







# Stand by Me

**Inside this issue**  
**Research Grants**  
**Tai chi & Parkinson's**  
**Walking & balance**  
**Unity Walk & Run**

**+ all the regular contributors**



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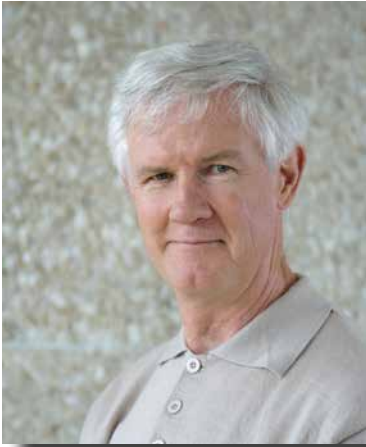


Carer's Quilt.

This quilt has lovingly been put together by a number of Carers of people living with Parkinson's or Parkinsonism within the Shoalhaven area. The Carers Quilt was part of a small project for carers to recognise the importance of taking the time out from their extremely busy lives. Joining a carer's support group is one way to fulfil some of these needs. There are two Carers of People with Parkinson's, Parkinsonism and Parkinson's Plus Syndromes Support Groups within the Shoalhaven, in the Nowra and Ulladulla areas. The support groups consist of carers who join together to give and get support and assistance in coping with common challenges in dealing with Parkinson's, by sharing their experiences and providing support for each other.

If you would like more information on these support groups, please contact Marilia Pereira, Shoalhaven Neurological Nurse Educator, on 44246341 or 0448881669.

# FROM THE PRESIDENT



## I have two issues to mention in this Stand By Me.

Firstly, the campaign to have PD nurses available around NSW is not going to be an easy one, but it's such a logical development for all concerned; we simply cannot afford to back off. As spelled out in previous correspondence, the new structure to bring primary care into the community is centred on Medicare Locals (ML), of which there are to be 18 in NSW. Each Medicare Local has its own structure and priorities, based on the needs of the local community. That means we have to interact at the local level – matching each of our Support Groups to the ML in its area. Communicating the needs of the Parkinson's community to each ML is certainly do-able, especially in view of the energy and passion of Support Group leaders.

The next, much larger, challenge will be to help find the funds to put nurses out in the community. The funding model is complex and, to a degree, unique to each ML; so our task will be to collaborate with ML boards and to pursue every possible avenue for the necessary money. Given the chief source of funds for MLs is federal, coordination among the individual PD organisations across Australia will be necessary too. We'll keep you posted but, if you are keen to play an active role, please contact our office.

The other issue to mention is that there is a lot of promotion about for stem cell and gene therapy, offered both locally and,

more commonly, internationally. I have noticed advertisements next to at least one Support Group web page link. That is a problem because, although this area of treatment holds great promise, it is not, to the best of my knowledge, mature enough to be offered to patients on a routine basis. Undergoing unproven therapies risks, at best, very uncertain benefits and, at worst, serious problems. I appreciate that people in the advanced stages of Parkinson's can be desperate for any possible relief from symptoms; so the gamble may seem worth taking. I fear the odds are too long, though, so I urge anyone contemplating stem cell or gene therapy to consult a neurologist first. In my book, there are some warning signs: many glowing testimonies; suggestions that the therapy can be used for a range of disease conditions; and cost of treatment which is significant, but just within reach for many patients. What people should appreciate is that the many PD advocacy organisations around the world follow all possible therapies with great interest, so any positive development will be announced widely.

To end the year on a positive, note: best wishes for the festive season and we will all work together to make 2013 a year in which the Parkinson's community is able to live well and to face PD with renewed confidence.

A handwritten signature in black ink, appearing to read 'C. Davis'.

Chris Davis

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**Lorna White\***  
**Andrew Whitton**

\* new members

# FROM THE CEO



## New Staff

Our Support Group Coordinator, Trish Morgan, has decided to retire from Parkinson's NSW after eight years of enthusiastically working with our Support Groups throughout NSW. Our best wishes to Trish in her well earned retirement!

Michelle Turner will our new Support Group Coordinator. Like Trish, Michelle has a social welfare background.

Margi Edmondson, Lois Finn and Penny Mawer have all joined the InfoLine Team. All have a wealth of experience in health care. Both Margi and Lois are from a nursing background while Penny is an occupational therapist.

Shushann Movsessian has joined the Counselling Team. Shushann will be establishing the Bondi Lions Parkinson's Clinic at War Memorial Hospital and will be attending the Concord Clinic. She will be available in our North Ryde office on Monday's for counselling.

Crystal Jacobs has joined the Admin/Fundraising Team. She has come to us from South Africa where she worked in Human Resources.

## War Memorial Hospital

It is with delight that we are able to announce a brand new counselling service for the Eastern Suburbs of Sydney. With the financial support of the Bondi Lion's, we will provide a counselling service at War Memorial Hospital, Waverly. Shushann Movsessian will be available on Tuesday's, please call our Freecall InfoLine on 1 800 644 189 to make an appointment.

## New Volunteers Program

Parkinson's NSW has received funding through the Australian Chinese Charitable Foundation for a new initiative - Volunteers Parkinson's Visiting Program. This program is an outreach program for people housebound or living in residential care facilities. The volunteers will be drawn from the Parkinson's community targeting those who are bi-lingual, and members of Support Groups.

This training program will include information on Parkinson's disease, communication and diversional therapy. Please call the InfoLine 1800 644 189 if you would like to register for the training program to commence in Feb/March 2013.

## Postcards Campaign

A big thank you to our members who have embraced our campaign to have each Medicare Local employ a specialist neurological nurse. There are tentative plans for two regional Medicare Locals to employ a specialist neurological nurse within their area and we are hopeful more will come on board.

We continue to lobby both the Federal and State Governments for this funding in establishing specialist nurses in Medicare Locals.

Wishing everyone Season's Greetings and a wonderful New Year! We look forward to an exciting 2013 at Parkinson's NSW with new initiatives.

Miriam Dixon



Margi Edmondson



Shushann Movsessian



Penny Mawer



Lois Finn



Crystal Jacobs





The exercise machine in action

# Research Grants

Is an innovative muscle power training program an effective exercise intervention in Parkinson's disease?

