

Stand_{by}Me



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**Eye Movements & Balance
in Parkinson's Plus**

Tremor & Parkinson's Disease

A Marathon and a DASH

Helping Hands

Frozen Gait

+ all the regular contributors

JOIN US TO PROVIDE “HELP FOR TODAY AND HOPE FOR TOMORROW”



The Big Ride 4 Parkinson's 4-5 May 2013 | Sydney to Parkes NSW

Get your motors runnin'. Head out on the highway - for charity. Lookin' for adventure at the end of the ride - The Big Dish!

Parkinson's disease affects 80,000 Australians and the Parkes region of western NSW has one of the highest incidences of Parkinson's disease per capita in the country.

With your support, we hope to fundraise a substantial amount of money, which will help us to improve services for the Parkinson's Community across NSW, especially in regional and rural areas, like Parkes.

To register and show your support visit:
<http://thebigride4parkinsons.gofundraise.com.au>

Don't let
Parkinson's
fly under
the radar



RUDY'S STORY

Rudy's passion has always been motorbikes.

When diagnosed with Parkinson's disease Rudy was just 46 years of age.

Now 54, he is restricted

to a radius of 100 km and cannot ride at night. Imagine what that means to someone who has enjoyed the wide open spaces for most of his life. Rudy is supported by Parkinson's NSW counselling service and attends our Support Group meetings.

PLEASE LEND A HAND TO FIND A CURE

- For someone living with PD for 12 years, the average lifetime financial cost is around \$144,000, which is on par with the lifetime financial cost of cancer (\$165,000)
- PD is the second most common neurological disease, after Dementia
- 10,500 new cases of PD were diagnosed in 2011
- 30 new diagnoses every day
- 19% of people living with PD are of working age (15-64)
- Approximately 1 in 350 people in Australia lives with PD

Phone 1800 644 189

Email pnsw@parkinsonsnsw.org.au

Visit www.parkinsonsnsw.org.au



Parkinson's NSW

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Parkinsong! gives voice

It's over a year now since Parkinsong! kicked off in Sydney. Every Tuesday, from 5 pm, the Abraham Mott Hall echoes to the sound of voices: exercising, yelling, harmonising and crooning. Choir leader Nadia Piave (who, by the way, is a fabulous singer herself) puts the group through its paces. Breathing, voice exercises and improvisation put everyone into the right trim for some songs, all unaccompanied (acapella) and ranging from rounds to rock'n roll. The emphasis is on loud, and people whose speaking voices have trailed off can be heard producing a veritable bellow.

We'd like to grow bigger, but distance may be a challenge. If there are people out there with talent and teaching skills, Nadia could pass on her PD experience to be used elsewhere, to form new, local groups.

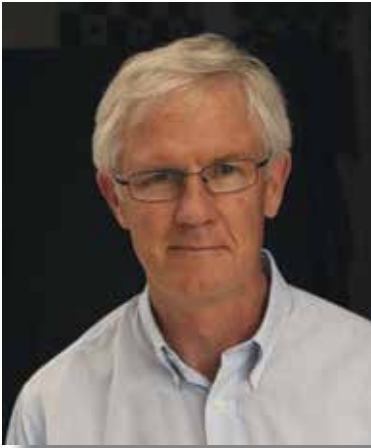
Parkinsong! has been good for breathing, socialising, learning to read music and, of course, the ancient joy of sharing the magic of harmony.

Front Page. Woman L to R: Jan Cummings, Nadia Piave, Pauline Trennery, Judy Dennison, Lois Dannecke.

Gentlemen, L to R: Chris Davis, Jim Croll, William, Terry Wiesner.

**For more information on Parkinsong!
phone the InfoLine 1800 644 189**

FROM THE PRESIDENT



Parkinson's NSW is embarking on its next exciting journey; the outcome of some months of discussion by the Executive and Board.

Our Mission is to improve the quality of life for all people living with Parkinson's. This principle has been our guide in the development of effective programs and services; however, we are hampered by a lack of government penetration at both the federal and state levels.

PD is still not recognised as a major, chronic illness; we don't receive significant or reliable recurring funds to underpin our service delivery; assistance with consumables and drugs is spotty, at best; and we barely have one neurological nurse specialist in rural/regional NSW.

Until now, Parkinson's NSW has relied on Parkinson's Australia to increase recognition and effect change at a national level, however, Parkinson's Australia does not have the relevant staff infrastructure to lobby government, nor has it developed an in-depth plan to address this situation.

Historically Parkinson's NSW has consistently supported a national organisation. However, effectively engaging with government is the keystone to maintaining and expanding all of our essential services and therefore we have made the decision to:

1. Withdraw from membership of Parkinson's Australia. As a member, Parkinson's NSW was unable to independently lobby the federal government.

2. Adopt the trading name, Parkinson's Foundation of Australia, to better reflect our mission to aid all people with Parkinson's.

3. Employ professional representation to take Parkinson's case to Canberra and to energetically pursue meaningful government funds to improve services for people living with Parkinson's.

4. Actively revitalise the informal group of concerned Parliamentarians, known as the Parliamentary Friends of Parkinson's, to further encourage the support of our elected members.

With an election looming, we strongly feel that seeds must be sown now, to precipitate change. It is the time when all political parties are fine tuning their health policies and the possibility exists to secure commitments from both sides of politics. Promises made during campaigns have some hope of eventuating, but the chances of securing fresh commitments once a government has been formed are much slimmer.

What do these decisions mean for our members? All of our services remain in place, but additionally there will be an immediate step up in advocacy and awareness for Parkinson's, with the appointment of a professional firm to represent us in Canberra.

Longer term we hope for the re-emergence of a vibrant national body, with a unified approach.

I hope members will be supportive of these moves. Please contact me via the office if you have questions or comments.

A handwritten signature in black ink, appearing to read 'C. Davis'. The signature is fluid and cursive, written on a white background.

Chris Davis
President
Parkinson's NSW

FROM THE CEO

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*Westmead Clinic on Wednesday

** Concord Hospital
Clinic on Wednesday

***War Memorial Hospital
Clinic on Tuesday



Welcome to our first issue of Stand by Me for 2013.

