



Stand By Me

Parkinson's Disease Research Clinic

Researchers from the Parkinson's Disease Research Clinic at the University of Sydney's Brain & Mind Research Institute (BMRI) were thrilled to have the opportunity to explain some of their ongoing work with the Governor-General of the Commonwealth of Australia, Ms Quentin Bryce AC in early November. Parkinson's disease (PD) currently costs the nation over \$6 billion per annum and with an ageing population, there is a pressing need to address optimal management approaches for this debilitating neurodegenerative disease.

Dr Simon Lewis and Assoc Prof Sharon Naismith from the BMRI, as well as Sister Marilia Pereira and Mr Roger Norton from Parkinson's Australia, were invited to discuss a wide range of topics, specifically those focussing on improving the quality of life of people living with PD. Much attention was directed towards the role of community based specialist nurses to support both patients and their carers. The impact of this approach is currently being assessed by a Commonwealth Government supported pilot project conducted by the BMRI team in the Shoalhaven region of NSW.

Dr Simon Lewis, Director of the BMRI Parkinson's Disease Research Clinic explained, "We are very confident that community based nurses will become an established resource in Australia and

improve the quality of life for thousands of patients and their families. The 'Shoalhaven Project' may represent the first step in the launch of a national network of specialist nurses serving regional and remote communities."

Her Excellency Ms Quentin Bryce AC was delighted to hear about the very positive advances being made in the field and looks set to be a firm supporter of future efforts in combating PD.



(L-R) Marilia Pereira, Sharon Naismith, Governor General, Quentin Bryce, Roger Norton, Dr Simon Lewis.

The Winston Churchill Memorial Trust

The Winston Churchill Memorial Trust was established in 1965 shortly after the passing of Sir Winston, in honour of his memory.

The aim of the Churchill Trust is to support Australians in all lines of work whose expertise has progressed to such a level that an overseas research project would be valuable and would improve their contribution to their field and the Australian community.

Parkinson's NSW has been asked to bring to the attention of our community the call for applicants in 2011 who may benefit from an overseas Churchill Fellowship. There are many Fellowships available in areas that are relevant to Parkinson's NSW, such as the Dr Dorothea Sandars Churchill Fellowship for medical/veterinary parasitology or Parkinson's disease, or advances in medicine in general.

Applications for the award of Churchill Fellowships in 2011 need to be submitted between 1 November 2010 and 26 February 2011, and application forms can be downloaded from the website at www.churchilltrust.com.au or by contacting the National Office on 1800 777 231.

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President's Report

My first duty as incoming President of Parkinson's NSW must be to thank the retiring incumbent, John Silk, for his mammoth contribution to Parkinson's NSW over the last four years or so. I am too

new on the scene to have a first-hand appreciation of the changes wrought by John, but my understanding is that he came to office at a time when our financial situation was precarious; our Council was well intentioned but not effective; we had little or no political clout, accommodation was a problem and staff morale was not ideal.

John applied his considerable talents, energy and general chutzpah to his Presidential role and gradually turned our fortunes around. Despite being a long term Parkinson's sufferer himself, John persevered and prevailed. We moved from Concord Hospital to Khartoum Road, North Ryde, then to Cox's Road. Our finances are now on a solid footing. We've established a charitable trust which will fund valuable research into PD on an ongoing basis. Council was gradually populated with people who brought skill, judgement and an entrepreneurial flair to their roles. John worked with CEO Miriam Dixon to ensure that Parkinson's disease featured on the radar of key politicians and health bureaucrats. We developed training opportunities for nurses and doctors as well as medical students. The successful Unity Walk was initiated as an annual event and the list goes on.

John also had the vision to tackle the national PD scene; being a key player in ensuring collaboration among our parochial peers in other states. Not content with that, John also climbed onto the global bandwagon and was an active contributor to, and participant in, the World Parkinson's Congress held this year in Glasgow, where he forged valuable relationships for the future.

This has been just a small sample of John Silk's contribution to Parkinson's NSW. Not surprisingly, all that sustained effort has taken its toll and John very wisely decided to step down as President, although he will serve on Council.

I am humbled and thoroughly daunted by the prospect of following in the footsteps of such a strong contributor. My hope is that I can build on his considerable achievements, thanks to his groundwork and the calibre of the incoming Councilors.

My ambition for Parkinson's NSW in the coming year is to sustain the excellent initiatives which John took, and to focus on service to PWP across the State, through our central resources and the network of support groups which interfaces with members in local areas.

Our vision of eradicating PD is not going to be achieved tomorrow, but there is much that we can and must do to make the lot of the Parkinson's community better than it is at present. I hope to have constructive support from all members and that our current members will bring in their fellow PWP to join our cause.

Chris Davis



Questions or Concerns? Ring the InfoLine

The Information and Resource Officers at the Parkinson's NSW InfoLine busily take phone calls about many issues relating to Parkinson's disease. Many of our callers who have been recently diagnosed with Parkinson's disease are provided with information and are offered support. Other callers include family members and friends wanting to know how to best support their loved one who has been diagnosed with Parkinson's and to better understand the disease. Recently, there has been an increase in phone calls from Health Professionals seeking advice/information and education for those working as Aged Care Nursing Staff, Occupational Therapists, Speech Pathologists and Physiotherapists.

The InfoLine is available to the community and is a Freecall number. There is a wealth of information available including factsheets on topics such as mobility, nutrition, sleep and communication as well as many others. The InfoLine answers many enquiries about issues such as assistive aids and technologies, needing extra help at home and where to go to access home and community care services. There is also information available about the continence aids payment scheme, the medical energy rebate and enquiries about research. Other times people may phone just to talk, if they are having a difficult day with their symptoms or they are not sure where to turn when their doctor is not available.

