

PARKINSON'S NEW SOUTH WALES INC. NEWSLETTER

Issue 108, SUMMER 2009

Stand By Me

Energy bill rebate helps get temperatures back to normal

A combined lobbying effort of Multiple Sclerosis Australia and Parkinson's NSW has resulted in a new rebate!

A \$10 million medical energy rebate from the NSW Government will help more than 10,000 people with conditions – including Parkinson's disease - which make it difficult to control their core body temperature.

Minister for Energy John Robertson said the rebate would help to pay the quarterly energy costs of heating and cooling the homes of those patients who cannot live without temperature controls.

"People with Parkinson's or MS for example often develop a condition known as Thermoregulatory Dysfunction which means their body is unable to regulate their core temperature," he said.

"The effects of excessive heat or cold can be extreme – from general pain and discomfort to hypothermia, heatstroke and even death. The rebate is \$130 per annum indexed to CPI."

He added, "This is in addition to the increases to the Pensioner Energy Rebate, payment vouchers and Life Support rebates already in place".

To be eligible for the rebate, starting on 1 January 2010 and increased annually from 1 July 2010, the account holder or anyone living at the residence must be:

• Diagnosed with Thermoregulatory Dysfunction. This requires a signed form by a medical practitioner;

AND must have one of the following concession cards:

- Pensioner
- Department of Veterans Affairs Gold Card
- Health Care

Your treating doctor must certify the dysfunction and complete an application form. If you think you are eligible or would like to find out more, contact your electricity supplier – phone numbers are on your electricity bill. Payments will be made as installments on each electricity bill and can be received in addition to other assistance such as the Energy Rebate, the Life Support Rebate and the Energy Accounts Payment Assistance (EAPA) scheme.



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Miriam Dixon, Minister for Energy John Robertson. Ross Jones gentleman living with Parkinson's disease and volunteer and long time supporter and Member for Drummoyne Angela D'Amore.

In celebration of the 30th Anniversary of Parkinson's NSW, we recognise the following for their long time support with Honorary Life Membership:

Con Diamond

- Les Norris
- Vera Heil
- Dr Ron Joffe
- Prof John Morris
- Diana Rynkiewicz
- Alan Stephenson
- Patricia Stephenson
- See story on page 2 for more details.



President's Report

Summer 2009—and the first edition of Stand By Me since our AGM. It would seem an ideal time to welcome the returning Council members and newly elected Councillor, Bernard McGrath, and to talk

about what is new on the PNSW agenda.

With thanks to our members and supporters, the Unity Walk and our annual Parkinson's Golf Day were both marvellous events. This success, coupled with some very generous bequests and donations, will allow PNSW to fund some very exciting projects.

- The DASH project –which seeks to identify the symptoms of Depression, Anxiety, Sleep disturbance and Hallucinations to the frontline Doctors and to provide information and assistance by encouraging people to use the Infoline.
- The 2 year trial for Neurological Nurses which will • begin at Nowra in the New Year, under the direction of Dr. Simon Lewis. This is a Parkinson's Australia project, being managed by PNSW. The study will underscore the value of specialised Nurses, both for their economic value to the general community, and their individual value for Parkinson's sufferers and their carers. It will look at quality of life issues, such as delayed nursing home admission, need for hospitalisation, and carer's needs, as well as negotiating the many physical demands of the condition. A positive outcome for this project could see the Federal Government funding these nurses Australia-wide. The project is approximately 50% funded by the Federal Department of Health. Council feels this study to be of such importance, that we have agreed PNSW will meet the shortfall if additional funds cannot be sourced by any other means.
- Research grants to the value of \$150,000 have been advertised and our adjudicating panel will make their recommendations before Christmas. I know we are all looking forward to seeing what new avenues our scientists have found to explore.
- We will continue to offer 'top up' grants to 4 PhD students.

This year, again due to the great success of our Golf Day, the Infoline will remain open for the entire month of January. After logging 400 calls on our answering service during this period last year, we regard this as a priority.

Becky joins me in wishing you all a joyous festive season; may you have a Happy and a Healthy New Year!

John Silk

Honorary Life Members for 2009

Con Diamond: Parkes; Vera Heil: Coffs Harbour; Les Norris: Central Coast; Diana Rynkiewicz: Hornsby Ku-ring-gai and Patricia and Alan Stephenson from Port Macquarie have been recognised by Parkinson's NSW for their outstanding service to their support groups and to People Living with Parkinson's.

Between them, Con, Vera, Les, Diana, Patricia and Alan have given more than 60 years of service to their communities. That's not just a couple of hours each month when the support group meets; it includes the time spent organising speakers, arranging fundraising activities, participating in research projects, speaking about Parkinson's disease at community groups and service clubs, lobbying local politicians, raising funds to train nurses and other health providers on how to use best practice methods with people with PD.

These dedicated people have given so much to ease the burden of the members of their support group 'family'. For this we say a heartfelt "Thank You, Con, Vera, Les, Diana, Patricia and Alan".

Dr Ron Joffe & Professor John Morris

Parkinson's NSW also presented Hon Life Membership to Dr Ron Joffe & Professor John Morris for their tireless, ongoing support for many, many years to the PD community and for their leadership as founding members of the Movement Disorder Society of Australia.

Break away for the weekend

Get away from the humdrum of the every day, and join Parkinson's NSW for a weekend away.

Young onset men and women and their partners can take advantage of the fantastic facilities at Breakaway Retreat on the NSW Central Coast from March 5-7, 2010.

There's a tennis court, putt putt golf or table tennis. Less active pursuits include board games, massage and enjoying the tranquil gardens.

Explore the surrounding area and feed the pelicans at The Entrance or go whale watching at Nora Head.

