



Stand By Me

Parkinson's NSW new home!

Parkinson's NSW staff are now settled into the new premises at Building 21, Macquarie Hospital. We are pleased that the building is easily accessed by a ramp and is single story. Our InfoLine can now comfortably accommodate three staff members taking calls.

You are welcome to visit our office, please call 1800 644 189 to let us know of your visit.



The Lions Club of Sydney Pacific Inc supports Parkinson's NSW

On Sunday 2 May Parkinson's on Parade Fashion Parade was held at the Four Seasons Hotel in Sydney.

\$27,000 was raised at the event! Parkinson's NSW is excited to announce that funds raised will fund five scholarships for the Neurodegenerative Disorders Graduate Certificate Scholarship at Notre Dame University in 2011.

A special thank you to Monica and Sam Chu and all their volunteers for their support!



Great News!!!

Free transport to the Unity Walk from within NSW

Parkinson's NSW is thrilled to announce that the State Government, via the Transport Minister, is providing free bus and train travel to the Parkinson's Unity Walk. This includes the following – free travel for participants travelling to and from the event on 29 August on City Rail Services, Country Link services within NSW and Sydney metropolitan and outer metropolitan bus services. (*See inside for further details*).



**Sydney
29 August 2010**





President's Report

Parkinson's NSW has settled into its new home, thanks to the hard work of our staff. As part of the relocation, we have implemented improvements to the InfoLine area that provides for greater privacy and space. We thank the Bondi Lions, once again, for their generous assistance. They have been

wonderful supporters of PNSW. Our last appeal letter highlighted the important work of the InfoLine and the essential service that it provides; your valued support ensures its continuation.

The move represents a milestone for our organisation; the premises have been made available to us at a peppercorn rent from the State Government. This is the first time we have received ongoing assistance of this kind, a step towards recognition of our needs and very appreciated. We continue to liaise with Alzheimers and appreciate the goodwill and ability to share some facilities.

We have had two successful fundraising events staged on our behalf in this quarter of the year. The Macquarie Bank held a jazz concert at The Basement, which proved to be a great night for those who attended, as well as a great fundraiser for PNSW.

The Lions Club of Sydney Pacific held their 14th Anniversary Fund Raising Lunch at the Four Seasons Hotel in May. President Monica Chu, and her team of volunteers, created an amazing fashion parade and fun afternoon from which PNSW has generously benefited; monies raised at this event will fund five scholarships for the Post Graduate Course in Neurological Nursing at Notre Dame University next year. What a marvellous contribution!

The Nurses Trial is now well established in the Shoalhaven, and the early indications are very positive.

The latest Federal Government recognition of nurses' importance to Community Health would seem to be a perfect fit with our own view, and hopefully will translate into more positions for Parkinson's nurses.

Future doctors should also be mentioned. As part of their Independent Learning Project, the three students placed in Wagga, Coffs Harbour and Albury have submitted their reports. All three are of an excellent standard and give us the enthusiasm to continue to subsidise and encourage more students to work with our support groups. We'll need to think of ways to encourage them to progress into Neurological Specialists.

Two 'big' things to look forward to are the Annual Unity Walk and the World Parkinson's Conference.

The Unity Walk continues to build momentum and plans are well underway to make it 'bigger and better' so remember to save the last Sunday in August to put on your walking shoes!

The second World Parkinson's Conference is being held in Glasgow, Scotland from 28 September to 1 October. I have been sitting on the Organisation and Government Relations Committee, representing Parkinson's Australia, and will co-chair a session. Australia is well represented with eight speakers and around 20 attendees. Of special note is Professor Phillip Thompson from SA, the World President of the Movement Disorder Society, who is on the Management Committee and our own Professor Glenda Halliday, who was singled out by the committee as the first person to be featured in the weekly highlighted speakers.

This being the last issue of SBM before our AGM, I will encourage you to consider if you would like to nominate for Council. I look forward to seeing as many of you as possible at the AGM.

Regards

John Silk OAM

Coffee Information Morning

Come and meet staff and volunteers at Parkinson's NSW

Talk to people living with Parkinson's

10.30am start – 31 August 2010

Family Visiting Area, Vincent Fairfax Centre, Macquarie Hospital, Cox's Road, North Ryde

RSVP – 24 August 2010

Ph 1800 644 189

Young Women's Group

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

The group usually meets on the third Wednesday of the month 10:30am – 12:00noon at our office

We welcome newcomers and their female family members or carers.

The next group will meet on 16 June.

To register contact our InfoLine 1800 644 189



CEO's Report

Unity Walk 2010 – Free Transport

The New South Wales Minister for Transport and Roads has arranged for free transport to be available to participants in our Unity Walk 2010 on 29 August.

The free transport will be available on CountryLink, City Rail and metropolitan, and outer metropolitan bus services. To be eligible, participants need to register for the Unity Walk online. Our Unity Walk website will be available from early June.

If anyone has difficulty registering online, please call us on 1800 644 189. Once you are registered for the Unity Walk, you will be able to download a Transport Voucher to show the ticket seller that you are attending the Unity Walk.

Participants travelling by CountryLink still need to book their seats in advance with CountryLink. This can be done through the CountryLink call centre on 132 232 and by notifying the telephone operator that you are participating in the event. Alternatively, participants can book in person at a CountryLink booking office. For this they will need to present the official Unity Walk Transport Voucher.

Participants travelling on CountryLink services, whose journey may require travel a day before or after 29 August, will be able to do so free of charge if they book a return ticket to the event, clearly identifying to the ticket seller that they are participating in the Unity Walk by showing the Transport Voucher.

Advanced Therapy Seminar

We recently held an Advanced Therapy Seminar at Westmead Hospital. Over 75 people attended. Topics included Deep Brain Stimulation (DBS). This was topical, coming shortly after an article in the Daily Telegraph on John "Strop" Cornell, Paul Hogan's offside, who reported on good results from DBS. DBS has been available, to suitable patients, for over 16 years and over 75,000 people worldwide have undergone that procedure.