The InfoLine is staffed by a Registered Nurse, Aged Care Assistant Nurse and a Registered Psychologist and is available Monday to Friday between 9am-5pm. Phone (freecall) 1800 644 189 with your questions or if you need information or support.

Learning to use computers

The InfoLine is happy to provide you with contact details for your local computer teaching service provider. There are numerous low cost companies across almost all suburbs of Sydney that can teach you the basics of computer use and get you up and running. To find out more (freecall) 1800 644 189.



CEO's Report

As we come to the end of this busy year, I would like to share with you some of the exciting projects we have planned for next year.

Newly diagnosed information program

We are pleased to announce a specially tailored information program for people newly diagnosed with Parkinson's, to be held at our North Ryde offices on each Wednesday afternoon in February 2011 – that is on 2 February, 9 February, 16 February and 23 February 2011. Our guest speakers include a Parkinson's disease nurse, a physiotherapist and a dietician. If you or someone you know has been recently diagnosed, please contact our Infoline on 1800 644 189 for further details and to register.

Young onset break away weekend

On 18, 19 and 20 February we will be having a weekend away for people first diagnosed with Parkinson's under the age of 60. The camp will be at Elanora Heights, and if you or someone you know come within this category, please call our Infoline.

Young onset research project

We are delighted that the Hon. Peter Primrose, Minister for Ageing and Minister for Disability Services, has announced funding to allow us to carry out a research project into the needs of people with young onset Parkinson's disease. We plan to commence this project early in 2011, and will provide information through our support groups, website, Facebook and Twitter, with an update in our next edition of *Stand by Me*.

Information kit for hospital

Sister Laraine McAnally and David Tsui, Parkinson's nurse specialists based at Westmead, together with Julie Austin (our information officer), are working on a "passport" which can be used by a person with Parkinson's when they enter hospital. This will be available early next year and will have space to insert personal information about medication, neurologist and other useful details to make the hospital stay less distressing.

DASH booklet to be translated into Chinese

We are grateful for a grant through the Australian Chinese Charitable Foundation for providing some funding for the printing of our DASH booklet in Chinese. We expect this to be ready in the first half of next year and are hopeful that it will be distributed nationally and internationally.

Follow up to World Parkinson's Congress 2010

I met representatives of many overseas Parkinson's organisations during the recent World Parkinson's Congress in Glasgow and we have discussed working on joint awareness strategies and other ways of assisting our respective members. Over the coming year I look forward to liaising with members of many like organisations such as the Parkinson's Society of Canada, the Hong Kong Society and the European Federation of Neurological Associations.

Research editorial team

The coming year will see some changes in the research editorial team, who review research articles in *Stand by Me*. We welcome to this role Dr Paul Clouston and Dr Bryce Vissel. They will succeed Assoc. Prof. Kay Double and Dr Simon Lewis, who have been of great assistance with this task in the past – in Kay's case for 5 years. Both Kay and Simon will continue to assist in other ways, including on our expert Advisory Committee and Council.

Changes in Council

As you may be aware from letters we have sent out, Council members Alan Poole and Chris Wilson have retired from Council – in Chris' case because he and his family have relocated to Victoria.

At the recent AGM, our retiring President, John Silk OAM, and his wife, Rebecca, were presented with certificates of life membership by our new President, Chris Davis.

The AGM also heard a presentation by Dr Bryce Vissel on recent developments in his research, which has been assisted by a Parkinson's NSW research grant.

Season's Greetings

I take this opportunity to wish you and your families Season's Greetings and all the best for the New Year.

Yours in Parkinson's Friendship

Miriam Dixon, CEO

Proud to support
'Stand By Me.'

M&CSAATCHI

2nd WORLD PARKINSON'S CONGRESS

28 September – 1 October 2010
Glasgow, Scotland, UK

A Personal Overview by Irene Gibbons



World Congress Exhibition Hall

It is impossible to report all I heard and learnt at the recent congress in Glasgow. I have included information from some particular sessions, as well as some useful websites. A CD of all abstracts is available.

Parkinson's Australia had a stand at the Congress and I manned this along with other Australian participants. This was a valuable tool in disseminating information about the Access Economics Report and the On-line GP Education Program as well as meeting other participants. This latter was one of the major benefits of attending such a conference. I established some very valuable contacts and have been volunteered to assist with the planning for the third WPC in Montreal, Canada in 2013.

The Global Parkinson's Pledge was launched at the Congress to help build a global Parkinson's movement. The pledge aims to make Parkinson's a priority health, social and economic issue around the world and, of course, find a cure. The goal of the organisers is for one million people to sign the pledge by the next congress in 2013. Sign at www.worldpdcongress.org/pledge/pledge

Multidisciplinary Care

This important session addressed the nature of interdisciplinary teams including who is involved, what their roles are and why it is important to offer this type of care. The speakers were from Israel, Australia (Victoria) and the Netherlands as well as team members such as the physiotherapist, occupational therapist, sex therapist, social worker, dietician, speech pathologist and, most important, the carer. They examined a number of case studies highlighting the spectrum of care that can be given using this model.

