



# Stand By Me

## Marilia Pereira starts work as Australia's first Neurological Nurse Educator!

In February Parkinson's NSW welcomed Marilia Pereira in her role as Australia's first Neurological Nurse Educator. This exciting 2 year pilot project is partly funded by the Commonwealth Government and a private donor. Bendigo Bank is supporting the project by providing a car and services. The project is located in the Shoalhaven region. The Neurological Nurse Educator will work with local doctors and health care professionals to assess the impact of Parkinson's disease on the local community.

Based at the Nowra Community Health Centre, the project aims to ease the symptoms and financial burdens on those living with Parkinson's disease and Motor Neurone disease, their carers, families and the community as a whole by implementing innovative and personalised patient care systems.

One of the major responsibilities Marilia will tackle during her two year appointment will be the assessment of all Parkinson's patients living in the Shoalhaven area. She will take a hands-on role with tasks such as overseeing medications and helping with early risk identification.

Marilia has over 12 years experience in Neurology, having worked in a variety of roles, including Clinical Nurse Specialist in Clinical Neurophysiology and Area Clinical Nurse Consultant in Neurosciences. Recently, she has been working in the role of Parkinson's Research Nurse Specialist at the Parkinson's Research Clinic in Sydney whilst also undertaking a Postgraduate Masters in Philosophy (Nursing) at the University of Sydney.

The project will be overseen by Dr Simon Lewis, Neurologist and Director of the Parkinson's Disease Research Clinic at the Brain & Mind Research Institute and a member of Parkinson's NSW Council. The project is based on a successful British model which has seen the creation of an effective network of over 200 Parkinson's nurses throughout the UK. The presence of the Neurological Nurse Educator in Shoalhaven will prove invaluable to the people in the area living with Parkinson's.

It is hoped that a similar initiative will be rolled out nationwide. This would serve to significantly decrease the costs of Parkinson's disease to the community and helping to prevent people living with Parkinson's from entering hospitals and aged care facilities.



Photo by Adam Wright, courtesy South Coast Register.

### Office Relocation

#### **Parkinson's NSW is moving!**

We will be relocating to new offices over the weekend of 20-21 March, 2010.

Our new address from Monday 22 March will be:

**Building 21, Macquarie Hospital  
120 Coxs Road, Cnr Norton Rd  
North Ryde NSW 2113**

Our postal and email addresses, as well as phone and fax numbers will remain the same.



## President's Report

Firstly, I would like to welcome our new Councillor, Chris Wilson, a Partner at Deloitte's. He replaces Patricia Barkley who has found her health impeding her capacity as Country Councillor. Allan Poole has replaced Patricia as a Country Councillor.

### 2010 may well become known as the 'Good News' year.

We wish Pat all the best in her retirement and I will be keeping in close contact with her. The Council thanks Chris for his willingness to participate on Council.

The Parkinson's profile is becoming more prominent in the community and this shows every sign continuing, with two of our hardest working support group stalwarts being recognised for their outstanding contribution to their communities; Vera Heil of Coffs Harbour was named 'Volunteer of the Year' in Coffs Harbour, and Dick Babb of Hornsby Ku-ring-gai has received a commendation from Hornsby Council for his hard work. I was both honoured and humbled on receipt of my own award. Hopefully, the public acknowledgement of our work for Parkinson's will help us to make further inroads in championing the cause of people living with Parkinson's throughout our state.

The eagerly awaited Nurses trial, supervised by Dr. Simon Lewis, has started in the Shoalhaven, based in Nowra. The Commonwealth Government is part funding this trial and along with the help of Bendigo Bank and a very generous private donor we were able to employ Marilia Pereira in the role of Parkinson's Nurse Educator. So if you are visiting the South Coast and you see a Toyota Yaris with both Parkinson's and Bendigo Bank logos, give a toot to Marilia.

The expected outcomes of this trial should enable us to approach the Federal government to support a network of Parkinson's Nurses countrywide. Parkinson's NSW Council, with an optimism that comes out of information from overseas studies, has awarded 10 scholarships to Notre Dame University's new Postgraduate course in Neurological nursing, to ensure trained people are ready to work in the field. This is its inaugural year and we thank Cardinal Pell for his support and the University for establishing the course.

Another important milestone is our move to Macquarie Hospital at a 'peppercorn rent'. The recognition of Parkinson's NSW by NSW Health is a major breakthrough, establishing Parkinson's NSW as one of the important organisations in the voluntary health field.

The Lions Club of Sydney Pacific Inc. is holding its 14th anniversary fund raising Lunch/Fashion Parade at the Four Seasons Hotel in May, the proceeds of which will be shared with Parkinson's NSW. These extra funds will be used to offset the cost of the Nurses scholarship program. We greatly appreciate these generous supporters of Parkinson's NSW.

In a second event, to be held in April, the Macquarie Group Foundation Band – The Financial Instruments will perform at the Basement and 50% of the proceeds from the night will come to Parkinson's NSW.

These kinds of sponsorships are invaluable to us.

The recipients of our research grants have been highlighted elsewhere but I do want to add my own good wishes to them all, for success in their projects. These grants, together with the PhD top-up scholarships, and some consultative work from the University of Sydney, bring our investment in research and education for the 2009/10 year to over \$250,000.

I look forward to what we can achieve in the coming year!

