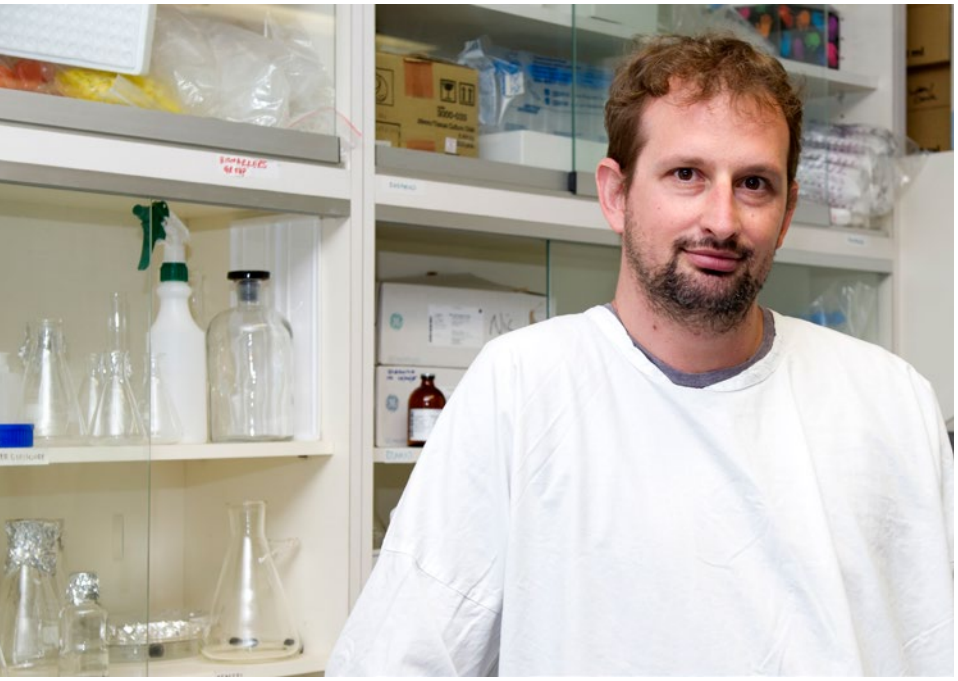
With this valuable research grant from Parkinson's NSW, we will be aiming to answer these questions for three particular neuroprotective interventions that we have found to be effective in animal models. These interventions are (i) the treatment of tissue with certain wavelengths of infrared light, (ii) dietary consumption of the spice saffron, commonly used in Asian cuisine and (iii) temporarily blocking blood flow in an arm or leg. We will investigate whether these interventions stimulate common or distinct protective systems within the brain, and whether combining these treatments provide more effective protection than each alone.

Our hope is that by better understanding these neuroprotective interventions, we can accelerate their progression from animal studies to trials in patients with PD. We believe that this line of research has the potential to make a profound difference to the health and wellbeing of all people with PD.

SEED GRANTS

Does VPS35 influence alpha-synuclein pathology in Parkinson's disease brain?

Dr Nicolas Dzamko (Neuroscience Research Australia)



The causes of Parkinson's disease are mostly unknown, however, approximately 10% of cases are caused by genetic factors.

These factors are often a result of a single genetic alteration in a person's DNA. Parkinson's disease caused by genetic factors is called "familial" Parkinson's disease, reflecting the fact that the genetic differences are inherited through families. By tracking the DNA of families with a strong history of Parkinson's disease, eighteen genes have been discovered that if altered can cause Parkinson's disease. Unfortunately, little is known about these Parkinson's disease associated genes and how they actually cause the disease. Determining the function of these genes in the brain is therefore a very high priority, as it will provide clues of where to look for, and how to identify the biology of familial Parkinson's disease. Once it is understood how genetic alterations alter the biology of the brain in familial Parkinson's disease, it can then be determined if the same biology is altered for the remaining 90% of cases.

One such Parkinson's disease associated gene is VPS35, which stands for vacuolar protein sorting-associated protein 35. A single specific alteration in VPS35 is enough to dramatically increase the risk of Parkinson's disease. VPS35 is part of a protein complex called the "retromer", and the retromer is important for regulating how proteins are moved from place to place to carry out their functions inside a cell. This is of interest as it has long been thought that protein trafficking pathways may be dysfunctional in Parkinson's disease, largely due to Parkinson's disease being associated with the accumulation of the protein alpha-synuclein.

Like most aspects of Parkinson's disease, exactly what alpha-synuclein does is unclear, however, its accumulation and aggregation in the brain is a hallmark disease feature. Indeed, the accumulation of alpha-synculein in Lewy bodies in brain cells is a required pathological feature for the diagnosis of Parkinson's disease. It is known that the alpha-synuclein protein spreads through the brain in a predictable pattern, transferring from brain cell to brain cell over the disease course. Sometimes the disease course is very long, sometimes it is more aggressive however, the pattern of alpha-synuclein transfer remains largely the same for all Parkinson's disease cases. What is unknown however, is how and why this protein should transfer around and accumulate in the first place.

NeuRA's Parkinson's NSW funded project will explore the potential role of VPS35 in the transfer and accumulation of alpha-synuclein. We hypothesise that defects in VPS35 lead to defects in the protein trafficking pathways that allow brain cells to send alpha-synuclein for degradation, instead allowing it to accumulate and transfer from brain cell to brain cell. We will explore the relationship between VPS35 and alpha-synuclein in Parkinson's disease brain and develop tools to measure how defects in VPS35 affect alpha-synuclein accumulation. There is currently much interest in trying to find ways to prevent the accumulation of alpha-synuclein in the Parkinson's disease brain, as this may slow down and potentially even halt the disease process.