It is with pleasure I can report Parkinson's NSW has received a donation from a private benefactor to employ Marilia Pereira, our Neurological Nurse Educator until June 2013

There continues to be a ground swell of support for specialist nurses. The State Member for the South Coast, Shelley Hancock MP has arranged a petition in support of funding and Federal Member for Gilmore, Joanna Gash MP recently made a speech in Parliament in support of neurological nurses and the need for ongoing funding.

Our campaign to have a neurological nurse employed in every Medicare Local in NSW continues. Thank you for your support.

We are seeing historic changes in the way Australia will provide disability support and services. On 6 December 2012 the NSW and Australian Governments reached an agreement that fully establishes the National Disability Insurance Scheme across NSW from 2018.

Currently the scheme will provide support and services to people diagnosed with a disability before they turn 65. The Government's reasoning is those aged 65 and over are eligible for long term assistance under the aged care provisions. We plan to feature more about the scheme in the next edition of Stand By Me.

There are exciting conferences and seminars scheduled for this year. One is right here in Sydney, the other in Montreal, Canada.

I am hoping many of you will attend The 9th Asian Pacific Parkinson's Association Meeting sponsored by The Movement Disorder Society, held on 15 - 16 June 2013, Sydney Convention Centre, Darling Harbour. This meeting provides a fantastic opportunity to hear from internationally renowned speakers. The program is especially targeted for people living with Parkinson's, their partners, families and carers.

Topics include: Emerging therapeutic developments, environmental factors and Parkinson's disease, genetics of Parkinson's disease, new and novel treatments, anxiety

and depression, neuroplasticity, sleep disturbance in Parkinson's disease, benefits and types of exercise, stem cell therapy, and more. There will be ample time for the audience to ask questions with a panel of experts taking questions from the audience on both days. Registrations open on 12 March 2012 with early bird discounts. Please go to our website to register.

The third World Parkinson's Congress, (WPC) is to be held from 1 - 4 October 2013 and is just 7 months away. The Congress will be held in Montréal, Canada at the Palais des congrès de Montréal and will highlight research and care models, raising awareness about Parkinson's and increasing the quality of life of people living with the disease.

I had the pleasure of attending the Congress in 2010, and I would highly recommend anyone that is thinking about travelling to Montreal to attend. Registration is now open. Register to secure your place in the Roundtable workshop (ticket required) and book your hotel room in your preferred hotel before they are all booked out.

The Provisional Program and Call for Abstracts is now available to view and download. Take a look at the informative and relevant sessions planned for October. Be sure to submit your abstract before the deadline on Monday, 15 April.

The WPC 2013 Video Competition will accept submissions until 8 May 2013. View the videos as they are submitted on YouTube (just search for World Parkinson's Congress). This competition will elevate Parkinson's to a global health priority. Make your own video letting the world know how Parkinson's has affected your life. The sky is the limit.

Again, this year, we will be running a number of free surgical intervention seminars. The first in Dapto 5 April and the second in the Springwood/Blue Mountains area on Friday 3 May. This seminar will feature Dr Paul Silberstein and Dr Raymond Cook. We would like to thank Medtronic for sponsoring these seminars.

If you or someone you know is anxious, panicky or worries a lot, then come and join a group to learn ways of managing anxiety on Wednesday 8 May at North Ryde.

If you have been diagnosed within the last 12 months, or know some who has been, you might like to attend one of our First Steps programs. These are especially designed to provide information for people new to the diagnosis of Parkinson's.

To find out more or register for seminars phone the InfoLine 1800 644 189

Yours in Parkinson's Friendship

Miriam Dixon
CEO

Eye movements & balance in Parkinson's Plus syndromes



Video-based system to study eye movements might become the way in the future. On the left is a large screen displaying target jumps for saccade, in the middle is the laptop computer containing the software to drive the entire system, and on the right lightweight video goggles capable of capturing eye movements from both eyes.

By Dr. Luke Chen, Research Officer and Neuro-otology Fellow, Hearing and Balance Clinic, Department of Neurology, RPA Hospital

Parkinson's Plus refers to a group of disorders that may appear to look like Parkinson's disease, and include conditions such as progressive supranuclear palsy, multiple system atrophy and corticobasal syndromes. The difference is that in Parkinson's Plus there are additional features such as abnormal eye movements, severely affected balance, blood pressure alteration or bladder problems, early change in memory and most importantly, poor response to medications used to treat Parkinson's disease. These features can take years to develop, and deciding between Parkinson's Plus and Parkinson's disease is often difficult early in the course even by experienced specialists. The need to separate between Parkinson's Plus and Parkinson's disease is obvious: they have different outlook and respond differently to treatment.

We have known for a long time severe and abnormal eye movements are a hallmark of Parkinson's Plus syndromes. However, observation alone is frequently inaccurate even in the best of hands. If we could record these precisely then we have a very good chance of differentiating Parkinson's Plus from Parkinson's disease. Together with movement disorder experts including Associate Professor Victor Fung, Dr. Neil Mahant and Dr. Ainhoa Ha at the

Department of Neurology, Westmead Hospital, and the specialists here at the Hearing and Balance clinic (Dr. Swee Aw, Professor Michael Halmagyi and myself), RPA Hospital, we have been working towards one goal: to accurately measure eye movements and balance function in Parkinson's Plus.

Eye movements made when we look quickly from one point to another in our field of view are called saccades; an example would be glancing between the two side mirrors when driving. The balance pathway connects the inner ear and the eyes, and if we stimulate the balance organs, the eyes move very fast in a certain manner: these eye movements are used to ensure we have proper vision and good balance at all times, without us thinking.

We can measure eye movements precisely with contact lenses, a technique that is very specialised and available here at the Hearing and Balance clinic, RPA Hospital. This method has been around for many decades, and is the "gold-standard" in eye movements recording. After placing eye drops to help with wearing the contact lenses, the person sits in a large wooden frame which generates a weak magnetic field, of the same strength as the earth's. The contact lenses move when the eyes move, and the movements can be picked up by computer. Contact lenses can be worn up to 30 minutes.