Parkinson's Self Assessment Tool

This tool was designed by the Cure Parkinson's Trust to assist PWP to gain a better understanding of the overall pattern of their Parkinson's. After self assessment, the results can be shared with healthcare professionals. The tool can be downloaded from the Cure Parkinson's website at: www.cureparkinsons.org.uk

Tom Isaacs

Tom was one of the most inspirational people I met at the Congress. He gave a number of presentations on living with Parkinson's, advocacy and the Cure Parkinson's Trust of which he was co-founder. He was diagnosed with PD at aged 27 and has raised substantial funds for the Trust, part of it from a 4,500 km walk around the UK. The fundraising arm of the Trust is called movers and shakers. Tom shared his 25 top tips for PWP with Congress participants:

1. Engage/understand your condition
2. Be self aware
3. Listen to your body
4. Watch where you sit
5. Try to see the same doctor
6. Sleep
7. Be optimistic
8. Exercise, exercise, exercise
9. Tomorrow will be better
10. Make sure it's the right type of exercise
11. Take your pills on time
12. Keep mentally active
13. Communication – tell everyone how you feel
14. Think of others
15. Be upfront – spread awareness
16. Keep hydrated
17. Manage your eating habits, eg protein at night?
18. Maintain a balanced diet
19. Keep your gut in working order
20. Don't go to fine art auctions
21. Have regular massages
22. Never act weirdly as a joke
23. Burglary is not the answer
24. Compartmentalise
25. Teamwork – use all the services that are available

Tom says that there are 3 things that assist his quality of life:

Being – winning the psychological battle

Belonging – engage in all things Parkinson's

Becoming – involve in all research

And finally: **Replace anger by passion**

Advocacy

I attended a number of sessions on advocacy to assist in my roles with Parkinson's Australia and SA. There was an interesting case study in Canada where they formed a neurological alliance and received funding to undertake a brain conditions study. There are 24 organisations involved which all contribute financially. More details at: www.mybrainmatters.ca

Parkinson's Action Network at: www.parkinsonsaction.org

Parkinson's UK at www.parkinsons.org.uk previously the Parkinson's Disease Society have recently rebadged themselves as Parkinson's UK with a much stronger advocacy focus. Their mission is:

- Change attitudes
- Find a cure
- Join us

It is worth looking at their website as they have a wealth of excellent resources.

The website: www.unidoscontraelparkinson.com can be translated from Spanish to English. Their presentation was titled 'start small, think big' and outlined various things they had done to raise awareness, culminating in a run for Parkinson's held in 12 cities.

Younger onset versus older families

This presentation stressed the need to focus on carer burden for younger onset – both physically and psychologically. The family characteristics of those under 55 are very different from those older families and studies done indicate that young spouses of PWP will experience more negative reactions than the older carers. Therefore there is a need for:

- Good social networking
- Assistance with child rearing
- Help to problem solve and multi task
- Assistance in the area of communication strategies

Use of Technology for PWP

The internet is being used by PWP around the world to connect and advocate. E-advocacy uses blogs, forums, message boards and social media such as Facebook and Twitter. There is much to learn. A very good presentation was given by Jean Burns from Plan4life – www.pdplan4life.com particularly the section on e-advocacy.

The European Parkinson's Disease Association uses Facebook, Twitter and YouTube as tools of communication.

Lobbying using social media:

Twitter – link to press releases, politicians, local council, mention news articles, link to video

Facebook – write to supporters, link to press releases, link to video on YouTube

Create a signature block in emails, on posters etc that has details of Facebook, Twitter and YouTube pages

For security purposes ensure you provide as little personal information as possible – never provide your address or birth date nor phone numbers and set up an email account with gmail or similar

Ethics

There was some interesting discussion on the ethics involved in clinical trials. This included the need for education of the physician and patient, consent issues, disclosure issues (ie if something else is identified), confidentiality issues, the need for patients to feel in control and the wisdom of counselling.

PD Community

How do we fit together as a global community? We all have the same challenges and we all do the same things so we need to communicate, educate and exchange information. We can assist by 'buddying' other countries, by providing translated materials, both printed and on our website. To assist with the conference, an on-line information network was created and organisational partners grew to 157. The aim is to have 200 partners by 2013.

General

The book *My father, my brother and me* by David Iverson was shown as part of the Frontline program in the USA in 2009. David was the third in his family after his father and brother to be diagnosed with PD. There are various videos on the internet showing interesting excerpts from the program.

Membership is free on the PD Online Research site: www.pdonlineresearch.org and it was suggested that PWP might like to become members.

A relatively new online resource is: www.myPDinfo.com

Conclusion

Finally, something that resonated with a lot of participants was the following:

Parkinson's disease asks a lot, it's how we answer that counts.

"Captain" Pat McGeown

Spreading the message of Parkinson's NSW is greatly assisted by civic leaders informing their local community about the symptoms and incidence of Parkinson's disease.

"Captain" Pat McGeown has vigorously promoted the Parkinson's cause in the Macarthur community. Pat is a radio announcer and former Creative Director of local radio station C91.3FM. He is also Vice President of the Campbelltown Chamber of Commerce.

Since 2008 he has authorised and produced \$8,000 of free advertising on C91.3FM publicising the Unity Walk and Macarthur support group events. He has conducted four interviews with a member of the Macarthur support group to help inform the community about services available in Macarthur for people affected by Parkinson's disease.

In June this year, Pat produced a YouTube video interview of Macarthur support group member Neil Sligar, who described the challenges of living with Parkinson's disease and discussed his very active gym regime. The Northwest Parkinson's Foundation of the United States has provided its members with a link to Pat's interview.

Parkinson's NSW is very grateful for the energetic support of Pat McGeown.



Research

NEW LIFE BREATHED INTO NEUROTROPHIN CLINICAL TRIALS

Dr Eryn Werry, Neuroscience Research Australia

Whilst current available treatments for Parkinson's disease improve symptoms, a treatment that slows the progression of the disease is urgently needed. The process of developing drugs to treat and slow the progression of Parkinson's disease is a lengthy one, but this process is necessary to ensure only safe and effective medications are available to patients.