SEED GRANTS

Highly Effective Alternative Mitophagy in Parkinson 's Disease

Dr Jin Sun Park (Senior Research Fellow)

Parkinson's disease is pathologically characterised by the loss of dopaminergic neurons in the substantia nigra and the formation of protein aggregations called Lewy bodies in the affected brain regions of patients with Parkinson's disease, but the cause of these largely remains unknown.

An important factor that contributes to the loss of neurons in Parkinson's disease is a lack of adequate energy supply to the affected cells. Cellular energy is supplied by small parts of the cell called "mitochondria". Mitochondria supply most of the cell's energy in the form of a molecule called ATP. Loss of mitochondrial function has been observed in common sporadic forms of Parkinson's disease as well as the rarer familial forms of Parkinson's disease. To maintain healthy mitochondria, the cell removes old and dysfunctional mitochondria via a process called "mitophagy." When mitophagy is impaired, dysfunctional mitochondria accumulate in the cells and reduce the amount of cellular energy available to active neurons.

Genetic errors (e.g., mutations) in the two genes named PINK1 and Parkin have been shown to cause early-onset Parkinson's disease and recent studies revealed that the molecules encoded by these genes play a crucial role in mediating mitophagy. Among the patients who visited the Parkinson's disease clinic at Royal North Shore Hospital, we identified an unusual mutation carrier who carried disease-causing mutations in Parkin, but did not have Parkinson's disease. We surprisingly detected normal mitochondrial function in cells from this mutation carrier despite the complete loss of functional Parkin and impairment of PINK1/Parkin-mediated mitophagy. In further investigation, we identified Parkin-independent alternative mitophagic pathway was compensating for the loss of the PINK1/Parkin in the mutation carrier and also confirmed that activation of alternative mitophagy improved mitochondrial function in cells derived from PINK1- and Parkin-associated Parkinson's disease patients.

These findings suggest that activation of alternative mitophagy may improve mitochondrial dysfunction in Parkinson's disease. In the research project, we will investigate how alternative mitophagy can be used to best treat patients with Parkinson's disease. We will develop an innovative therapeutic approach to improve mitochondrial function and reduce the loss of neurons in Parkinson's disease patients.

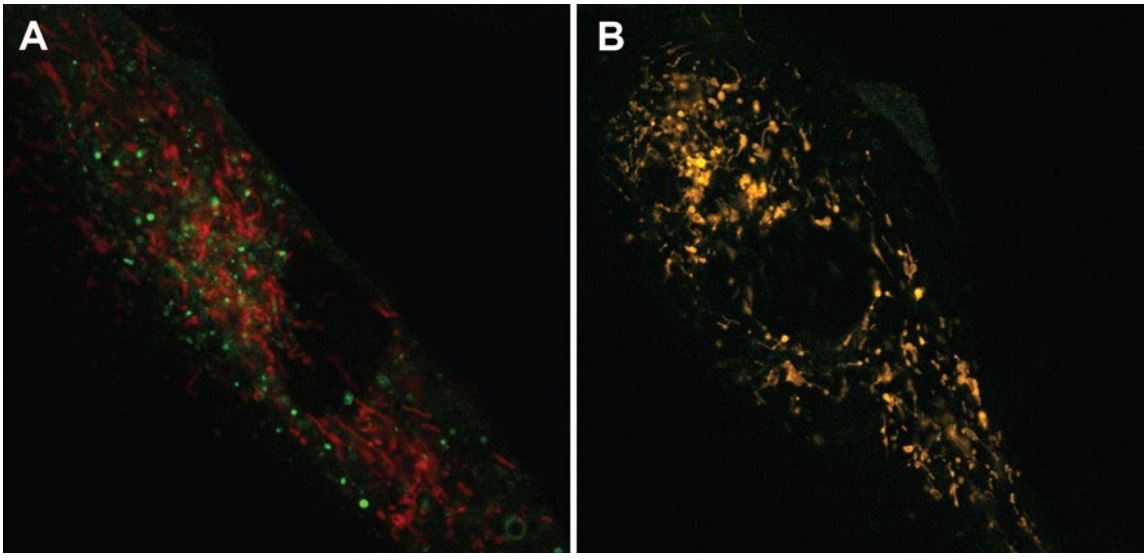
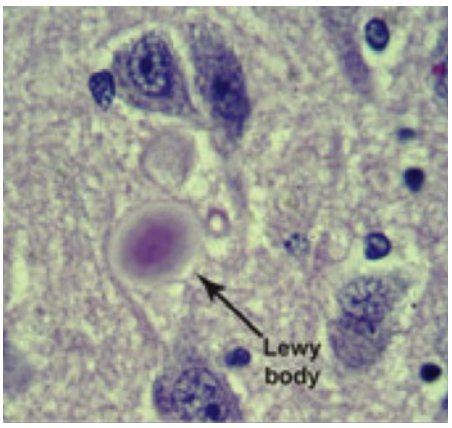


Figure. As opposed to no sign of mitophagy in the skin fibroblasts derived from a PD patient with Parkin mutations
A: activation of alternative mitophagy restores degradation of dysfunctional mitochondria in the same fibroblasts
B: Overlaps (yellow dots) of mitochondria (red) and autophagosomes (green), indicates an active process of mitophagy.

NEW THOUGHTS ON THE PATHOGENESIS OF PARKINSON'S DISEASE

Dr Paul Clouston



The diagnosis of Parkinson's disease (PD) during life relies on the presence of cardinal motor criteria: tremor, rigidity (limb stiffness) and bradykinesia (slowness of movement).