To measure saccades, we simply get the person to look at jumping targets (either sideways or up-and-down) projected on a white screen. To stimulate the balance organs, we could: 1) turn the head by a small amount quickly (called

head impulses), or 2) provide weak electrical currents behind the ears. In the future, it would be nice to do all of these in the clinic and bypass the contact lenses; we are trying to see if a video-based system could do the job.

It would also be very convenient if we have a quick way to test the balance system in the clinic without contact lenses, and we have a very neat test called vestibular evoked myogenic potentials. We could measure the balance pathway between the inner ear and the eyes or neck muscles, by providing gentle tap on the forehead whilst getting a person to look up, or playing click sounds via a headphone whilst the person lifts his or her head off the pillow.

The preliminary results from our research are quite exciting. First, in Parkinson's Plus, saccades are almost always slowed as one would expect, but they are frequently very subtle; this explains why it is very difficult to detect this abnormality in the clinic because it is below the threshold of human observation. Secondly, we have found that in response to rapid head turns or electrical stimulation, eye movements made are often too large or too small, or the reaction time prolonged. This delayed in reaction time is also supported by results of vestibular evoked myogenic potentials. We do not observe these abnormalities in Parkinson's Disease and think this explains why falls are so prominent in Parkinson's Plus. Most importantly, for those whose diagnosis remains uncertain, we have found measuring eye movements abnormalities useful in clarifying the diagnosis.

Our research is ongoing and we are examining as many different types of Parkinson's Plus as possible, and also those instances where there is uncertainty about the diagnosis. We still have much to learn about eye movements and balance function in Parkinson's Plus. We do not know how they change with time, something that will take many years to study. New brain imaging methods could allow us to compare the area of brain involved in the abnormal eye movements or balance problem. In the future, as new treatments become available for Parkinson's Plus, we think measuring eye movements and balance function could allow us to track response to treatment.

Tremor & Parkinson's Disease

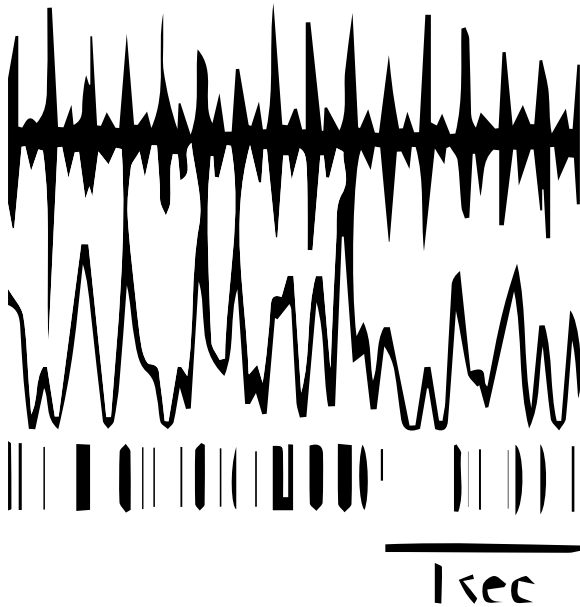


Figure: A recording from the triceps muscle of a patient with Parkinson's disease and tremor showing the characteristic rhythmic bursts of muscle activity (top trace)

The two lower traces are recordings of rhythmic firing of basal ganglia neurons in the brain that are synchronised with the tremor

**Dr Paul Clouston,
Neurologist
MBBS (Hons), PhD, FRACP**

Tremor is characterised by involuntary, rhythmic and alternating movements of one or more body parts. A tremor is the presenting feature of Parkinson's disease in around two thirds of patients.

The features of the classical tremor of Parkinson's disease is that it usually begins on one side of the body, is present when the affected limb is not being used (resting tremor) or if the limb is kept in a sustained posture but disappears during action. This tremor has a frequency of between 4-5 per second up to 8-10 per second. Besides the arms this tremor may also involve the legs or the jaw.

A less common tremor in Parkinson's disease is a faster tremor (> 10 per second) that is present only during posture and action of the limb. This sort of tremor can sometimes

be confused by medical practitioners as an inherited tremor but, unlike inherited tremor it starts in one arm. It may be the presenting feature of Parkinson's disease in younger patients. Some neurologists believe that Parkinson's patients presenting with tremor may have a more benign course for their illness. The reason why many patients develop tremor and some do not is not understood but the origin of the tremor is thought to be due to release of oscillatory neuronal circuits deep in the brain.

In most patients the tremor actually gets worse or even stabilises as the disease progresses, but in a few patients it may actually improve. As the tremor worsens it often can increasingly affect action of the limb in a few patients and result in worsening disability.

In most patients the tremor of Parkinson's disease is not disabling but can be socially embarrassing. Emotional stress and fatigue can make the tremor worse. It is important to note that some drugs such as caffeine, bronchodilators or other anti-asthma drugs, used to treat mental illness such as lithium or neuroleptics, and sodium valproate

used in epilepsy may make the tremor worse so it is important to have your medications reviewed by your neurologist if you have a tremor.

The classical triad of motor symptoms used to diagnose Parkinson's disease are tremor, akinesia (slowness of movement) and rigidity (stiffness of muscles). Of these three symptoms it is the tremor that responds least well to medication with marked improvement in 15 to 60% of patients depending on the study.

The mainstay of treatment remains combination therapy with levodopa/carbidopa but occasionally addition of newer dopamine agonists such as pramipexole or ropinirole may be helpful. In patients where this therapy fails it is worth trying one of the anticholinergic drugs such as benzotropine. These drugs may be helpful occasionally but are limited by their side-effects (e.g. dry mouth, fatigue, blurring of vision). For patients with severe medically refractory disabling tremor Parkinson's surgery using deep brain stimulation is an effective therapy.

Tamsin's story

by Tamsin Jackson

Hi, my name is Tamsin Jackson, I'm married to Ian and we have three teenage children. We live on a few acres with a menagerie of animals and run our own business from home. I was diagnosed with Parkinson's disease (PD) when I was 39. I visited my GP with a slight tremor in my little finger and after a few months I knew something was seriously wrong; I was then diagnosed with PD. My family and I were engulfed by a myriad of emotions including shock, anger and devastation. Why me? Why us? What about the plans we had for the future?