A/Prof Colleen Canning,  
The University of Sydney  
Ms Serene Paul,  
The University of Sydney

In February 2011, Parkinson's NSW provided us with \$59,892 in funds to conduct this project. The aim of the project was to determine whether the benefits of muscle power training on improving muscle power, muscle strength, walking speed and balance demonstrated in the older general population can be gained by people with Parkinson's disease. Forty participants with Parkinson's disease took part in this three month training study, and recorded falls for an additional three months.

Participants were randomly allocated to one of two groups: One group used specially-designed power-training equipment at the University of Sydney in Lidcombe, and the other group trained at home. All 40 people with Parkinson's disease who took part in this study have now completed their training

sessions. There are still a dozen people continuing to record falls for another few months. Participants were from the St George/Sutherland, Parramatta/Dundas, Ultimo and Bankstown support groups, or other members of Parkinson's NSW who volunteered for this project after reading *Stand By Me*.

We wish to thank our enthusiastic participants. We also wish to thank Parkinson's NSW for funding and supporting this initiative. As well as providing the required funds to establish the project, they have given valuable assistance with recruitment by informing members in the relevant areas about the study. Trish Morgan deserves a special mention for her help in linking us to the various support groups.

Preliminary analysis shows three months of power training (using specially-designed power training equipment) is effective and improves muscle power of the leg extensors by 15%. Participants also reported power training improved their mobility. Data analysis for this project will be completed early next year when all participants have finished their falls monitoring periods. We will then submit this project for publication. A summary of results will be made available in *Stand By Me*.

# Copper changes in Parkinson's disease: Implications for cell vulnerability

Chief Investigator, Associate Professor Kay Double (NeuRA).

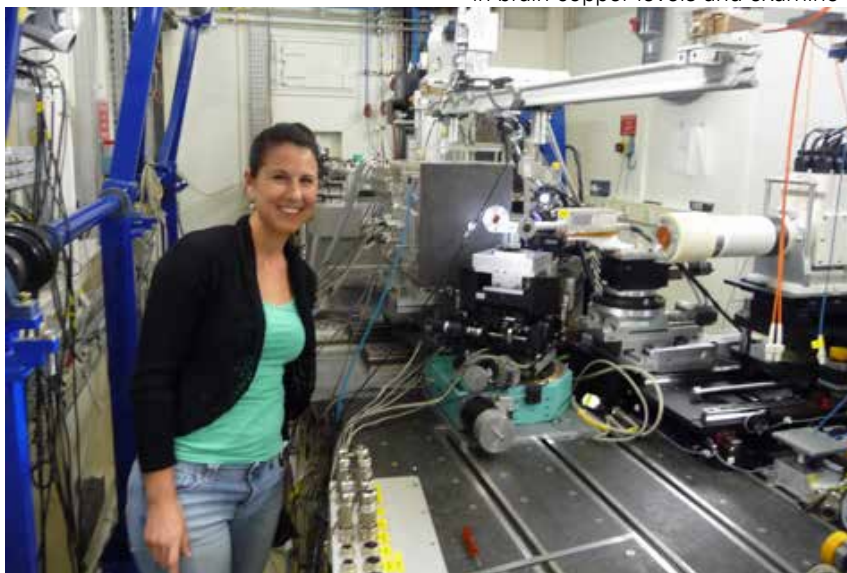
Key researchers are:

Katherine Davies PhD student, Neuroscience Research Australia (NeuRA), Dr. Sylvain Bohic, European Synchrotron Radiation Facility, Dr. Dominic Hare, University of Technology, Sydney, Veronica Cottam, Research Assistant, NeuRA Vanessa Krapp, student, NeuRA, and collaborators, Professor Julian Mercer, Deakin University, and Associate Professor David Finkelstein, Mental Health Research Institute of Victoria.

Too much copper in the brain can be toxic to brain cells, but too little copper can also compromise brain cell health. Thus, a delicate balance of copper in the brain is required for normal brain development and function. It is known that major disruption of brain copper levels is implicated in rare but devastating neurological disorders, including Menkes' and Wilson's disease, and evidence now suggests that disrupted brain copper levels may also play a role in other more common neurodegenerative diseases, including Parkinson's disease. Recently, our group identified a significant reduction in copper levels in the Parkinson's disease brain, specifically in the region where the cells die, called the substantia nigra. There are many proteins vital for brain cell health that depend on copper to function correctly. Thus, we believe this reduction in substantia nigra copper levels in the Parkinson's disease brain is resulting in a reduction in the activity of some of these vital copper-dependent proteins, and this is contributing to the progressive cell damage and death observed in this vulnerable brain region. If this is so, then we would expect that normalisation of brain copper levels in Parkinson's disease would increase the activity of the copper-dependent proteins to normal levels and make the brain cells less vulnerable to damage. We plan to test our hypothesis using a mouse model of Parkinson's disease.

There are many mouse models of Parkinson's disease which each recreate different aspects of the disease in humans. However, no mouse model recreates Parkinson's disease exactly. To test our hypothesis we need a mouse model with reduced copper levels and cell loss in the substantia nigra, as well as reduced copper-dependent enzyme activity. Our aim for 2011 was to identify

and validate such a suitable model. The most commonly used mouse model of Parkinson's disease is called the MPTP model. MPTP is a neurotoxin that recreates the brain cell loss in the substantia nigra that we see in the Parkinson's disease brain. In a preliminary study, we investigated substantia nigra copper levels in a small group of MPTP mice and found that copper levels were not different to control mice, suggesting that this mouse model is not suitable to test our hypothesis in. So, to identify an appropriate mouse model of Parkinson's disease for our investigation, we designed our study to include not only the commonly used MPTP mouse model, but also a novel mouse model of Parkinson's disease. This novel mouse model has a mutation in a gene that encodes a protein that is thought to pump copper into the brain, causing these mice to have reduced total brain copper. We used the neurotoxin MPTP



in these mice with the aim of producing a mouse model with reduced copper and cell loss in the substantia nigra; an ideal model for our investigation. We then set about validating this model.