A local neurologist will be a guest speaker.

The retreat will be subsidised, but there will be a cost. Pencil it into your diaries and look forward to a fun and informative weekend.

Contact Miriam Dixon at Parkinson's NSW on 8875 8901 or miriam@parkinsonsnsw.org.au



CEO's Report

Over the past year we have had some fantastic individual fundraising efforts from our members and supporters. I would like to share with you some examples of the events.

Louise Young, a young woman living with Parkinson's,

started the year with a fundraising dinner in honour of her husband becoming an Australian citizen! She raised over \$5000.



Tom Pollard, whose mum has Parkinson's, shaved his head and beard of 28 years. He raised over \$7000.

Tom Pollard having his beard shaved.

Jan Dowling, a young woman living with Parkinson's, held a dinner and raised over \$3500.

The Parkes support group held a concert and, together with a raffle raised, over \$3500.

The Kiama Social Club at Blue Haven Village had a variety of fundraising events including an afternoon tea, a concert and a trading table during Awareness Week and raised \$1800. They hope to beat this target next year!

The Cowra Parkinson's support group raised \$3500 from a variety concert held in August and general fundraising held throughout the year. Their concert attracted local media. One of the show stoppers was lan Snow who is a group member living with Parkinson's disease.

Tony and Beryl Coombes managed to stir the town of Glen Innes into a fundraising frenzy for Parkinson's NSW Unity Walk. They raised over \$2000 and encouraged several of their family members to participate in the walk in Sydney.

Helmets off to the riders from Wellington Motorcyclists and the Dubbo & Western Plains Ulysses Club, who held a charity "Dice Run" bike ride and a Soup and Stew fundraiser (see later article).

Parkinson's NSW is indeed honoured and truly grateful to all who fundraise on our behalf. These are only some examples of fundraisers held throughout the year. The dollars raised go directly to services or research helping the entire Parkinson's community.

Visit by Local Federal Member

Maxine McKew visited our offices to learn more about Parkinson's disease. She had the opportunity to speak to our President and members of Council along with young women living with Parkinson's disease. She was particularly taken by Clare and Gordon Renneberg who were to celebrate their 55th wedding anniversary the next day. Maxine's visit was reported in the local press, again helping to raise the awareness of Parkinson's disease.

DASH to the InfoLine Project

You may have seen the story on DASH on Channel 10 on 25 November. As our President has mentioned, DASH stands for Depression, Anxiety, Sleep Disturbances and Hallucinations. We are soon to produce a booklet talking about these often hidden symptoms of Parkinson's disease, and tips for managing them. Our InfoLine staff has also received training about the management of these symptoms. I encourage you to call our 1800 644 189 number if you are experiencing any of these symptoms, or to register for the booklet.

"Step by Step" Seminar

In September we held our annual Awareness Seminar in State Parliament House, once again to a sell out audience. The seminar featured:

Dr Simon Lewis - Can We Stop Dementia in Parkinson's?

Dr Bryce Vissel – Harnessing the Brain's Own Ability for Repair

Assoc Prof Carolyn Sue – Degeneration of Neurons in Parkinson's

Dr Victor Fung - Update on Treatments for Parkinson's

Sarah McDonald and Winnie Suen – Generation Y and Parkinson's

Participants really enjoyed the seminar and we are once again able to offer a DVD of the seminar for sale. Please call the office if you would like to order. DVDs can be purchased for \$28 which includes postage and handling.

Parkinson's Artisans Show

Our seminar was complemented by our Parkinson's Artisan Show. We are delighted that the following artists exhibited works: Paul Miller, Kari Hanet, Jenny Meyers, Bruce Peel, Gareth Devries-Robbe, Robin Eliovson, Michael Quelch, Leone Harris, Roy Stokes, Ruth Matthews, Greta Argyropoulos and Glenda Rawlinson.

We would like to acknowledge the support of fine art auctioneer, Dalia Stanley, and gallery owner, Carlos da Silva, in helping arrange transport and hanging the paintings.

Season's Greetings

I wish you and your family season's greetings and best wishes for the New Year.

Yours in Parkinson's friendship

Miriam Dixon CEO

Atypical Parkinsonian conditions

Dr Emma Schofield, Prince of Wales Medical Research Institute

Parkinsonism is a term referring to slowness of voluntary movement (bradykinesia) and muscular stiffness (rigidity). Exact numbers are difficult to determine, but roughly 250 people out of 100,000 develop parkinsonism each year.

Although the majority of people with parkinsonism have Parkinson's disease (PD), more than a quarter have other types of diseases, collectively known as "atypical parkinsonian" or "Parkinson's-Plus" conditions. The most common are progressive supranuclear palsy (PSP), multiple system atrophy (MSA) and corticobasal degeneration (CBD). Good specialists can diagnose these conditions well, however around 15% of people with parkinsonism are still incorrectly diagnosed. This is because atypical parkinsonian disorders can appear very similar to PD, especially in the early stages. An accurate diagnosis is critical however, as prognosis and treatment can differ from PD. One indication that a person may have an atypical parkinsonian disorder is that they do not respond to L-dopa treatment, or that the there is only a very mild benefit (less than 30% subjective improvement in motor symptoms).