There were so many questions, questions that couldn't be answered.

I thought, PD is an older person's disease without a cure, why do I have PD in my thirties? So I set about trying to find out as much information as possible about PD. My first phone call was to the support line at PNSW who put me in touch with other young onset woman with PD from all over the state. We teleconference once a month, which has become an integral part of my busy routine and a chance to share experiences, and support each other. I have met some of these woman and fantastic friendships have been formed.

I decided that if I was going to tackle this disease, I needed someone who was at the forefront of research, someone who cared for their patients and someone who was dedicated to finding a cure for PD. I found this in a Professor of Neurology in Brisbane. Next I attended information sessions for people newly diagnosed with PD at the local hospital. Run by a physiotherapist with 90% of the participants from my immediate area. I got to meet locals with PD even if they were all at least twenty years older than me. With no support group for young people with PD I decided to coordinate a support group in my locality for young onset people.

I wondered why there were so many people in this area with Parkinson's and if there was a link with the apparent high incidence of people with Parkinson's in rural areas, including this locality, and the use of pesticides and herbicides. The local newspaper ran an article about my PD and the possible link with pesticides which led to the ABC 730 report investigating and airing a story. I'm not going to sit around and wait for something to happen,

for a miraculous cure. I have to do something constructive. I organised a morning tea to raise money for PNSW and to raise the awareness of PD at the same time. I have since held further

fundraising events for research into PD for the University of QLD. My family, friends and colleagues are fantastic supporters with all my events. I have also participated in clinical trials and surveys, been on television, radio, newspapers and lobbied politicians and support organisations. I sometimes provide information or a brief presentation at the local support group when I have time to attend. These opportunities have all helped me to raise the awareness of PD while meeting fantastic people working in many different organisations.

All of this has to be fitted around working full time, managing the kids, their school and sport commitments, the home and

numerous volunteer positions. My family are a fantastic support; the disease is probably harder on my family than me as they see me getting worse and are powerless to stop this degenerative disease. They will have to help me more and more as I deteriorate and they will eventually be my carers. The kids' questions have to be answered, their needs taken into account when considering my future treatment options especially deep brain stimulation (DBS).

In the meantime I'll keep on supporting others living with Parkinson's, keep fundraising and raising awareness within the community, awareness in political circles that thirty people every day are diagnosed with Parkinson's disease in Australia. This is more than many rates of cancer and the cost to the community is immense and not just financially. People need to ask why, what are the causes? They must ask these questions and lobby governments for funding and services for PD. I have found that the majority of health professionals, support groups and organisations are working hard to help people living with Parkinson's. However I'd like to see these groups; the drug companies, researchers, politicians, support groups and organisations stop, listen and re-evaluate their goals, their ethos of 'us and them' between organisations. Everyone needs to work collaboratively for the benefit of all people with Parkinson's disease. Come on, together let's find the cure for this chronic, degenerative condition – and soon!

by Tamsin Jackson



to R. Ian, Mark, Clara, Finn and Tamsin

Make 2013 your year to get your medicines on track with the help of TabTimer™

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Les Norris & Central Coast Support Group



Les in action

In 1995, Les Norris became convenor/secretary of the Central Coast Support Group, a role he has played now for 18 years. The Central Coast Support Group began in 1986 under the leadership of Mr and Mrs Scott Young. In the early years street stalls were held with handicrafts made by the members.

In the late 1990s there were annual conferences in conjunction with the Gosford Area Health Service and other NGOs. Les was involved

in promoting liaison with hospital administration and annual dinner with the members of the area health board.

Les is a great 'attender'. He has been to meetings and seminars with PNSW, other support groups in the Lower Hunter Area and Parkinson's Australia's National Conference in Melbourne and conferences at Prince of Wales Hospital, the location of the Brain Bank. But just being there was never enough for Les. He is a sincere, dedicated ambassador for Parkinson's and has been instrumental in promoting and winning support from The NSW Lawn Bowlers Association. The Parkinson's nurse

at Gosford Hospital, Greg Harris, is there as a result of lobbying by Les and PNSW, with Les attending many functions at NSW Government offices with Health Ministers, promoting the work of Parkinson's NSW and its support groups. Les' leadership and dedication have been outstanding and he is believed to have given the longest continuous service of any member in the 27 years of the Central Coast PD support Group.

Our thanks to Jim Sanders for this story.

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

Parkinson's NSW Support Groups

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

Are you suffering from Parkinson's disease + slow stomach emptying?

GSK has a study in Sydney that is looking at the effect on a new drug for slow stomach emptying on L-dopa in people with Parkinson's disease



This study has been approved by Bellberry HREC,
Ref no: 2012-11-1157 and operates within Australian &
International guidelines for medical research
MOT115816 Print Version 01, 07 NOV 2012

Many people with Parkinson's Disease have symptoms of slow stomach emptying which may contribute to "on-off fluctuations".

Slow stomach emptying can cause:

- Nausea and vomiting
- Bloating and feeling excessively full after a meal
- Belly visibly larger
- Loss of appetite
- Abdominal pain or discomfort
- Delays in medication entering the blood stream and thus taking effect

You may be eligible to participate if you:

- Have Parkinson's Disease
- Are taking daily medication containing L-dopa (eg. Sinemet, Madopar or Stalevo)
- Have symptoms of slow stomach emptying
- Are between the ages of 40 and 80



Our trial participants are reimbursed for their time, travel costs and inconvenience

Prince of Wales Hospital
Level 10, Parkes Building East
High St. Randwick, NSW 2031

**Contact: 1800 GSK GSK (1800 475 475)
Email: volunteers.4.trials@gsk.com**

Phil's story



Sue and Phil Rance at home

I was diagnosed with Parkinson's 15 years ago. I loved my work as a painter and decorator and had my own successful business. Well known, disciplined, and enjoying assisting my customers; priding myself doing any other little jobs they needed.

