



## Ease the Burden and Find a Cure

# Stand By Me

## Our Seed Grant grew 29 times from \$19,880 to \$574,000

Dr Colleen Canning has been awarded \$574,000 by the National Health and Medical Research Council for ongoing research over the next three years, 2008-2010. Dr Colleen Canning was a PNSW Seed Grant recipient in 2007 researching "Can Support group-based exercise reduce risk factors for falling people with Parkinson's disease" please see page 6 for her detailed report on the progress she has made so far.

*Dr Colleen Canning leading an exercise group at the PNSW Seminar 2007.*



## Visiting Professors from Japan & Israel



Professor Lynn Chenoweth from University of Technology Sydney, accompanied visiting Professors from Japan and Israel for an information session held at the PNSW office in early January. The Japanese Professors were sponsored by the Ministry of Education, Culture, Sports, Science and Technology. The Israeli professor was on a three month sabbatical with Professor Chenoweth. The PNSW staff shared how education and support services are provided to people living with Parkinson's, their partners, families and carers.

## New Group News

**Manly/Mosman** support group was formed on Tuesday 5 February when 23 people gathered at Balgowlah Memorial RSL Club. The meeting was kept informal, with people encouraged to mingle after briefly introducing themselves. Counsellors Janine Rod and Deborah England addressed the group and gave support to individual members. Several attendees volunteered to form a committee, and everyone expressed appreciation to have the group 'up and running'. Thanks to the Board of Balgowlah RSL for providing the venue for free. The Terrace Room on the first floor has lift and ramp access and audio-visual equipment. There is undercover parking. The group will meet on the first Tuesday of the month at 10.30am. Members of other groups are invited to attend.

**Bingara** in the far north west, north of Tamworth and west of Inverell, will soon have a support group. Joan Bush rang PNSW wanting to start a group. A package of information has been sent and, with the support of community nurses, Joan is preparing to hold a public meeting. Joan went to Tamworth support group – a two hour drive – for advice and support. Members in the Gwydir and New England areas will be notified when a meeting is arranged. Please get behind Joan in helping with the Bingara support group.

Blacktown members and those in surrounding suburbs please come to the "Facing the Future" seminars on 10 and 11 April at Blacktown Workers' Club, when we will make plans for a new support group. For information phone **1800 644 189**.

## FEATURES

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## President's Annual Report 2007

2007 has been a full and productive year for Parkinson's NSW Inc; a year that continued to build and develop the initiatives of 2006 while creating a few milestones of its own.

Last year I reported that we had moved our offices to North Ryde. Officially opened by the Deputy Premier, John Watkins in November 2007, the office is comfortable and functioning more and more efficiently.

Even when taking a conservative approach to the furnishing and fitout of new office space, a move of this dimension can require significant financial outlay. Through a generous grant from the J T Reid Charitable Foundation, the financial burden of the move was lifted, allowing us to maintain our reserve funds.

Our continued dialogue with the NSW Government has resulted in a one-off grant of \$50,000 which was announced by the Minister for Health, Reba Meagher, at our Seminar at Parliament House in September. While it falls short of the recurring funding that we are seeking, it is an important first step towards Government awareness of PD.

Fund raising has continued to be a priority, as we strive to maintain and extend services. Several successful events were held, among them, the Australian Chinese Charitable Foundation Dinner and the inaugural Parkinson's Golf Day, now scheduled as an annual event.

I feel very gratified by the support from Charitable Foundations, Service Clubs, our Members, Friends and Family and the Public at large.

This year our Life Members were invited to a morning tea at Parliament House to honour their many and varied contributions to PNSW.

At the year's end our positive financial situation allowed us to fund the following:

- Three seed grants for research.
  - Dr Kay Double - Half-salary for Research Assistant.
  - Professor Lynn Chenoweth - Keeping Well in Chronic Illness.
  - Assoc. Professor Martin Krause - Impulse Control Disorder and Quality of Life in Parkinson's Disease.
- Top up Grant, under the UTS Partnership Grant Scheme, to UTS researcher Professor Lynn Chenoweth: Parkinson's Disease Medication Management Protocol research project – a pilot study.
- Two supplementary living allowances for PhD candidates.
- Three grants to Medical students from the University of NSW, commencing their Independent Learning Projects with the Rural Clinical School in March 2008.
- Patrick Rositano, Wagga Wagga campus; Parkinson's Disease in regional Australia.