Table: Estimations of the proportion of parkinsonism represented by atypical parkinsonian conditions and their incidence (values are approximate)

	Proportion of people with parkinsonism	Number of new cases per 100,000 people each year
Progressive supranuclear palsy (PSP)	13%	5-6
Multiple system atrophy (MSA)	24%	3
Corticobasal degeneration (CBD)	3%	1

The first signs of PSP are unstable posture and frequent falls. The most characteristic symptom however, is "vertical gaze palsy", that is, difficulty in voluntarily moving the eyes up and down. PSP usually causes dementia affecting the frontal lobes, leading to apathy and a lack of planning skills. PSP is often mistaken for PD, because the tell-tale signs take time to develop and may occur late in the disease. The effect of PSP on the brain is also is different to PD. In PD a protein called alpha-synuclein aggregates in cells into clumps called Lewy bodies, whereas in PSP another brain protein called tau is abnormal. It is important for researchers to understand why these different proteins aggregate in brain cells in PSP and PD as new drug therapies are being aimed at clearing these different types of protein from the brain.

MSA, or Shy-Drager syndrome is a syndrome mistaken for PD in as many as 30-50% of people with parkinsonism, making it difficult to accurately determine the real number of people affected. Up to twenty percent of people with MSA will have serious problems with movement but others will have symptoms caused by dysfunction in an area of the brain called the cerebellum. The cerebellum is important for controlling balance and walking so these patients have an increased risk of falling. MSA is also characterised by other symptoms which result when the brain's control of the body is compromised. This can cause drops in blood pressure with standing (postural hypotension), impotence and incontinence. MSA also commonly affects the voice (dysarthria) and the respiratory system which can lead to sleep apnoea. Many of these symptoms are treatable by conventional methods, such as blood pressure medication and continuous positive air pressure therapy. Like PD, alpha–synuclein protein is abnormal in MSA, although different brain regions and cells are affected, suggesting a different process is occurring in this disease.

CBD is rarer than PSP and MSA. Like PSP, it causes dementia which affects the frontal lobes, often leading to behavioural changes and language problems. More often than not the first symptom of CBD is parkinsonism. Additionally, CBD causes prolonged involvement of only one side of the body as well as myoclonus (sudden, brief jerky movements) and dystonia (abnormal muscle posture). Unlike other parkinsonian disorders, a part of the brain called the parietal lobe is affected in CBD and this can cause "apraxia", or difficulty performing purposeful movements, due to the brain sending incorrect messages to the limb. Some patients develop "alien limb syndrome" where one arm behaves as if it has a will of its own. CBD is similar to PSP in that tau protein, rather than alpha-synuclein, becomes abnormal within brain cells.

Atypical Parkinsonian conditions (continued)

Dementia with Lewy bodies (DLB) is a disorder that causes parkinsonism but usually later in the disease. Visual hallucinations, daily variations in thinking and dementia often occur early. Lewy bodies form not only in the substantia nigra (as in PD) but also in other areas of the brain. In addition, another type of abnormal protein called senile plagues (which are also found in the brain in Alzheimer's disease) are also present. Not only are levels of brain dopamine reduced in DLB but there are also reduced levels of another brain chemical called acetylcholine. Consequently L-dopa treatment may not be effective to manage motor dysfunction. Some medications which affect brain levels of acetylcholine can help treat hallucinations in DLB but because several brain systems are affected, patients with DLB need to manage medications carefully.

Parkinsonism can also have other causes, such as strokes which affect the regions of the brain which control movement (the basal ganglia) and some drugs (in particular, antipsychotics and antinausea drugs). Postencephalitic parkinsonism, a condition that can develop after a person has had an episode of brain inflammation also causes parkinsonism. Other extremely rare conditions are the parkinsonian complex of Guam and Caribbean parkinsonism which are more likely caused by environmental toxins, as they are geographically localised.

Some promising tools for aiding accurate diagnosis and treatment of atypical parkinsonian disorders include ultrasound of the brain (transcranial sonography) and various forms of magnetic resonance imaging (MRI) which detect differences in brain structure in PD, PSP, MSA and CBD. Measurements of eye tracking can also help to detect PSP. New treatments still need to be developed, however, deep brain stimulation is an effective treatment for PD and can potentially alleviate parkinsonism symptoms in other disorders. Some symptoms of atypical parkinsonian conditions can also be effectively treated, however research into the development of agents that can reverse the abnormal protein deposition in the brain are critical.

In addition to the Parkinson's NSW website, the website of the National Institute of Neurological Disorders and Stroke in the USA

(http://www.ninds.nih.gov/disorders/disorder_index. htm) contains useful information on atypical parkinsonian disorders which are listed alphabetically.

Bowel & bladder problems for people with Parkinson's disease

While not glamorous, toileting difficulties are known to decrease an individual's quality of life. From the earliest descriptions of Parkinson's disease (PD), bowel and bladder difficulties have been described as significant symptoms. However, very little is known about the type, incidence and impact that bowel and bladder problems have on those living with PD. It is not always clear if these problems are a direct outcome of the condition or a side effect of the medications used to help control PD. Furthermore, it is well known that such symptoms can occur with normal ageing and there is currently very limited scientific evidence that enables us to differentiate the specific underlying causes for these problems.

The major bladder difficulties experienced in PD include, but are not limited to, being concerned about whether you will make it to the toilet in time, needing to go to the toilet very frequently during the day or waking up more than you would like overnight to pass urine. Then there are symptoms associated with the bowels, in particular constipation or experiencing embarrassing feelings related to problems with bowel function. Many people living with PD have to use laxatives and still find it difficult to move their bowels and it can be very difficult to find a long-term solution.

Research into this very interesting, yet much ignored, clinical area of PD is currently being undertaken by Joanne Lawrence, a clinical nurse consultant who has specialised in neurological disorders of the bowel and bladder together with the Brain and Mind Research Institute, who are currently investigating the effects of PD over time. Together this diverse team of experts are expecting to gather some very interesting and useful insights that will provide benefits, such as appropriate bowel and bladder clinical guidelines, for people living with PD and healthcare practitioners alike.