There is no test to diagnose the disorder and so these features must be ascertained by an experienced clinician. Around 95% of the time an experienced neurologist will be correct in the clinical diagnosis when compared with subsequent neuropathologic findings at autopsy

The diagnostic neuropathologic feature of PD is the presence of "Lewy bodies" in dopaminergic neurons in the upper brainstem (substantia nigra pars compacta). Lewy bodies are intraneuronal aggregates of a number of cellular proteins, the most prominent being a misshapen (misfolded) version of a normal neuronal protein called alphasynuclein. Conventional thinking is that Lewy bodies containing alpha synuclein are toxic to neurons and lead to eventual neuronal death.

An underappreciated feature of the pathology of PD is the distribution of Lewy bodies in other areas of the nervous system besides the upper brainstem. PD patients who come to autopsy frequently have Lewy bodies in non dopaminergic neurons in the central nervous system particularly the lower brainstem, especially in groups of brainstem cells involved in control of sleep physiology and cells controlling the vagus nerve. The vagus nerve mediates colonic intestinal motility amongst many "autonomous" bodily functions. Of particular interest is that Lewy bodies are also found in the walls of the bowel, raising the intriguing possibility of the spread of Lewy body pathology into the central nervous system from the gastrointestinal tract via the vagus nerve.

Lewy bodies may also often be present in the anterior olfactory nucleus of the brain, a group of neurons that mediate the sense of smell. The pathologic distribution of Lewy bodies may also involve the surface of the brain, the cerebral cortex in some patients, which, in part, may be responsible for the end-stage dementia seen in PD.

Some "non-motor" symptoms can precede the motor symptoms of PD by years. These include constipation, sleep disturbance (REM sleep behaviour disorder) and impairment of smell (anosmia).

A pathologic staging system has been proposed for PD that involves a premotor stage with Lewy bodies just in the lower brain stem, spreading up the brain stem over many years, followed by a mid-stage involving the upper brainstem with the characteristic motor symptoms, followed by an advanced stage with Lewy bodies in cerebral cortical neurons. This staging has an underlying hypothesis, of a very slow spread of Lewy bodies from the lower brainstem upward to the brain, and implies slow cell to cell transmission of an agent causing PD pathology

Needless to say the assertion of very slow cell to cell transmission of PD pathology has caused much controversy amongst PD researchers. Supporting evidence for the hypothesis comes from autopsy findings in patients who had transplants of fetal dopaminergic neurons for their PD. Lewy bodies have been found in the transplanted fetal tissue at autopsy suggesting "spread" of Lewy bodies from the patients' own neurons. More recently Lewy body extracts from Parkinson's brains have been shown to trigger a cascade of alphasynuclein pathology and neurodegeneration in mice and monkeys. These animals showed accumulation of pathological (misfolded) alphasynuclein in neurons with subsequent neurodegeneration of dopaminergic neurons in the upper brainstem.

The idea of a "toxic" form of alphasynuclein that slowly spreads from neuron to neuron provides a rationale for developing a vaccine against this protein to block its spread. Such vaccines are currently in the early stages of clinical trials. Results are awaited with great interest.

IMPROVE YOUR Handwriting....

Julie Austin & Penny Mawer, Parkinson's NSW InfoLine

Many people with Parkinson's disease experience problems with handwriting. Common problems are the size becomes smaller – this is called micrographia. The writing may become 'spidery' and difficult to read and hand tremors make it too difficult to write.

Below are some helpful tips to improve your writing.

- Choose a good, easy flowing pen – one that glides over the paper.
- Use a pen grip (round or triangular shape) or a larger size pen to keep your hand more relaxed.
- Use a clipboard or non-slip mat to prevent the paper from slipping.
- Practise your handwriting using lined paper. Use the lines as a guide to write at a constant size.
- Think BIG and concentrate on the size and form of each letter. This can be hard to do at first, but is very effective in improving legibility. Conscious attention is required for the performance of well-learnt motor skills that have been performed automatically prior to the onset of Parkinsons's. Focus on one letter or word at a time.
- Write short sentences at a time. Take regular rest breaks to reduce fatigue.
- Rest your hand if it is beginning to feel "tight". Do simple stretches to exercise your hand.
- You can break larger words down into syllables, and you can break sentences down by halving them, or into individual words or letters.
- Sit at a desk that is a good height for you, in a chair well positioned with your feet flat on the floor and maintain a good posture.
- STOP after 3-4 words or if you notice your words are becoming small or bunched up. Avoid hurrying or trying to write longer passages if you are stressed.
- THINK about your letter size, about the words or letters before you write them, and PLAN bigger, and spaced out letters.
- DO restart your writing.
- After writing a line, stop, relax, breath deeply, stretch using wide arm movements and then recommence writing.
- It may be easier to print letters rather than use cursive writing (since cursive writing involves longer, more complex movements).
- Keep practicing — some people have found it very useful to sit down and write a paragraph a day from a book or magazine to maintain their writing ability.
- The use of a computer can be helpful especially if there is a need for writing documents.
- Doing exercises by writing in the air using BIG, exaggerated, movements. You may like to hold a hairbrush. Repeat this several times.
- Practise helps. Remind yourself to slow down, aim BIG and pause often.

Involve your team. An occupational therapist can provide an assessment and individual recommendations of your handwriting.

A NEW SUSTAINED RELEASE FORMULATION FOR PARKINSON'S DISEASE

summarised by Dr Michael Ortiz

As Parkinson's Disease (PD) progresses, carbidopa/levodopa medication preparations may fail to adequately reduce disease-related symptoms.

These medication related problems include:
1. Medication dosages taking too long to "kick in" and start working
2. Medication wearing off before the next scheduled medication dose
3. Severe on-off medication fluctuation periods (e.g. rapid cycling during the day ranging from feeling completely 'on' medication to completely "off" medication)
4. Dyskinesia (too much movement, usually resulting from too high of a blood level of dopamine)
5. Too many pills
6. Too many medication dosage intervals (e.g. taking medications every 2-4 hours throughout the waking day).