John Silk OAM

## Coffee Information Morning

Come and meet staff and volunteers at Parkinson's NSW

Talk to people living with Parkinson's

10.30am start – 25 May 2010  
Cox's Road, North Ryde  
RSVP – 19 May 2010

**Ph 1800 644 189**

An Australian Government Initiative

### DASH to the InfoLine

Promoting a Healthy Brain and Mind in Parkinson's Disease

**DASH to the InfoLine!**  
**1800 644 189**  
**Booklets available now.**

brain&mind RESEARCH INSTITUTE  
Parkinson's Australia



## CEO's Report

### DASH to the InfoLine

The gateway to many of our services is our InfoLine phone number 1800 644 189. By calling, members and other people living with Parkinson's disease are able to access our free services

including information, counselling, education, events and support groups. The InfoLine is supported by trained professionals and can often provide ready answers to concerns.

As mentioned in the Summer edition of *Stand by Me*, we have been enhancing our support for non physical symptoms which sometimes occur with Parkinson's, including depression, anxiety, sleep disturbance and hallucinations (DASH). We have been greatly assisted in this by Dr Simon Lewis, Neurologist and Director of the Parkinson's Disease Research Clinic and by Dr Sharon Naismith, both of the Brain & Mind Research Institute which is at the University of Sydney. They have written a booklet and, with assistance from the Commonwealth Government and a private trust administered by The Perpetual Trustee Company Ltd, we have received funding to publish the booklet as well as book marks advertising the DASH to the InfoLine service.

The booklet is available to members on request by calling 1800 644 189 or by emailing us at [pnsw@parkinsonsnsw.org.au](mailto:pnsw@parkinsonsnsw.org.au).

The booklet and bookmark advertising the InfoLine will be distributed to GPs through the Divisions of General Practitioners. The bookmark will also be distributed to Guild pharmacists through the New South Wales Pharmaceutical Guild.

If you are aware of anyone else who might benefit from contacting the InfoLine, please do not hesitate to let him or her know about our services.

### Recognition of volunteers

The extensive work by our President, John Silk, over recent years both for Parkinson's New South Wales and Parkinson's Australia, has been recognised by the award of an Order of Australia. Congratulations to John and his wife Becky.

In addition, Vera Heil was awarded the Coffs Harbour region "Volunteer of the Year" award on Australia Day.

I would also like to acknowledge the efforts of others, including Tamsin Jackson raising \$1,394.50 from a "few cups of tea", and Jan Cummings who was one of our artists featured in the Parkinson's Artisans Show. We also record the sad passing of Con Diamond, who was awarded an honorary life membership last year for his contributions to the Parkes Support Group and the Parkinson's community.

There are of course many others who I haven't mentioned here and their efforts are no less appreciated.

### Website and emails

I would like to encourage anyone who has internet access to regularly check our website for updates of activities and information. The website is [www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au). In addition, please feel free to provide to us your email address as this may assist us to contact you. Our email address is [pnsw@parkinsonsnsw.org.au](mailto:pnsw@parkinsonsnsw.org.au).

We also welcome any suggestions, offers of assistance and ideas, whether by telephone, mail or email.

Yours in Parkinson's friendship

Miriam Dixon

## Parkinson's NSW Unity Walk

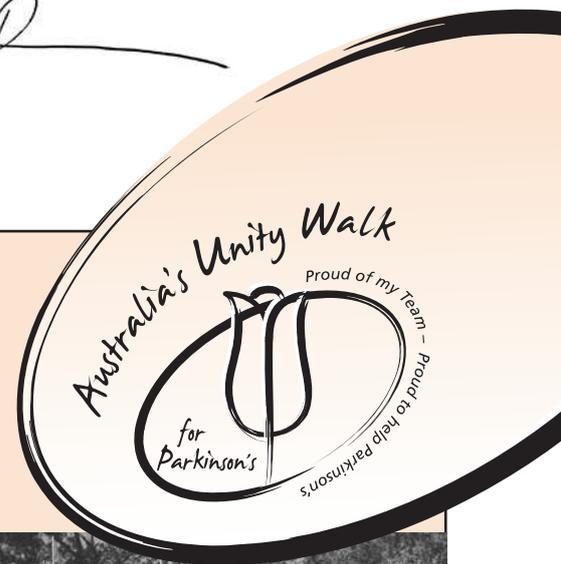
Make a note in your diaries, the Parkinson's NSW Unity Walk will take place on Sunday, 29 August at Sydney Olympic Park.

As has been the case in the past, we are designing a new walk, taking into account all the feedback from previous Walks and incorporating as much of the feedback we received as a result of the survey we conducted post event in 2009.

The exciting news this year is the confirmation of Her Excellency Ms Quentin Bryce AC, Governor General of Australia as our Ambassador. The Governor General has filmed a television community service announcement for us.

WA and SA are joining the eastern states this year in staging the Walk so we are well on the way to making this a truly national event but we would like to think that, as the originators, we can still lead the way in terms of our numbers.

So start spreading the word. The 2010 Parkinson's Unity Walk will be the biggest and the best to date but we do need all of your support to ensure we continue the growth of the event into one of the biggest of its kind in Australia.



## Research Grants 2010



### **Carolyn Sue – \$60,000 Unity Walk Grant**

#### **CREATION OF NEW INDUCED PLURIPOTENTIAL STEM CELL MODELS TO INVESTIGATE PARKINSON'S DISEASE**

*Professor Carolyn M Sue  
Principle investigator*

Understanding of the cause of Pd has been advanced by studying the genetic forms of Parkinson's disease (Pd). However, it is still not known how the cells in the brain degenerate in this disorder. In this project, we will use new technologies to create human cell models that will help us investigate how neurons degenerate in Pd.