- Tenelle Camilleri, Port Macquarie campus; Descriptive study of Parkinson's Disease in a regional environment.
- Jessie McKenna, Coffs Harbour campus; Assessment of a remote monitoring system for assessing Parkinsonism.

These students will liaise closely with our Support Groups in their area, aiming to gain an understanding of Parkinson's. We hope to engage their interest in both neurology and rural practice.

I'm pleased to report that, as a result of last year's grant to Dr Colleen Canning, the Federal Government has awarded her and her team \$500,000 to continue their study. This is a positive step that we certainly hope will be replicated.

Support Groups have maintained their importance within Parkinson's NSW Inc and continued to grow in numbers. At the end of 2007 our Support Groups numbered 52. We welcomed new groups in the Blue Mountains, Ulladulla, Maroubra and Narrabri and 2008 has started with a new group forming in the Mosman/Manly area.

The Support Group leaders/representatives Conference, held at Novartis in North Ryde, provided a platform to discuss directions and promote understanding. We were, once again, fortunate to have sponsors for the occasion, an excellent venue and catering from Novartis and airline tickets from REX. Sensational!

Our relationship with Parkinson's Australia continues to be highly supportive. Parkinson's NSW Inc recognises the need for a coordinated national approach to many issues affecting people living with Parkinson's. The appointment of Norman Marshall as CEO, and the release of the Access Economics Report into Parkinson's Disease in Australia, have been positive steps forward.

Through Coalition for the Advancement of Medical Research Australia (CAMRA) we were successful in lobbying all governments in Australia to allow the use of therapeutic cloning. The focus now is on what advances lie ahead.

Two members of the Council's executive will be retiring this year: Vice President Allen Cropp is stepping down due to ill health, but has accepted an honorary role of advisor to the Council on Support Group matters, and Secretary Dick Babb is cutting back his work load to spend more time with his family. We thank them both for their many contributions to PNSW and wish them both well.

I wish to recognise the Council as a whole for their consistent cooperation and support during the year. The smooth functioning of the Council has had a significant impact on our ability to achieve so many of our goals. Special thanks also must go to our CEO Miriam Dixon, and to all our staff and volunteers for their dedication, which at times far exceeds their job description.

I look forward to the larger challenges of 2008/9.

John Silk  
President



## CEO's Report

In this report I would like to share some details of our services and development during 2007.

### Information and Education Services

In 2007, Our InfoLine (1800 644 189) responded to over 1800 calls, a substantial increase from 2006. The

InfoLine provides accurate and up-to-date information on Parkinson's Disease for people living with Parkinson's, health professionals, GPs and the general public.

Our Annual Seminar "Shaking up Parkinson's" at NSW Parliament House, held in September, was again booked out. The Hon. Reba Meagher, the NSW Minister for Health, opened the seminar and announced a one off grant of \$50,000. At the Seminar attendees heard leading clinicians and researchers including Prof George Mellick, Dr Michael Hayes, and Assoc Prof Anthony Cooper. A panel of three people living with Parkinson's, who have maintained their sense of adventure, also spoke: Anne who toured Australia with her husband on a Harley-Davidson motorbike, Eddie who went skydiving for his 40th birthday and Ray who successfully completed the City to Surf.

### Support Groups

We now have 52 support groups across NSW. Support groups allow people living with Parkinson's Disease, their partners, families and carers to meet to share information, experiences and tips for managing the challenge of living with Parkinson's. Four new groups were established - in the Blue Mountains, Maroubra, Narrabri and Ulladulla. Support groups from across NSW also sent representatives to Sydney to attend a two-day conference in July.

### Living Alone with Parkinson's Program

Parkinson's NSW received a grant from the Cecilia Kilkeary Foundation to hold seminars in regional and metropolitan venues for people living alone with PD. The program was designed to give specialised information

and support and to offer strategies to help those people face the uncertain future. Speakers including a neurologist or a PD specialist nurse; representatives from Centrelink and Carelink; a legal practitioner and a PD specialist counsellor. For people unable to reach the venues, teleconferencing groups were held, each over five mornings. All the seminars provided opportunities to share experiences with others in a similar position, reducing feelings of isolation, fostering encouragement and exchanging information and ideas, empowering participants to face the future with a renewed positive attitude.