When I had to give up work, I became very anxious, losing my confidence

and self esteem. Frustrated I pay people to do work I could do easily before, I even have to ring friends to get presents for Sue for special occasions as I can't get out to the shops on my own.

Early on, Sue and I decided to keep as active as possible and do something every day, even if it's just going out for a drive and a cup of coffee. I'm so grateful Sue can drive. If I had to rely on public transport I wouldn't get to any of my activities

Every week is full. Exercise classes run by the Parkinson's Clinic at Concord Hospital, and also a supervised gym session at The Centre for Healthy Aging, Lilyfield. Both help improve my mobility.

Singing is my passion! I sing with two community choir; both relaxed and informal. This keeps me inspired and exercises my lungs — singing is recommended for people with Parkinson's Disease (PD). I play scrabble or go out and have fish and chips every week, during flexible respite. Sue 'does her own thing' time alone without worrying about me.

We also work hard at feeling part of our community rather than being closed in and isolated. I really enjoy the companionship and connection with The Working Age Men's Network. Ten to twelve of us meet monthly at the Parkinson's NSW offices at North Ryde to talk.

Before I was diagnosed, I thought money made you successful and happy. I've been reading *The Road Less Travelled*, by Scott M Peck (who had PD). It helped me to change my attitude to life. I now realise it has a place, but love of my wife and relationships with others are more important. Losing my independence and needing to rely heavily on others is a hard thing to come to terms with. But the love Sue and I share makes coping with an illness like PD a lot easier.

I have left a bequest to Parkinson's NSW to help others in the future, as it's a chance to make a donation that incurs no personal sacrifice now.

Phil Rance

If you would like to know more about leaving a gift in your will contact Isabelle Clark, Bequest Officer
m: 0403 324486
e: bequest@parkinsonsnsw.org.au

The 9th Asian Pacific Parkinson Association Meeting

Sponsored by The *Movement* Disorder Society
June 15 and June 16, 2013 • Sydney, Australia

SAVE THE DATE!

Registration will open on March 12, 2013.

Registration Fees	Early Rate On or before May 1, 2013	Standard Rate From May 20 onward
Single (Person Living with Parkinson's/Partner/Carers/Others)	\$80 AUD	\$100 AUD
Dual (Person Living with Parkinson's + Partner/Carer)	\$150 AUD	\$175 AUD

Meeting Description

This meeting is specially designed for People Living With Parkinson's and their partners, families and carers.

Topics Include

- Emerging Therapeutic Developments • Environmental Factors and Parkinson's disease •
- Genetics of Parkinson's disease • New and Novel Treatments • Anxiety and Depression •
- Neuroplasticity • Sleep Disturbance in Parkinson's disease • Benefits and Types of Exercise •
- Impulse Control Disorders in Parkinson's disease • Stem Cell Therapy •
- Cognitive Impairment and Dementia in Parkinson's disease •
- Strategies for Improving Speech and Swallowing



The *Movement* Disorder Society



Important New Factor linked to Parkinson's Disease damaged Neurons

Dr Michael Ortiz
Associate Professor (conjoint)
St Vincents Clinical School

Parkinson's disease (PD) is caused by the selective degeneration of dopaminergic neurons in the brain. A neuron (also known as a nerve cell) is an electrically excitable cell that processes and transmits information through electrical and chemical signals. A chemical signal occurs via a synapse, a specialised connection with other cells. Neurons connect to each other to form neural networks.

Current drug treatments are efficient in the early stage of the disease, but with continuous use, these medications may become less effective and cause motor complications. Cell therapy is emerging as an alternative strategy to manage PD and consists of the replacing damaged neurons with new cells that restore the dopamine pathway function (Pradal et al 2012).

Stem cells can provide new sources of cells to be used for transplantation studies in PD. Stem cells are mother cells that have the potential to become any type of cell in the body. One of the main characteristics of stem cells is their ability to self-renew or multiply while maintaining the potential to develop into other types of cells.

Stem cell therapies for Parkinson's disease are not yet ready for widespread use in patients. For now, the main challenges for scientists are:

- To identify the type of cells that have the most potential for research and new treatments. So far, researchers have had most success making dopamine-producing neurons from embryonic stem cells, but it is not yet clear whether the lab-grown neurons are close enough to naturally produced neurons to succeed in therapies.
- To find out how to grow neurons in sufficient quantities and at high enough safety standards to treat patients.
- To establish exactly how and where to transplant the cells so that they work properly in the brain without causing side effects. The area of cell transplantation has been encouraged by the emergence of novel methods of generating dopamine neurons. Results of previous clinical transplantation trials in Parkinson's disease have been

variable in terms of motor function recovery (Allen et al 2010). Stem cells have emerged as an alternative source for the generation of dopamine connections. Progress has been made in the use of human embryonic stem cells and focus on the emerging field of induced pluripotency (Allen et al 2010). In cell biology, pluripotency refers to a stem cell that has the potential to differentiate into multiple types of cells like skin and nerves. The method involves direct reprogramming to convert fibroblasts into neurons without inducing a pluripotent state. The suffix "blast" is used in cellular biology to denote a cell in an activated state of metabolism.

Recent findings published in *Nature* (October 2012) may lead to new ways to diagnose and treat Parkinson's disease. The LRRK2 gene mutation predisposes some people to develop Parkinson's disease. By reprogramming skin cells from Parkinson's disease patients who have a known LRRK2 genetic mutation, scientists were able to identify damage to neural stem cells associated with their Parkinson's Disease (Liu et al 2012).

The scientists found that a common mutation to a gene that produces the enzyme LRRK2, deforms the membrane (nuclear envelope) surrounding the nucleus (central gene core in a cell) of a neural stem cell. Deformation of the nuclear envelope can decrease their ability to grow neurons (connections between brain cells) that respond to dopamine.

The researchers used human induced pluripotent stem cells (iPSCs). These cells are similar to natural stem cells, such as embryonic stem cells, except that they are derived from adult cells not embryonic cells. Use of these cells has excited the medical community due to their transplant potential, in that adult skin stem cells can be modified and used to replace dysfunctional brain cells.