In 2007, Takahashi and colleagues were able to successfully create a new form of stem cell model called human iPS cells (induced pluripotent stem cells) from skin cell lines. These iPS cells had similar characteristics to human embryonic stem cells. Subsequent studies showed that these iPS cells could be successfully differentiated into dopaminergic neurons with a high level of efficiency. Thus, it has become possible to create neurons from a human skin biopsy using this iPS cell methodology.

In this project, we will create human derived stem cell models of Pd by using this iPS technology on skin fibroblast cultures generated from affected patients with genetic forms of Pd. This will create patient-derived disease specific cell models, as the cell lines will contain the Pd gene abnormalities that have caused disease in the donor patient. These cells will thus create an accurate cell model to investigate the cause of Pd with closer relevance to humans. Using these cell models, we will also be able to test whether various treatments can be used to slow down or stop the progression of Pd.



### **Bryce Vissel – \$50,000 Seed Grant**

#### **INVESTIGATION OF A NEW THERAPEUTIC STRATEGY FOR PARKINSON'S DISEASE**

*Bryce Vissel, Ph.D., Head of Research into Neural Plasticity and Regeneration.  
Research to discover the mechanisms and treatments for Parkinson's disease, Alzheimers disease and spinal cord disorders.*

The symptoms of Parkinson's disease result primarily from loss of a select population of nerve cells from the brain, called dopamine nerve cells. The reasons the nerve cells die and the reasons that Parkinson's disease symptoms occur is not fully understood. Further, there are currently no drugs available that will prevent the loss of the dopamine nerve cells, although some drugs are available that will provide symptomatic benefit. The drugs that are used to provide symptomatic benefit work by replacing the dopamine that is lost from the brain in some way. L-dopa (found in Sinemet) is a classic example of a drug that works in this way.

We think that we have found a unique new therapeutic strategy that works in a completely different way to L-dopa, that might offer an alternative or adjunct treatment for Parkinson's disease. We are now confirming if our therapeutic strategy is indeed able to prevent loss of the dopamine nerve cells and also partially restore symptom control in mouse models of Parkinson's disease. In doing so, we will be the first to identify this potential new therapeutic approach to help both manage Parkinson's symptoms and to slow its progression.



### **Gilles Guillemin – \$20,000 Seed Grant**

#### **TRYPTOPHAN METABOLISM AND PARKINSON'S DISEASE**

The kynurenine pathway (KP) represents the main catabolic pathway for the essential amino acid tryptophan. We have previously shown that this pathway is activated in other neurodegenerative diseases such as Alzheimer's disease and motor neuron diseases. We believe that the KP is also likely to be involved in the pathogenesis of Parkinson's disease (Pd). We have already strong preliminary data demonstrating that prolonged KP activation leads to accumulation of a potent neurotoxin. We propose to investigate the involvement of KP in Pd using cultures of human brain neurons, brain sections from Pd patients, animal models of Pd and to test new drugs targeting the KP for their ability to control neuroinflammation and dopaminergic neurodegeneration.

## Research Grants 2010

### Kay Double – \$20,000 Seed Grant COPPER IN PARKINSON'S DISEASE

Associate Professor Kay Double, Prince of Wales Medical Research Institute



Researchers involved in the study on copper in Parkinson's disease at Prince of Wales Medical Research Institute. From left: Veronica Smoothy, Katherine Scarpin and Assoc Prof Kay Double.

The reason for the relatively selective brain cell death that leads to the symptoms of Parkinson's disease is unknown but changes in levels of metals within the brain are widely believed to play a role. Working with our collaborator Dr Sylvain Bohic at the European Synchrotron (a kind of "super microscope") in Grenoble, France we found that levels of copper are reduced in the vulnerable brain regions in Parkinson's disease. Copper is important for the normal function of several key brain proteins and decreased brain copper causes cell damage and death in other brain disorders. Thus it is feasible that reduced brain copper may contribute to cell damage in the brain in Parkinson's disease. In this seed project we will investigate how copper moves into these regions of the brain and if brain copper transport is altered in persons with Parkinson's disease. This knowledge will help us understand why brain copper levels are changed in Parkinson's disease. In future work we will investigate the effects of reduced copper on brain cell health in Parkinson's disease. This work will involve research assistant Veronica Smoothy and new PhD student Katherine Scarpin at the Prince of Wales Medical Research Institute, as well as our collaborators Professor Julian Mercer at Deakin University and Associate Professor David Finkelstein at the Mental Health Research Institute of Victoria.

## Research

### MICHAEL J FOX FOUNDATION FUND LOCAL RESEARCH INTO FREEZING OF GAIT

Dr Simon Lewis

Medical researchers from the University of Sydney's Brain and Mind Research Institute have launched a world-first study investigating the phenomenon of Freezing of Gait which commonly affects people with Parkinson's disease (Pd). The study is the first to be funded by The Michael J Fox Foundation in NSW and uses functional magnetic resonance imaging (fMRI) together with a computer generated 'virtual reality' environment to elicit freezing episodes in patients with Pd.