### Counselling

Our service provided 731 phone counselling sessions and 428 face-to-face counselling sessions in 2007. The counselling service provided by Parkinson's NSW aims to reach as many people as possible by face to face contact or by telephone, to individuals, couples, families or groups. The counselling offered is drawn from different theoretical perspectives all with a sound psychological base; the aim of this is to offer a service that suits the person/s involved. Telephone counselling appointments are also available.

### Advocacy and Awareness

Throughout 2007, we attended meetings with the Honourable Reba Meagher and the Honourable Kristina Keneally, Minister for Ageing and Disability, and their respective advisers. We drew attention to the Access Economics Report that highlights the social costs of living with Parkinson's and the economic and other benefits of various support strategies.

### NSW Stem Cell Legislation

We were able to draw the Parkinson's NSW Position Statement on Stem Cell Research to the attention of MPs and their advisers. We contacted members of both Upper and Lower Houses encouraging them to vote in favour of the proposed legislation. On June 7, the legislation was passed in the NSW Legislative Assembly by a vote of 65-26.

Miriam Dixon, CEO

## Burwood Rotary Xmas Stocking 2007

At Burwood Westfield Shopping Centre, Burwood



Rotarians and members of Parkinson's NSW manned the desk on two hourly shifts, 9am-6pm, seven days per week in the build up to Christmas.

There was a metal stocking that was 2.5m high and held over \$3,600 worth of goodies. A board showing information about Parkinson's NSW and the services they provide, including newsletters and information brochures, was displayed.

The President of Parkinson's NSW, Mr John Silk, was presented with a cheque from the Burwood Rotarians at their meeting held on 3rd March.

Parkinson's NSW would like to thank Burwood Rotary for their dedication in supporting local charities, and appreciates the effort and hard work that goes into organising these events.

Thank you, Burwood Rotary, and good luck with your future endeavours.

## Research

### KEEPING WELL IN CHRONIC ILLNESS: PARKINSON'S DISEASE

This Pilot Project will be conducted in a pre- and post-test design over 12 months. It will employ Action Learning, with the aim of optimising self-efficacy for self-management in community-dwelling persons with Parkinson's Disease. Self-efficacy is a person's judgement of their capability to organise and execute a course of action required to attain desired performance in an activity.

This study aim will be achieved through the following objectives:

1. Teach family carers strategies to help a family member with Parkinson's Disease (PD) improve their capacity for self-efficacy (for self-management)
2. Support family carers to implement and evaluate the self-efficacy (for self-management) strategies for a family member with PD
3. Evaluate the outcomes and effectiveness of the carer-implemented strategies for the person with PD, and the impact of implementing the strategy for the family carer

The education and support program will be conducted with volunteer carers of persons with PD who attend any of the clinics at the War Memorial Hospital for example, Walk Well, or Speech programs, and with family carer volunteers from the Bondi and Randwick PD Support Groups. The Program will be conducted for one hour once each week for 8 weeks, and include teaching and modelling the following aspects:

1. **how to encourage and support performance accomplishments** – experience of success increases one's SE, and regular failures contribute to reduced SE.

2. **how to enable vicarious experiences** – witnessing others perform self-management successfully is an important source of SE and a measure of one's own progress in SE and self-management, eg at the clinics
3. **how to provide verbal persuasion in a non-challenging way** – provides positive re-enforcement and encouragement
4. **how to encourage positive self-appraisal** – estimation of one's capacity to achieve specific behaviour/s, and employing information about one's physiological and emotional stressors to monitor symptoms and take appropriate actions, eg for pain, stiffness, fatigue, tension and anxiety

Any family carer of a person with Parkinson's Disease living in the central or eastern suburbs of Sydney who feels their family member would benefit from increasing their self-efficacy for self-management, is welcome to join the study. You can contact Lynn Chenoweth on 02 9369 0288, or June Sheriff on 02 9369 0238.

### Speeding Vibrations

YOUNG ON-SET NETWORK

Diagnosed under 60?

Come and join our group for a Sunday Lunch every 2 or 3 months at various locations

**ALL WELCOME!**

Contact: Sarah Lines 02 4627 5632  
jsl022@bigpond.com

### Volunteers needed

Parkinson's NSW is planning the biggest event in its history in 2008!