Patients also have other issues that levodopa does not address, including walking, balance, talking, and thinking issues, but these will likely require a totally different approach than simple levodopa replacement.

Hauser and others (2013) published a paper on a new extended release formulation of carbidopa/levodopa called Rytary. The new formulation that was studied, carbidopa/ levodopa extended release (Rytary), is different from the controlled release tablet available on the PBS in Australia (Sinemet CR). It contains special beads designed to dissolve at different rates within the stomach and the intestines. The medication capsule was in general designed to provide longer lasting benefit for patients with PD.

This study was conducted on 393 PD patients who all reported at least of 2.5 hours of "off time," defined as periods when they felt the medication was not working. The new treatment aimed at reducing the number of hours of "off time" each day for patients randomized to the new extended release formulation (Rytary) as compared to the older and standard regular release carbidopa/ levodopa.

The results revealed that participants taking Rytary:

- Had about an hour less "off time" during the day, as recorded in their diaries.
- Experienced more "on time" without troublesome dyskinesia.
- Fewer doses were needed throughout the day — three or four, versus five or six for the standard therapy.
- A higher dose of levodopa was needed to get the optimum benefit from Rytary compared with the immediate-release form.
- Appeared to better manage PD movement symptoms as assessed using a standard measurement scale (UPDRS).
- The most common side effects were insomnia and nausea.

If we return to the six areas where Parkinson's disease patients have been seeking improved medication formulations, Rytary was observed to improve issues in two categories: wearing off between dosages, and improvement by increasing the time interval between dosages.

The new extended release formulation increased the total blood-stream levodopa exposure by 30-40% as compared to conventional immediate release levodopa. Increasing levodopa in the bloodstream is thought to decrease the threshold for dyskinesia, as has been observed with other Parkinson's drugs such as Entacapone and Stalevo.

What Does It Mean?

Levodopa is an excellent treatment for the motor symptoms of PD. Unfortunately, as the PD progresses, many people need to take their levodopa medication more frequently during the day, and the effect may not last as long. Doctors may increase the "on" time, the hours a day levodopa works efficiently, by adjusting carbidopa-levodopa dosage and frequency, or by adding other anti parkinons's medications. These can include monoamine oxidase-B inhibitors - such as rasagiline (Azilect®) and selegiline (Eldepryl®) and dopamine agonists (pramipexole (Sifrol®) or ropinirole (Requip®)), or entacapone (Comtan®).

Standard carbidopa-levodopa therapy, is already available in a controlled-release version (Sinemet CR®). The controlled-release dosage form is designed to release these ingredients over a 4 to 6 hour period. With this formulation there is less variation in plasma levodopa levels than with conventional Sinemet. However, because it releases levodopa into the body gradually, it may take effect more slowly than conventional Sinemet®. The time to peak plasma levodopa level after Sinemet CR was approximately two hours compared to 0.75 hours with Sinemet. Rytary was formulated to address the slow onset issue by allowing a portion of the medication to be released initially and the rest gradually of time.

If and when this new drug becomes available on the PBS in Australia, Rytary will provide another treatment option for people with PD and their doctors. Future research is needed to compare its benefits with those of non-levodopa drugs with respect to "off-time".

Hauser RA, Hsu A, Kell S, Espay AJ, Sethi K, Stacy M, Ondo W, O'Connell M, Gupta S; IPX066 ADVANCE-PD investigators. Extended-release carbidopa-levodopa (IPX066) compared with immediate-release carbidopa-levodopa in patients with Parkinson's disease and motor fluctuations: a phase 3 randomised, double-blind trial. *Lancet Neurol. 2013 Apr;12(4):346-56.*

THE ROLE OF THE SHOALHAVEN NEUROLOGICAL NURSE

by Nina Cheyne (second from left)

I commenced the role as Shoalhaven's Neurological Community Nurse in March 2015 following from Marilia Pereira who initiated the program in the Shoalhaven in 2010, thanks to the support of PNSW and Professor Simon Lewis. The role involves home visits to patients referred by their GP, Specialist or hospital team member for a comprehensive nursing assessment based on the Unified Parkinson's Disease Rating Scale addressing motor and non-motor function and quality of life questions. I identify appropriate and timely interventions and ongoing management of treatments, psychosocial support, referrals to appropriate medical, allied health and social services and practical support depending on individual needs and the needs of family/ carers.

These assessments require expertise, and sound knowledge to address the needs of persons with PD and their families. I liaise with GPs, Specialists and members of the multidisciplinary team to meet a patient's need for a quality life, despite their neurodegenerative condition. I'd like to think I give hope and positive strategies for their day to day challenges. As their condition deteriorates more complex and advanced treatments are required. Working with extended team members at Westmead, Concord, St Vincent's and the Brain & Mind Institute means there is always support from experts in the large city hospitals. I am grateful for the support of my city colleagues who have been supportive of my professional development and in providing clinical advice as needed.

As the community Neurological Nurse it is a privilege to often be the patient's first point of contact with the Neurologist, GP and other health team members, who provide sound evidence based strategies to manage the multifaceted aspects of PD. I also am privileged to be part of the Parkinson's Support and carer groups building up awareness about PD. I also join with local fundraising for exercise and dance classes for people living with PD.

I also educate Aged Care Facilities, GP Practices (mainly for Practice Nurses), health workers in the community and local hospitals and nursing students. GP Education is provided by Neurology guest speakers visiting the area.

One of the service delivery goals is to provide a PD clinic in the Shoalhaven area so people can access timely neurological services without travelling long distances. There is overwhelming support for this initiative in the community. Watch this space as this service delivery plan evolves.

Every day I am enjoying the challenges of being a Neurological Nurse in the Shoalhaven and look forward to making a difference in the lives of people with Parkinson's and their carers.