Over the past year we have completed detailed analyses of substantia nigra copper levels in these mice. We were granted access to use a specialised facility in Grenoble, France, called the European Synchrotron Radiation facility. This rare opportunity enabled us to measure copper levels in the mouse substantia nigra with extremely high precision. While we found no change in substantia nigra copper levels in the MPTP mouse model, substantia nigra copper levels were significantly reduced in our novel mouse model. These findings were confirmed using a second independent method, laser ablation (LA)

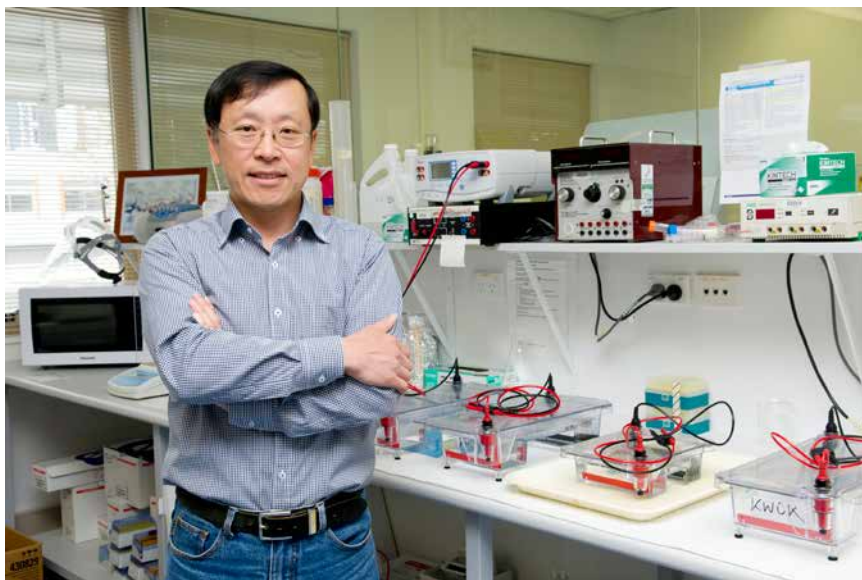
ICP-MS, which used different principles to measure copper levels at the larger, regional, level in the mouse brain. These two complementary methods have provided us with robust, reliable data suggesting that, with regards to substantia nigra copper levels, our novel mouse model is suitable to test our hypothesis in, and confirming that the MPTP model is not appropriate. We are now in the process of investigating dopaminergic cell loss in the substantia nigra, and striatal dopamine levels (a measure of brain cell activity), and will soon know whether our novel model has reduced copper levels in the substantia nigra, as well as brain cell loss, and diminished brain cell activity, as seen in the Parkinson's disease brain.

In the next stage of this project we will soon look at the activity of various copper-dependent proteins to assess the functional effects of the reduction in brain copper levels and examine

this matches with what we see in the human brain in Parkinson's disease.

The outcome of this project will be the establishment of a mouse model of reduced brain copper associated with substantia nigra cell death and reduced copper-dependent protein activities. We will use this mouse model for subsequent experiments that demonstrate supplementation with copper can restore brain copper levels, and copper-dependent protein activities, and reduce brain cell death. Ultimately, our project will lead to a better understanding of why specific brain cells are vulnerable in Parkinson's disease and may lead to the development of novel therapeutic targets for Parkinson's disease which aim to correct reduced levels of brain copper.





Dr Scott Kim

# Research Grants

Dr Scott Kim  
Neuroscience Research Australia

## The role of lipid in $\alpha$ -synuclein pathology

Firstly, I would like to thank Parkinson's NSW for the generous Unity Walk grant in 2011. This grant has allowed us to undertake research in a new developing area of Parkinson's disease research – the role of lipid in  $\alpha$ -synuclein pathology.

Our study has produced data revealing new insights into how lipid may regulate  $\alpha$ -synuclein production in neuron. Our findings have now been published as a peer-reviewed paper in a leading international journal, the *Journal of Parkinson's Disease* (Kim and Halliday 2012 Changes in sphingomyelin level affect alpha-synuclein and ABCA5 expression. *Journal of Parkinson's Disease* 2:41–46).

Although the human brain is extremely rich in lipids (fats), such as cholesterol and sphingomyelin, very little is known about their role in the pathological processes of Parkinson's disease. Recently, we and others have identified a group of proteins called ATP-binding cassette (ABC) transporters that regulate lipids in the brain and a number of neurodegenerative disease processes.

However, the role of ABC transporters in the neurodegenerative processes of Parkinson's disease was fundamentally unknown. A recent paper indicated that one member of the ABC transporter family, ABCA5, was genetically associated with a reduced risk for Parkinson's disease. Until now virtually nothing was known about the functional role of ABCA5 in the pathological

processes of Parkinson's disease, although loss of ABCA5 in mice replicated a lysosomal storage disorder similar to Gaucher's disease, which is caused by GBA mutations. Heterozygous GBA mutations are the most common genetic risk factor for Parkinson's disease.

We therefore proposed a hypothesis that ABCA5 functions as a lipid transporter in neuron and regulates the  $\alpha$ -synuclein neurodegenerative process in Parkinson's disease.

Our principal aims of this project were: to determine the impact of sphingomyelin (a major lipid component of the neuron plasma membrane) on  $\alpha$ -synuclein and ABCA5 expression; and to determine whether the expression of ABCA5 is altered in Parkinson's disease brain.

We have found that when neurons were treated with sphingomyelin the expression of both  $\alpha$ -synuclein and ABCA5 was significantly increased, indicating that  $\alpha$ -synuclein production is intrinsically linked to the neuronal sphingomyelin level. We also measured the level of ABCA5 expression in Parkinson's disease brains and age and gender-matched control brains.

The expression of ABCA5 in Parkinson's disease brains was significantly elevated compared to the control brains, possibly as a protective response to the disease.

These new data, along with the fact that the sphingomyelin level is elevated in Parkinson's disease brain and that ABCA5 is genetically associated with a reduced

risk for Parkinson's disease, provide new evidence indicating that the neuronal sphingomyelin level may be important in the  $\alpha$ -synuclein neurodegenerative process in Parkinson's disease.

Our findings have been published as a peer-reviewed paper in a leading international journal and also reported as a poster presentation at the Australian Neuroscience Society conference at the Gold Coast on 29 January –1 February 2012.

The kind support from Parkinson's NSW has been acknowledged in both the paper and in the poster presentation.