A telephone questionnaire has been designed to explore the toileting problems encountered by people with PD. The information gathered will facilitate the description of the most common bowel and bladder problems and will also explore where people seek help from and if this assistance is beneficial. Finally, it is important to know what impact these toileting problems have on quality of life, especially looking at the way people manage their day-to-day activities and whether these symptoms have an influence on the important decisions people living with PD make or have made.

If you have had, or are having, bowel and/or bladder difficulties and are interested in participating in this very important research then please contact the Brain and Mind Research Institute on (02) 9351 0702 and ask for a Bowel and Bladder information pack to be sent to you.

Joanne Lawrence has worked as a Registered Nurse since 1981. Most of her clinical experience has been gained in working with people who have acquired congenital or chronic disabling conditions.

She holds two positions: the first as an academic at the Australian Catholic University, the second, as a Clinical Nurse Consultant at a Private Rehabilitation Centre, where she conducts a regular Bowel and Bladder Management Clinic.

Joanne is currently undertaking a PhD within the Faculty of Medicine, at Sydney University. Her thesis is entitled "The significance and impact of bowel and bladder dysfunction on personal burden for people who have Parkinson's disease".

Research – ROTIGOTINE PATCH

by Sr Susan Mercer and Dr Michael Hayes, Concord Hospital Parkinson's Clinic

At the time of writing this article, rotigotine can only be purchased with a private script and is not currently subsidised for supply under the auspices of the Australian Pharmaceutical Benefits Scheme (PBS). Patients should be aware that active efforts are being made through Parkinson's Australia/NSW, along with other organisations to ensure that a full range of medication choices do become available locally. Parkinson's NSW would encourage its members to canvas their elected representatives regarding the provision of new medications through the PBS.

Replacing the brain's missing dopamine with L-dopa tablets represents the most common treatment used for Parkinson's disease (PD). However, a number of other medications have been developed including the dopamine agonist medications (DAs), which work by mimicking the missing dopamine and stimulating the same receptors in the brain. The DAs have been found to be effective when used in combination with L-dopa as well as when they are used on their own.

The major appeal of the DAs is that they have a long duration of action, which is believed to be better for reducing the side effects that patients commonly run into during the advanced stages of disease, such as the 'switching off' phenomenon and involuntary (dyskinetic) movements.

Rotigotine is a new DA with a number of potential benefits:

- Long duration of action
- · Applied via a skin patch, which is changed daily
- More stable stimulation of the dopamine receptors in the brain
- May reduce complications of treatment in later disease
- If used as first line may offer extra freedom of not having to take tablets several times a day.

The patch is usually applied to the body and upper arms and the site is rotated daily to reduce the risk of skin redness or irritation. Other common side effects include dizziness, nausea and sedation with particular caution to be taken when driving. Rotigotine has not been associated with any reports of scarring of the lungs and heart valves. As with most medications, if not tolerated, gradual withdrawal is recommended rather than abrupt discontinuation, which might provoke a sudden rebound of symptom severity.

The skin patch has been trialled extensively worldwide and has proven to be effective in treating the physical symptoms of PD both in the early and advanced stages of disease, although its potency may not necessarily match that of L-dopa. Different strengths of patch are available and although started low to avoid any side effects, doses usually need to be increased with advancing disease.

References

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RGH Pharmacy E-Bulletin. Volume 30 (5):June 2, 2008. Editor A/Prof Chris Alderman, University of South Australia – Director of Pharmacy RGH.

Schnitzler, A. et al June, 2008. Twelfth International Congress of Parkinson's disease and Movement Disorders "Compliance of dopamine-agonist-therapy with transdermal rotigotine (Neupro) in patients with early-stage Parkinson's disease".

The James Parkinson Society Isabelle Clark – Bequest Officer

Our bequest lunch was held on 15th September, at the Bel Parco Restaurant, in Bi-Centennial Park at Olympic Park, Sydney. It was a time for members and supporters of the James Parkinson Society to get together in a beautiful setting, enjoy each other's company, make new friends and have a delicious lunch. This day was made possible by the generous sponsorship of Allen Mathews Funerals, North Ryde, a Guardian Funeral Provider.

Peter McWilliam OAM, Alan Poole and Assoc Professor Kay Double represented the Council. Peter inducted Glenda Rawlinson into the James Parkinson Society.

Glenda spoke to attendees of the lunch and said, "I was born in Blackall, Central Western Qld, and celebrated my 60th Birthday this year. I have 3 sons myself and my husband, Brian, has 2 daughters and a son so we are a blended family. I have 9 grandchildren. I have worked as a Nurse's Assistant, and as a Phlebotomist (drawing blood for Pathology) and also trained and educated staff. I enjoyed my work and was passionate about it, but unfortunately I had to leave when diagnosed with Parkinson's 4 years ago.

"Even though I am a new member of Parkinson's NSW I have been able to see the benefits of joining this organisation. I have made many new friends, and I always look forward to my Support Group meetings.

I also appreciate the knowledge and camaraderie I have received. I feel confident about the future knowing that great researchers are investigating a cure.

"I want to be able to help others. I know leaving a bequest will not assist me, but I am leaving it for future people who may unfortunately acquire Parkinson's."

Some members, like Glenda, are willing to share their stories. Others may be prefer privacy and we will always respect their wishes. A bequest is the ultimate gift to Parkinson's NSW and, no matter how large or small, it has an enormous impact on our ability to plan for the long term and may help to find a cure.

I would also like to thank and congratulate to Tom and Hazel Tolhurst who have just celebrated their 60th Wedding Anniversary. In lieu of gifts, their family made a gift payment to Parkinson's NSW.

If you or any members of your family have made provision in their Will to support Parkinson's NSW, we would encourage notification to us of this wonderful gesture. It would be an honour to welcome them to the James Parkinson Society.