North Ryde RSL
Crn. Pittwater and Magdala Roads
North Ryde NSW 2113

Parkinson's Disease Seminar
Treatment Update
Friday, 24th July, 2015

Proudly sponsored by Medtronic

10:00 – 10:05am	Introduction & Welcome	*Miriam Dixon, CEO, Parkinson's NSW*
10:05 – 11:15am	Surgical treatment for Parkinson's Disease, "Who, Why & When"	*Dr Raymond Cook, Neurosurgeon, Dr Paul Silberstein, Neurologist*
11:15 – 11:45am	MORNING TEA	
11:45 – 12:30pm	"The Good the Bad and the Ugly"	*A/Prof Simon Lewis, Neurologist*

Registration: 9:30am
RSVP: By 17 July to Parkinson's NSW Infoline 1800 644 189 or infoline@parkinsonsnsw.org.au

IN THIS TOGETHER parkinson's NSW

GASTROINTESTINAL DYSFUNCTION IN PARKINSON'S DISEASE

summarised by Dr Michael Ortiz

Our understanding of gastrointestinal dysfunction in patients with Parkinson's disease (PD) has increased substantially over the past decade.

The entire gastrointestinal tract is affected in PD, causing complications ranging from drooling and swallowing problems to delays in gastric emptying and constipation. Additionally, bacterial overgrowth in the small intestinal interferes with the absorption of antiparkinsonian drugs affecting PD symptoms.

Alpha-synuclein is abundant in the human brain, while smaller amounts are found in the heart, muscles, and other tissues. In the brain, alpha-synuclein is found mainly at the tips of nerve cells in specialized structures called presynaptic terminals. Presynaptic terminals release chemical messengers, called neurotransmitters, from special storage compartments known as synaptic vesicles. The release of neurotransmitters relays electrochemical signals between nerve cells and is critical for normal brain function. Studies suggest that alpha-synuclein plays an important role in maintaining a supply of synaptic vesicles in presynaptic terminals. It may also help regulate the release of dopamine, which is critical for controlling the start and stop of voluntary and involuntary movements.

Fosano and others (2015) reviewed the current knowledge of gastrointestinal involvement in PD.

1. They assessed the growing body of experimental evidence supporting the hypothesis that the gastrointestinal tract might be the site of initiation of PD, along with the potential use of gastrointestinal alpha-synuclein deposition as a diagnostic biomarker for PD.

2. They assessed the effect of gastrointestinal dysfunction on PD clinical symptoms, including drooling, difficulties swallowing problems gastric emptying and constipation. As a result of their frequency, these gastrointestinal symptoms may be an important indicator of disease progression and constitute a major source of disability.

3. They also reviewed the effect of bacterial overgrowth in the small intestine on the absorption of antiparkinsonian drugs and the potential effects on the changes in Parkinson's disease symptoms including motor fluctuations.

Synucleinopathy in the gastrointestinal tract

Synucleinopathies are neurodegenerative diseases characterised by the abnormal accumulation of alpha-synuclein protein in nerves and glial cells in the brain. Two of the main types of synucleinopathy are Parkinson's disease and dementia with Lewy bodies. However, evidence for abnormal alpha-synuclein accumulation outside the brain, including throughout the nervous system of the gut, is growing.

A study mapping the distribution of alpha-synuclein throughout the gastrointestinal system reported the highest concentrations of enteric alpha-synuclein in the lower oesophagus, lower concentrations in the stomach and small intestine, and lowest concentrations in the colon and rectum. In PD there is evidence of early gut nervous system changes which suggests gut alpha-synuclein has potential as a biomarker for diagnosing Parkinson's disease. The distribution of synucleinopathy is associated with gastrointestinal symptoms along the entire gastrointestinal tract. The extent of gastrointestinal dysfunction, with corresponding widespread gut nervous system synucleinopathy, could suggest that a disruption in the physiological function of alpha-synuclein might have a pivotal role in gastrointestinal dysfunction.

Gastrointestinal Problems

Dental problems
Patients with Parkinson's disease brush their teeth and seek dental care less frequently than healthy individuals. The ability of PD patients to brush their teeth effectively is hampered by decreased manual dexterity and difficulty opening the jaw, leading to increased periodontal disease, an increased frequency of caries, and fewer remaining teeth. Excessive saliva might change salivary pH and composition in some patients, and xerostomia might impair the mouth's self-cleaning mechanism in others.

Drooling
Drooling is defined as excessive saliva in the mouth due to overproduction of saliva or impaired salivary clearance, caused by swallowing difficulties or inability to maintain saliva within the mouth. Drooling has several negative effects: social embarrassment, poor oral hygiene, bad breath, difficulty eating and speaking, increased risk of aspiration pneumonia, and a profound effect on quality of life.

Olfaction
Impaired sense of smell (olfaction) is well established in PD, but impairment of taste has received less attention. Several studies have documented impaired taste in patients with Parkinson's disease.

Swallowing disorders
Difficulty swallowing (dysphagia) is frequently reported in patients with Parkinson's disease. Pharyngeal dysfunction and transit abnormalities increase the risk of aspiration, thus contributing to risk of upper respiratory tract infection and pneumonia. Dysphagia typically emerges in more advanced PD, but it can develop early.

Malnutrition
Malnutrition is an established determinant of health in elderly people and is linked to reduced functional ability, quality of life, and survival in patients with PD. Motor impairment, fear of increased off -time, fasting associated with drug administration, drug-induced nausea, and anorexia can all affect food intake. Female sex, ageing, loss of appetite, depression, apathy, and loss of olfaction or taste might also contribute to malnutrition. Administration of levodopa has been associated with impaired nutritional status in a dose-dependent manner. Conversely, weight gain is associated with treatment with dopamine agonists and neurosurgical procedures, such as deep-brain stimulation (DBS).