# FROM THE CEO, PARKINSON'S AUSTRALIA



The past few months have been busy with many different issues occupying my time.

In relation to our national focus on promoting the need for more Parkinson's nurses around Australia, I met with, and addressed, the Executive of the Movement Disorders Faculty of the Australian Nursing Association. They strongly support our approach and will actively lobby for the cause.

On a beautiful Sunday in late August, with my wife, daughter, son in law and two gorgeous granddaughters, I joined over 400 supporters of Parkinson's in the ACT Unity Walk. It was a great day.

I continue to be involved in preparations for the 3rd World Parkinson Congress in Montreal, Canada, from 1 to 4 October 2013. This is a wonderful opportunity for us to promote awareness of the needs of people with Parkinson's on a world wide basis.

The National President, John Bird, and I visited Perth to meet with Brenda Matthews and her staff and

John McDonald and the Board of Parkinson's WA. It was an enjoyable, if brief, visit. I have now visited all of the mainland states.

This month we held our Annual General Meeting and our Annual Report will be available on our website soon.

My best wishes to all for Christmas and the New Year.

Daryl Smeaton

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# Walking & BALANCE

in Parkinson's Disease



Dr Paul Clouston, Neurologist

Impaired walking and balance are two of the major therapeutic challenges in Parkinson's disease.

In early Parkinson's disease walking speed may be reduced and the size of each step may be smaller but often, this may be compensated by increasing the speed of each step. Accompanying this may be a pattern of walking called 'festination' where rapid small steps are made in an attempt to keep the centre of gravity between the feet while the trunk is involuntarily stooped forward. These walking patterns often respond to medication, at least in the early years of the disease

Later on, both falls and 'freezing of gait' (FOG) may become major issues, unresponsive to current medical treatment. Falls are a major

source of morbidity and mortality leading to dependency, institutionalisation and reduced quality of life. Most falls are due to loss of control of balance and may occur during changes in posture. FOG is a transient disruption of walking that lasts a few seconds where patients feel their feet are glued to the ground. It may occur during initiation of walking or be triggered by seeing an obstacle, a confined space or if the patient is fatigued. Occasionally FOG may lead to a fall.

The response of walking and balance disorders to medication, used either to increase levels of dopamine in the brain or to stimulate dopamine receptors, decreases over time. This has led to the conclusion that the neurons that degenerate and cause balance and walking problems later on in the disorder may lead to a loss of effectiveness of neurotransmitters, other than dopamine, that mediate walking. Medications that target the

receptors of these other neurotransmitters are currently under investigation.

Later onset walking difficulties may also occur in patients who have undergone deep brain stimulation (DBS) of the subthalamic nucleus (the most common form of DBS). For this reason, other groups of neurons within the brain, such as the pedunculopontine nucleus, which has a role in mediating walking, have been targeted for DBS with mixed results.

Currently the mainstay of treatment of medication resistant disordered balance and walking in Parkinson's disease is rehabilitation. Compared with no intervention almost any graded exercise or balance program has been shown to be beneficial. These programs can be tailored to a patient's specific problems, under the guidance of a physiotherapist or rehabilitation specialist with a specific interest in Parkinson's disease.

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## Tai chi for balance & falls reduction

Recent research published in the prestigious international *New England Journal of Medicine* shows that Tai chi improves balance and mobility and reduces falls in people with mild to moderate Parkinson's disease.

This large randomised controlled trial conducted by Fuzhong Li and colleagues at the Oregon Research Institute (USA) included 195 people with mild to moderate PD. Participants were randomly assigned to one of three exercise types: tai chi exercise, resistance exercise and stretching exercise. Tai chi exercises are designed to progressively challenge balance and these exercises were performed while standing, stepping and walking. Resistance exercise is designed to increase strength in leg muscles using weighted vests and ankle weights to progressively increase resistance to movement, and these exercises were performed in standing. Stretching exercises included low-intensity breathing, flexibility and relaxation performed in sitting. All groups participated in 60 minute exercise sessions, twice a week for six months and all exercise sessions were conducted in a supervised group format.

The tai chi group made the largest improvements in balance compared to the other two exercise groups. The

tai chi group also showed a lower rate of falls compared to the stretching group. No major adverse events were reported

for any exercise group, although there were infrequent reports of falls during exercise, muscle soreness or pain and dizziness or feeling faint.

This study adds further evidence to support the potential for people with PD to improve balance by practicing exercises which deliberately challenge balance, ie, exercise while standing, stepping and walking encouraging the person to work close to their balance limit. In addition, this is the first study to show that exercises which challenge balance reduce the likelihood of falling in PD.

It should be noted that the majority of participants in this study were in the earlier stages of the disease, so it cannot be concluded that exercises that challenge balance will have the same effect on those with more advanced disease. People with PD are advised to seek advice from a physiotherapist to ensure that exercises performed are both safe and effective, and that the exercise program is updated on a regular basis.

To access physiotherapy services:

- Public or private hospitals – enquire whether the physiotherapy outpatients department offers services for people with neurological conditions
- Private physiotherapists. Contact the Australian Physiotherapy Association [www.physiotherapy.asn.au](http://www.physiotherapy.asn.au) and click on the red Find a Physio button on the right of screen) and request the

contact details of physiotherapists in your local area with an interest in neurology or aged care (gerontology).

To access falls prevention/exercise classes (which generally are not specifically designed for people with PD, but which may be appropriate for some people with PD, go to the following websites:

[www.activeandhealthy.nsw.gov.au](http://www.activeandhealthy.nsw.gov.au)

[www.heartmoves.heartfoundation.org.au/](http://www.heartmoves.heartfoundation.org.au/)

If you require further assistance in accessing physiotherapy services, please call the infoline on 1800 644 189.

Summary of published paper:

Li, F et al (2012) Tai chi and postural stability in patients with Parkinson's disease. *N Engl J Med* 336;6:512-519

Summary by:

Associate Professor Colleen Canning  
The University of Sydney

# AN EXTRAORDINARY DAY

The 5th Anniversary Parkinson's NSW Unity Walk & Run, held on Sunday August 26th, was once again a great success.

Since its inception five years ago, this event has become an eagerly awaited fixture on the sporting calendar, attracting growing numbers of participants, fundraisers and sponsors.