#### 'Pride for My Team, Pride for Parkinson's'

Walk the Walk

A 4km walk around the magnificent Olympic precinct, culminating in entry to ANZ Stadium on game day, to see the National Rugby League (NRL) game between

Dragons vs Eels

Sunday 29th August  
Olympic Park, Homebush  
9.30am to 2.00pm

We need volunteers on the day to act as marshalls and be ambassadors for Parkinson's. So please put your name forward and be part of this historic day.

**To register call 1800 644 189**



### Koala T Care

[www.koalat.com.au](http://www.koalat.com.au)

*Is proud of its association with Parkinson's NSW.*

Our super friendly service encompasses all Aids to Daily Living and Mobility products, including Lift Chairs from \$2,300.

We also supply Fitness and Exercise Equipment for all ages, and a full range of electric vehicles including power chairs.

Our association with Parkinson's NSW enables ALL members to receive **10% discount** on all products from Koala T Care once notified. *(excludes freight & spare parts)*



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*Locations: Laurieton, Tuncurry & Port Macquarie.*

# Parkinson's NSW Research Grant Report

## Project Title

### **CAN SUPPORT-GROUP-BASED EXERCISE REDUCE THE RISK FACTORS IN PEOPLE WITH PARKINSON'S DISEASE FOR FALLING?**

#### **Project Investigators**

Dr Colleen Canning, The University of Sydney  
 Dr Catherine Sherrington, The University of Sydney  
 Professor Stephen Lord, Prince of Wales Medical Research Institute  
 Dr Victor Fung, Movement Disorders Unit, Dept of Neurology, Westmead Hospital  
 Dr Jacqueline Close, Staff Specialist Physician, Prince of Wales Hospital  
 Dr Mark Latt, Staff Specialist Geriatrician, Prince Alfred Hospital  
 Ms Natalie Allen, The University of Sydney

#### **Project Outline**

In 2006, Parkinson's NSW provided us with \$19,880 in funds to conduct this pilot project. The aim of the project is to determine whether a 6-month program of *support-group-based* exercise can reduce the risk factors in people with Parkinson's Disease for falling. Forty participants with Parkinson's Disease will be randomly allocated to an experimental or control group. The experimental group undertakes a monthly *support-group-based* exercise class combined with home exercises. The exercise program targets potentially remediable risk factors for falls, ie, impaired balance, reduced leg strength and freezing. Both groups receive falls prevention advice and are provided with a falls diary for recording falls. Measures of falls risk factors are taken before and after the intervention period.

#### **Progress**

In 2007, 25 people with Parkinson's Disease from three Parkinson's NSW support groups (St George/Sutherland, Dundas/Parramatta and Liverpool) were involved in the project. A further 15 people from two groups (Blue Mountains and Campbelltown) will commence participation early in 2008.

We wish to thank Parkinson's NSW for funding and supporting this initiative. As well as providing the required funds to establish the project, they have given valuable assistance with recruitment by informing members in the relevant areas about the study. Trish Morgan deserves a special mention for her help and support in establishing the project in the chosen groups.

We also wish to thank the three participating groups in 2007. Special thanks to all our enthusiastic participants – and to David and Maureen Morrison, and Ian and Jan Wiseman (St George / Sutherland), Warwick and Liz Brown (Liverpool) and Margaret Byron (Dundas/Parramatta) for helping to organise groups and venues.

This project, analysing the effect of exercise on risk factors for falling in people with Parkinson's Disease, will be completed and submitted for publication by the end of 2008. A summary of results will be made available in Stand By Me.

#### **Successful funding for Large Trial**

We are delighted to inform Parkinson's NSW members that our research team has now been successful in attracting a large National Health and Medical Research Council Project Grant (\$574,000 over 3 years, 2008-2010) to conduct a larger randomised controlled trial. This trial will include 230 people with Parkinson's Disease which will allow us to determine whether the exercise programs reduces actual fall rates. We believe that part of our success in attracting this large grant is due to the seeding funding provided by Parkinson's NSW, which allowed us to undertake the pilot study and demonstrate the feasibility of the procedures and need for the larger trial.

#### **More Volunteers Needed**

The larger trial will be recruiting participants from the greater Sydney metropolitan area, Newcastle, Central Coast, Illawarra and Canberra areas. We would like to invite any person with Parkinson's Disease who would like to be involved in the project, or who would like to know more about the project, to contact us at The University of Sydney.