Freezing of gait affects over half of all advanced cases of Pd where people feel like their feet become suddenly 'stuck to the floor' while walking or turning. Sadly, freezing of gait responds poorly to current treatments and is a leading cause of falls. Principle Investigator of the study, Dr. Simon Lewis said, "While the mechanisms underlying freezing of gait are unknown, our group has recently proposed that these episodes may reflect a temporary overload in specific circuits of the brain. Our initial results have been very exciting and certainly confirm our belief that this study will be able to identify the processes that underlie freezing of gait in Parkinson's".

It is hoped that identifying the nature of this problem will lead to new directions for targeting therapy and enhance quality of life for people living with Pd. People wanting more information or looking to volunteer for this research should contact Dr. Mac Shine at Brain & Mind Research Institute on 02 9351 0702 or pdclinic@med.usyd.edu.au.

## Research study looking at leg muscle power, balance and walking in Parkinson's disease.

**We are looking for people with Parkinson's disease who are aged 40 years or above and can walk unassisted, with or without a walking aid.**

Participants will attend Cumberland Campus of The University of Sydney at Lidcombe for a 2½ hour measurement session.

If you would like to be involved and/or would like to know more, please contact:

**Serene Paul**

Ph: 9351 9435 or 0405 303 102  
Email: serene.paul@sydney.edu.au

or **Dr Colleen Canning**

Ph: 9351 9263  
Email: colleen.canning@sydney.edu.au

## Completed PhD Stipend Recipient

### FINAL REPORT

*Yun Ju Christine Song, Prince of Wales Medical Research Institute*

I was fortunate enough to be awarded the Parkinson's NSW Student Stipend Award in 2008. This award allowed me to successfully complete my PhD within the expected time frame of 3.5 years. After receiving the Parkinson's NSW Student Stipend Award I was able to publish 2 papers on Parkinson's disease titled "Degeneration in different parkinsonian syndromes relates astrocyte type and astrocyte protein expression" (*Journal of Neuropathology and Experimental Neurology*) and "Clinical correlates of similar pathologies in parkinsonian syndromes" (In submission for *Movement Disorders*). An additional paper is in preparation titled "Microglial parkin in Parkinson's disease and atypical parkinsonian syndromes" (In preparation for *Journal of Neuropathology and Experimental Neurology*). Parkinson's NSW was acknowledged as funding sources in these publications. In addition to these publications, I also received a travel

award to present my work at the 12th International Congress of Parkinson's Disease and Movement Disorders. The successful completion of my PhD with receiving awards such as the Parkinson's NSW Student Stipend Award allowed me the honour of receiving the prize for the Dean's List for Excellence in Postgraduate Research Studies at University of NSW.

It has been a great privilege to have received the Parkinson's NSW Student Stipend Award and I believe it is awards like these that have been pivotal in the successful completion of my PhD. In total through my PhD I have 6 publications, 6 conference presentations and 10 awards/prizes. I am most grateful to Parkinson's NSW and will strive further to contribute to the body of research for Parkinson's disease.

### Young Women's Group

If you are a young woman living with a diagnosis of Parkinson disease and are under the age of 60, you might like to join our Young Women's Group.

The group usually meets the 3rd Wednesday of the month 10:30am – 12:00noon at our office.

We welcome newcomers and their female family members or carers.

**The next group will meet on the 18 March.**

**To register contact our InfoLine 1800 644 189**

### Continence Aids Payment Scheme

From 1 July 2010, the Australian Government will introduce the Continence Aids Payment Scheme (CAPS), replacing the existing Continence Aids Assistance Scheme (CAAS). Under the new scheme, eligible clients will receive an annual payment of up to \$489.95 (plus indexation). Medicare Australia will deliver the payment directly into the client's bank account, or the account of their authorised legal representative.

For further information on CAPS, please contact on email [continence@health.gov.au](mailto:continence@health.gov.au) or contact InfoLine 1800 644 189.



*The illustrious Macquarie Group Band*

## The Financial Instruments

Invites you to a Charity Fundraising Bash  
Excellent entertainment for commendable causes!  
Supported by the Macquarie Group Foundation in aid of  
**Cure Cancer Australia and Parkinson's NSW**

Wednesday 21 April 2010 – 7pm  
The Basement, 29 Reiby Place, Sydney

RSVP by Wednesday 14 April 2010  
1800 644 189 or [pnswn@parkinsonsnsw.org.au](mailto:pnswn@parkinsonsnsw.org.au)

## Newest Council member – Chris Wilson



Chris Wilson is a Partner with Deloitte Australia – part of an international organisation providing audit, consulting, financial advisory, risk management and tax services to selected clients. He is also a Director of the Deloitte Foundation and leads the national Corporate Responsibility initiatives. Away from work, Chris is a Director of Eastern Respite and Recreation (ERR), a non-profit organisation focused

on providing services and relief for families of disabled children.

Chris has developed many skills during his years of working for various corporate and not-for-profit organisations, most recently focussing on Strategy and Operational Consulting.

Chris Wilson's connection with Parkinson's began in 1998 when his father was diagnosed with the disease. He battled valiantly until his passing in October 2006. His father was constantly looking for a cure and a way to manage his Parkinson's and Chris shares his passion to drive not only support, but also research and development into finding ways to help those living with Parkinson's.

Parkinson's NSW is delighted that Chris Wilson brings such expertise to the Council and we welcome his enthusiasm to give his time and skills to enhance the quality of life of those living with Parkinson's.