Our thanks to the Westmead team – Neurologists Dr Neil Mahant and Dr Victor Fung, Neurosurgeon Dr Jacqueline McMaster and Clinical Nurse Consultant Laraine McAnally.

A further seminar on advanced therapies will be held in July.

Medical Energy Rebate

You will recall that following joint lobbying by Parkinson's NSW and MS Australia, the New South Wales Government agreed last year to provide an Energy Rebate, recognising the difficulties that unregulated temperature can present for people living with Parkinson's, MS and other conditions. The Government has now announced that from 1 July 2010, the Energy Rebate will be increased to \$145 per year, with a further increase to \$161 per year from 1 July 2011. These increases are intended to reflect the average rise in regulated electricity prices.

Also from 1 July 2010, eligibility for the Energy Rebate will be expanded to include customers who hold Commonwealth Health Care Cards. More information can be found at www.industry.nsw.gov.au/energy/customers/rebates/medical-energy-rebate-questions.

Speakers Group

Our speakers group now has 21 enthusiastic volunteers. Special thanks to John Carlton, and more recently Doug Malouf, for their support in training our volunteers. Doug has provided copies of his book *How to Create and Deliver a Dynamic Presentation* to all our volunteers, and has been generous in making his staff available for additional training.

Our speakers group volunteers are keen to provide presentations to local service clubs such as Rotary and Progress, and are willing to travel for appropriate presentations. This is an important way of raising awareness of Parkinson's at a grass roots level.

Trivia Quiz Fundraisers for World Parkinson's Day

You will see Trish Morgan's grapevine story in this issue, a story on the support groups who ran Trivia Quiz Fundraisers for World Parkinson's Day. We were fortunate to have the free assistance of Barry Benjamin who designed the quiz kits. Barry has over 17 years experience of designing and running trivia events at St George Leagues Club. A special thanks to the support groups who participated.

Passing of Con Diamond

It's with sadness that I record the passing of Con Diamond. Con was one of our longest serving volunteers, and played a key role in the Parkes Support Group. He was recognised for his services with Honorary Life Membership in 2009.

Increased InfoLine Staffing

We are delighted to have increased our InfoLine staffing, to assist in meeting enquiries from people (including family members) living with Parkinson's disease. We have been joined by Michelle Skor who is a registered psychologist. Michelle is experienced in assisting people with a variety of chronic health conditions, as well as their families.



Michelle Skor - New InfoLine Staff member

Yours in Parkinson's Friendship

Miriam Dixon

Update AGM
Change of date for AGM to
Monday 15 November



Parkinson's NSW Unity Walk

Bigger and Better Than Ever Before

Mark Sunday 29 August in your diary for the 2010 Unity Walk. Let all your friends and family know too so they can come along and be part of the fun. All to raise money for Parkinson's research and to help those living with Parkinson's, their partners, carers and families.

The Top Fundraising Team this year will win a fully catered corporate box for eight to the opening night of Ben Hur, the Arena Spectacular at ANZ Stadium.

BEN HUR is the dramatic and passionate story of a slave turned hero who dared defy the Roman Empire.

Direct from Europe, this stadium spectacular, complete with an awe-inspiring full-scale chariot race and gladiator battles, will be the biggest theatrical event ever seen in Australia!

Based on the Academy Award-winning movie starring Charlton Heston, BEN HUR comes exclusively to ANZ Stadium in Sydney for two nights only in 2010 – Friday 22 October and Saturday 23 October.

For more information, including details on how to secure your ticket, visit www.benhur.com.au.

Great Southern Rail is giving a memorable trip for two on the magnificent Indian Pacific, travelling Gold Service, to the person who raises the most fundraising dollars. In addition, anyone who raises over \$250 will go into the draw to win that once in a lifetime holiday to Hawaii courtesy of our good friends at Hawaiian Airlines, Hawaii Tourism and Outrigger Luana Waikiki. Outrigger Luana Waikiki invites you to discover an unexpected Waikiki, completely serene and superbly cool. Awake to views of adjoining Fort De Russy Park, lounge poolside under the shade of a private cabana, and renew your senses at Ville de Coco spa. It's just a short stroll to the faster-paced heart of Waikiki and the warm sands of Waikiki Beach. This means that EVERYONE who fundraises now has the opportunity to win one of these fantastic prizes. Register by 22nd August and be in the running to win overnight accommodation at Novotel Sydney Olympic Park, thanks to Accor Hospitality.

There will be more entertainment, new rides for the kids and plenty of food and drink on offer. There is also a brand new walking course and a short course, both of which are user friendly. The new course will take Unity Walkers into the beautiful surrounding gardens at Sydney Olympic Park.

For the first time the State Government is providing free travel on Country Link, the day before and after, to the Unity Walk. This is coupled with free metro bus and train travel. So consider making a weekend of it in Sydney. Check the travel timetables on 131500 or www.131500.com.au and the website www.unitywalk.com.au for details of how to secure your free travel. What an amazing development for all our friends in regional NSW.

So get the family together and tell all your friends because there is also a prize for the top team fundraisers. It is going to be a great day. The new national website which includes the NSW site will be active early June so make sure you register online and start fundraising so we ensure the 2010 Parkinson's Unity Walk is the biggest and most successful to date.



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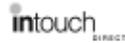
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Event Partners



This year, Hawaiian celebrates the 80th anniversary of its first flight between the islands of Hawaii. Hawaiian Airlines operates three weekly nonstop flights from Sydney to Honolulu, with onward connections to the islands of Hawaii and 10 US mainland cities. Hawaiian's fares from Australia include complimentary meals, snacks, drinks, main screen entertainment and a generous baggage allowance of two 32kg items per passenger – no hidden extras!



What is the Medical Energy Rebate?