In this study, the researchers used skin fibroblast cells taken from Parkinson's disease patients who have the LRRK2 mutation, and they reprogrammed them to iPSC stem cells and then developed them into neural stem cells.

Then, by using an approach to model what happens when these neural stem cells aged, they found that older Parkinson's disease neural stem cells increasingly displayed deformed nuclear envelopes. This meant that, over time, the LRRK2

mutation affected the nucleus of neural stem cells, hampering both their survival and their ability to produce neurons.

The researchers then checked their laboratory findings with brain samples from Parkinson's disease patients and found the same nuclear envelope impairment.

This discovery may help explain how Parkinson's disease, which has been traditionally associated with loss of neurons that produce dopamine and subsequent motor impairment, could lead to locomotor dysfunction and non-motor effects, such as depression and anxiety (Liu et al 2012) by affecting other neurons in the brain that do not produce dopamine.

The researchers don't yet know whether these nuclear envelope changes cause Parkinson's disease or are a consequence of it, but they say the discovery could offer clues about potential new treatments in those patients with the genetic mutation.

For example, they were able to use targeted gene-editing technologies to correct the mutation in patient's stem cells. This genetic correction repaired the damage to the nuclear envelope, and improved overall survival and functioning of the neural stem cells.

They were also able to chemically inhibit damage to the nucleus, producing the same results seen with genetic correction. This could open the door for new drugs to treat patients with this genetic mutation.

The area of cell transplantation has been revitalised by the identification of novel methods of generating dopaminergic neurons. Hopefully, this study will stimulate future trials employing stem-cell-derived neurons.

References:

Allan LE, Petit GH, Brundin P. Cell transplantation in Parkinson's disease: problems and perspectives. *Curr Opin Neurol*, 2010 Aug;23(4):426-32.

Liu GH, Qu J, Suzuki K, et al. Progressive degeneration of human neural stem cells caused by pathogenic LRRK2. *Nature*. 2012 Nov 22;491(7425):603-7.

Pardal R, López-Barneo J. Neural stem cells and transplantation studies in Parkinson's disease. *Adv Exp Med Biol*. 2012;741:206-16.

The year of the snake

The Australian Chinese Charity Foundation was established in 1991 as a broad based community charity organisation. Its major aims are: to help charitable/non-profit community organisations operating in NSW with specific projects and; to support individuals and families in emergency circumstances.

Parkinson's NSW was honoured and greatly appreciative to be the recipients of a \$33, 000 cheque, raised through the efforts and generosity of the ACCF at their Community New Year Celebration Dinner, held on the 16th of February.

It was a marvellous night, attended by nearly 400 people; a record for this event. The festive room was filled with red lanterns and music. The tables groaned under a multi-course dinner and, of course, there was the Dragon Dance. Attorney General and Minister for Justice, Greg Smith; Dr Peter Wong AM (founding chairman of ACCF) and Dr Victor Tsang were wonderful leading the singing of the National Anthem. Catching up with long-time friends was a highlight of the evening.

Mrs Elaine Mah again demonstrated her concern for people with Parkinson's by her generous donation to the event.



PNSW members and their friends added nine tables to the numbers, and it was wonderful to see us supporting those who support us .

To Mr Hudson Chen KHS OAM, ACCF Chairman, Dr Michael Tse, Event Chairman, and the committee members of the ACCF who worked so hard on our behalf, and to all those who contributed on the night to assist PNSW in their mission, a heart-felt thank you and gung hay fat choy.



Are you worried, anxious, even panicky sometimes.

Join a group of fellow worriers for an interesting, enlightening morning and learn some excellent strategies for coping with anxiety.

Where: Room 1, Vincent Fairfax Building, Macquarie Hospital Campus North Ryde

When: 10.00am to 1.00pm

(Morning Tea included)

Date: Wednesday 8th May 2013

Parkinson's NSW

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Parkinson's NSW Golf Classic

A full golf course, 140 diners and a fine day all accompanied the 6th anniversary of the Parkinson's NSW Golf Classic on 15 November 2012.

The inaugural David Samer Memorial Trophy was won by the Beverley Park Team; Nigel Stamaloft, Ross Sands, Clint Johnson & Scott Bremner. This trophy is in memory of David Samer, a tireless worker on the golf day for many years.

The Zappier Brothers team won the President's Cup.

This year, the \$43,500 raised will assist the Parkinson's NSW Counselling Service; a phone service staffed by trained and experienced counsellors who support people living with Parkinson's and their carers

Again we thank everyone for their continuous support,

great playing and generosity for this enjoyable event

Our special thanks goes to our sponsors.

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A Marathon and a DASH

Report on Dr. Simon JG Lewis' talk
at Pantai Hospital, Kuala Lumpur,
Malaysia

By Sara Lew
President, Malaysian Parkinson's
Disease Association



L - R. Prof. Dr. Lim Shen-Yang,
Dr. Simon, Dato' Maulud Maamin
and Sara Lew



Dr. Simon literally went down to the
floor to speak to our members up
close and personal. Here,
Mamudah is discussing with
Dr. Simon. her husband, Jaharuddin
Adam's condition.



The talk was very well attended



Dr Simon having a light moment
with Dato' and Datin Malek Merican.

I was thrilled when I received an email from John Silk on August 17, 2012 informing me that Associate Professor Simon Lewis, a prominent Movement Disorder Specialist and Board member of Parkinson's NSW would be arriving in Kuala Lumpur to deliver a lecture on September 14, 2012 and that before his departure for home in Australia the next day, he would be pleased to give a talk to a Parkinson's Disease Group in Kuala Lumpur.

John, whom I have known earlier through our association with the 3rd World Parkinson Congress where we both sit on its Government Relation Committee, further reiterated that Dr. Simon was the co-author of DASH to the InfoLine booklets which deals with Depression, Anxiety, Sleeplessness and Hallucinations. He is also the Associate Professor in Cognitive Neuroscience at the University of Sydney and Royal Prince Alfred Hospital. With the credentials behind him Dr. Simon's talk was an opportunity not to be missed, and we were very honored indeed to have him in person for a talk.