### Problems keeping medications on time?

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## Free to good home!

### Bed and Hoist

The bed is an Invacare Etude with a Blue Wave Alternating Overlay.

The hoist is a KH 401 Multi-Lift with access padded sling and standing sling.

*Transport costs would be to be the borne interested party. Currently located in Eastern Suburbs of Sydney.*

### Commode and toilet surround

In good condition.

Pick up from PNSW office only.



**Please call PNSW Office 8875 8900 to  
express your interest.**

## Parkinson's Plus Seminar

**Vincent Fairfax Centre  
Macquarie Hospital  
2nd July**

To register your interest, please call InfoLine.

## Advanced Therapy in Parkinson's disease Workshop

*Featuring*

Do I need an "advanced therapy"

Dr Neil Mahant, Neurologist

Apomorphine and Duodopa

Dr Victor Fung, Neurologist

Deep Brain Stimulation (DBS)

Dr Jacqueline McMaster, Neurosurgeon

**9:30am – 12:30pm, Friday 30 April**

RSVP: By 16 April to

InfoLine 1800 644 189 or

infoline@parkinsonsnsw.org.au

## On the groupvine

by Trish Morgan

### Border Groups

**Albury/Wodonga** support group has taken on a new persona. It is the first group to be shared by Parkinson's New South Wales and Parkinson's Victoria, and is an amalgamation of two groups that met at Albury and Wodonga. Jamie Saines a Physiotherapist who is attached to Wodonga Regional Health Service, is steering the group and has worked hard to develop a support group brochure that acknowledges both Parkinson's organisations. The group meets on the first Wednesday of each month at 10.30 - 12 noon at Mc Farland House, 11A McFarland Road, Wodonga, Victoria. Trish Morgan and Lyn Smith are planning a visit to this new group in April to celebrate its inauguration and congratulate Jamie for his work in setting up the group. **Thank you and well done Jamie!**

**Tweed** support group is located in another border community. Helen Boddington reports that the group is thriving and looking to become more social with a picnic in April and a Christmas in July lunch. The group staged a very successful Awareness Seminar in August 2009, without cost due to community support – including a donation of \$500 from Tweed Heads Bowling Club. Tweed is in regular contact with the **Broadbeach** support group in Queensland.

### Coastal Groups

**Yamba** support group is nearly two years old and has grown to over twenty members. They meet in the Presbyterian Church hall on the third Friday of each month at 2pm. Members enjoyed seeing a 'Coffee Morning' presentation at their February meeting when Trish Morgan visited – the same as is held at PNSW Head Office. Leader Heather Wilson and her husband Graeme were fine hosts. Leader of the Grafton support group, Cathy Eggins, drove to Yamba for the meeting. Members are planning to have a movie premiere to raise funds for Parkinson's. They have been inspired by **Bingara** support group who organised a Saturday matinee last year.



Yamba support group

Members of support groups are often asked to represent Parkinson's NSW when local community organisations hold fundraising events. Recently, Keith and Ros Smithers of **Shoalhaven Nowra** attended the **Albion Park Ladies Bowling Club Charity Fundraising Day** – and were presented with a cheque for \$1,300. This was the proceeds raised from raffles, lucky door prizes

and trading tables and from a great day of bowling. Neighbouring clubs also took part. Ros gave an account of various aspects of Parkinson's, support groups and the role of PNSW in supporting research. Special thanks to the Albion Park Ladies and to Keith and Ros Smithers.

### Groups in Between

**Hawkesbury** support group has monthly bus trips planned to places as varied as the Art Gallery, the Flight Museum at Dapto and a river cruise on the Hawkesbury Princess. The group is small but the trips are so well known that people from around the area make up the numbers, and the coach owned and driven by Jim Scanlon is usually full. In March there is Jim's Mystery trip. There is great diversity in our support groups.

**Illawarra North** support group has two bus trips a year in May and October. Membership has grown to almost forty.

**Yass** support group members gave a presentation to their local Rotary and Lions clubs. There were plenty of questions and the service clubs will support the annual street stall run by the support group later in the year.

**Young Onset** members enjoyed a weekend of pampering and relaxation at Camp Breakaway, San Remo on 6 and 7 March. There was massage and reflexology, tai chi and counseling for participants. Dr Scott Whyte, Neurologist, Greg Harris, Parkinson's Nurse and Jim Preece, Physiotherapist with the Community Outreach Team provided up to date information and answered questions. The Trivia Quiz and Mamma Mia movie screening – Karaoke style – made Saturday night lots of fun!

From the supplier,

## Information for Patients on SINEMET® CR

### **SINEMET® CR (levodopa/carbidopa) 200/50mg Controlled Release tablets – out of stock**

MSD (the Australian supplier of SINEMET CR tablets), regrets to inform you that SINEMET CR will be in very short supply from now until early 2011.

**Please contact your doctor as soon as possible  
so that arrangements can be made  
to change your prescription.**

This worldwide shortage of SINEMET CR is related to a change in the source of supply. It is not related to any product quality or safety issue.

Please note that the shortage of SINEMET CR does not affect the availability of SINEMET 100/25mg or SINEMET 250/25mg tablets.

## Treatments for Depression

by Deborah England

In late February I volunteered at a community event which entailed speaking with folk from a variety of backgrounds about various health issues. During the course of the day I had an interesting conversation with a fellow who was a representative of 'The Black Dog Institute'. Most of their work is centred on the various manifestations of depression. The 'Black Dog' is the name that Sir Winston Churchill gave to the depression that bothered him throughout his life. Our conversation was about 'positive psychology' and I would like to share some of the ideas that we discussed.