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

Grace

by Deborah England

I have been thinking a lot about 'grace' and the importance of grace and graciousness in our lives. A definition of 'grace' that I read recently defines it as 'consideration for others and a disposition of kindness and compassion'. When someone or someone of significance to you is diagnosed with something like Parkinson's it can be a worrying and confronting time. This time is likely to be peppered with many conflicting thoughts and emotions not always touched by grace. In no way am I suggesting that the period of adjustment needs to be prescriptive or that a person automatically adopt a particular stance with regard to 'accepting' a diagnosis but it does raise some ideas and some questions in my mind.

With regard to seeing a therapist, too often therapy is seen as unnecessary or self-indulgent. From my experience, it can be helpful in supporting psychological and sometimes even spiritual development. It can be an aid to teaching us more about compassion, both for ourselves and each other. Again, grace and graciousness can come in to play here. Many of the choices we make grow out of our social conditioning and level of awareness at that time and are not necessarily the choices we would make under different circumstances. Talking some of these factors over with someone can help us develop empathy for ourselves and, as importantly, for each other.

From here we begin to recognise that we did the best we could with the resources we had at the time. Having grace with ourselves is operating here. This can then flow on to the premise that this may well be the case that others too, are doing the best that they can at the time. Graciousness and compassion facilitates dealing with some of the feelings that may arise as a result. We would probably all be familiar with the feeling and have probably even said 'I am struggling with this right now' but also have the 'knowing' that at other times 'It wouldn't worry me'. This is when 'how resourced we are' comes into play. If we feel a bit depleted, or under-resourced we may not manage as we would choose. This may well be true of others around us as well. Having this realisation can then strengthen our connection with others and facilitate more 'grace' and graciousness in our lives.

New dental plan for people with chronic and complex conditions

People living with Parkinsons may now be able to receive dental services under Medicare, due to their chronic and complex condition. To see if you are eligible, check with your GP. The benefits will cover such services as dental assessments, fillings, dentures, restorative work and more, and can be carried out by most privately practicing dentists, dental specialists and dental prosthetists. For further information about the Medicare dental services, go to the Department of Health and Ageing's website at www.health.gov.au/dental or call the Medicare Australia Patient Enquiry Line on 132 011.

Natalie Allen,

physiotherapist and PhD student at The University of Sydney,

recently won an award for the best presentation by a student researcher at the Australian Physiotherapy Association's National Neurology Group Conference.

Natalie's presentation was entitled Support-group based exercise to address risk factors for falls in people with Parkinson's disease.

The project was funded by a Parkinson's NSW research grant and involved five Parkinson's NSW support groups. Natalie is also supported by a Parkinson's NSW Research Student Award. The full results of this project will be published soon, followed by a report in Stand By Me.

Bendigo Bank Community Enterprise Foundation (CEF)

Our community bank, Bendigo Bank, has become a very strong supporter of Parkinson's NSW, sponsoring our Unity Walk and the 'Christmas Gift' program we have just launched. Earlier this year Parkinson's NSW joined the bank's Community Enterprise Foundation. We see this as a very important initiative because it gives not only supporters of Parkinson's but the community at large the opportunity to go into any branch of Bendigo Bank and make a donation to the Parkinson's cause. These are then transferred via the Foundation's accounting processes to Parkinson's NSW. It thus brings our organisation in closer philanthropic contact with people across NSW.

Originally set up to support the Community Bank® network in the distribution of the profits that they generate, the long-term goal of the Foundation is to make giving more accessible to everyone, and through economies of scope and scale minimise the administrative burden and expense associated with giving money away – making sure more gets to those charitable projects and programs people want to support. As such the CEF is made up of two philanthropic funds, a deductible gift recipient fund and Tax Concession Charity.

Parkinson's New South Wales is a management account of Community Enterprise Foundation and donations for the group can be made by donating at any Bendigo Bank branch or online at www.bendigobank.com.au/ foundation/parkinsons

Please spread the word that donations to Parkinson's NSW can be made at any branch of Bendigo Bank and by doing so also support those who support Parkinson's NSW.



On the groupvine

by Trish Morgan

New energy – new groups!

On **26 September** a public meeting was held in **Orange** with great success. 36 people attended from Blayney, Cowra, Dubbo and Orange. Isabelle Clark, Bequest Officer, was the 'meet and greet' person on the registration table. Dr Simon Hammond, neurologist, and Mark Nelson, physiotherapist, were the speakers with support from ABC country radio and the local paper, The Central Western Daily. Orange Ex-Services Club donated the venue for the public meeting. As a result, the 61st support group was formed! The local committee of Martha Brown, Bill and Rita Baker, John and Elsa Simpson will steer the group, their first meeting was held on Wednesday 28 October with 20 present.

San Remo, at the northern end of the Central Coast, has a support group! More than 20 people attended the public meeting held on 9 November. Thank you to San Remo Neighbourhood Centre staff for their hospitality in providing tea and coffee and the room. Allan and Jenny Poole, from the Central Coast Support Group, reported that it was a good location, with easy parking and wheelchair access. Greg Harris, a newly appointed Parkinson's nurse consultant from area health at Gosford Hospital, was welcomed at the meeting. He is very keen to learn from support group members. Seven people from the Central Coast Support Group (CCSG) attended, it was good to see that the meeting had captured other people with PD living in the area. John Swivel and Les Norris from CCSG presented the San Remo leaders, Cheryl Brown and Jan Dowling, with a cheque for \$100 to assist with setting up the group and to offset petrol costs to attend the Central Coast meetings at Niagara Park. Members of CCSG who live at Norah Head (closer to San Remo) have been meeting socially for coffee in between meetings. Allan and Jenny attended their Central Coast Support Group Meeting on the next day and noted more new members from Blue Haven. These people also indicated their intention to join the San Remo Support Group.