Motility disorders
Recognition of impaired gastric emptying in PD is growing; although not all affected individuals have symptoms. Delayed gastric emptying (Gastroparesis) can be present in both early and advanced PD, with delays in gastric emptying more likely to be associated with solid meals. Nausea, vomiting, early satiety, excessive fullness, bloating, and abdominal distension characterise gastro paresis. Because levodopa is absorbed in the small intestine, delayed emptying from the stomach will result in delayed benefit of the levodopa dose.

Small intestinal bacterial overgrowth (SIBO)
In healthy people, intrinsic mechanisms control the number and composition of small intestine microbiota: gastric acid destroys many bacteria entering the stomach; biliary and pancreatic secretions limit bacterial growth; the intestinal mucus traps and fights bacteria; and the ileocaecal valve inhibits migration of bacteria back from large intestine into the small intestine. There is evidence of increased prevalence of SIBO in patients with PD. PD patients with SIBO have been reported to have more severe motor fluctuations (off-time, delayed on-time, and no on-time) than those without SIBO.

Constipation
Constipation is the most common gastrointestinal symptom in PD, reported in 80–90% of patients and constipation emergences long before the onset of motor symptoms, Not only is the risk of PD is increased in individuals with constipation, but constipation is one of the earliest features of autonomic dysfunction in Parkinson's disease. Constipation is also a common adverse effect of many Parkinson's disease drugs, particularly anticholinergics and dopamine agonists. Nevertheless, delayed large bowel transit has been reported in patients with PD independent of drugs.

In conclusion, this article described how the entire gastrointestinal tract is affected in PD patients, causing complications from drooling and swallowing problems to delays in gastric emptying and constipation. Additionally, bacterial overgrowth in the small intestine interferes with the absorption of antiparkinsonian drugs leading to worsening of PD symptoms.

Alpha-synuclein may regulate the release of dopamine, which is critical for controlling the start and stop of voluntary and involuntary movements. There seems to be evidence supporting the hypothesis that the gastrointestinal tract might be the site of initiation of PD, along with the potential use of gastrointestinal alpha-synuclein deposition as a diagnostic biomarker for PD.

Reference;
Fasano A, Visanji NP, Liu LWC, Lang AE, Pfeiffer RF. Gastrointestinal dysfunction in Parkinson's disease. *Lancet Neurol 2015; 14: 625–39*

INTERNATIONAL SPEAKER

Dr Jaime Kulisevsky

Director of the Movement Disorder Unit at Sant Pau Hospital, A/Prof at the Autonomous University of Barcelona, Coordinator of the Postgraduate Master Degree in Neuropsychological Diagnosis and Rehabilitation.

Tuesday 25 August 2015
9.30am to 3.30pm
Theatrette, State Parliament House
Macquarie Street, Sydney

NUMBERS ARE STRICTLY LIMITED - BY TICKET ONLY
To reserve your place and make a payment contact our InfoLine by *Tuesday 18 August.*

1800 644 189 or infoline@parkinsonsnsw.org.au
Cost:$35.00 member $45.00 Non-member
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A LATE QUARTET

by Dahlia Brigham

Dance for Parkinson's Sydney celebrated World Parkinson's Day 2015 with a special screening of the movie "A Late Quartet" at Palace Cinema, Leichhardt. The successful, well attended, fundraiser attracted much interest for the program.

Dance for Parkinson's Australia, is an exciting and innovative program recently established in Australia with the sole purpose of improving quality of life for people living with Parkinson's Disease. The program, established in 100 communities in 7 countries around the world, is modelled on Dance for PD, which originated at the Mark Morris Dance Centre in New York in 2001. It offers specialised dance classes for people with PD and their carers.

Leading neurologists and physiotherapists have endorsed the program based on research and data from around the world strongly indicating the immense benefits of dance on movement disorders, specifically Parkinson's Disease.

The concept was first introduced to Sydney in 2012 by Erica Rose Jeffrey at Parkinson's NSW annual seminar in Parliament House, where all attendees embraced it whole-heartedly.

In January 2013, my husband Brian and I had the opportunity to participate in a Dance for PD class in Oakland, San Francisco. This free class was truly inspiring; apart from visibly relieving physical symptoms it created a sense of shared joy and confidence amongst all participants.

Following our experience in Oakland, my aim was to start Dance of PD classes in Sydney to help the Parkinson's community.

L to R: Cathie Goss Dahlia Brigham Erica Rose Jeffery

In October 2013 the Sydney classes started in Rozelle, with seed funding from Leichhardt Council. We had two trained dance teachers and 10 participants. In less than two months the numbers doubled with the numbers of participants continuing to grow on a regular basis. We now have four dance teachers for the weekly classes in Rozelle and Alexandria.

A leading Sydney neurologist is currently conducting a quality of life study with class participants. It is hoped this study will confirm the impact this program has on improving quality of life for people living with Parkinson's Disease.

The benefits of the program are indisputable. Participants unable to stand in the first class are now standing and participating. The added social and psychological aspects of the class make Dance for Parkinson's Australia a truly holistic approach for helping people with Parkinson's.

In Sydney, Dance for Parkinson's Australia is under the auspices of Parkinson's NSW. Classes are free of charge for members of Parkinson's NSW and their carers. The objective of our fundraising is to ensure this continues.

The program is funded entirely through donations, grants and sponsorships. I have been fortunate this year to secure a grant from the Aged Persons Welfare Foundation to establish new Dance for Parkinson's classes in the St George/ Sutherland area, Sydney's North Shore and Bankstown. The new dance classes will help more people living with PD across Sydney.