Dr Colleen Canning 9351 9263  
 Ms Natalie Allen 9845 5538

## Guidelines for Physiotherapy Practice in Caring for People with Parkinson's Disease

West Australian physiotherapists, Liz Bell, Vivian Lee and Babette Lynch, have written a comprehensive manual that provides guidelines for physiotherapists working with people with Parkinson's.

Commissioned by Parkinson's WA, the manual is divided into two parts providing detailed information about Parkinson's, and addressing practical physiotherapy considerations in the context of that information. Of particular interest is the focus on the patient – Part 2 opens with excerpts from a longer contribution by a patient which forms an appendix to the manual. It gives an insight into what it is like to live with Parkinson's and therefore what health professionals need to keep in mind when treating people with Parkinson's.

The authors recognise that management of people with Parkinson's is best achieved through a team approach and provide physiotherapy readers with indications for referral to other health professionals.

Bell I, Lee V, Lynch B (2007), *Guidelines for Physiotherapy Practice in Caring for People with Parkinson's Disease*. Available from Parkinson's WA – \$110 + postage [www.parkinsonswa.org.au](http://www.parkinsonswa.org.au).

## Research

*One of Parkinson's NSW Seed Grant Recipients, Assoc Professor Martin Krause, has a medical student, Helen Lo, assisting him with his research into "Impulse control disorders and quality of life in Parkinson's Disease". Helen has written the following article setting out the goals they have for the research project.*

To the average person, Parkinson's is seen primarily as a disease of the motor system and certainly changes in walking, stiffness, tremor, and decreased arm swing are symptoms PD sufferers need to deal with everyday. However, the non-motor symptoms associated with Parkinson's are hidden features that, for some, can affect daily functioning even more so than the classic motor ones. Depression is the most recognised and the most studied of the psychiatric associations. Dementia is another more well-known non-motor possibility. Having said that, it has been only recently that the question of impulse control disorders and their possible link to Parkinson's has come up.

Impulse control disorders, or repetitive and reward-seeking behaviours, are disorders in which certain behaviours are done over and over to achieve pleasure or gratification but cause harm or guilt. This can manifest as anything from pathological gambling to compulsive eating or spending to hypersexuality. As can be imagined, the potential impact on a patient who has an impulse control disorder can be devastating, affecting their finances, relationships, and possibly even resulting in incarceration. It is not known what causes this, although it has been hypothesised that because dopamine, the same chemical lacking in Parkinson's

Disease in a motor control area of the brain, is used to signal reward in another part of the brain, the addition of dopamine to the brain through medication could possibly potentiate the development of these reward-seeking behaviours.

Several past studies have shown that impulse control disorders are more prevalent in people with PD, with the numbers going up even more with Parkinson's patients on certain medications. Significant though these numbers may be, we think that these figures are underreported as most people would not voluntarily divulge these behaviours because of fear, embarrassment, or shame. Our study aims to find the true prevalence of impulse control disorders among Parkinson's patients through the use of a rigorous psychiatric assessment by a qualified clinician specialising in these disorders. Thanks to your support and generosity, we will hopefully know the true proportion of Parkinson's patients with impulse control disorders and identify the risk factors for their development. With your continued support through participation in the study, we may find out who would be at highest risk and perhaps one day we will be able to treat the disorder early or even prevent its onset altogether.

## Maureen and David Morrison – honorary life members



David and Maureen Morrison are two amazing people. Both they, and their family, have always been very active in the local community. Maureen was diagnosed with Parkinson's Disease 13 years ago when she was only 52 years of age. A

year before her diagnosis, Maureen battled with cancer, but this she overcame and the fight put her in good stead to face the road she has to travel with PD.

Her first GP wanted to give her some pills to stop the shaking of her hand but Maureen was not having any of that. As time progressed, she was referred to a Professor, who gave her just a quarter of a tablet and it helped her very quickly, though not for long. This led to further investigation and her coming to terms with medication for the future.

Maureen heard about the St. George and Sutherland Support Group, went along to a meeting and saw other people there with PD, and decided it was not for her. Two years later, after much soul searching and educating herself through all the information about PD she could find, they decided to return to the fold and become members, where they immediately became the backbone of the group. Maureen is a veritable font of knowledge about PD and is always there to help others in any capacity that she can. If you want to know anything at all about PD – ring Maureen!