The Medical Energy Rebate is for eligible customers who have an inability to self-regulate body temperature when exposed to extremes (hot or cold) of environmental temperatures. It is associated with certain medical conditions such as Parkinson's disease and multiple sclerosis. However, to be eligible for the Rebate a customer will require a separate diagnosis that they are unable to self-regulate their body temperature.

How much is the Medical Energy Rebate?

The Medical Energy Rebate is currently \$130 a year increasing to \$145 a year from 1 July 2010. The Rebate will further increase to \$161 per year from 1 July 2011.

For further information, please call InfoLine 1800 644 189 or visit <http://www.industry.nsw.gov.au/energy/customers/rebates/medical-energy-rebate-questions>

Shoalhaven Support Group presents a seminar "Parkinson's, The Future"

**Friday 12 November
at Bomaderry Bowling Club**

Guests speaker:
Dr Simon Lewis

Brain & Mind Research Institute

Registration & Morning Tea: 9:30am

Start: 10.30am Lunch: 1pm

A small contribution of \$10 will be charged to PWP and carers to help cover lunch

RSVP: 02 4464 3028

Members from surrounding support groups are more than welcome to attend, and are encouraged to advise their local health professionals to attend as well.

Have a great Unity Walk Weekend in Sydney courtesy of Country Link and ACCOR

- Travel individually or come as a group
- You can travel to Sydney FREE on Country Link the day before and/or after and stay at Sydney Olympic Park
- Stay at your choice of one of 3 great ACCOR hotels. ACCOR is offering a 10% discount off the hotels' best available rate of the day for Pullman, Novotel and Ibis Sydney Olympic Park for stay dates from Friday 27 August to Sunday 28 August 2010.
- You can attend the Unity Walk, an NRL game at ANZ Stadium (subject to scheduling) and take in Sydney's sights

For all details go to www.unitywalk.com.au



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Research

APOMORPHINE IN THE TREATMENT OF PARKINSON'S DISEASE

Dr Stephen Tisch, Consultant Neurologist, St Vincent's Hospital Sydney

What is Apomorphine?

Apomorphine was first synthesised in the 1850s by the reaction of morphine with hydrochloric acid and was originally marketed as a drug to induce vomiting. Unlike morphine it has no narcotic properties but is a potent activator (agonist) of brain dopamine receptors types D1 and D2. It is the only dopamine agonist as effective as Levodopa (Sinemet or Madopar) in helping the symptoms of Parkinson's disease such as tremor, stiffness and slowness. In this regard it is more potent than available oral dopamine agonists such as Pramipexole, Ropinirole or Rotigotine.

How is Apomorphine Administered?

Apomorphine is not effective when administered orally because it is rapidly eliminated by the liver. It needs to be given by injection into the skin (subcutaneous) as intermittent injections or continuous infusion. Because Apomorphine causes nausea, patients are treated with Domperidone (Motilium) for about three days prior to and during Apomorphine treatment. Over time the nausea lessens and Domperidone can usually be stopped. Intermittent Apomorphine injections are useful as "rescue" therapy for OFF periods, providing rapid improvement in mobility. An Apomorphine injection acts within minutes and lasts about 60 minutes. Patients with more frequent OFF periods and dyskinesia benefit more from continuous infusions which provide uninterrupted dopamine replacement to the brain thereby reducing motor fluctuations (OFF periods, dyskinesia).

Who is suitable for Apomorphine treatment?

Apomorphine is beneficial for patients with Parkinson's disease who are experiencing unsatisfactory control of motor symptoms (tremor, stiffness, slowness, gait difficulty) with oral medications. Patients who retain a good ON response to oral medication but have developed disabling motor fluctuations (OFF periods or dyskinesia) are likely to benefit from Apomorphine.



How effective is Apomorphine treatment?

Intermittent injections of Apomorphine increase ON time by 40-50% but do not help dyskinesia. Continuous infusions of Apomorphine increase ON time by about 50%, and reduce dyskinesias, particularly in those patients able to discontinue Levodopa. The infusion is usually limited to the waking day, but can in some circumstances be given 24 hours a day. Like other treatment for Parkinson's disease Apomorphine is not a cure but can be very effective in controlling symptoms.

How is Apomorphine started?

To start Apomorphine patients are given test doses under supervision of the neurologist and movement disorders nurse to determine the effective dose and any side effects. Apomorphine infusions require a small infusion pump to be worn (see Figure). Patients or their carers are instructed in the setup of the infusion. Regular follow up with the treating neurologist and movement disorders nurse is required to adjust dosages, check pump programming and monitor for any side effects.

What are the side effects of Apomorphine?

Once established, Apomorphine injections and infusions are usually trouble free. Most patients develop skin nodules at the injection sites and anaemia can occur rarely. Excessive sleepiness, low blood pressure when standing up (postural hypotension) and worsening of psychiatric problems such as hallucinations or paranoia can also occur.

How can I access Apomorphine treatment?

Apomorphine is licensed in Australia for intermittent injection and continuous infusion and is available under the Pharmaceutical Benefits Scheme. For more information about Apomorphine and your nearest treatment centre contact Parkinson's NSW.

Speeding Vibrations Christmas in July

Briars Country Lodge & Inn

653 Moss Vale Road, Bowral NSW
12 noon Sunday 11 July
in the Bong Bong Room.

Children welcome.

Check website for menu www.briars.com.au

(Accommodation also available).

**RSVP Trish Morgan 1800 644 189
by 30 June**

Research

THE RELATIONSHIP BETWEEN MEDICATION AND GAMBLING IN PARKINSON'S DISEASE.