Preparation for the talk ensued, and John helped us make arrangements with Parkinson's NSW for the delivery of educational resources comprising DASH booklets in both the Chinese

and English versions to our association. These booklets were later distributed to the participants at Dr. Simon's talk and were going like hot cakes.

Dr. Simon Lewis' talk on "A Marathon and a Dash" was held at 10 am at the Pantai Hospital, Kuala Lumpur and was well attended by about 80 people. He arrived early before the talk, and our medical advisor, Prof. Dr. Lim Shen-Yang was also present to welcome him. Dr. Simon took the opportunity to mingle with the participants before the talk

Although he attended to many eager members discussing their condition with him before the talk, he did not forget those patients who were not able to go up to him. Instead, Dr. Simon went up to them, and literally went down to his knees to talk to them and their caregivers. He was up close and personal with Jaharuddin Adam, a person with PD for 15 years and listened intently as Jaharuddin's wife explained her husband conditions. Later, Dr. Simon moved across the hall and had some light moments with Dato' Malek Merican and his wife. Although Dato' Malek has had PD for almost 18 years, he's coping well with his condition.

As Dr. Simon took the stage, the participants were very attentive.

There were participants who do not understand English but this did not deter them from attending the talk. The talk was also an opportunity for them to come out and interact with others; to exchange information with each other.

During the Q & A session, the members were very engaging, and many questions were posed to Dr. Simon. Unfortunately, there was insufficient time to answer all the questions, and many took the opportunity to talk to Dr. Simon during lunch break. I was also asked by many when he would be back to Malaysia to give talks again. It appears that Dr. Simon has found many new fans among the participants.

Helen Yeoh, a caregiver puts in, "Dr. Simon has answered a lot of my questions relating to my husband's present condition, especially on the non-motor symptoms in PD."

We would like to thank Dr. Simon for his excellent talk, and hope to have other opportunities to listen to him again. I also like to thank John Silk for his help in connecting Dr. Simon with us, and Miriam Dixon, CEO, Parkinson's NSW for the DASH Booklets and other resources.

Terima Kasih! You made our day!

HELPING HANDS

What assistance is available after an Aged Care Assessment?

An aged care assessment is for people 65 years of age or older who are in need of assistance with activities of daily living. The assessment can be provided while in hospital or an Aged Care Assessment Team (ACAT) can be arranged to visit your home. The team consists of health professionals who will ask you a series of questions to understand how much and what type of assistance you need.

Assessments are government funded and come at no cost. The ACAT team will make recommendations on the level of care they feel you may need. The decision to accept any recommendations for care services is with the individual being assessed. The main purpose of an ACAT assessment is to assess eligibility and level of care

ACAT can refer you to community services such as meals on wheels. If the care needs are higher and you wish to stay in your own home you may be eligible for a government funded care package. These packages are assessed on the type of assistance you may need. The Community Aged Care Package (CACP) provides low level care and will provide on average four hours of

support per week. The services may include personal care, social support, transport to appointments, home help, meal preparation and gardening.

The Extended Aged Care Package (EACH) provides high care support and can provide morning and afternoon assistance. The support can include

needs of those living with dementia who are experiencing behavioural and psychological symptoms.

The services are provided by government approved care providers. The government subsidise the service providers, and then a subsidised fee is charged to you based on a percentage of your pension.

ACAT can also arrange Transition Care which is assessed when in hospital and is to help the transition from hospital to home easier. Up to 12 weeks of nursing and allied health support is provided after leaving hospital.

An ACAT assessment is needed if you decide on residential care. The assessment will be for either high care (nursing home) or low care (hostel). Nursing home care provides full assistance whereas hostel care provides some help with showering, medications, meals and group activities. Most hostels have unit type rooms and less nursing staff than a nursing home.

ACAT will also assess the level of care needed for respite. Respite is so you and your carer can have a break. Respite may be in a residential facility, a day-centre or at home. The main aim of assessment for respite is to make sure the level of care matches the assistance needed.

To understand more about the Aged Care Assistance Team assessment and how you might benefit, call Aged Care Australia on 1800 200 422 or the InfoLine 1800 644 189.



registered nursing care, allied health care such as a physiotherapist, podiatrist etc., personal care, transport to appointments, social support, home help and assistance with oxygen or enteral feeding.

The Extended Age Care Package dementia specific provides the same services as the EACH package and includes service approaches and strategies to meet the care

Frozen GAIT



By A/P Simon Lewis
Brain and Mind Research Centre

In combination with the Michael J Fox Foundation, the Parkinson's Disease Research Clinic at the Brain and Mind Research Institute (BMRI) will soon be commencing a special program for people with Parkinson's disease who experience symptoms of Freezing of Gait (FOG). This is the common problem where people feel as though their feet have become "stuck to the ground" while they are walking. Unfortunately, there are frustratingly few options available to help treat the condition. Recently, our work at the BMRI has identified that FOG is strongly linked with impairments in thinking.

In this study we will be 'training the brain' to think more efficiently - no medications or surgery is involved. We are now looking to recruit patients with FOG to see if our brain training program will work.

Neurologist, A/Prof Simon Lewis, and neuropsychologist, A/Prof Sharon Naismith, both of whom are committed to improving the lives of people living with Parkinson's disease, designed this program.

The program has been developed to specifically target freezing and cognition (i.e. thinking skills) and is like a gym workout for your brain. For example, different exercises will help to improve your memory, concentration or your ability to multi-task. By training you to perform these tasks well, we hope to make your brain better at handling the problems that lead to episodes of Freezing of Gait.

The program would require your attendance twice a week over a seven-week period and involves computer-based brain training exercises as well as group-based discussions regarding factors affecting 'Healthy Brain Ageing'.

The study also involves your attendance at the Parkinson's Disease Research Clinic for assessments both before and after the program. A number of the participants in our study will also have the chance to undergo functional brain scanning, allowing to identify the specific regions of the brain that are responsible for any improvements we see in Freezing of Gait.

Previously, several other Cognitive Training programs have been successfully conducted at the BMRI for people with Parkinson's disease, Mild Cognitive Impairment and depression, and have shown improvements in thinking skills and quality of life.