David was an auto electrician and has always been there to support Maureen. He is the current Secretary of the group, plus general factotum. If anything needs to be done, ask David. He will be at the hall early to help set up and organise the PA system and the guest speaker. He has been the co-editor of Chit Chat (our Newsletter) with Jan Wiseman for many years. Maureen provides many of the very interesting and helpful articles for it. She also takes care of our extensive library, for which she has sought and procured appropriate books as she has had extensive training in this area during her working life. Who could do it better? These two people visit members in their own homes or in hospital; check up on anyone who misses a meeting and will pick up members and take them to meetings or to our picnics. During Senior's week and Parkinson's week, these two people man the booths, meeting people and letting them know all about PD. If there is a chance to meet and greet and help people they will be there.

As if this is not enough, some years ago they joined Parkinson's NSW and David held office on the Council. After a while this became too much for David when Maureen underwent the DBS operation well over a year ago. There have been some ups and downs but their fighting spirit and outgoing nature is just so wonderful. We are indeed fortunate in having these two people in our group. What would we do without them? Life for many Parkinson's sufferers has been made a little easier, and our lives are richer for knowing these two wonderful people.

*Myra Chalmers.*

## On the groupvine *by Trish Morgan*

**Canterbury** support group has gone into recess. They have raised \$3,300 from donations for 'morning tea' since they started in 1995. The members have been very loyal to the group, and have joined in activities organised by PNSW. Overseas visitors have attended picnics - these included Marie Oxtoby from UK who was President of the European Parkinson's Association. Canterbury members will meet twice a year for lunch – Christmas in July and December!

**Coalfields** support group is in the hands of mother and daughter team, Betty and Cecily Rumbel.

They are bringing energy and fresh ideas, and are considering holding meetings in different places to assist members in attending. Following a talk by Neville and Thelma Elphick at Mt Providence Nursing Home in Muswellbrook last year, the Coalfields group are planning to hold a meeting at Mt Providence, which has been requested by the nursing staff. Muswellbrook support group closed last year as there were not enough members able to attend. Coalfields has been very involved in raising awareness by running seminars and stalls in shopping centres. Carol and Fred Bateson and the Elphicks are to be commended for their years of hard work.

### **Pittwater/Warringah New name - new venue**

The original group, Pittwater/Mona Vale, met for over 10 years at Mona Vale Hospital in the Activities Centre. The closure of this centre caused the group to look for a central meeting place that was well serviced by public transport with wheelchair access and adequate parking for as low a cost as possible. **The Tramshed Arts and Community Centre**, 1395A Pittwater Road, Narrabeen which is operated by Warringah Council provided all of these features. This Centre is located in the heart of Narrabeen on the site of the terminal of the electric tramway, which operated between Manly and Narrabeen from 1913 to 1939. A successful first meeting was held there in February and five new members were welcomed into the group. Meetings are held on the second Thursdays of February, April, June, August, October and December commencing at 1.30pm.

## A Message from NSW Ambulance Service

We all carry our mobile phones with names and numbers stored in their memory but, if we were to be involved in an accident or were taken ill, the people attending us would have our mobile phone but wouldn't know who to call.

Yes, there are hundreds of numbers stored, but which one is the contact person in case of an emergency?

Hence this "ICE" (In Case of Emergency) Campaign.

The concept of "ICE" is catching on quickly. It is a method of contact during emergency situations.

As mobile phones are carried by the majority of the population, all you need to do is store the number of a contact person or persons who should be contacted during emergency under the name "ICE" (In Case Of Emergency).

The idea was conceived by a paramedic who found that when he went to the scenes of accidents, there were always mobile phones with patients, but he didn't know which number to call.

He therefore thought that it would be a good idea if there was a nationally recognised name for this purpose.

In an emergency situation, emergency service personnel and hospital staff would be able to quickly contact the right person by simply dialling the number you have stored as "ICE".

It really could save your life, or put a loved one's mind at rest.

For more than one contact name simply enter ICE1, ICE2 and ICE3 etc.

Please forward this - it won't take too many "forwards" before everybody will know about this great initiative.