Dr Jacqueline Olley Doctor of Clinical Psychology / Master of Science candidate, University of Sydney; Alex Blaszczyński Professor of Clinical Psychology, University of Sydney /Conjunct position with Westmead Hospital ; Dr Simon Lewis Senior Lecturer in Cognitive Neuroscience / Neurologist, Parkinson's Research Clinic, Brain & Mind Research Institute

Gambling is viewed as a common and socially acceptable activity within our society and is only viewed as a problem when it adversely affects relationships, family, employment and personal finances. There are many reasons why people gamble; to win, for excitement and enjoyment, to interact socially or to escape problems or relieve certain feelings, (eg, helplessness, guilt, anxiety and depression). Some describe the excitement and action of gambling as more important than the money won or lost. Despite repeated efforts to cut back or stop the behaviour, some people are unable to cease gambling. Research has shown that between 2% - 7% of the adult population engage in problem gambling behaviour.

From the perspective of the brain, gambling has much in common with many addictive drugs, like cocaine. Substance and behaviours become addictive through the influence of the brain's reward system. These reward systems originally evolved to help motivate animals to pursue activities that were crucial for survival, for example food and reproduction. Dopamine is one of these powerful chemical neurotransmitters that are associated with reinforcing feelings of well-being and pleasure. It is also known to be associated with the emergence of other compulsive type behaviours; exactly why is not known.

Symptoms of Parkinson's disease appear when 70% of dopamine producing cells cease to function normally. The primary treatment for Parkinson's disease is medication that restores dopamine production. Dopamine is necessary for the smooth and coordinated function of muscle and movement and lessens tremors and rigidity.

Recently, a few studies involving Parkinson's patients taking dopamine agonist medication have reported increased gambling behaviour and severe problems following commencement of medication. This gambling ceased following a change in medication. To explain this, it has been suggested that increased gambling emerges in response to the effect of dopamine agonist medication. Evidence is now emerging to suggest that 9.3% of Parkinson's disease patients treated with dopamine replacement medication may meet criteria for problem gambling. This observation has led a number of authors to believe that a direct causal relationship exists between pathological gambling and dopamine agonists and there is a clear need for further research to investigate this possible link.

Most previous studies into this problem have not evaluated alternative explanations (independent of dopamine agonist medication), that may account for the onset of problem gambling, for example, a pre-existing gambling problem. Due to this gap in the research, a study is currently being proposed at the University of Sydney. This study will commence once approval from relevant ethics committees has been obtained. The study will aim to investigate the relationship between dopamine medication and pathological gambling taking into account other risk factors. The results obtained from this study will better the understanding of the role of dopamine agonist medication and other risk factors in the emergence of problem gambling in individuals diagnosed with Parkinson's.

For more information on this study, please contact Dr. Simon Lewis at Brain and Mind Research Institute on 02 9351 0672.

DOES BRAIN TRAINING WORK IN PARKINSON'S DISEASE?

Medical researchers from the University of Sydney's Brain and Mind Research Institute have launched a study which aims to examine whether brain training can improve memory and other thinking functions in Parkinson's disease. This technique has been shown to be successful in healthy ageing and in other diseases that affect memory. However, it has not been investigated in people with Parkinson's disease. This is despite the fact that around one quarter of patients with PD show at least subtle difficulties with memory and other thinking skills at disease onset.

The group-based program begins on 5 July and will run twice-weekly (Monday and Thursday 1.30pm-3.30pm) for seven weeks. The program is being conducted in Camperdown and each session will run for two hours. The first hour will provide you with information about healthy brain ageing and will cover topics such as diet, exercise, sleep, depression and anxiety. It also includes strategies for improving memory. The educational sessions are conducted by doctors, neuropsychologists,

clinical psychologists and sleep experts. The second hour involves the use of computer-based exercises to target important functions such as concentration, thinking speed, memory and problem-solving.

The research is being conducted by A/Prof Sharon Naismith (Neuropsychologist) and Dr Simon Lewis (Neurologist), both of whom have published widely on memory problems in Parkinson's disease and have conducted prior studies using this brain training technique.

Participation requires that you undergo two assessments, prior to and at the end of the seven weeks of training. There is no charge for the assessments or training. If you would like more information or if you are interested in participating, please phone the Parkinson's Disease Research Clinic at the Brain & Mind Research Institute (ph: 9351 0702, email: pdclinic@med.usyd.edu.au). Please phone early as the first round of groups will be limited to ten participants.

How to choose a private physio for Parkinson's disease rehabilitation

Melissa McConaghy, NSW National Neurology Group Chair

Current literature looking at physiotherapy intervention for Parkinson's disease shows that appropriate intervention is essential in optimising function, mobility and quality of life. Physiotherapy is important throughout the disease process, especially on initial diagnosis, with a change in medication or when clinical impairments start to impact function.

Most people who have Parkinson's disease will have crossed paths with a physiotherapist, however if you are making the move to seek a private physiotherapist after public services have ceased or to enhance your program, this can be a whole different kettle of fish.

Physiotherapy is a broad term which can cover a range of therapeutic techniques from massage and manipulation to gait retraining and sporting injuries. Most physiotherapists will know a bit about everything but tend to specialise in one particular area such as sports injuries, manipulation or neurological conditions. To get the best out of your therapy, it is important to choose a physio who has neurological experience, especially in Parkinson's disease. To do this you may need to search further than your local physiotherapy practice for the best care.

So how do you find a physio in the community that knows about Parkinson's disease? The first thing I would suggest is accessing the Australian Physiotherapy Association (APA) through their phone number or website. The Australian Physiotherapy Association is the national professional body for qualified physiotherapists. They have a 'find a physio' link that will filter your search specific to your location and special needs. The APA has long supported the concept of categorising physiotherapists in their special interest and clinical areas as well as providing a pathway for continued education and specialist recognition. Narrowing the field to neurology will automatically select physios who are members of the National Neurology Group.

Physiotherapists in this category have a special interest in Neurological conditions and will have a better

understanding of the neurological system and prognostic treatment pathways, particularly for Parkinson's disease management. Most of these physios have a background working in multidisciplinary rehabilitation units, they have had more exposure to treatment of neurological conditions, focused their professional development on management for neurological conditions and know how to access more services such as aids, equipment and new treatment strategies.