Members of Orange Support Group.

Sunday 8 November saw **Speeding Vibrations** members meet for lunch again, this time at **Zita's Restaurant** at Woy Woy. The day was overcast but the mood was high. David and Maureen Morrison from Gymea and Neil Sligar from Campbelltown travelled the furthest to join 18 fellow members and friends. Christmas Roasts were on the menu, followed by a generous serving of Pavlova or Christmas pudding. Two 30th birthday cakes were the lucky spot prizes. Kel Healy – the 'stamp man' – won a cake – the first time he's won anything!

The **Tulip Belles**, the support group for women diagnosed under the age of 60, met for lunch at **Eden Gardens** at North Ryde. Five members were joined by staff from PNSW and four members sent apologies. This group is establishing its identity and Sandra Way has produced personal business cards, a card for doctors' rooms, a banner and a sign. The 'Belles' are looking forward to the retreat for Young Onset people to be held at San Remo Camp Breakaway in March next year.

25th Birthday Celebrations for **Newcastle** support group were held on **Saturday 3 October**. Seven original members joined the 60 members and friends for a BBQ lunch and concert with keyboard and didgeridoo players, and a guitarist who led a singalong. Congratulations to Newcastle support group. On behalf of Parkinson's New South Wales, Miriam Dixon presented a pewter platter to the support group's president of 25 years, Verlie Sullivan, OAM.

The last few months have given us all reasons to celebrate and we look forward to 2010!



Lyn Smith

Lyn Smith, a graduate nurse educator and carer, met with four support groups in three days during Melbourne Cup week. Starting at Armidale on Monday, Lyn gave practical demonstrations of emergency first aid for skin tears using products that can be found in most homes. She showed how to give assistance with mobility especially when someone is on the floor or stuck half way between there and the upright position. Nambucca Valley support group travelled to Coffs Harbour where over 30 members had some 'hands on' experience in Lyn's second session. Usual Melbourne Cup celebrations were put aside to get the most from Lyn's visit. All of this was repeated at Port Macquarie on Wednesday. Everyone appreciated her downto-earth, practical lessons. Thanks to Lyn for undertaking these invaluable information sessions to these groups whilst she was travelling privately and visiting family.

Lyn Smith at Coffs Harbour.

Building Better Airport

We're building for the future. We're building a better airport for Sydney and NSW.



Initial **8.25%** pa¹ + capital growth potential¹ 15yr lease to Qld government owned corporation²



Cromwell Riverpark Trust Cromwell

("the Trust" ARSN 135 002 336)

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- Monthly tax deferred³ distributions¹
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Parkinson's NSW golf classic

The third Annual Parkinson's Golf Classic, the second to be staged at Monash Country Club, was held on a mild late October day.

We welcomed 28 teams including representatives from some of Australia's biggest companies, such as Sydney Airport Corporation, Qantas, Sydney Markets, Leighton Holdings, Tooheys, M&C Saatchi and Cromwell. Teams teed off at 12 noon for an Ambrose. The round was spiced up by a competition within a competition, with the Sydney Fish Markets challenging the Sydney Fruit Markets for the 'President's Cup'; a trophy put up by Parkinson's President and Monash member, John Silk. The 'Fishies' again triumphed over the 'Fruities' and retain the cup for another year.

A significant number of participants were also Monash members but local knowledge didn't help because the outright winners came from as far away as the Argyle Inn, Camden. One of the ladies teams had the advantage of having Australian touring professional Joanne Mills as their team captain. Joanne had only just returned from a tournament in Milan.

The official dinner was a highlight with one of Australia's leading entertainers, comedian Vince Sorrenti, as special guest. He put the audience in a good mood for the fundraising auction to follow. The day raised a magnificent \$120,000 for Parkinson's NSW which will go towards the Parkinson's NSW counseling service. This invaluable service provides information and support to those with Parkinson's, their families and carers.

Next year's event will return to Monash once again. If you are interested in participating contact Parkinson's NSW on 8875 8900 and book your place now.



Claudios' Quality Seafoods, representing Sydney Fish Markets won by a very narrow margin, pipping Steve Zappia's Team, representing Sydney Markets, for the second year in a row. Claudios retain the Presidents Cup for another year!



Overall winner was Argyle Inn, Camden. Team members were Russ, Barry, Don and Peter.



Winning women's team – Joanne Mills, Glenda, Gillian and Tracy.



Mick O'Connor representing Goulburn Support Group and his team Spiro, Eddie and Peter.







ANDREW VARASDI MANAGING PARTNER

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75 ARGYLE STREET CAMDEN NSW 2570 PH: 02 4655 8189 FAX: 02 4655 9472 russ@argyleinn.com.au www.argyleinnbistro.com



Dear Members,

At Christmas time we think about the wonderful people in our lives and how much they mean to us. We also like to choose gifts which we hope will have a special importance to them.

As a previous supporter of our organisation, we are delighted to let you know that this Christmas, Parkinson's NSW with the continued generous sponsorship of **Bendigo Bank**, has created a unique way for you to show how special those people are.

We have produced a website which will allow you to give that thoughtful gift whilst donating to Parkinson's NSW.

www.everydayhero.com.au/donation/ parkinsonsnsw_christmasgiving

At this website you can purchase a **Donation as a Gift**. It's quick and easy to do and will help us to assist people living with Parkinson's, their partners, carers and families. The great thing is that you can also let YOUR friends and family know that you would like them to purchase a donation to Parkinson's NSW as a gift for you this Christmas. Just send them the link above and tell them how much it would mean to you.

Parkinson's NSW offers a number of services as well supporting research projects into this debilitating disease. Your generosity will help to ensure that we can continue our work.