**Enquiries regarding ICE:**

[http://www.ambulance.nsw.gov.au/community\\_info/](http://www.ambulance.nsw.gov.au/community_info/)

## My Pop *by Jemma Harlow (aged 7)*

My poppy can't walk.  
He can't talk.  
Sometimes he can whisper.  
He can't feed himself.  
He can't wash himself, go to the toilet by himself or shower himself.  
He can't get into his wheelchair himself.  
He doesn't live with my grandma any more.  
He lives in hospital.  
He has a thing called "Parkinson's Disease".  
A long time ago he could do everything.  
He could walk, milk the cows, work and talk.  
Then he started to shake a little, and then he shook a lot.  
When you have Parkinson's you shake.  
He was only about 30 when he started to shake.  
Now he is 71 years old.  
That means he has shook for 37 years.

That is a long time to shake.  
I remember a little bus use to take my poppy to a place to do craft work.  
It was like preschool for sick people.  
Poppy made some good things.  
Poppy can't get in a car.  
Sometimes a little bus will bring him back to his farm for a visit.  
He doesn't like being in the bus.  
It is too bumpy for him.  
When my mum and dad got married my poppy hardly could walk.  
He needed a walking stick.  
He could speak then.  
I love my poppy and I wish he didn't have Parkinson's disease.  
He is the best poppy in the world.  
Maybe they will find a way to fix Parkinson's one day.

## Myra's teddy bears for Parkinson's



About eighteen months ago, a friend gave me the pattern to knit a teddy bear out of fringed 'wool' that was very popular with young people who were knitting scarves. This pattern was given to me so that I could knit some bears to put on the trading table at our Parkinson's Support Group meetings to make some money. I made three, and much to my surprise they

were sold as soon as they hit the table. The next meeting I took a few more and they too were sold very quickly. I was asked to make some in specific colours and bring them to the following meeting. I was on a roll, it became addictive - I had to make more! Two other ladies in the group asked for the pattern and they too started knitting. Soon I had a row of teddies sitting on my settee and when visitors came to the house they too bought them. I couldn't knit them fast enough to keep up with the demand. My daughter, granddaughter and daughter-in-law were so impressed they bought me 'wool' to knit more. Now I had three laundry baskets full of 'wool', how in the world was I going to knit all that into bears? I took quite a few to the Parkinson's Annual General Meeting and they sold very fast. Then my granddaughter, Katie, got hooked and she made quite a few, and we sold them all. There are three teddies in England, two in the USA, one in New Zealand and many have gone interstate. Not all of the bears have been bought for children. I know a few adults who have bought them for themselves, one even takes the bear to bed each night! What have I started?

The first teddies had flat faces, but after a while I improved the pattern by adding a snout, these were even more attractive. I always use safety eyes and noses and use pillow filling to stuff the bears. The bears sold for \$10 each but the purchasers told me they were too cheap, so now we have put up the price to \$15. We have raised over \$1,000 towards research to date and I have more orders to fill. I had no idea when I knitted the first bear that we would sell so many. Now sadly, after knitting 80 bears, I have tendonitis in my hand and I am on a 'go slow', but I hope to be able to get back to knitting soon. However, three or four ladies in our group have offered to make some teddies. If all the Parkinson's Support Groups could make some teddy bears, who knows how much money we can raise for research and how many little children will have a smile on their faces when they receive one.

The name of the wool that I use is FLUTTER but any similar 'wool' can be used, it takes 3-4 balls to make a bear and the bear is knitted all in one piece so there are no fiddly bits to worry about. I am a fast knitter and can make one in 2-3 evenings.

*Myra Chalmers*  
St. George and Sutherland Support Group

## Dear Parkinson's research team

Our Pa has had Parkinson's for 25 years so we thought it would be nice to raise money for people with Parkinson's. We decided to sell lemonade, rocky road and mars bar slice out the front of our house and have raised \$54.55. We hope you can find a cure for Parkinson's disease.

Love Jodie, Kate & Matthew



## A Hint for Stand by Me

*by Simone Bowskill*

Here is a hint to help those who find turning in bed difficult.

Rather than buy satin sheets which are expensive, I have a length of satin lining material which I call my "slithery". It is 1.2 metres wide and 2.7 metres long, which is enough to place across a queen size bed and to tuck in the sides.

The fabric is approximately \$8.00 per metre, making a cost of \$21.60.

The advantage is that the piece of material is easily portable for times when one is travelling or staying away from home.