Therapists found under this search will be listed hierarchically. At the top of the list will be Specialist Neurological Physiotherapists. As a Fellow of the Australian College of Physiotherapists, this therapist would have attained the highest level of expertise in neurology via a rigorous training and examination process. They may contribute to the professional education of colleagues, actively engage in their own professional development and have had involvement in research activities. There are currently seven specialist neurological physiotherapists in Australia.

Below this will be Titled Neurological Physiotherapists. To qualify as a Level Two or Titled Member, further study is required – (eg, a coursework Masters Degree in neurology, or study through the alternate pathway established by the National Neurology Group). When a member becomes a Titled Member of the National Neurology Group the member has the right to use the words 'APA Neurological Physiotherapist' after their name. There are currently 49 Titled Neurological Physiotherapists in Australia.

Finally, other qualified physiotherapists and APA members will be below this as a Level One member of the group. A new subset of neurological physiotherapists has also been introduced and we are currently collating a list of physiotherapists with a special interest in Parkinson's disease specifically. To access this list, please contact PNSW InfoLine 1800 644 189.

To contact the APA National Office please call 1800 811 481 or visit www.physiotherapy.asn.au

The Parkinson's Quilt Project

The Parkinson's Quilt Project is the first global quilt project to focus the world's attention on the nearly one million people in the US and more than 4.1 million people worldwide living with Parkinson's disease (Pd). The project's aim is to raise awareness of the impact that the disease has on people living with Parkinson's – along with their families, care givers and friends – and our continued urgency to find a cure.

The Parkinson's Quilt will be displayed for the first time at the 2nd World Parkinson Congress in Glasgow, Scotland from 28 September through 1 October, 2010.

The Quilt will consist of panels made by individuals and groups affected by Parkinson's, in honour of the cause, of their group or in honour of their loved ones affected by Parkinson's. Each panel will be two feet tall and two feet wide, and will be sewn together in eight foot sections.

There have been 6 panels from Parkinson's NSW supporters; Amanda & Yvonne Blake, Blue Mountains; Jan Wiseman, St George/Sutherland, Dubbo, Lorna White; Karen & Meryl Lees, Cowra.

To view the progress of quilts, check out the link www.facebook.com/parkinsonsquilt.



On the groupvine

by Trish Morgan

Fun and Fundraising in April to celebrate World Parkinson's Day!

Movie premiere was held in Yamba on Thursday 8th April.

Heather Wilson thanked the supporters the next day by saying "Last night there were 109 friends at our Movie Premiere of 'Crazy Heart'. All who attended and contributed helped to make our fundraiser a huge success for PNSW - Research into a cure for Parkinson's. I don't as yet have the final figure – however, the funds raised are in excess of \$1,501.75. A little old lady gave me a handful of coins!!"

The final figure was \$1,636.75. This function was organised by Yamba support group in six weeks. What a fantastic effort!

Trivia Quiz and Luncheon organised by the Central Coast support group on Tuesday 13 April. Jenny Rybolowik-Poole and her husband Allan, PNSW council member, reported:

"At 11am Bob Smith, Radio Five-O-Plus personality, started the Trivia with a lucky door prize, followed by two rounds of Q & A, a raffle, two more rounds of a heads and tails game (which was a lot of fun) and lastly an auction. In between we had a delicious lunch with cake donated by Bakers Delight and bottomless tea and coffee. By 3.00pm our Trivia friends were no doubt getting weary ... time to go home!

Our Trivia day was a huge success and we had a full compliment of 100 people in attendance with \$3,000 raised (including some gift certificates that came in late, valued at \$110)."

I'd like to extend a big thank you to Jenny and Allan, who gathered huge support from the community to make this event such a success.

Southern Highlands support group decided to hold a Trivia Afternoon at The Scottish Arms at East Bowral on Saturday 24 April. Rob Shearman, retired school principal, compared the quiz with skill and another school teacher tallied the results. Gemma Bernasconi, a 16 year old music student, entertained those present playing guitar and singing her own compositions. There was a guessing competition of *How many lollies in a jar?* Over 50 people attended and more than \$600 was raised.

Support groups having a Trivia Quiz experience at their usual meetings were **Armidale, Ballina, Bathurst, Newcastle** and **Pittwater/Warringah**.

The quiz at Newcastle was won by new members and Ken Begley. They were presented with Trivia Champion certificates at the May meeting.

Cooma has a new support group, Snowy/Monaro, following a public meeting on 16 April. Roger Norton, President of Parkinson's ACT chaired the meeting and the CWA ladies gave practical support and served afternoon tea. 68 people were there, which is a great response from the community. Regular meetings will be held on the second Wednesday of the month at 2pm.

Albury/ Wodonga support group (pictured) was featured in the Midweek Express with an interview with Valerie Leyden – seated right front. The article mentioned World Parkinson's Day 11 April commemorating James Parkinson's birthday.



Albury/Wodonga support group – photo by Midweek Express, Albury Wodonga

Special celebrations

Jean Whillock, member of **Illawarra North** SG since its inception 23 years ago, turned 90 in December. Jean remains an active member of the group, sharing her experience as a carer and assisting with administration.

Bette and Frank Young from **Bankstown** SG celebrated their 60th Wedding Anniversary recently. Their photo appeared in the Daily Telegraph and their family treated them to a special dinner at Carnarvon Golf Club. They treasure cards received from the Queen and the Governor General.

Congratulations Jean, Bette and Frank!

Surgical Interventions for Parkinson's disease

200 Deep Brain Stimulation Surgeries for Parkinson's disease

What have we learnt?

28 July, 2010

Featuring Neurologist Dr Paul Silberstein and Neurosurgeon Dr Raymond Cook, as well as people who have experienced DBS. Northern Sydney Education Centre, Macquarie Hospital, North Ryde (Entry via Wicks Road).