This year, total attendance was almost 2 000, an increase of more than 15% on the previous best, with Walk numbers up 14% and the Run attracting some of Australia's elite athletes. Ben St Lawrence, who represented Australia in the 10 000 metres at the London Olympics, was the men's winner; while the women's winner, Chloe Tighe, represented Australia at last year's World

Cross Country Championships.

Also making a welcome appearance were the spectacular new T-shirts, which made a stirring sea of purple in the crowd. Entertainment was provided by this year's Talent Development Project graduates, while the performance by David De Vito from Australia's Got Talent brought the audience to its feet!

Sponsors include loyal major supporter Bendigo Bank, which has supported the event for five years enabling Parkinson's NSW to begin a Research Grant program. Proceeds from the Walk & Run helps finance researchers to understand, improve treatment and find a cure for Parkinson's.

Of the team fundraisers, the St George/Sutherland Support

Group was the winner, raising \$18 260. Everyone who raised \$100 and more won a ticket to a prize draw. The winner, Anita Byrne, earned 10 tickets and took home a Samsung Galaxy Tab 2, plus a financial planning session courtesy of Bendigo Bank.

Top individual fundraisers Andrew and Karen Whitten raised more than \$10,000 and will soon be on their way to Hayman Island to enjoy their reward. Other invaluable support was provided by fundraisers who made more than \$2 000 each – Coffs Harbour Banana Benders, Elise Norton, Lauren Warburton, Simon Lewis, Natalie Anderson, Myra Chalmers, John Silk, Ben Sprange, Bernie Atkinson Ella Martin, Owen Streatfield, Robyn Rota and Edwina Hughes.





# UNITY WALK & Fun Run



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# The James Parkinson Society Bequest Lunch

The 6th Annual Bequest Lunch was held on 25th October, The Grand Pittwater Room, North Ryde RSL, attended by 80 members of the James Parkinson Society and staff.

The 6th Annual Bequest Lunch was held on 25th October, The Grand Pittwater Room, North Ryde RSL, attended by 80 members of the James Parkinson Society and staff. This is a day

of celebration and thanks to those who have left a bequest to Parkinson's NSW and members who support the program. Bequests insure we can look after people living with PD for generations to come.

Guardian Funerals, Northern Suburbs Crematorium and Memorial Gardens at North Ryde are always generous sponsors of this event. They are members of the Invocare Group who give generous financial support to many community events like ours.

Billie Wilde, a regular guest on many TV variety shows, entertained us. Billie was in Jesus Christ Super Star with John Farnham and a support act for Frank Sinatra, Frankie Lane and Peter Allen.

Associate Professor Kay Double, a neurochemist and Parkinson's disease researcher at the Sydney Medical School, University of Sydney was inducted into the James Parkinsons Society by our President Chris Davis. Kay, a long time supporter of PNSW, was a member of

Parkinson's NSW Council from 2006 to 2011 and continues to serve on the Advisory Committee. Following her induction, Kay said she made her bequest to the association because she was aware of how much good a bequest to PNSW can make to the lives of people with Parkinson's disease and she strongly supports the work of the association.

If you would like to find out more of how you can leave a gift in your will to Parkinsons NSW and/or need assistance with information or wording please feel free to speak with me in confidence, I am available to assist in any way. Knowing your memory will live on in the gratitude of strangers is certainly a contribution worth making.

Isabelle Clark – Bequest Officer

e: [Isabelle@parkinsonsnsw.org.au](mailto:Isabelle@parkinsonsnsw.org.au)  
m: 0403-324486 or telephone  
the InfoLine 1800 644 189



A/Prof Kay Double with Chris Davis

## The Winston Churchill Memorial Trust Fellowships

**2013 applications are now open.**

These Fellowships support Australians to travel overseas to conduct a research project which will improve their contribution to the Australian community. Specifically the Dr Dorothea Sandars Fellowship supports research into Parkinson's disease.

### Closing date:

Wednesday 20 February 2013.

Application forms can be downloaded from  
[www.churchilltrust.com.au](http://www.churchilltrust.com.au)

or contact the National Office on 1800 777 231.



# Accredited **TOASTMASTERS** for **PARKINSON'S**

We are thrilled to introduce three enthusiastic people for our Toastmasters Accredited Speakers Program! This program mentors and trains Toastmasters and members of Parkinson's NSW to raise awareness of Parkinson's to the wider community.

Lucky Joeng is the Chairperson for the Parkinson NSW Toastmasters Awareness Group.

Lucky's scientific and engineering background enables him to explain scientific publications and research to the general public in a concise, simple manner and is keen to provide mentorship in presentation skills and tips.

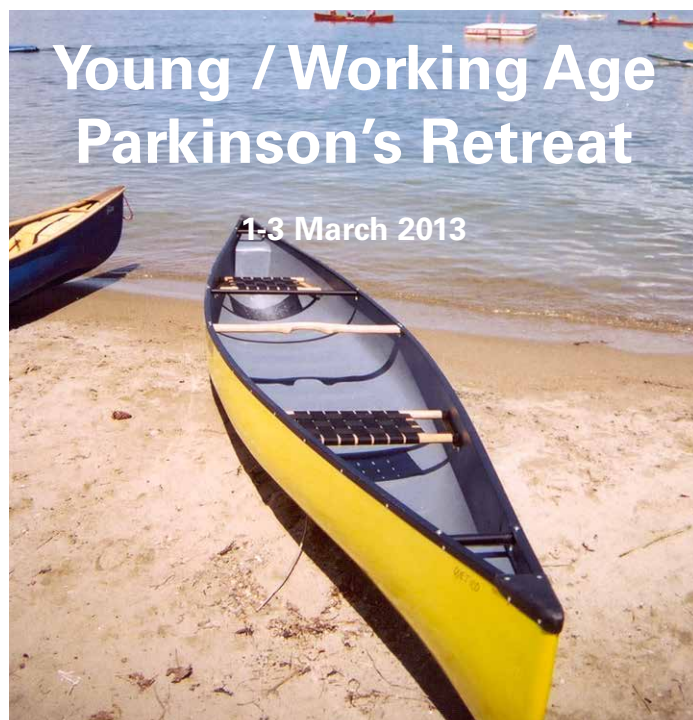
Gloria Carter has been a professional singer, former President of Randwick-Botany Meals on Wheels and inaugural President of Kincoppal-Rose Bay Toastmasters. Her husband has Parkinson's, she has first hand experience of living with Parkinson's. Gloria is passionate about raising awareness of Parkinson's in the community and gaining more help for all those affected by Parkinson's.