Our most recent Cognitive Training program showed that 100% rated the quality of this service as good or excellent, and over 90% of the group reported that the program helped to improve their thinking skills, provided strategies to improve daily functioning and also improved their mood. Several participants also said that they specifically enjoyed spending time with a group of similar-aged people who shared their experiences.

Please join us at the Brain and Mind Research Institute for this opportunity to test an exciting new treatment for Freezing of Gait in Parkinson's disease.

If you would like to obtain further information about this study or about our Parkinson's Disease Research Clinic in general, please call our clinic on 02 9351 0702.

FUNDRAISING Fun



A Musician's tribute to Graeme Bell 1914 - 2012

On the 2nd December 2012, Parkinson's NSW gratefully accepted the proceeds of just over \$2000 from a musical performance held at the Independent Theatre, North Sydney.

The concert, featuring Australia's leading jazz musicians, was a special tribute to their bandleader, mentor and dear friend, Graeme Bell AO MBE. Musicians who worked with Graeme over several decades were joined by some of today's brightest young players. The music traced the many peaks of Graeme's stellar career. Throughout the concert many rare and historic photos were shown on a stage screen. The capacity audience, truly delighted, rose to their feet with appreciation on several occasions. Graeme would have been very proud.

Some of Graeme's closest friends formed a committee to organise and collate the many chapters of Graeme's musical life. The concert, featuring 14 musicians, played the music made famous by the man known as The Father of Australian Jazz.

Graeme Bell died on 13th June 2012 at the age of 97. His career in jazz

spanned from the early 1940s to 2003, when at he age of 90 he announced his retirement.

Graeme was diagnosed with Parkinson's disease late in life.

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FUNDRAISING Fun

Linen & Lace

Sharyn Crockett leads our Snowy-Monaro Support Group near Cooma and has a beautiful collection of antique and vintage linen that she displays and sells throughout the year. Sharyn raised in excess of \$7,000 for Parkinson's NSW last year through various craft stalls and community fundraiser events. Her handmade linen wares are simply delightful, and we encourage you to support Sharyn wherever possible.

Sharyn is in need of a small hall or a large entertainment room, that would be available at minimal or no cost for her linen displays and is looking for venues in the following locations Sydney, South Coast, Southern Highlands, Central Highlands or Riverina areas. Sharyn would also be grateful if anyone has accommodation contacts, as she needs accommodation at reasonable rates near each venue for herself and a few helpers.

If you need more information please contact Sharyn on crocketts@people.net.au or 02 6452 3211



Sharon's handiwork



Snowy-Monaro Support Group

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GOLD CHARITY ENTRIES

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- Brochures, posters, lapel pin, donation envelopes and more
- Team spirit and a chance to make a difference
- We will also send you regular news and updates.

After overwhelming demand and success in 2012, this year we are releasing our Golden Charity City2Surf tickets early.

We have limited tickets available to keen runners and fundraisers. The tickets require a \$100 registration fee and minimum \$900 fundraising pledge.

For your chance to be part of the 2013 Parkinson's NSW Golden Charity Team please register your interest at <http://tinyurl.com/cp3rukz> by the 20 February. All enquires will be re-viewed and our team selected by 15 March. We will notify those lucky enough to be part of the team by phone or email.

Good luck and thank you for your support.

Dance for Parkinson's



Martin Thall, a member of the Brooklyn Parkinson, dances with David Leventhal of the Mark Morris Dance Group. Photo by Katsuyoshi Tanaka

The Brooklyn, NY-based Dance for PD® program brings its acclaimed training course to Australia this May. Developed by the Mark Morris Dance Group and Brooklyn Parkinson Group, Dance for PD® training workshops are designed to enrich, inform and inspire a diverse group of dance and movement professionals who want to introduce people with Parkinson's to the joys and benefits of customised

dance. Although the workshops are designed primarily for dance teachers, the training is open to therapists, yoga, fitness and Pilates teachers, group coordinators, Parkinson's community leaders, care partners, allied health professionals and others who wish to attend as Active Auditors through the program's Educational and Professional Enrichment program. Since 2007, more than 350 people from

10 countries have participated in Dance for PD® workshops, fostering more than 100 classes based on the Brooklyn model.

Workshops will take place in Sydney May 8-9 and in Brisbane May 11-12. For more information or to apply, please visit www.danceforpd.org or email david@danceforpd.org.

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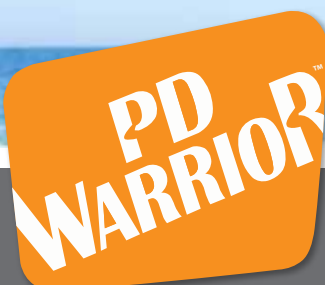
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More
than just
a meal

WHAT'S ON

5

APRIL
DBS Seminar Dapto

11

APRIL
World Parkinson's
Day

Guest Contributors

A/Prof Simon Lewis
Dr Paul Clouston
Sara Lew
Dr Luke Chen
Tamsin Jackson
Dr Michael Ortiz
Phil Rance
Jim Sanders

Editor

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

Parkinson's NSW Inc

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

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www.twitter.com/parkinsonsnsw

3

MAY
DBS Seminar
Springwood

4-5

The Big Ride
4 Parkinson's

14

JUNE
Support Group
Leader's meeting
(Sydney)

15-16
JUNE

The 9th Asian Pacific
Parkinson Association
Meeting
Sponsored by The Movement Society

11

AUGUST
CITY 2 SURF

25

AUGUST
Unity Walk
and Run

4

SEPTEMBER
Allied Health
Awareness Seminar
(Health Professionals only)

1-4

OCTOBER
World Parkinson's
Congress (Montreal)

24

OCTOBER
Bequest Lunch

12

NOVEMBER
AGM

14

NOVEMBER
Golf Day

To RSVP for events please call the InfoLine 1800 644 189

Parkinson's NSW Inc ABN 93 023 603 545

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The 9th Asian Pacific Parkinson Association Meeting

Sponsored by The *Movement* Disorder Society

June 15 and June 16, 2013 • Sydney, Australia

SAVE THE DATE!

Registration will open on March 12, 2013.