Once potential Parkinson's disease treatments are shown to be effective in preventing cell death or repairing damaged cells grown in the lab or in animals, trials of the treatment in humans are carried out. These are called **clinical trials** and have several phases. **Phase 1** clinical trials are where the treatment is given to a small group of typically 5 – 80 volunteers. The purpose of these phase 1 trials is to find evidence that the treatment is safe in humans. If a treatment is shown to be safe in this group of volunteers, a **phase 2** clinical trial is carried out on a larger group of volunteers (typically 100 – 300) to get further evidence of the safety of the treatment and to assess the treatment for effectiveness. If the treatment continues to be safe and effective, the trial is extended to a **phase 3** trial, where the safety and effectiveness of the treatment is monitored in 1000 - 3000 volunteers. Once a treatment passes a **phase 3** assessment, regulatory bodies such as the Therapeutic Goods Administration may approve the treatment to be sold to patients. A **phase 4** clinical trial will then be conducted, monitoring the risks and benefits of the treatment in the wider population.

Recently clinical trials have examined the use of **neurotrophic factors**, brain proteins which nourish and protect brain cells as possible new treatments for Parkinson's disease. **Phase 1** clinical trials showed two of these factors, called **neurturin** and **GDNF** can safely be given to patients. Unfortunately, **phase 2** clinical trials on larger numbers of patients were not effective at reducing PD symptoms.

The failure of GDNF and neurturin to be effective in **phase 2** clinical trials has been attributed to two challenges inherent to these kinds of treatment approaches. The first challenge is being able to get the correct amount of neurotrophins into the damaged areas of the brain, as the brain is protected by a barrier which is very selective about what which proteins it lets in. Neurotrophins are one group of proteins that are not allowed to enter the brain. This means that rather than using traditional oral, intravenous or intramuscular drug delivery methods, the neurotrophins have to be delivered via direct injection into the brain. A further challenge is that once neurotrophic factors are administered to the correct brain region, they are quickly removed by the brain's immune system, which means these proteins have little time to help the damaged cells.

In June, one of the major private charities raising funding for Parkinson's disease research in the USA, the Michael J Fox Foundation for Parkinson's Research, announced they would be giving \$4.6 million to fund two new trials

of neurotrophins using innovative methods to circumvent these problems. The first trial will use a so-called **"convection-enhanced delivery mechanism"**, which uses a newly developed computer program to accurately and safely implant a specially developed narrow tube into an area of the brain affected in Parkinson's. This tube will allow GDNF to be delivered repeatedly by a neurologist only to the areas of the brain where it is needed.

The second trial will use **gene therapy** to deliver neurturin to the brain of Parkinson's patients. Genes contain instructions that tell cells what proteins to make. In neurturin gene therapy, a safe virus will be used to insert neurturin genes into the cells affected by Parkinson's disease. It is hoped that this will allow the damaged cells to constantly produce their own neurturin protein. If these trials can successfully give the brain a sustained boost of neurotrophins, they hold great promise in leading to the development of a treatment which can slow the progress of Parkinson's disease.

Do you have any info on the timing of trials, ie How long they are, and when might results be known? Everyone will want to know this.

If you would like to find out more about these clinical trials, please visit: http://www.michaeljfox.org/newsEvents_mjfflnTheNews_pressReleases_article.cfm?ID=423

Information Sessions for people newly diagnosed with PD

Parkinson's NSW is pleased to announce a specially tailored program of Information Sessions for people newly diagnosed with Parkinson's.

The sessions will be held at our offices at Building 21, Macquarie Hospital, North Ryde on four consecutive Wednesday afternoons in February next year.

Scheduled dates are:

2 February, 9 February, 16 February
and 23 February 2011.

Guest speakers will include a PD nurse, a physiotherapist and a dietician.

If you, or someone you know, has been either diagnosed with Parkinson's in 2010 or commenced Parkinson's medications during 2010, please contact Infoline on 1800 644 189 for further details and to register.

Medical Alarm Systems

A medical alarm is a system designed to signal the presence of a hazard requiring urgent attention and to summon emergency medical personnel. Other terms for a medical alarm are *PERS (Personal Emergency Response System)* or *medical alert*.

These alarm systems come in many forms, however, the most common is a wireless pendant or transmitter that can be activated in an emergency. When the medical alarm is activated, the signal is transmitted to an alarm monitoring company, other emergency agency or other programmed phone numbers. Medical personnel are then dispatched to the site where the alarm was activated.

The choice of device will depend on many things, such as who can come to help, the distance over which the device works, how easy it is to carry and use the device, and how much it costs.

Some of the most common devices are:

- cordless and mobile phones – carried on a belt clip or in a pocket, with pre-programmed numbers
- Autodiallers – worn around the neck as a pendant, which is linked to the telephone. When activated, it automatically dials certain pre-programmed numbers until it gets an answer
- intercom systems – baby monitors or two-way intercoms between houses/flats
- neighbour-to-neighbour alarms – sirens and flashing lights outside the house or in a neighbour's home, activated by a pendant or wristband transmitter
- Telstra Delayed Hotline – automatic connection to a relative's or friend's number when the telephone receiver is removed
- Telecross – a daily phone call from a Red Cross volunteer
- person-to-person alarms – one person carries the transmitter and the other carries the receiver
- portable alarms – anything that makes a noise, for example a whistle, bell or battery-operated alarm
- monitored emergency call system – the most common system is a 24-hour monitored response service or personal alarm.

To find out more about these devices you can contact the Parkinson's NSW InfoLine (Freecall) 1800 644 189.



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Parkinson's Plus

Parkinson's Plus conditions are neurodegenerative disorders that differ from the classical Parkinson's disease in certain clinical features; this includes a poor response to levodopa or, at best, only a mild response. They can be difficult to diagnose at first due to the similarities in presentation with Parkinson's disease. The most common are Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Corticobasal Degeneration (CBD).