For those of you perhaps not familiar with the term 'positive psychology', it would be fair to say that it is a fairly recent branch of psychology. It seeks to understand the positive emotions such as joy, optimism and contentment that allow groups and individuals to flourish.

Some strategies for increasing happiness that were suggested by this fellow are as follows:

- **Mindfulness**

Instead of acting and interacting automatically, without thinking, pay attention to the moment and respond rather than react.

- **Savouring**

Developing awareness of pleasure and consciously enjoying the moment.

- **Sharing with others**

Tell others that you value the moment and their contribution to it.

- **Memory building**

Take mental photographs or even a physical souvenir of an event and reminisce about it later.

- **Sharpening perception**

Focus on some elements and block out others, the example he used here was closing your eyes and listening to music allowing your attention to be only on what you are hearing.

He also spoke about nurturing relationships and identifying and using your strengths. The conversation also included ways of constructing or finding meaning in our experiences. Some of the ideas we discussed included:

- Learning to forgive. Letting go of anger and resentment.
- Performing small acts of kindness. This can enhance your connectedness with others.
- Consciously finding things to be grateful about. It can be as simple as something like a sunny day.

In short, I found the conversation to be very interesting and would be happy to discuss aspects of these strategies with any of you should you so choose.

## In Loving Memory

There has been a move in recent years for the family of the deceased to request making donations in lieu of flowers. This enables friends and family of the deceased to support people with Parkinson's and to help raise funds in memory of the person who may have had Parkinson's.

An "In Memory" online donation is a means of enabling donations to be processed easily, via a secure website. Parkinson's NSW has set up an **In Loving Memory** page on the Everyday Hero website at [www.everydayhero.com.au](http://www.everydayhero.com.au) (similar to the online fundraising for the Unity Walk). It can be customised to have your loved one's photograph as well as a few words about them. There is also an area where people can leave a special anecdote or memory about your loved one.

The In Memory Page can easily be set up by someone in the family or we can do it for you. It takes about 10 minutes to do. If you wish to do it yourself you just:

- go to [http://www.everydayhero.com.au/event/pnsw\\_in\\_memory](http://www.everydayhero.com.au/event/pnsw_in_memory)
- click on "Create In Memory Page now"
- complete all the details required

Once you have done this, you will be allocated a special link. You can email people to let them know about the In Memory Page and that you would like them to donate if they wish to.

The donation process is very simple and straightforward. A receipt will be issued online to the donor.

If we are going to set it up for you:

- Think about what you would like to say. We need just a couple of short paragraphs about the person and some words about why you would like people to donate to PNSW.
- If you like, we can add a photo onto the fundraising page as well – we will need a digital version of the photo.

Phone Parkinson's NSW (1800 644 189) to discuss the details.

We will then create the In Memory Page and let you have the details for the link. Once it is set up, the information (link) about the donation page can be sent to your family and friends close by, or even interstate and overseas. You can let them know that you wish for money to be donated to Parkinson's NSW either in lieu of flowers or if they just want to support the organisation. This is a wonderful way for people who can't attend the funeral to be able to support your family and Parkinson's NSW as well.



## The James Parkinson Society ... bringing hope for the future

Isabelle Clark – Bequest Officer



I have enjoyed visiting some of our Support Groups. When groups meet, much is exchanged, stories shared, support offered. There is also the opportunity to get practical tips and resources. One of the greatest gifts is someone willing to listen. I am grateful to have this opportunity to meet you all and will continue to get out just saying hello.

The greatest blessing of all though is that people care enough to want to give to others. James Parkinson Society members are regular Australians wanting to give so that others, who may come after them, can be assisted by Parkinson's NSW to enjoy a more fulfilling life.

If I can help in anyway, please feel free to contact me on 1800 644 189.

## Pedal 4 Parkinson's

On the 9th January, a team of cyclists set out on a grueling 13 day journey, 1400km from the Sydney Opera House to Federation Square in Melbourne – Pedalling for Parkinson's. The aim of the ride was to generate much needed funds for Parkinson's Australia and to increase community awareness about Parkinson's disease.

Now in its second year, the annual ride was the brainchild of young Sydney engineer, Sarah McDonald." In 2004 my father was diagnosed with Parkinson's. It's hard watching someone you love deteriorate and even harder knowing you can't fix it. While I can't cure Parkinson's, by organising Pedal 4 Parkinson's I can show my support for my father and the countless other Australians living with Parkinson's disease," she said.

Sarah and her riding team, Jimmy and Warwick and Sri in the back-up car, were greeted by all the coastal support groups along the route in New South Wales and by Parkinson's ACT on a diversion to Canberra. After completing more than 1,000kms Sarah took a spill from her bike which landed her in Bairnsdale Hospital. Despite the best treatment Sarah was forced to drive the car and follow the boys. She parked the car and ran into Melbourne with her arm in a sling. Medical tests on return to Sydney found 4 – not 2 – broken ribs and a displaced collar bone.

The ride attracted publicity in major newspapers and on television and in many country newspapers, on radio and television. Support groups helped to publicise the ride and Ian Parr, 79, rode a section with Sarah into Nowra. The ride grabbed the attention of our members, many of whom kept up to date by following the blogsite.