Crystal Jacobs will be the point of contact for requests for presentations and she is writing to service clubs, encouraging them to take up the offer of a presentation on Parkinson's.

If you would like to become a presenter or would like to nominate a venue for a presentation please contact Crystal at Parkinson's NSW through our InfoLine 1800 644 189 or email [crystal@parkinsonsnsw.org.au](mailto:crystal@parkinsonsnsw.org.au).



L to R Lucky, Gloria and Crystal



**Point Wolstoncroft Sport and Recreation Centre is located on the eastern foreshore of Lake Macquarie, just one hour north of Sydney or 45 minutes south of Newcastle.**  
**To register your interest and receive more information, contact the InfoLine**

# On the groupvine

What a wonderful eight years it has been. There are so many faces and memories. Shoalhaven Shakers sent me a letter of welcome on my appointment in February 2005.

Coalfields were the first to invite me to their meeting so I was happy to travel to the Hunter Valley to meet in the pub at Neath and stay for lunch. This was the start of my life with PNSW.

Highlights have been the first road trip to Tamworth where I learnt people needed to book an appointment a month in advance just to get a script from the GP. From there I went over the Dorrigo to stay with Vera Heil and attend Coffs Harbour support group at the Catholic Club with members coming for a bistro lunch before the meeting. I went up to Casino to the support group and the meeting was put back an hour to allow for my driving time from Grafton, where I had stayed overnight.

Chinatown Bi-Lingual Support Group started in March 2005 and members of the board and other support groups were there.

In my first year I also travelled to Yass via Bathurst and Cowra and later in the year visited coastal groups at Newcastle, Nowra and Forster.

In the metropolitan area there was a need for new groups at Liverpool, Bankstown, Blacktown, Manly/Mosman and Maroubra. Other groups just started themselves with the input of keen leaders at Gunnedah,

Bingara, Yamba, Nambucca Valley and Kings Langley. New groups were formed at Bega Valley, Myall/Tea Gardens, Ultimo, Narrabri, Goulburn, Blue Mountains, and San Remo. Some were developed in more than one location as Shoalhaven Shakers at Nowra opened a support group in Ulladulla. A few groups closed, namely Canterbury, Griffith, Muswellbrook, Quirindi and Orange, which closed in 2006 and re-opened in 2009.

I flew to Albury, Parkes and Wagga Wagga and to the far south coast to Eurobodalla and Bega Valley Support Groups. In 2011 I flew with Deborah England to Lismore to start the group and drove to Glen Innes to have dinner with their members. This year Miriam Dixon, Deborah England and I flew to Lismore and visited groups in Casino, Grafton and Ballina. I took a week's holiday in May this year to Broken Hill and was treated by the support group to a wonderful experience. Last month we drove to Mudgee for a full day seminar organised by the new Mid Western Support Group and attended by over 90 people including support groups from Dubbo, Tamworth, Narrabri and Cowra.

Many support groups have organised seminars including St George/Sutherland, Southern Highlands, Central Coast, Coffs Harbour, Goulburn, Newcastle, Coalfields, Tweed, Parkes and Port Macquarie. Others have hosted seminars in the 'Living Life with Parkinson's' series.

There are our longest running support groups of Dundas/Parramatta and Newcastle closely followed by Hornsby/Ku-ring-gai, St George/Sutherland, Central Coast, Hawkesbury, Tamworth and Eurobodalla which turned 20 this year. Other support groups like Macarthur, Castle Hill,

Nepean, Eastern Suburbs, Pittwater/Warringah, Manning/Great Lakes, Lower North Shore, Tomaree and Illawarra North and South have been serving their communities for many years.

I have managed to visit nearly all of you – with a rail trip to Cooma in September this year to attend the Snowy/Monaro group. Unfortunately, Deniliquin/Finley was beyond my reach.

One of the most enjoyable times has been the Bi-annual Support Group Leaders Meetings held at North Ryde. It is wonderful to see members getting together. Great friendships have been made and members keep in touch with each other. The Unity Walk has also been a wonderful gathering place where I have met your extended families.

The Young Men's Network has been a success and the Young Women (Tulip Belles) are supporting each other by teleconferences, email and Facebook. The Central Coast Young Onset Group, aka 'The Medusa Club', is enjoying its varied social life. These groups are coming together with the original Speeding Vibrations group who meet for lunch on Sundays three or four times a year.

I feel confident that Michelle Turner brings a lot of skill and understanding to the role of Support Group Coordinator and I know she will enjoy meeting you all.

Thank you for your friendship and the happy memories I take with me.



# On the groupvine

Parkinson's NSW welcomes Michelle Turner.

Michelle is Parkinson's NSW new Support Group Coordinator, replacing Trish who has retired.

Michelle worked as a social welfare worker with neurology patients while at Royal North Shore Hospital. She has just begun in the Parkinson's office working Monday to Thursday.

Michelle believes support groups help people in many ways, enabling them to understand more about their condition and to share information and to support with one another.

In her first month, sharing this time with Trish, Michelle has met with the Bankstown, St George/Sutherland, Hornsby/Ku-ring-gai and the Coalfields Support Groups. She also met support group members at the Parkinson's Awareness Seminar at State Parliament House and the Bequest Lunch.

She said, "what was evident to me with every group was the warmth and the outstretched hand of friendship generated when members and carers come together. Groups are varied in size, but what seemed evident was all were busy with events and activities. I believe in the philosophy, aims, objectives, development and maintenance of support groups. By being or becoming a support group member there are many positive aspects gained for better health and well-being.

So far Parkinson's NSW has shown itself to be an impressive organisation, full of dedicated, caring and skilled workers and I am proud to have been chosen to be part of this valuable group. I am happy to be contacted at any time you may have any queries, information to share, concerns or just to have a chat."