Register your attendance by
23 July on 1800 644 189

Proudly sponsored by Medtronic

Young Onset Breakaway Weekend

Garry Cearns

In March the Young Onset Groups held their first weekend away for us and our partners. The object of this weekend was simple, for all to have copious amounts of enjoyment, rest, relaxation and pampering, and from all the feedback this was well and truly achieved. While the weekend was a casual affair there was time available to attend some presentations from those Pd professionals working on the Central Coast and to just talk to others in a similar situation.

When you walked into Camp Breakaway you immediately felt a strong sense of camaraderie amongst all of the 50 people who came along, as we were all together because of a common cause. Everything was inclusive; meals, pampering time with massage, tai chi and reflexology. The karaoke night was a blast where we all got stuck into a karaoke version of the movie Mamma Mia. Most people got into the theme of Abba by dressing like their favourite Abba person. As you can see from the photos of the weekend everybody had a good time.

When the idea of a weekend was first raised, one of the requirements was to offer this to every Young Onset person throughout the State so it wasn't just another city based event. Well we had people from Newcastle, Wagga Wagga and Nowra come along. To make the weekend more affordable to all, the Young Men's Parkinson's Network (YMPN) subsidised some of the costs.

One thing that came out of the National Young Onset meeting held in November in Melbourne was that the term Young Onset encompasses more than three generations and we need to cater for everybody within the Young Onset Network. So we are looking to see if there is

enough interest in a weekend away for those people with young children i.e. a family weekend. If you're interested contact Trish at PNSW so they can start the ball rolling. The YMPN will again look at subsidising this to make it an affordable event for all. Thank you also to all who contributed either as a speaker, therapist or as donors of pamper products.

Lastly from all of us that came along we would just like to say thank you to Trish, Claerwen and Deb. All too often people come along to this type of event and have a great time with little understanding of the work involved in making it happen. We would like to say a very big THANK YOU to all of you for the enormous amount of planning and unseen effort you so generously put in. We realise you sacrificed very precious time away from your own families to give us all such a wonderful fun-filled weekend and we want you to know it was deeply appreciated.



Happy campers



Dr Scott Whyte answering questions

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Parkinson's Plus Seminar

**Northern Sydney Education Centre,
Macquarie Hospital, North Ryde
(Entry via Wicks Road).**

1st July

To register your interest, please call InfoLine.

Problem ... solved!



Robert Beech first became aware of his symptoms in 1996 when cramps started in his abdominal muscles and toes, as well as a general feeling of nervousness and shaking. His GP referred him to a specialist neurologist who diagnosed the early onset of Pd at age 54.

Robert advised his workplace of his diagnosis. Unfortunately he was unable to continue in the position he had held for almost 30 years. Robert was unsure what to do next, was medically retired, so decided to return to a dream that he had abandoned 35 years before. The University of Western Sydney offered a Bachelor of Technology degree and Robert saw this as the opportunity to finish something he started many years before.

He jumped at the chance to attend an evening course at UWS in Bridging Mathematics, and started at UWS on 1 Mar 1999 as a freshman. Robert started research for his PhD on 1 January 2003 and graduated with distinction, on 23 September 2009. For his PhD Robert decided to investigate why radio signals phase in and out. He will receive his Doctorate in Mathematics at graduation in September.

It just goes to show how when faced with a change in circumstance you can do one of two things. Robert decided to battle through and came out on top!

Here are some words from Robert ...

How has Pd changed my life?

It has made me aware of how good I had it without realising, or acknowledging it. It has put limitations on me that have resulted in the most frustration imaginable. I am not noted as one who suffers in silence. If I feel like giving loud vent to my anger I do. If asked for the most difficult aspects of it I would have to put restriction of freedom at the top of my list. I had always been very independent and now I find myself having to ask a nurse to help me into bed. It is not all negative however. It gave me the motivation to go as far as I have. In time I realised that the ability to humble myself to ask for help is a good thing, not a bad one. Humility and patience are a blessing, not a curse! That was the hardest lesson I have ever had to learn. They have brought me nearer to God than I ever would have come had I not had Parkinson's disease.

I have also found, to my surprise that the average human being is kind, warm hearted, compassionate and helpful. I would have never discovered that without Parkinson's disease.

What is my advice to my fellow Parkinson's disease sufferers?

You can't fight it, you have to accept it and try your best to live with it. You can't fight it and win, I thought I could and I lost. You are never too late to learn, Go for it. Surprise yourself.

A personal account

Being born in 1937 in Kogarah, I am a pre-baby boomer. I have an older brother Ken and a younger sister Lois. In 1999 I had been an accountant for almost 30 years when the tremors began. At first I passed them off as work related stress due to the introduction of the GST. In the later part of 2000 I was convinced to seek help with the result that I was diagnosed with early onset of Parkinson's. So into the path of being angry, why me, and saying good bye to our retirement plans. In retrospect, it is so easy to become depressed, without will power and determination, I would probably be there.

When I retired in 2005, I knew about Deep Brain Stimulation (DBS) surgery. By 2008 I was seeking a better quality of life, for my wife and myself and asked my local neurologist for a referral.

Thankfully she referred me to Dr Mahant, a neurologist who specialised in DBS. After some consideration, my wife Wilma and I decided that the pros outweighed the cons, so we said yes. Dr Mahant organised for us to see a neurosurgeon, Dr Owler at Westmead Medical Centre.

Dr Owler told us of the possible downsides of the operation, the worst case scenario being the small possibility that there could be bleeding in the brain and I could end up in a stroke-like condition. The small chance was worth the risk.

The day was set for Friday 13 March 1999. The following Sunday the miracle came to life when I had a visit from Dr Mahant and he turned the stimulator on.

I began doing all the things we would normally take for granted. I felt so good I wanted to go back to work and being productive.

Of course, there have been side effects with balance, speech, concentration, sleep, walking, etc. Normally it is not difficult to multitask but with Parkinson's I find it difficult to do three tasks. I will never give up though.