As the number of people with these conditions is smaller than those with Parkinson's disease, those with Parkinson's Plus conditions and their carers can often feel isolated, particularly in regional NSW. At Parkinson's NSW we offer contact with others by way of telephone conferencing. These calls occur every two months on a set date. We request that people participating in the telephone conference be members of Parkinson's NSW as well as having a Parkinson's Plus diagnosis or a carer of someone who has Parkinson's Plus. This is due to the sensitive nature of some of the discussions and also helps us to keep track of the group and provide more individual support if required.

The process for getting involved in one of our telephone conferences is easy. One week before the telephone conference is due to take place we send out a letter with details and instructions on how to place the call and join in. These telephone conference calls are free for

members of this support group and last up to an hour, depending on the number of people that join in.

The members of the support group consists of members and their carers who suffer from one of the Parkinson's Plus conditions, this includes MSA, PSP and CBD. Over the past year the group has grown to 26 members. As a group of this size can be difficult to manage on a telephone conference, we are going to trial a separation with one group of people with MSA and another group of people with PSP, (people with CBD will be able to join either or both sessions). This will allow for smaller group discussion so that everyone will be able to listen and contribute.

We also plan to initiate a small Parkinson's Plus newsletter to keep everyone informed as to what's new, with a brief overview of new research, conferences and tips for care issues including services available within local areas. The newsletter will also profile people's personal journeys and we therefore welcome contributions from members.

If you have been diagnosed with one of the Parkinson's Plus conditions or if you are a carer of someone who has been diagnosed and would like to join one of the many support groups we have available, please call the InfoLine (freecall) 1800 644 189 for further details.

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2010 Parkinson's NSW Golf Classic

Following three successive days of afternoon thunderstorms and heavy rain, the golf god smiled on Parkinson's NSW and the event went off like clockwork. It was warm and balmy with a slight sea breeze coming off the Pacific Ocean. Fifty five little white golf carts zooming across the green fairways of Monash Country Club ... the scene was an absolute picture even if at times some of the displays of golf weren't!

David Samer's team won on a count back from the People Bank team. For the third year running, Claudios Seafoods representing the Fish Markets again triumphed for the President's Cup over Zappia Bros representing Sydney Markets. The putting competition was shared amongst four and the chipping into the boat was shared by an unprecedented seven. Next year, to make it harder, we are mooring the dinghy down at Collaroy and the putting hole will be thimble size!

The official dinner followed with more than 100 guests enjoying a magnificent meal prepared by The Monash Country Club's chefs and washed down with beautiful Casella Wines; Toohey's Ales and Schweppes lemonade for those who preferred the lighter stuff. Bidding for the auctions was enthusiastic and the raffle tickets were well sought after ... or was it the lovely Toohey's girls Kasy and Jo selling them? Either way, everyone walked away with a prize gratefully obtained through the Herculean efforts of David Samer.

Our thanks to our Platinum Sponsors who have been with us since day one: Cromwell, Sydney Airports Corporation plus Argyle Inn Camden, M & C Saatchi, Kemp Strang Lawyers, Facilitate Digital and David Samer. Our thanks also to our Presenting Sponsor since day one: Sydney Markets plus Lundbeck, Golf Link and Silver Sponsors: Crane Group, Banjo Media, Zappia Bros and thanks to everyone else who supported Parkinson's NSW on the day, including our hard working committee members.

Money raised on the day will come close to reaching \$50,000 which places the Parkinson's NSW Golf Classic amongst the most successful charity golf days in Australia.



Monash Country Club 2010 Golf Day

We received this lovely letter from Myra Chalmers who was part of the winning team from Unity Walk Highest Fundraisers. Their prize was a corporate box at "Ben Hur the Arena Spectacular".

On behalf of the eight people who were able to go and see Ben Hur, I would like to thank you very much indeed for arranging for us to attend.

We had a fantastic evening, the Private Suite was everything we hoped it would be, all our needs were met and Jenny Meyers who is in advanced state of Parkinson's was also pampered. The food was enjoyed by all and was delicious. We managed to get Jenny out of her wheelchair so that she could sit outside in a normal seat to watch the show. She had raised almost \$3,000 by herself and was able to enjoy the evening.

The show lived up to the spectacle it promised to be and we were all impressed with the performance. I must admit we all waved our flags and cheered for the Gladiators and booed the opposition.

The instant construction of the galley and the forum was exceedingly well done before our eyes. The chariot race was the highlight of the evening. "Well done" to the charioteers.

Thank you once again. I wonder what delight you will have for next year?

*Kindest Regards
Myra Chalmers*

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On the groupvine

by Trish Morgan

GROUPS REFRESH, RENEW!

Many groups up and down the coast and in the country have needed to make changes and try new strategies to keep the group interesting for members.

Port Macquarie has a brand new committee, full of enthusiasm. Port Macquarie Golf Club held its annual golf day on 6 November, with proceeds to PNSW. A Christmas BBQ is planned with poetry readings and a choir.

Eurobodalla decided to hold a meeting every second month with a social event in between, for example coffee and cake at Chef's Cap Café in the Eurobodalla Botanic Gardens. Kevin Brown is the group librarian and he gives a book review at each meeting.

Hawkesbury continues to enjoy the bus trips to places of interest. This is a very successful fundraiser for Parkinson's. They held their AGM in October and several members have joined the committee.

Quirindi has moved its meetings to Quirindi Bowling Club with an invitation to have lunch before the meeting. Les Howard is patron and Len Turner is secretary/treasurer. Len's story of his life as a cyclist, boxer and musician (trumpet) was featured in a magazine, Qlife, which is published four times a year by the Quirindi Advocate. Len is prepared to speak to local schools about Parkinson's.



Quirindi Support Group

Narrabri support group is fortunate to have a lively committee and a wonderful working relationship with Jessie Hunt Aged Care Facility. On Wednesday 25 November a large number of personnel representing community health, nursing and allied health attended an information session by Deborah England, Parkinson's Specialist Counsellor. The afternoon was organised by Narrabri Leader, Anna Thomson and Director of Nursing, Cheryl Gleeson. A special thank you to them for organising the afternoon and for the use of the facility.