You can contact Michelle by calling the Parkinson's NSW office or email [michelle@parkinsonsnsw.org.au](mailto:michelle@parkinsonsnsw.org.au)

**Phone the InfoLine for your nearest Support Group**  
**1800 644 189**



Miriam Dixon, Deborah England and Trish Morgan meet with Support Group Leaders from Ballina, Lismore, Tweed and Yamba



Pat & Allan Johnson celebrating 20 years of Tamworth Support Group

## Parkinson's NSW Support Groups

Albury/Wodonga Support Group	Goulburn Support Group	Port Macquarie Support Group
Armidale Support Group	Grafton Support Group	San Remo Support Group
Ballina (Northern Rivers) Support Group	Gunnedah Support Group	Shoalhaven/Nowra Support Group
Bankstown Support Group	Hawkesbury Support Group	Shoalhaven/Ulladulla Support Group
Bathurst Support Group	Hornsby/Ku-ring-gai Support Group	Snowy/Monaro Support Group
Bega Valley Support Group	Illawarra North Support Group	Southern Highlands Support Group
Bingara Support Group	Illawarra South Support Group	Speeding Vibrations Support Group
Blacktown Support Group	Kings Langley Support Group	St George/Sutherland Support Group
Blue Mountains Support Group	Lismore Support Group	Tamworth Support Group
Broken Hill Support Group	Lower North Shore Support Group	The Medusa Club
Casino Support Group	Macarthur Support Group	Tomaree Peninsular Support Group
Castle Hill Support Group	Manly/Mosman Support Group	Tweed Support Group
Central Coast Support Group	Manning/Great Lakes Support Group	Ultimo Support Group
Chinatown Bilingual Support Group	Maroubra Support Group	Wagga Wagga Support Group
Coalfields Support Group	Mid Western Support Group	Working Age Men's Support Group
Coffs Harbour Support Group	Myall/Tea Gardens Support Group	Yamba Support Group
Cowra Support Group	Nambucca Valley Support Group	Yass Support Group
Deniliquin Support Group	Narrabri Support Group	Young Women's Support Group (Tulip Belles)
Dubbo Support Group	Nepean Support Group	
Dundas/Parramatta Support Group	Newcastle Support Group	
Eastern Suburbs Support Group	Orange Support Group	
Eurobodalla Support Group	Parkes Support Group	
Fairfield/Liverpool Support Group	Pittwater/Warringah Support Group	
Glen Innes Support Group		

# Pancakes for Parkinson's

As part of our studies at The University of Western Sydney (UWS), Hannah Sampang, Katrina Willis and I have taken on the Pancakes for Parkinson's project.

This project is designed to create a means of sustainable fundraising and awareness for Parkinson's NSW, whilst providing our group

with valuable experience to complement our education.

An important landmark in the project occurred on Wednesday October 17 at the UWS Parramatta campus, where we held a Pancakes for Parkinson's event. This event raised awareness of Parkinson's disease through the distribution of pamphlets and pens (the latter a big hit amongst students), whilst raising funds for Parkinson's NSW through the sale of pancakes and donations. In financial terms the event raised \$115 for Parkinson's NSW, a solid result which was greatly assisted by the kind donation of pancake mix and maple syrup from

Greens General Foods Pty Ltd. However, the greater outcome was the number of times students came along and asked questions about Parkinson's disease and left with a greater awareness of the disease (and a pancake or two). The final stage of our project will be to provide Parkinson's NSW with an online pamphlet with tips and instructions for other groups to host their very own Pancakes for Parkinson's event and continue the fund raising and awareness efforts.

By Jeffrey Ransom, on behalf of the UWS Pancakes for Parkinson's team



The cooks



The cook waiting for the hungry hordes

## ADVERTISEMENT

Arnold Thomas and Becker, solicitors, have called an information meeting for sufferers of Parkinson's, restless legs or pituitary gland tumours and who were prescribed **PERMAX, CABASER** and **DOSTINEX** and suffered changed and abnormal behaviours. A class action has been commenced in the Federal Court claiming compensation for groups of such persons who have suffered loss or damage.

The Federal Court has ordered that information be provided to people who might be group members and has required that any person who is a group member and who does not wish to be bound by the result of this class action, must opt out of the proceeding by completing an opt out form **BEFORE 15 FEBRUARY 2013**.

With the assistance of the Salvation Army, Arnold Thomas and Becker have arranged for Mr. John Rowe, barrister, to explain the nature of the process, who may have claims, nature of the claims and answer questions.

**WHERE:** SALVATION ARMY  
140 ELIZABETH STREET, SYDNEY.  
**WHEN:** 17 DECEMBER, 2012 at 2PM

In attending this meeting you will incur no obligation and no cost. For more information contact Arnold Thomas and Becker at

[www.arnoldthomasbecker.com.au](http://www.arnoldthomasbecker.com.au),  
Telephone 1300 333 300  
or (03)9614 1433.



# HOP HOP for Parkinson's

On Saturday, 15 September North Balgowlah Dance School hosted their 20th Anniversary Party.

All money raised was donated to Parkinson's NSW. Teresa Geraghty, Principal of the School, generously organised the event and fundraising for Parkinson's, inviting past and present students, and the local community. Paula Argy, a young mum with Parkinson's, two girls Greta 12 and Mary 10, have been attending North Balgowlah Dance for more than eight years.

There was a HIP HOP class for everyone with a gold coin donation, cake stalls, jumping castle and face painting. Before the class started, Greta performed a solo HIP HOP dance. Paula and her girls set up a merchandise and information table. The day was a huge success raising \$683.40 for Parkinson's NSW support services and research



L to R Paula Argy, Mary Argy age 10, Greta Argy Age 12, Geraghty, Principal Dance, Erin Geraghty age 6

## The Golden Team

On Sunday the 12th of August Parkinson's NSW entered a team of 10 into the Golden Charities section of the City2Surf.

Our team of Sonya Gillies, Maria Boznovska, Jolyon Dare, Graham McDonald, Beatriz Martinez, Simon Lewis, Rosemary Lotorto, Sophie Jiang, Debora Harris & Katherine Peverell together exceeded our target of \$20,000 and raised \$23, 995. Well done and the money will be used towards extending the services we offer on the free InfoLine and counselling services to those suffering with PD, their families & carers.



The Parkinson's cheer zone.  
The photograph shows the speed of the runners rather than the ability of the photographer.