## Ironman Euan

Euan McNair sure knows about struggle. However, Euan's type of struggle is not something which most people have ever experienced. His struggle centres around the 226km course for the Australian Ironman Triathlon championship race being held on 28 March this year. A 3.8km swim, 180km cycle and 42.2km marathon run will be sure to test his endurance.

Last year, as a part of his commitment to the race, he also committed to raising funds for Parkinson's NSW. Euan said "my grandmother suffered from Parkinson's so I am keen to continue to raise funds for the cause".

This year, he wants to beat his 2009 race time of 10 hours 38 minutes and wants to surpass his 2009 fundraising efforts as well!

You can encourage Euan on his race to the finish line and also raise money for Parkinson's NSW by logging onto [www.everydayhero.com.au/ironmanaustralia\\_euan](http://www.everydayhero.com.au/ironmanaustralia_euan). There you can make a donation and leave him a message of encouragement.

So be quick, as with your support we can help Euan to achieve a personal best race time as well as a personal best fundraising result.

## Donations

### IMPORTANT NOTICE

### regarding General Donations

All general donations will now be acknowledged in our Annual Report which will be published for the Annual General Meeting on the 29 September 2009.

There has been a significant increase in our general donations and as there is limited space in our newsletter, this decision has been made for all general donations received in this financial year. We will continue to publish in Stand By Me, donations made for In Memoriam and for Birthdays.

Thank you for your continuing support.

### Donations have been received in memory of the following people between 3 December 2009 and 2 March 2010.

We offer our sympathies to the families who have lost their loved one.

We also thank the friends and families who have donated to Parkinson's NSW in their memory.

#### IN MEMORIAM

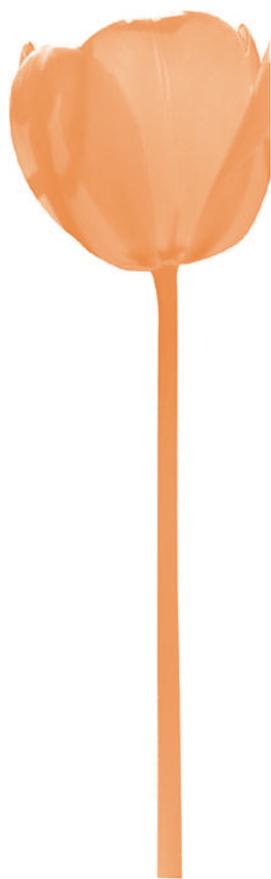
Heather Adamson  
Bernie Alexander  
Stanley Bird  
Mr Blizard  
Agnes Brown  
Edna Chidley  
Donald Coleman  
Elaine Crawford  
Colin Davey  
Joan Mary Deacon  
Arthur Deacon  
Carmela Di Francesco  
Trevor Donald  
Ester Dowd  
Charles Gilberd  
Mr Godbold  
John Harrison  
Peter Hughes  
William Jacobs  
Geoffrey Lee  
John Merrall  
Bill Needham  
Ada Nelson  
Giuseppe Privitera  
Chris Randall  
An Smit  
George Somerville  
Bruce Stackman  
Mervyn Tumeth  
Noel Walsh  
Ken Wooley

#### CELEBRATION DONATIONS WERE RECEIVED FOR:

John Silk receiving the Medal of the Order of Australia (OAM)

#### BIRTHDAYS

Ivan Begonja  
Shirley Cohen



## Support group contact details

GROUP	CONTACT	PHONE
Albury/Wodonga		02 6051 7400
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown	Glenda Rawlinson	02 9707 2791
Bathurst	Jennifer Mannell	02 6332 8963
Bega Valley	Sue Nelson	02 6495 9932
Bingara	Joan Bush	02 6724 1976
Blacktown	Bryan McAlister	02 9674 6827
Blue Mountains	Hazel Tolhurst	02 4751 9903
Broken Hill	Colleen O'Brien	08 8087 2175
Casino	Dawn Dennis	02 6662 6141
Castle Hill	Gayle Parker	02 9634 0578
Central Coast	Les Norris	0418 607 684
Chinatown Bi-lingual		0421 224 712
Coalfields	Betty Rumbel	02 4931 5210
Coffs Harbour	Vera Heil	02 6652 9959
Cowra	Ray Heilman	0428 639 850
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta	Margaret Fyfe	02 9638 4451
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla	John Vaughan	02 4471 2891
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Finley	Glenis Gordon	03 5436 9293
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	02 4822 6732
Grafton	Cathy Eggins	02 6642 2156
Griffith	Angela Bortolin	02 6962 3289
Gunnedah	Lisa Hagley	02 6742 0018
Hawkesbury	Jill Sykes	02 9621 1794
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South		02 4232 2807
Lower North Shore	Jan Cumming	02 9412 2740
Macarthur	John Philpott	02 4647 8990
Manly/Mosman	Bill Lindsay	02 9949 3991
Manning/Great Lakes	Bruce King	02 6555 9409
Maroubra	Trish/Lyn	02 8875 8900
Nambucca Valley	Margaret Butcher	02 6564 8231
Narrabri	Janice Holmes	02 6792 1468
Nepean	Joe Golding	02 9670 5093
Newcastle	Verlie Sullivan	02 4954 0338
Orange	Martha Brown	02 6362 2755
Parkes	Ivy Rook	02 6862 1783
Pittwater/Warringah	Margaret Smith	02 9913 7745
Port Macquarie	Patricia Stephenson	02 6584 0212
Quirindi	Les Howard	02 6747 1459
San Remo	Jan Dowling	02 4390 7321
Shoalhaven/Nowra	Jonathan Morgan	02 4464 3028
Shoalhaven/Ulladulla	Barry Mitchell	02 4454 0747
Southern Highlands	Marj Webb	02 4871 2615
St George/Sutherland	Myra Chalmers	02 9525 7215
Tamworth	Pat Johnson	02 6765 6948
Tomaree	Heather Grimmett	02 4981 4853
Tweed Heads	Helen Boddington	02 6676 2549
Ultimo	Gerald Ganglbauer	0411 156 309
Wagga Wagga	John Allen	02 6925 2713
Yamba	Heather Wilson	02 6646 1369
Yass	Clarrie Schlunke	02 6226 4150
Young Onset	Trish Morgan	1800 644 189
Young Men's Network	Garry Cearns	02 9871 1853
Young Women		1800 644 189