Now I have established a new business as a specialised Auditor of self managed Superannuation funds.

Because I am of the belief that there is a cure for Parkinson's, probably in the area of stem cells, I decided to donate a minimum of 1% of fees to Parkinson's NSW as a living bequest and encourage others to do so.



Racing the Planet for Parkinson's



On April 25, Alex Dalglish set off on a walk. It was a BIG, 250km walk that began in Kununurra, Western Australia and was to end on May 1 at El Questro, a million acre property in the Kimberly region

Why, you ask? Well, Alex is a determined woman who has been inspired and encouraged by her father, who was diagnosed with Parkinson's disease eight years ago at the age of 62. From an early age Alex's father instilled a love of landscape and the outdoors and the perfect opportunity arose to participate in the Racingtheplanet.com challenge, exposing her to some of the world's most beautiful landscapes, while raising money for Parkinson's NSW.

During her journey Alex was faced with physical challenges such as soreness and blisters, the elements of high humidity and 40 degree plus heat daily, as well as mental and emotional strain. During the race Alex received a message from her father saying that he wished he could have gone with her. She kept walking as long as she could for him.

Although Alex did not finish the walk, making it to Day 5 of 7, her experiences in such an ancient landscape, seeing amazing rock art, learning about native flora and fauna and spending time with friends and new acquaintances was something that will stay in her memories and heart for a long time.

Alex is happy she was able to achieve something that was just amazing, despite being incredibly challenging.

Racingtheplanet.com organises self assisted foot races through the 4 great deserts, Atacama, Gobi, Sahara and Antarctica, adding a fifth roving location every year. Australia was chosen this year, with the event going to Nepal in 2011. Participants are able to raise funds for their nominated charity, just as Alex has done for Parkinson's NSW.

Parkinson's NSW is extremely proud of Alex's huge effort, and is grateful for the \$10,255 plus she has raised for the Parkinson's community.

In Loving Memory

Parkinson's NSW has set up an **In Loving Memory** page on the Everyday Hero website at www.everydayhero.com.au. It can be customised with your loved one's photograph as well as a few special words about them. There is also an area to leave a special anecdote or memory about your loved one.

The In Memory Page can easily be set up by someone in the family or we can do it for you. To do it yourself just:

- go to http://www.everydayhero.com.au/event/pnsw_in_memory
- click on "Create In Memory Page now"
- just complete all the details required

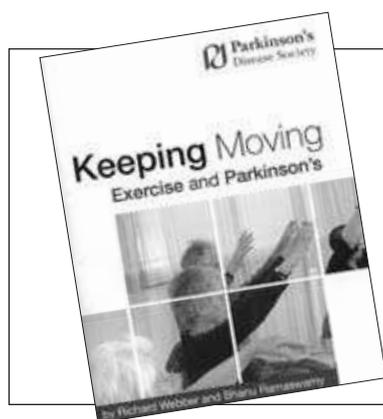
Once this is done, you will be allocated a special link. You can email people to let them know about the In Memory Page and that you would like them to donate if they wish to. The donation process is simple and straightforward. A receipt will be issued online to the donor.

If we are going to set it up for you:

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

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

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



Keeping Moving

Exercise and Parkinson's Booklet and DVD by Richard Webber and Bhanu Ramaswamy.

Produced in the UK and distributed previously only through the Parkinson's Disease Society in the UK. The book has sections for exercises in lying, sitting and standing positions, making it a valuable resource for all levels of fitness. Available now \$20 inc GST and postage

Please call 1800 644 189 to order your copy!

Counselling corner

Deborah England

One of the most complex roles that any of us can find ourselves in is that of carer. Many folk find themselves in a situation where the variety of needs of the person for whom they care become the focus and take up most of the time, leaving tiredness and overwhelmedness in their wake.

None of us knows accurately what kind of 'patient' or 'carer' we will be. Unnecessary anxiety can ensue when the person for whom care is given feels a burden and the person delivering the care feels under-appreciated by either the patient and or the medical team.

When the patient overlooks, is overly critical or trivialises the carer/caring because what is happening does not match with their idea of what should be happening, a lot of frustration and miscommunication is inevitable. When the carer is not empathic or becomes annoyed by the limitations of the patient, it can become the royal road to exhaustion and resentment.

The lives of the patient and carer are intimate and may arouse deep and unexpected emotions. Emotional support matters greatly with this changed dynamic. This, in my opinion, deserves as much attention as the illness itself.

Dependency and great need arouse many emotions no matter how up to the challenge (or not) the folk involved are feeling. It is difficult for any of us not in the situation to understand how vulnerable and anxious that can make either party feel.

The message here is that both the patients and carers need care. Care without the feelings of guilt for needing care attached. With support and validation for both parties and the myriad of complexity attached to changed roles, caring can be a rewarding and fulfilling gift of love that brings its own joys and rewards.

Congratulations David on your Seniors Week Award!



David King works tirelessly on the Speakers circuit, educating Probus, Lions Club and many other community groups about Parkinson's disease.

He received an award during Seniors Week in March in the Community Service/Volunteering category.

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



Isabelle Clark –
Bequest Officer

Bequests help us to ease the burden for people living with Parkinson's and allow us to continue and plan ahead to support people living with Pd.

We are hearing more and more from younger people newly diagnosed. These people are often under

40 years old, have a career, mortgages and children to support as well as manage their own health and wellbeing. How wonderful if we are able to expand our services, ease the burden and support them in the future, and most importantly find a cure.

I was very pleased recently when one of our members notified me they had left a bequest to Parkinson's NSW when updating their will and a family member had also thought of us. By notifying Parkinson's NSW it gives us the opportunity to thank them for such a generous gift.

By including Parkinson's NSW in your will your memory will live on in the gratitude of strangers, and you can assist many people. That is a contribution worth making.

We are currently planning another sponsored Bequest Luncheon later on in the year.