Donors at our Christmas **Donation as a Gift** website, can also print a personalised Gift Certificate which can be presented to the recipient to let them know that you are thinking of them.

We hope that you will consider the gift of giving this Christmas.

Wishing you a very Happy Christmas, The Team at Parkinson's NSW

Do you have Parkinson's disease experiencing dyskinesias?

Medical Specialists are currently looking for volunteers for a clinical trial who:

- Are the age of 30 80
- Have moderate to severe Levodopa induced dyskinesias with Parkinson's disease.

For more information please contact Jane Griffith CNC / Neuroscience Trials

Phone: 98459139

Department of Neurology Westmead Hospital



If you have a Parkinson's disease we would like to ask and offer you to join a trial. To take part in this trial it is only required that you have a Parkinson's disease and we need 1 hour of your time. The trial investigates impulse control disorder like pathologic gambling and non motor symptoms like depression in Parkinson's disease. You can participate in the trial even if you have none of these disorders since we need controls as well as people who suffer from this condition.

If you are interested and have a Parkinson's disease, please call A/Prof Martin Krause on **02 4734 4278**! In return we will review your medication very thoroughly and give you the best advice on future treatment. Thank you!

Australia's Unity Walk for Parkinson's 2009

The scene was the Overflow at Sydney Olympic Park and the grassy surface was decked out amphitheatre style with marquees festooned with lots of bunting. All that seemed missing were the knights upon their horses ready for the jousting to begin!

Yet this was not Camelot but 'Find A Cure Park' (for Parkinson's) and in the space of two hours it would become filled with parents, grandparents, kids and people with their dogs as they set off at noon on the 4km trek around what has become one of Sydney's iconic landmarks.

The weather gods were smiling because despite an early very gusty westerly wind, by walk time it had abated and under cool, clear skies some 1660 Unity walkers (up 62 per cent on the previous year) set out to cover at least one half of the magnificent Sydney Olympic Park precinct.

The front 'runners', mostly kids on skates, arrived back at the park inside the hour and over the next 25 minutes the rest ambled back into tent city for the food, the entertainment, kids' rides and the tattoo lady. A special Australia's Unity Walk for Parkinson's tattoo was in great demand once parents were reassured that the tattoo would wash off in the bath that night!

The atmosphere was light hearted and very festive and the crowd remained, eating and listening to the bands, My Future Lies and One Eyed Jacks, who had donated their time and music. Around 2.30pm about half the crowd made use of the complimentary admission to Rugby League star Hazem el Magic's final home match and went off to the footy. The other half made their way home contented in the knowledge that through them over \$125,000 net had been raised for Parkinson's research and to help people with the disease.

Melbourne's Unity Walk, on the same day at the same time, went off very well also with 1027 attending and there is a strong chance that the event will expand to other states in 2010.

The positive impact of this event should not just be measured in dollars. The publicity which included free TV ads in prime time and messages on electronic signboards at Sydney's rail stations is priceless in getting the message about Parkinson's across to a wider community.

Our hard-working staff and volunteers made it possible for everyone to enjoy the occasion and our sponsors provided us with the financial means to do what we could to make the day a memorable one. Our major sponsor, Bendigo Bank, provided great additional support by



Sam, Steve and Noel.



Walkers from Medtronics.

providing many volunteers on the day. They, along with our other sponsors, helped make this event happen and we ask you to consider reciprocating that support.

Our biggest thanks for the day though goes to you. Our support groups and members have, in just two years, enabled us to establish Australia's Unity Walk as an important charity event and social occasion on Sydney's event calendar. The day might best be summed up by one attendee who was heard to comment –

"What more could you want out of a day? Great weather, great cause, exercise in the sun and terrific company. It was just a great way to chill."



Motorcyclists roll dice for Parkinson's research by Glenn Porter

A group of motorcyclists from Wellington and the surrounding districts got together for a "dice run" to raise funds for research into Parkinson's disease.

"What is a dice run?" I hear you say! At each of five stops on the ride, all participants who have paid to take part roll 3 dice. The total score of the three dice from each of the 5 rolls are added together and the participant with the highest score wins the day.

There were over 50 riders who left the historic Lion of Waterloo Hotel in Wellington on the morning of Saturday 24 October 2009. They rode to Stuart Town via the Burrendong Way and stopped at the only pub in the small village to roll the dice.

They once again mounted their various motorcycles and arrived in Molong for a barbecue lunch prepared by members of the Wellington Rotary club on behalf of the Wellington Parkinson's support group. The riders then circled out through Manildra and Cumnock and arrived back in Wellington to enjoy a social evening at the Wellington Caves complex where soup and stew were on the menu.

'Eat, drink and be merry' was the order of the evening with a keynote speaker who enlightened the group on the cause and effects of Parkinson's disease. A sizable group from the Ulysses RV (Recreational Vehicle) Club had their AGM at the Caves complex, so they also joined the festivities. Raffle tickets had been sold over the course of the day and the prize draw was conducted. The revellers then enjoyed themselves listening and dancing to music provided by Terry Leonard, aka Elvis. The main organisers, Phil Mehluish and John Janiss, were very pleased with the result of the day and are delighted to be able to donate the proceeds to Parkinson's New South Wales to help fund research programs.



Stuart Town pub.



The start of the ride at The Lion of Waterloo.



All lined up.



They are on their way.

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.

Parkinsons NSW has been asked to bring to the attention of our community the call for applicants in 2010 who may benefit from an overseas Churchill Fellowship. There are many Fellowships available in areas that are relevant to Parkinsons 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 2010 need to be submitted between 1 November 2009 and 26 February 2010, and application forms can be downloaded from the website at www.churchilltrust.com.au or by contacting the National Office on 1800 777 231.