**PARKINSON'S NSW INC.**

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Web: www.parkinsonsnsw.org.au

**COUNCIL**

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Chris Davis *Vice President*  
Phillip Maundrell *Treasurer*  
Peter McWilliam OAM *Secretary*

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Miriam Dixon  
Assoc Prof Kay Double  
Bruce King OAM  
Bernard McGrath  
Allan Poole  
Rebecca Silk  
John Hassett  
Dr Simon Lewis  
Chris Wilson

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Dr Colleen Canning  
Dr Dominic Rowe  
Assoc Prof Carolyn Sue  
Dr Bryce Vissel  
Sr Evelyn Collins  
Prof Glenda Halliday  
Dr Kay Double  
Sr Laraine McAnally  
Prof Lynn Chenoweth  
Assoc Prof Martin Krause  
Dr Michael Hayes  
Dr Paul Silberstein  
Dr Simon Lewis  
Dr Steve Tisch  
Sr Sue Mercer  
Dr Victor Fung  
Dr Neil Mahant  
Dr Martin Krause

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Trish Morgan  
*Support Group Coordinator*  
Tracy Gough  
*Office Senior*  
Deborah England and  
Claerwen Armstrong  
*Parkinson's Specialist Counsellor*  
Chris Searles and Marianna Sain  
*Administration*  
Susan Tait and Julie Austin  
*Information & Resource Officers*  
Isabelle Clark  
*Bequest Officer*

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Teddy Bradley  
Jane Goulding  
Walter Pearce  
Ross Jones  
Samantha Urry  
Alice Law  
Ellen Law  
Judy Marshall  
Sue Rance  
Angela Turnbull  
Neil Sligar  
Karen Whitton  
Dasia Black-Gutman  
Lyn Smith  
Sue Ford  
Sue Rooleht  
Joan Todd  
Margaret Byron  
Martin Ancelleri  
Amanda Blake

**Stand By Me Editor**  
Samantha Urry

**Ambassador**  
Glenn Wheeler

**PATRONS**

Her Excellency  
Prof. Marie Bashir AC CVO  
Governor of NSW  
Sir Nicholas Shehadie AC

**HON. ADVISOR**

Lady Angela Carrick

## Diary Dates

**APRIL**

- All month Trivia Fundraising Events – various statewide locations
- 11 World Parkinson's Day
- 21 Macquarie Foundation Fundraiser – The Basement, Circular Quay
- 30 Advanced Therapy in Parkinson's disease Workshop – Westmead Hospital

**MAY**

- 2 Parkinson's on Parade – Four Seasons Hotel, The Rocks, Sydney
- 25 Coffee/Information morning – PNSW Office, Cox's Road, North Ryde

**JULY**

- 2 Parkinson's Plus Seminar – Vincent Fairfax Centre, Cox's Road, North Ryde

**AUGUST**

- 24 Coffee/Information morning – PNSW Office, Cox's Road, North Ryde
- 29 Unity Walk – Sydney Olympic Park

**SEPTEMBER**

- 29 Aug to 5 Sept Parkinson's Awareness Week
- 1 Parkinson's Awareness Seminar – State Parliament House

**OCTOBER**

- 18 Annual General Meeting – Macquarie Hospital, Cox's Rd, North Ryde

**NOVEMBER**

- 11 Golf Day – Monash Golf Club
- 23 Coffee/Information morning – PNSW Office, Cox's Road, North Ryde

**DECEMBER**

- 4 Parkinson's Christmas Party – Venue TBA

Please contact the InfoLine on 1800 644 189 for more information.

## Bequests

Please consider leaving a bequest to Parkinson's NSW in your will. It is the ultimate gift you can make; to leave a lasting legacy in perpetuity and assist those with Parkinson's. Alternatively, a living legacy will mean that you can personally experience the benefit your generous gift provides.

To make a bequest or living bequest please call 1800 644 189.

## To become a member, visit our website:

**www.parkinsonsnsw.org.au**

or

Call InfoLine: 1800 644 189

At the December Council Meeting it was decided that, from 1st April, all subscriptions and joining fees will be increased as follows:

- Individual Membership: \$35
- Professional Membership: \$75
- Organisations: \$100
- Life Membership: \$350

Parkinson's NSW Inc. ABN 93 023 603 545

Disclaimer: The information provided is for guidance only and is not a substitute for professional medical advice. Parkinson's NSW 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.

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