# The RESULTS are IN

90%

OF OUR READERS  
ARE OVER 55

THE RESPONSE WAS OVERWHELMING

WHAT YOU LIKE

96%

People read *Stand by Me* to keep up with the latest medical research into Parkinson's. an overwhelming. This is closely followed by what is happening at Parkinson's NSW

95%

Like to read the magazine in print

Most readers, 80% found the layout easy to read with 20% of readers finding the layout good to read

The most important sections are,  
1. Research Updates, 2. Health/Symptom Management  
3. Personal Stories

55% of respondents read *Stand By Me* only once  
On average, two people read each issue of *Stand By Me*: the person living with Parkinson's and their partner or carer

Readers said they like the large print and new layout. "The magazine is not too technical and written in lay terms." It helped members feel they belonged within the Parkinson's community, with personal stories helpful and encouraging. "You like learning what help is available and how different people cope."

Many readers used the magazine as a way of keeping up with all aspects of Parkinson's including medication, events and activities.

**"The magazine is informative, interesting and well edited."**

## WHAT YOU MIGHT CHANGE

The majority of our readers are satisfied with *Stand By Me* and had no dislikes. Some think the glossy paper makes it hard to read and they thought the cost of the production of the magazine was too costly and suggested the newsletter be in email format, while others wanted the newsletter more frequently

You want more regular recognition of fundraisers, activities and people. Overwhelmingly you want more information on research in Australia and overseas including the trials available.

Thank you for all your comments and we are working to incorporate your input. This is your magazine and we want it to reach and fulfil the needs of as many people as is possible.



# Donations

## Donations over \$50 FY12

Jim McDougall  
Flora McDowell  
Ken & Mary McGovern  
Joy McGrane  
James Mcgrath  
John McGregor  
BF McInerney  
Alan & Evelina McIntosh  
Geoff McIntosh  
G & A McIntyre  
Donald McKay  
Don McKennan  
Alison McKnight  
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Rob McNeill  
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Shirley Michell  
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Steve & Jennie Panozzo  
George & Daphne Papapandos  
Phil Papworth  
Andrew Pardoe

John Pardoe  
Devang Parikh  
John Park  
Frank Parker  
June Parker  
Foola Parmax  
Elizabeth Parsons  
Alice Paton  
Sue Patterson  
Malcolm Paynter  
John Peachey  
Sheila Peattie  
Tony & Dell Pedemont  
Eion Pengilley  
Imelda Penny  
Mary Perrottet  
Beryn Petersen  
Doreen Petty

## In Memorium

Patricia Albury  
Yiannoulla Alexandrou  
Yvonne Ashton  
Todd Barton  
Gwen Benton  
Hazel Bevan  
Allan Bible  
Don Bland  
James Bunyan  
Giuseppe Calcagni  
Violet Camilleri  
Rina Casali  
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Maira Hodges  
Ros Holmes  
Gerald Hull-Moody  
Lester James  
Warren Jesson  
Alexander Jimenez  
Thelma Keane

Frank Kjeldsen  
Odysseas Klioufiss  
Joseph Lalor  
Violet Latty  
Leslie Law  
Jeffrey Ronald Lennon  
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Thea Spartalis  
John Allen Stormon  
Gordon Swan  
David Taylor  
Rosemary Thompson  
Nicholi Tokmakoff  
Markella Townsend  
David Townsend  
George Turner  
Adrianus Veenhuis  
Rex Waghorn  
Lee Walker  
Keith Waller  
Edwin Warby  
Lex Webb

## Celebration

80th Birthday of Gordon Boulous  
80th Birthday of Wally Budd  
80th Birthday of Marie Procter  
50th Wedding Anniversary  
of Rebecca & John Silk  
50th Wedding Anniversary  
of Judi & Allan Simpson  
60th Wedding Anniversary  
of Lea & Leon Portrate



Parkinson's NSW would like to acknowledge the support received from Eventide Homes over many years.

Photo. John and Becky Silk receiving the cheque from members of the Eventide Board.



*Golf Umbrella*

**\$40**



*Apron*

**\$20**



*Keep Cup*

**\$13**



*Tea Towel*

**\$10**

**Christmas is just around the corner!**

**Friends Shop**

Visit us at [www.nswmealsonwheels.org.au/Shop](http://www.nswmealsonwheels.org.au/Shop)



**More than just a meal**



# WHAT'S ON

1-3

**MARCH**  
Young Working Age  
Weekend

11

**APRIL**  
World Parkinson's  
Day

## Guest Contributors

A/Prof Colleen Canning  
Dr Paul Clouston  
Dr Scott Kim  
A/Prof Kay Double  
Darryl Smeaton  
Jeffrey Ranson

## Editor

Linda Davies (with the help of the Parkinson's  
NSW office)

## Parkinson's NSW Inc

1800 644 189  
PO Box 71  
North Ryde BC NSW 1670

**For your local Support Group please call  
1800 644 189**

[pnswn@parkinsonsnsw.org.au](mailto:pnswn@parkinsonsnsw.org.au)  
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[www.facebook.com.au/parkinsonsnsw](http://www.facebook.com.au/parkinsonsnsw)  
[www.twitter.com/parkinsonsnsw](http://www.twitter.com/parkinsonsnsw)

4-5

**MAY**  
Parkinson's Motorbike Ride  
- Sydney Olympic Park to  
Parkes

13-14

**JUNE**  
Support Group  
Leader's meeting  
(Sydney)

15-16  
JUNE

**Patient Movement  
Disorders Society  
meeting (Sydney)**

25

**AUGUST**  
Unity Walk and Run

4

**SEPTEMBER**  
Allied Health  
Awareness Seminar

13

**OCTOBER**  
World Parkinson's  
Congress (Montreal)

25

**OCTOBER**  
Bequest Lunch (TBA)

12

**NOVEMBER**  
AGM

14

Golf Day

**To RSVP for events please call the InfoLine 1800 644 189**

Parkinson's NSW Inc ABN 93 023 603 545

The information provided is for guidance only and is not a substitute for professional medical advice. Parkinson's NSW Inc. takes reasonable care (in the context of freely available information) to keep the information it provides accurate and up-to-date; however, Parkinson's NSW does not guarantee the correctness and completeness of the information. You should confirm that the information is applicable to your circumstances by checking it with your doctor or a qualified health care professional.