Support group contact details

GROUP	CONTACT	PHONE	GROUP
Albury/Wodonga		02 6051 7400	Illawarra South
Armidale	Julie Bowden	02 6771 4346	Lower North Shor
Ballina	Gerri White	02 6628 8278	Macarthur
Bankstown	Glenda Rawlinson	02 9707 2791	Manly/Mosman
Bathurst	Jennifer Mannell	02 6332 8963	Manning/Great La
Bega Valley	Sue Nelson	02 6495 9932	Maroubra
Bingara	Joan Bush	02 6724 1976	Nambucca Valley
Blacktown	Bryan McAlister	02 9674 6827	Narrabri
Blue Mountains	Hazel Tolhurst	02 4751 9903	Nepean
Broken Hill	Colleen O'Brien	08 8087 2175	Newcastle
Casino	Dawn Dennis	02 6662 6141	Orange
Castle Hill	Gayle Parker	02 9634 0578	Parkes
Central Coast	Les Norris	0418 607 684	Pittwater/Warring
Chinatown Bi-lingual		0421 224 712	Port Macquarie
Coalfields	Betty Rumbel	02 4931 5210	Quirindi
Coffs Harbour	Vera Heil	02 6652 9959	San Remo
Cowra	Ray Heilman	02 6341 3692	Shoalhaven/Nown
Dubbo	Lorna White	02 6882 7778	Shoalhaven/Ullad
Dundas/Parramatta	Margaret Fyfe	02 9638 4451	Southern Highland
Eastern Suburbs	Marion Welch	02 9369 0250	St George/Suther
Eurobodalla	John Vaughan	02 4471 2891	Tamworth
Fairfield/Liverpool	Warwick Brown	02 9602 8231	Tomaree
Finley	Glenis Gordon	03 5436 9293	Tweed Heads
Glen Innes		02 6732 1252	Ultimo
Goulburn	Mick O'Connor	02 4822 6732	Wagga Wagga
Grafton	Cathy Eggins	02 6642 2156	Yamba
Griffith	Angela Bortolin	02 6962 3289	Yass
Gunnedah	Lisa Hagley	02 6742 0018	Young Onset
Hawkesbury	Jill Sykes	02 9621 1794	Young Men's Netw
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092	Young Women
Illawarra North	John Coppens	02 4283 1346	

GROUP	CONTACT	PHONE
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	Con Diamond	02 6862 1925
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

Donations

Donations have been received in memory of the following people between 1 June and 2 December 2009.

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

Jack Andrew Harry Bennett Anthony Bennett Valerie Bezett Audrey Bissett Jim Boadle Gaetana Carollo Leila Clay Peter Cooper Hazel Cupples Pat Darton John Davies **Rosalie Davis** Malcolm Davis Jack De Saxe Laurel Deane John Dimitriou **Trevor Donald**

Arthur Evans **Clare Flaherty Brian Gerrard** George Gissing Kenneth Harris Margaret Harwin Milton Hedger John Higgins Peter Hilton David Hunt Malcolm Hutcheon Herbert Jackson Robert Jackson Margaret Kennett Robert & Gloria Kerr Lucelle King Thelma Lee Mike Leyland Peter Maher

Joan Mair Phyllis Maloney George McGoogan Shirley McGrane Mrs McInerney **Robert Mitchell Oleg Norvall** Mr O'Connor John O'Donnell **Raymond Pardey Despina Ploudias** Maureen Prince Nicholas Psaltis Dianna Radcliffe **Oswalk Reberger Ruby Reynolds** Tony Roberts James Rutherford Darrell Ryan

Mary Sackar Susan Sands Antonia Scavera Theodore Simos Ethel Solomon Keith Stollznow Sid Street Betty Tait Bryan Talty Meg Thompson Nicholi Tokmakoff Michael Vlachos Ellen Wojtynski Warren Weston John Willis Jean Wong

CELEBRATION DONATIONS WERE RECEIVED FOR:

Wedding Anniversaries

The 60th Anniversay of Hazel & Tom Tholhurst The 50th Anniversary of Jill & Harold Gold

Birthdays

Doreen Ford Graeme Heine Leon Portrate Shirley Silvertson Brian White

PARKINSON'S NSW INC.

PO Box 71 NORTH RYDE BC NSW 1670 Toll Free No: 1800 644 189 Phone: 02 8875 8900 Fax: 02 8875 8999 Email: pnsw@parkinsonsnsw.org.au Web: www.parkinsonsnsw.org.au

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Patricia Barkley Samuel Chu Miriam Dixon Assoc Prof Kay Double Bruce King OAM Bernard McGrath Allan Poole Rebecca Silk John Hassett Dr Simon Lewis

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Miriam Dixon CEO 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

Volunteers

Paula Argyropoulos 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 Graham Rattray Sue Ford Sue Rooleht Joan Todd Margaret Byron Martin Ancelleri Amanda Blake

Stand By Me Editor Samantha Urry

Glenn Wheeler

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

HON. ADVISOR Lady Angela Carrick

Diary Dates

FEBRUARY

23	Coffee/Information morning – PNSW Office, Khartoum Road, North Ryde.
MARCH	

5 - 7 Young Onset "BreakAway" Weekend

APRIL

month	Trivial Pursuit Events – Various Statewide locations	
11	World Parkinson's Day	

MAY

All

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

AUGUST

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

SEPTEMBER

29 Aug to 5 Sept 1	Parkinson's Awareness Week Parkinson's Awareness Seminar – State Parliament House
OCTOBER	
19	Annual General Meeting

NOVEMBER

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

DECEMBER

4 Parkinson's Christmas Party

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

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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