On June 6 and 7, the Mark Morris Dance group from New York is holding a Dance a PD workshop at the Sydney Opera House to train new teachers. Information on Dance for Parkinson's Australia is available at:
www.danceforparkinsonsaustralia.org

JOHN SILK: WORLD PARKINSON COALITION HONOUREE

John Silk, OAM at the World Parkinson's Day Morning tea

World Parkinson Coalition (WPC) friend and past committee member John Silk was diagnosed with Parkinson's in 2002 and first became involved in Parkinson's organisations by joining a local Australian support group two years later in 2004.

This led to being a part of Parkinson's New South Wales (PNSW)—first as acting Secretary and then as President. His wife, Rebecca, joined him on the board of PNSW in 2005. In his capacity as PNSW President, John joined the board of Parkinson's Australia. In both these organisations his wife and him have been fortunate enough to initiate some major changes and innovations to benefit people with Parkinson's in Australia.

After contacting Parkinson's Disease Foundation (PDF) President Robin Elliott in 2005 to thank him for some materials that PDF had kindly made available to Parkinson's NSW, Robin, who happened to be chairing the WPC 2010 Organisation and Government Relations Committee invited John to become involved in the planning for the WPC 2010 by serving on his committee. John not only served on that committee for the WPC 2010, he continued to serve on that committee for the WPC 2013.

His current focus is on setting up a lobbying/advocacy division of Parkinson's Australia, based in Canberra. They have high hopes that this direct advocacy will allow their voices to be heard far more clearly by the federal government of Australia. John's work in the community has also been recognised by the Australian Government with a Medal of the Order of Australia (OAM), two Honorary Life Memberships from Parkinson's Australia and PNSW. His wife's work was also recognised with a Honorary Life Membership from PNSW.

When asked about the WPC 2016, John says "I wish all who participate in Portland the best experience possible. I know you will benefit enormously."

The WPC team thanks John for all his hard work in raising Parkinson's awareness and his tireless advocacy work in Australia. John has helped the WPC gain a great following of friends in Australia and his sage advice and years of work with the WPC helped steer some important decisions.

This article first appeared in Parkinson's World Coalition newsletter December 2014.

OUR NEW BEQUEST OFFICER

Melanie Wiencke

would like to introduce myself. I joined Parkinson's NSW in February, coming from a background in community services.

I am currently contacting members to introduce myself and to find out more about Parkinson's Disease and how Parkinson's NSW helps you all in different ways. So, please do not be surprised to have a call from me. I will also be making appearances at some support groups.

If your support group is interested in speaking about bequests please contact me and I will do my best to come out to a meeting. Making a will or updating it is an important and very personal responsibility, especially when there are those, be they family, friends or others, who are dependent on you. Naturally, their interests come first. It is when they have been provided for that you may wish to remember charities or causes that are important to you.

Although we sometimes read in newspapers about large amounts being left to charities, most people leave modest amounts, we are very grateful for any gift. It all helps. Your gift supports Parkinson's NSW and allows us to expand and enhance our free programmes and services. Not only to people living with Parkinson's but their families and carers as well.

There are a few different sorts of bequests options; if you would like more information or would like to discuss any aspect of planned giving please contact me on 8875 8912 or melanie@parkinsonsnsw.org.au.

University of Western Sydney
Bringing knowledge to life

Do you have movement difficulties that interfere with your ability to manage day-to-day activities?

The University of Western Sydney has a new study that is examining whether different types of cues (internal and external) can help people with Parkinson's Disease initiate motor movement.
The first stage of this project is to understand how cues influence movement and you are invited to participate!

How will the project work?

You will be asked to complete a 2-hour computer-based session. During the session you will be exposed to three different types of stimuli:

- internal cues (to imagine a cue before executing a movement)
- external cues (to execute a movement when you see a red dot); and
- no cue

and you will be asked to tap on a key with your finger in response to the cues.

You will receive training at the start of the session. This will enable you to practice the finger tapping sequences for each of the different cues. Rest breaks will be provided throughout the session as necessary. The researchers will record the accuracy and reaction time of your responses.

This session can take place at the University of Western Sydney, Campbelltown campus, or at a venue convenient to you. As part of your participation, you will be asked to give simple demographic information including your age, gender and previous medical history.

Who can join the study?

You are invited to participate if you:

- Have been diagnosed with Parkinson's Disease;
- Have a mild to moderate severity of Parkinson's disease;
- Do not have problems in attention, comprehension, and short-term memory functions.
- You will undergo a short screening to confirm your eligibility. The estimate time required is 15 minutes.

Our participants will be reimbursed with $30 to compensate for their time and travel cost.

For more information, please contact:
Dr. Karen Liu, Associate Professor of Occupational Therapy
T: 02 4620 3432 or email at: Karen.Liu@uws.edu.au

Dr. Michelle Bissett, Lecturer of Occupational Therapy
T: 02 4620 3754 or email at: M.Bissett@uws.edu.au

SHARYN CROCKETT: FUNDRAISING

Sharyn and her friend Lorenza Knight.

> don't really know when I was diagnosed with Parkinson's, it doesn't really matter. I first became aware of my symptoms in 2008, hearing an interview on ABC radio. I realised many of the symptoms mentioned were ones I had. After testing and a consultation with a neurologist, I began medication. Six months later my diagnosis was confirmed.

I joined Parkinson's NSW and received a good-sized bundle of information. I wondered who funded these kits, they seemed like they could be very expensive, but they were very informative for someone who knew very little about PD.

I began to think how I could pay for my kit and hopefully some others as well.

I was walking with my friend Libby, about this time and I invited her to come home to see my linen collection. She was astounded at the quantity and commented that it was too good to keep for myself. And so the first exhibition was planned to make money for Parkinson's, and to share the beauty of my linen with others. The first exhibition was St Patrick's Day 2012 in Cooma. The local craft group supplied the morning teas and all money raised went to Parkinson's NSW.