North Western groups – Tamworth, Bingara, Narrabri, Quirindi and Gunnedah – share social events on a regular basis. These could be at a pub with rustic charm and a good chef – at a town in between the groups.

Manly/Mosman support group received a Certificate of Recognition from Freshwater Community Bank in recognition of their support to the local community. Fantastic!

WELCOME TO NEW GROUP LEADERS:

Alys Cummings (Albury/Wodonga); Robert Yeoh (Chinatown Bi-lingual); Phil Papworth (Coalfields); Betty Byrn (Eurobodalla); Anne Instone (Illawarra South); John Philpott (Macarthur); John Mills (Nambucca Valley); Gordon Wright (Parkes); Alan Stephenson (Port Macquarie); David Boulton (Quirindi); Louise Young (Snowy/Monaro); Ruth McLeay (Tomaree Peninsular).

Congratulations and best wishes to all these people as they lead their groups into 2011.

REGIONAL MEETINGS and SEMINARS

Parkes Support Group initiated a regional meeting in June. Members came from Cowra, Dubbo, Orange and Parkes. The purpose was to discuss the constitution and the responsibilities of support groups and to brainstorm on how to engage members, especially those who could "do without" formal meetings, and how to support carers. Miriam Dixon spoke about the constitution and the attendees agreed that less formality and more social activities encouraged members to attend. Some groups have a good relationship with their local media and others find it difficult competing for time/space with so many other community groups. There is a need for a focus on 'support for carers' in 2011.

Orange Support Group also held a regional meeting in September with a presentation by Speech Pathologist, Magdalene Rosa. Leader, Martha Brown, compiled a folder of useful information about walking/turning, exercises and posture. There were handouts about speech and swallowing. Members came from Bathurst, Borenore, Cowra, Orange and Narromine.

St George/Sutherland, Macarthur, Maroubra, Hornsby/Ku-ring-gai, Central Coast and Nowra held meetings or seminars with Dr Simon Lewis and his team from the Brain & Mind Research Institute as guest speakers. Approximately 800 people in total were able to hear this presentation. This was due to the wonderful job by the support group committees in organizing publicity through local media, health centres and libraries.



Narrabri Support Group

St George/Sutherland filled their new meeting hall to capacity on a very wet day and provided a delicious morning tea and lunch to 150 people. Well done!

250 people attended the **Central Coast Seminar** where Dr Simon Lewis fielded a lively Q&A session. Dr Ian Cooper, Epidemiologist, spoke on his study of the incidence of PWP in Australia and especially New South Wales. Central Coast support group deserves congratulations for its organization and management of such a large crowd.

Shoalhaven Nowra hosted a seminar with a star-studded line up including Marilia Pereira, Neurological Nurse Educator; Dr Colleen Canning, Clinical Educator and Researcher in Physiotherapy at Sydney University; Dr Simon Lewis and Dr 'Mac' Shine from the Brain & Mind Research Institute. 150 people, including health care workers and support groups from Eurobodalla, Illawarra South, Goulburn and Wagga Wagga were present.

Thank you to everyone who gave their time to organize these events!

Parkinson's Medications and Pharmaceutical Benefits Scheme

Parkinson's NSW keenly awaits news as to whether Neupro®, The Parkinson's Patch (rotigotine transdermal patch) and Duodopa (levodopa/carbidopa) have been made available through the Pharmaceutical Benefits Scheme.

Duodopa® is similar to Sinemet®, Kinson®, and Madopar® (levodopa/benserazide), but in a gel form. The medication is administered directly into the small bowel through a tube passing directly into the stomach (PEG-J tube), which has an inner tube leading to the small bowel where levodopa is best absorbed

Just listed on the PBS is Sifrol® ER (pramipexole) which is now available in a new, once daily formulation. Sifrol® ER is available in a variety of strengths. Switching to Sifrol® ER will reduce the number of tablets you take each day. Check with your doctor and ask for a medication review if you feel you will benefit from a once daily dose.



*Raymond Groves –
1977 NSW State
Championships*

On the Road Again

By Pip K

For a cyclist there is something undeniably alluring about the open road. There is a primal sense of self accomplishment that is evoked when you are able to transport yourself under your own steam. As a cyclist you become closer to nature and begin to have a profound understanding of what true freedom really is. For a cyclist your bike isn't just a bike. It becomes an old friend who is always with you and can carry you away from everything else in your life. Quite simply when you're cycling, it's you, the road and your old friend.

60 year old Raymond Groves is all too familiar with the joy and freedom you can experience cycling on the open road. As a young man working at Victa Limited in Sydney, Ray was introduced to cycling by a co-worker. Having always been physically fit, Ray thought he'd give cycling a go. Little did he know that his love for the sport would grow into something more.

In 1975, at the age of 25, Ray's love for cycling led him to take up the sport professionally. Being a professional athlete is not a feat many of us can claim we have achieved. However Ray can definitively say he did what it took to be at the top of his sport. He rode the required 700 kilometres a week and took his mental and physical ability to the max.

Over the next 15 years Ray completed 12 Goulburn to Sydney Classics, a notoriously gruelling 200km race and was once placed 34 out of 350 riders. In 1977 he competed in the New South Wales State Championship and in 1980 became the Senior Road Champion of the Lidcombe/Auburn Cycling Club.

In 1990 with an increasingly busy family life Ray retired from his much loved sport.

In 2002 Ray received the devastating news that he had Parkinson's disease. This led him to become a member of Parkinson's NSW and the Young Men's Group. Although suffering this debilitating condition, Ray was determined to remain as he always was, fit and healthy. Since his diagnosis he has managed to compete in not one but three City to Surfs (2007, 2009 and 2010).