Please feel free to contact me on 1800 644 189 (freecall) or isabelle@parkinsonsnsw.org.au if I can be of any assistance.



Free help to cut power bills

The NSW Government is helping vulnerable households save power and money on their bills.

Through the Home Power Savings Program, 220,000 households will save up to 20 per cent a year on their power use and cut carbon pollution.

The program is managed by the Department of Environment, Climate Change and Water (DECCW) as part of the NSW Energy Efficiency Strategy.

More information can be found at www.nsw.gov.au/articles/households-enjoy-63m-investment-reduce-energy-use.

Households can take part in the program now by calling 1300 662 416

Donations

IMPORTANT NOTICE

regarding General Donations

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

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

Thank you for your continuing support.

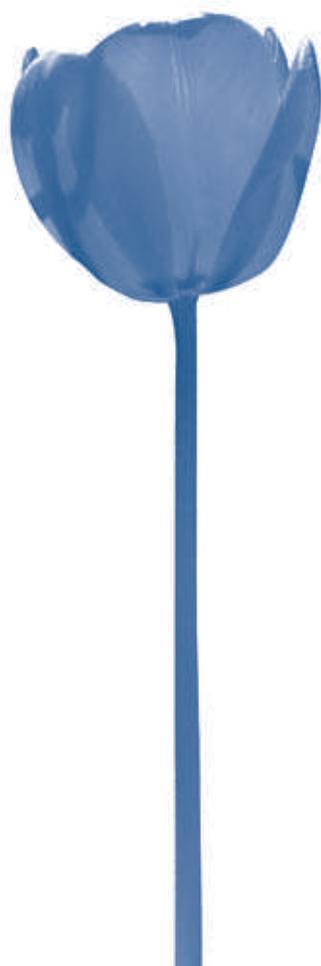
Donations have been received in memory of the following people between 3 March 2010 and 27 May 2010.

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

William (Les) Allman
 Peter Barrat
 Donald Buchhorn
 Raymond Carmody
 Lindsay Chapman
 Madge Cornish
 Una Dimmock
 Martin Farrell
 Mr Fichera
 Doris Annie Jones
 Catherine "Anne" McBurney
 Joan McNamara
 William J Murray
 Hugh Peek
 Peter Provan
 Mr U Radok
 Norma Rhodes
 Oliver Shaul
 Denis Shea
 Shirley Thomson
 Allan Yeaman



Support group contact details

GROUP	CONTACT	PHONE
Albury/Wodonga		02 6051 7400
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown	Glenda Rawlinson	02 9707 2791
Bathurst	Jennifer Mannell	02 6332 8963
Bega Valley	Sue Nelson	02 6495 9932
Bingara	Joan Bush	02 6724 1976
Blacktown	Bryan McAlister	02 9674 6827
Blue Mountains	Hazel Tolhurst	02 4751 9903
Broken Hill	Colleen O'Brien	08 8087 2175
Casino	Dawn Dennis	02 6662 6141
Castle Hill	Gayle Parker	02 9634 0578
Central Coast	Les Norris	0418 607 684
Chinatown Bi-lingual		0421 224 712
Coalfields	Betty Rumbel	02 4931 5210
Coffs Harbour	Vera Heil	02 6652 9959
Cowra	Ray Heilman	0428 639 850
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta	Margaret Fyfe	02 9638 4451
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla	John Vaughan	02 4471 2891
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Finley	Glenis Gordon	03 5436 9293
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	02 4822 6732
Grafton	Cathy Eggins	02 6642 2156
Griffith	Angela Bortolin	02 6962 3289
Gunnedah	Lisa Hagley	02 6742 0018
Hawkesbury	Jill Sykes	02 9621 1794
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South		02 4232 2807
Lower North Shore	Jan Cumming	02 9412 2740
Macarthur	John Philpott	02 4647 8990
Manly/Mosman	Bill Lindsay	02 9949 3991
Manning/Great Lakes	Bruce King	02 6555 9409
Maroubra	Lyn Smith	02 9387 4412
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
Snowy/Monaro	Roger Norton	02 6452 5817
Southern Highlands	Marj Webb	02 4871 2615
St George/Sutherland	Myra Chalmers	02 9525 7215
Tamworth	Pat Johnson	02 6765 6948
Tomaree		1800 644 189
Tweed Heads	Helen Boddington	02 6676 2549
Ultimo	Gerald Ganglbauer	0411 156 309
Wagga Wagga	John Allen	02 6925 2713
Yamba	Heather Wilson	02 6646 1369
Yass	Clarrie Schlunke	02 6226 4150
Young Onset	Trish Morgan	1800 644 189
Young Men's Network	Garry Cearns	02 9871 1853
Young Women		1800 644 189

PARKINSON'S NSW INC.

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

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Diary Dates

JULY

- 1 Parkinson's Plus Seminar – Northern Sydney Education Centre, Macquarie Hospital, North Ryde (Entry via Wicks Road)
- 28 Surgical Interventions for Parkinson's disease Seminar – Northern Sydney Education Centre, Macquarie Hospital, North Ryde (Entry via Wicks Road)

AUGUST

- 29 Unity Walk – Sydney Olympic Park
- 31 Coffee and Information morning – Family Visiting Area, Vincent Fairfax Centre, Macquarie Hospital, Cox's Road, North Ryde

SEPTEMBER

29 Aug to 5 Sept Parkinson's Awareness Week

- 1 Parkinson's NSW – State Parliament House Awareness Seminar

NOVEMBER

- 11 Golf Day – Monash Golf Club
- 15 Annual General Meeting
Vincent Fairfax Centre, Macquarie Hospital, Cox's Road, North Ryde
- 30 Coffee and Information morning – Family Visiting Area,
Vincent Fairfax Centre, Macquarie Hospital, Cox's Road, North Ryde

DECEMBER

- 4 Parkinson's NSW Volunteer 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.

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

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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