Since then I've had displays at Adaminaby, Belgenny Farm at Camden, Gosford, Wondalee a farm out from Cooma, in conjunction with ABC open gardens and Orange. I've also been to a few markets and sold off excess linen as well as craft items that my sisters and I make. I also take my linen to community groups and give a small talk bout Parkinson's Disease. I don't want to miss an opportunity.

As I told people I had Parkinson's it became clear the community knew very little about Parkinson's Disease.

The community seemed hungry for information. My campaign to inform the community about Parkinson's began. As Snowy Monaro PD Support Group Leader, I feel this is part of my job. I have adapted the Letter to My Friends to better suit my needs and it became A Letter to My Family and Friends and when I finish reading, there aren't too many dry eyes.

I still get comments about how the letter had given so much information in an easily understood way.

Much of my time is taken up caring for the linen, organising ways to make money and spreading the word about PD as well as doing my bit as leader of the group. I am called upon quite often from people in the community who want to know where to go for help. I visit members of our group who are unwell, and thankfully not very often attend funerals on behalf of the group. A group member sends cards when necessary, which is a great help. I try and contact members to let them know when there is something of significance about PD going to be on the news and distribute the support group newsletters to those connected to the web.

Our Support group meetings are very informal; we go with the flow. Members come along with all sorts of bits and pieces to share including an afternoon tea to die for. We discuss but don't make too many decisions. It is a friendly, warm atmosphere. We have a couple of guests a year who come to the group to give a talk. It doesn't necessarily have to be about Parkinson's. On one occasion a guest told us about a biking trip in Europe.

I'm still looking for a comedian to fulfil one wish!

Another fundraiser was the Snow and Ice Ball. It was hosted by Cooma Ex-services Club, and the Community Chest group and Parkinson's NSW the beneficiary of any profit.

I've also gone to each Unity Walk in Sydney since joining Parkinson's NSW and through the generosity of my family and friends have raised many thousands of dollars over the years.

My husband Malcolm and family are very supportive of me, and my whims. Without him and my three sisters, Lyn Marie and Sue's help it just wouldn't happen. We're a team.

Having Parkinson's hasn't been all bad, I've been able to take some positives. Being young onset has given me the opportunity to do these things before my symptoms come to the point that I'm no longer able. Also I feel PD has brought my team closer together and last but not least, before having PD I was not able to speak in public, the thought terrified me. Now, through my PD community education, I am not too afraid. I have even done a couple of radio interviews.

But I do need prompts or a written speech, as I still tend to forget lots of things.

Sharyn and the Snowy Monaro Support Group

L to R: Chris Searles, Karen Whitton and Teddy Bradley

A small gathering helped Chris Searles celebrate her retirement after 15 years with Parkinson's NSW. We wish Chris a wonderful retirement spending time with her husband Bruce and family.

OUR PEOPLE

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Margi Edmondson

Hospital Clinics:
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Shushann Movsessian (M)
War Memorial
Shushann Movsessian (T)
Wolper
Shushann Movsessian (W)**Westmead**
Deborah England (W)
Concord
Julie Austin (W)

Contact Antoinette Riley, Support Group Coordinator, on 1800 644 189 for more information on a local Support Group in your area

For more information on the Parkinson's Wellbeing Program phone Jeremey Horne (Senior Physiotherapist and program co-ordinator) on 02 95533023

Parkinson's NSW thanks Jeremy for writing and submitting this article in the Autumn edition of *Stand by Me*

IN THIS TOGETHER
parkinson's
NSW

INFOLINE: 1800 644 189

MAKE A DONATION

WORLD PARKINSON'S DAY

APRIL 11 IS WORLD PARKINSON'S DAY.
THIS YEAR, AUSTRALIANS SHOWED THEIR SUPPORT BY GOING #UNBUTTONED.
JOIN US AND GO #UNBUTTONED NEXT YEAR.

I am... **RECENTLY DIAGNOSED**

I am... **LIVING WITH PARKINSON'S**

I am... **YOUNG WITH PARKINSON'S**

I am... **LIVING WITH PSP, CBS OR MBA**

I am... **CARING FOR SOMEONE**

I am... **A HEALTH PROFESSIONAL**

I am... **A SPONSOR OR DONOR**

SUPPORT GROUPS

Albury/Wodonga
Armidale *
Avalon/Pittwater Palms
Ballina/Northern Rivers
Bankstown
Bathurst
Bega Valley
Bingara
Blacktown
Blue Mountains
Broken Hill
Casino
Castle Hill
Central Coast
Central Coast/Medusa Club
Chinatown – City
Coalfields/Lower Hunter
Coffs Harbour
Cowra
Dubbo
Deniliquin
Dundas/Parramatta
Eastern Suburbs
Eurobodalla
Fairfield/Liverpool
Glen Innes
Goulburn
Grafton
Griffith *
Gunnedah
Hawkesbury
Hornsby/Ku-ring-gai
Illawarra
North Illawarra
South Kings Langley
Kogarah/Calvary
Lower North Shore
Macarthur/Campbelltown
Mosman
Manning/Great Lakes
Maroubra
Mid Western/Mudgee
Myall/Tea Gardens
Nambucca Valley
Narrabri
Nepean
Newcastle
Orange
Parkes
PakinSong
Pittwater/Warringah
Port Macquarie
Quirindi
San Remo
Shoalhaven/Nowra
Shoalhaven/Ulladulla
Snowy/Monaro
Southern Highlands
St George/Sutherland
Tamworth
Tomaree Peninsular
Tweed
Ultimo – City
Wagga Wagga
West Wyalong *
Yamba
Yass Working Mens' Group
Younger Womens' Group

* New Support Groups formed in 2015

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