Ray's most recent challenge came from one of his Young Men's Group compatriots, Andrew Whitton. Not one to shy away from a challenge, Ray decided to take up Andrew's proposal to get back on his bike. Not for any old reason though. Ray and Andrew, together with fellow Parkinson's sufferer Peter Marshall, have embarked on a journey to tackle one of Sydney's most famous cycling rides, the "Sydney to the Gong". This 90km ride from Sydney to Wollongong is held on the first Sunday in November. Each year it attracts thousands of participants with the aim of raising funds to support people living with Multiple Sclerosis.

After almost 20 years away from the sport and finding himself suffering the effects of Parkinson's, Ray got back on the proverbial horse and hit the road again. Although riding only 15 km per day in preparation, he has found the same determination and love he experienced 35 years ago. By setting themselves a mental and physical challenge, these three cycling amigos have found an outlet on which to focus their energy. They have discovered that within themselves they have the strength of lions.

What truly sets these men apart is that in undertaking this challenge they have shown us that anything in life is possible. That having Parkinson's doesn't mean you have to shy away from the world and say, "I can't" but instead say "I can".

A follow up article on how the ride went will be available in the next edition of Stand By Me.

Kemp Strang is proud to be a supporter of the 2010 Parkinson's NSW Golf Classic



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Obituaries

By Deborah England Counsellor, Parkinson's NSW



Dr Norm Thomson

I was greatly saddened to learn recently of the death of Dr Norm Thomson. Norm was a scientist of some renown, very involved in developing our cotton industry. Earlier this year when I visited Narrabri, I had the very great privilege of visiting the CSIRO cotton headquarters and meeting some of Norm's former workmates. These scientists spoke about Norm and his contributions to the industry in terms approaching awe, but impressive as that all was, what stays with me, is the great affection they had for him. Norm's portrait hangs in the foyer of the building and his office still has his name on the door and remains as he left it, several years ago. A worthy tribute indeed for an esteemed colleague in anybody's book.

I didn't know Norm when he was working. I only met Norm on three occasions but his impact on me was profound. He was, in my opinion, first and foremost one of nature's true gentlemen; a man of grace and dignity. On occasion he was quite uncomfortable with some of the manifestations of Parkinson's disease. During our conversations he made no reference to his discomfort but was open to suggestions that were offered to hopefully make him more comfortable. I am told he was always well-mannered and appreciative of anything that was done to assist him in managing his illness.

Norm loved to sing! I discovered this on my last visit to Narrabri. Norm's speech had deteriorated to the extent that at times he was difficult to understand but his singing voice remained quite clear. We laughed about how he could now 'sing for his supper' and on occasion, I believe he did. One of the most touching things that I have ever witnessed occurred in the context of Norm's singing. He was singing with gusto at a sing-a-long at the facility where he was a resident when they began to sing 'You are my Sunshine'. Norm reached for and held his beloved Anna's hand and looked at her with such love and devotion that I felt moved beyond words and honoured to have observed this special moment.

Norm kept his dignity and charm amid great personal challenge and the world is richer for having had him in it.

Vale Norm



Rod Irwin

It is with great sadness that we inform you of the passing of Rod Irwin.

Rod served as a diplomat with the Department of Foreign Affairs. After he was diagnosed with Parkinson's disease he retired from his Diplomatic role and was appointed Chairman of the Brain Injuries Council. In 2004, Rod was elected as President of Parkinson's NSW Inc. During his time with Parkinson's NSW he and his wife Dympna, served as members of Council and were also both active members of their local support group. During his time as President, Rod lobbied tirelessly in favour of the Access Economics Report. Since the publication of the report it has developed a worldwide reputation amongst international Parkinson's organisations.

Rod will be greatly missed by his friends, many within the Parkinson's community. Our thoughts are with his wife Dympna and the family.



Self-Esteem

By Deborah England
Parkinson's Specialist Counsellor

When I started to write this item for 'Stand by Me' my intention was to write about 'Body Image' and 'Self Image'. The more I thought about 'body image' and the impact a negative body image can sometimes have on a person, the more I began to delve into 'Self-Esteem'.

Of all the 'judgments' we pass, none is more important than the judgment we pass on ourselves. It touches the very core of us. Although we often use 'self-esteem' interchangeably with 'self-image' the idea runs deeper than that. Self esteem, to me, seems to be a means or way of 'experiencing' the person that we are. It involves more than just a mental picture of ourselves because it contains emotional, cognitive and somewhat evaluative elements.

Our responses to other people, to life's challenges and life's beauty are all affected by our sense of who and what we think we are, what we are capable of and what we think we deserve. Self-esteem is not about the temporary 'feel-good' of praise or perhaps receiving a compliment but more about the kind of grounded trust in our abilities to think and to respond effectively to challenges and the confidence that success, achievement and contentment are appropriate for us. We are indeed worthy of friendship and love and respect, in fact happiness.

Self-esteem, I think then, involves facing relationships in particular, with a benevolent, non arrogant sense of one's own value. This kind of self-respect evokes respect from others. We can then move from the position of expecting others to create our value to actually seeing for ourselves that we have it. There are ways that we can grow and develop our self-esteem and they are not about how others deal with us, but more about how we ourselves operate in the face of life's challenges, the choices we make and the actions we take that are pivotal to this process.

Back by popular request!

Young onset men and women and their partners can take advantage of the relaxing surroundings at Elanora Heights near Narrabeen on the Northern Beaches and join Parkinson's NSW for two nights away **from Friday 18 to Sunday 20 February 2011.**

Saturday night entertainment will feature the Rocky Horror Show Movie as well as the usual mix of activities, pampering and relaxation.

Guest speakers will include a Neurologist, a PD Nurse, a Physiotherapist and a Dietician.

The retreat will be subsidised, but there will be a cost. Please pencil it into your diaries and contact Parkinson's NSW for further details and to register. Book early to reserve your place on this fun and informative weekend.

For daytime and overnight bookings contact:

Infoline at Parkinson's NSW on 1800 644 189



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

Isabelle Clark – Bequest Officer

Our annual Bequest Lunch was held on 28th October, in The Grand Pittwater Room, North Ryde RSL. It was a time for 80 members of the James

Parkinson Society and supporters to get together in a pleasant setting, catching up with old friends, meeting new ones and enjoying a delicious lunch. This day allowed Parkinson's NSW to thank everyone in a special way for playing such an essential role in the support of the future.

This event was generously sponsored by Guardian Funerals, North Ryde and Macquarie Park Cemetery and Crematorium, North Ryde.

Entertainment was provided by our own Fundraising Consultant, Marty Rhone, who sang some beautiful ballads. Tom Sweeney gave a humorous account of The Lantern Tour of the tombs of some famous and infamous people buried at Macquarie Park.

Barry Clarke was inducted into the James Parkinson Society by Miriam Dixon. We also celebrated three members' birthdays: Elsie Batistich, Bruce Elsgood and Paula Argyropoulos.

Paula Argyropoulos is a beautiful woman in every way. She knows how to live life to the full even though she was

diagnosed with Parkinson's in her 20s. Paula gave an inspiring talk and expressed gratitude to have been able to use the services Parkinson's NSW has provided and will continue to provide in the years to come.

If you would like to find out more of how you can include Parkinson's NSW in your will please feel free to speak with me in confidence. Your memory will live on in the gratitude of strangers, and that's a contribution worth making.

Isabelle Clark – Bequest Officer

e: Isabelle@parkinsonsnsw.org.au m: 0403-324486 or telephone the Info line and leave a message.



2010 Bequest Lunch



Capital City Airport of the Year

Australian Airports Association
Industry Excellence Awards 2010



Donations

IMPORTANT NOTICE

regarding General Donations

All general donations will now be acknowledged in our Annual Report. 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 28 May 2010 and 3 December 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

Stan Allen	Florence Hamilton
Henry Armstrong	Raymond Harrington
Alan Arnold	Vince Hervert
Florence Auld	Shelagh Hoyles
Peter Barrat	Wallace Jones
John Barrett	George Karakatsanis
Ken Barrett	Beat Kennedy
Richard Beatson	Patricia Kennedy
Charles Beddows	Thelma Knight
Shirley Beveridge	Kevin Knox
Lillian May Blankly	Tibor Lendvai
Willem Boogaart	Colleen Lester
Loretta Boslem	Santa Lombardo
Raymond Bowmer	Ian Maxwell
Philip Brown	David McMurray
Rinaldo Cattana	Josef Mohlenkamp
Peter Cheeseman	Fay Nesire
Dorothy Condon	Ross Neuendorf
Alan James Cook	Hope Newling
Shirley Cook	Glenda Orchard
Lefki Costakis	Gloria Pepper
Evangelos Critharis	Arthur Phillips
Colin Davey	Elwyn Phillips
Franco Del Pinto	Norman Picker
Roger Delhunty	Rev Duncan Richardson
Con Diamond	John Ryan
Una Dimmock	Peter Saxby
Raymond Downie	Theodore Smietana
Mary Duguid	Gar Smithers
James Duke	Jonna Sorensen
Neville Elphick	Ern Spencer
Leonard Fischer	Tony Stephens
Keith Francis	Patricia Stephenson
Bess Fraser	Dennis Straney
Carmen Galvin	Nicholi Tokmakoff
Peter Gilmore	Anton Vukelic
Ken Gould	Mary Webb
Edward Gregor	Valerie Weir
Siegfried Gross	William York
	Peter Young

Support group contact details

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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	Robert Yeoh	0449 049 140
Coalfields	Phil Papworth	02 4991 1037
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		1800 644 189
Eurobodalla	Betty Byrn	02 4474 4109
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	Val Tuckerman	02 4575 1403
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South	Anne Instone	02 4232 1227
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	Alan Stephenson	02 6584 0212
Quirindi	David Boulton	02 6747 1459
San Remo	Jan Dowling	02 4390 7321
Shoalhaven/Nowra	Jonathan Morgan	02 4464 3028
Shoalhaven/Ulladulla	Barry Mitchell	02 4454 0747
Snowy/ Monaro	Louise Young	02 6456 2237
Southern Highlands	Marj Webb	02 4871 2615
St George/Sutherland	Myra Chalmers	02 9525 7215
Tamworth	Pat Johnson	02 6765 6948
Tomaree	Ruth McLeay	02 4981 1028
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

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*Merry Christmas and
 a Happy New Year
 from Parkinson's NSW*



Diary Dates

JANUARY

4 PNSW office reopens after Christmas break

FEBRUARY

2, 9, 16 & 23 Newly Diagnosed Information Session
 Parkinson's NSW Office
 Macquarie Hospital, Building 21, 120 Cox's Rd
 North Ryde

18 - 20 Elanora Break Away
 Elanora Heights, Sydney

MARCH

30 Coffee Morning
 Parkinson's NSW Office
 Macquarie Hospital, Building 21, 120 Cox's Rd
 North Ryde

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.

PNSW InfoLine

Contact our InfoLine by phone 1800 644 189
 or email infoline@parkinsonsnsw.org.au

for information on Parkinson's,
 our support services including Counseling & Support Groups.

To learn about upcoming Educational Seminars you can also visit our website
www.parkinsonsnsw.org.au

To become a member, visit our website:

www.parkinsonsnsw.org.au

or

Call InfoLine: 1800 644 189

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

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