**Home Instead**  
SENIOR CARE

### Trusted Non-Medical Home Care and Companionship Services

Home Instead CAREGivers provide one to one support to help older people retain an independent lifestyle in their own home for as long as possible. From a few hours a day, up to 24 hours - seven days a week, including weekends and holidays - Home Instead CAREGivers can assist with some or all of the following services:

- Personal Care
- Companionship
- Light Housekeeping
- Meal Preparation
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Sydney Eastern Suburbs: (02) 9387 4800

## Young Men's Parkinson's Network (YMPN) goes regional

The YMPN has been going for about 15 months now, with the numbers steadily rising. After talking to many people, PNSW Counsellor Janine Rod saw a need for a group specifically targeted at the younger PWP men in the community - those diagnosed under 60 - and established YMPN. The men meet once per month at the PNSW offices.

The group's vision is:

*"to reach out to those men with young onset Parkinson's disease and provide support and camaraderie to them and their families with the goal to make their life better in some small way"*

The meetings are a mix of guest speakers, and are times when we just talk about issues that affect us blokes. Along this road of discovery, we have been approached by more and more by men in regional NSW - by those who are still working, and those who are house-bound. These men are wishing to not only receive the monthly news email, but also to participate somehow. After a suggestion by Neil Sligar (previous

PNSW council member), the idea of putting some form of teleconferencing facility together started. Traditional teleconferencing proved too expensive because of the charges each month, so the idea of using the Internet was born as this had no ongoing costs. After receiving a very generous donation we had the funds to pursue this venture.

The idea is to have up to 10 men in regional NSW attend the meetings from their homes, where they can converse with others in the same situation and look at a Webcam video stream of guest speakers and other features..

It is hoped that when this facility is fully operational, it will then be made available to any other support group that can benefit, and the whole PNSW organisation..

We are now at the stage where we need to test the system, for this we need volunteers to help in the fine-tuning before we proceed further. If anybody is interested in helping, please just contact PNSW and we'll give you all the assistance you need.

## Neil Sligar Celebrates 10 Years Since Diagnosis

Last week, as part of my "ten years since diagnosis" celebratory year, I competed in the Iron Man Challenge at my gym.

"Are you sure?", enquired the gym attendant when I approached her to time me.

I had to declare that if I dropped dead it would be all my fault, and also that I suffer from no medical condition that would mean that taking part could harm me.

So, off I went...

500 metres row – 20 unweighted squats + 20 pushups

2 kilometres bike ride – 20 squats + 20 pushups

500 metres run – 20 squats + 20 pushups

Reckon I had no more than two more pushups in me on finishing.

I was totally knackered.

My time was terrible, but at least I finished!

**Well done, Neil, our Parkinson's NSW Iron Man!**

### Young Men's Parkinson's Network

Are you under 60? Living with Pd?

Are you looking to meet other men who share similar experiences?

Your partners are welcome to come and enjoy a coffee with other partners while the Men's Network meets

Monthly Meetings  
Every third Tuesday from 10.30 – 12.00noon  
25 Khartoum Road, North Ryde

Contact: Garry Cearn  
Mobile: 0418 648 835 Phone: 9871 1853  
Email: Cearn@netspace.net.au

## Counselling

by Deb England

When people are sometimes confronted with an additional difficulty in their lives, it is easy to feel overwhelmed. Sometimes talking to someone not connected to the issue can be helpful. Often it is the 'saying it out loud' that helps a person discover an answer, and sometimes it is the 'fly on the wall' perspective offered by someone not connected to the situation that is beneficial.

We at Parkinson's NSW offer on-going or one-off support to people living with PD. This also includes the partners, families, friends and other carers. The service offered is confidential and available either face to face at the office or at either Concord or Westmead Parkinson's clinics, or if it is preferable, by telephone.

People need not feel isolated because someone to talk with is just a call away. The service incurs no cost to the person and if your concern cannot be dealt with straight away, we will return your call at the earliest opportunity.

Our toll free number is 1800 644 189.

### Young Women's Parkinson's Network

We have noticed there is a growing need for women under 60 who have PD to meet and share their concerns.

We would like to offer you the opportunity to meet with others. Please let us know a suitable time and day of the week for a meeting. We will let you know the details for the initial meeting.

Please ring Freecall  
1800 744 189 or 02 8875 8900

## Donations

### \$50 and over received between 1 December 2007 and 28 February 2008

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

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

#### GENERAL

Liam Barrett  
 Martin Barter  
 Bateau Bay Womens Bowling Club  
 Barbara Beames  
 Meg Bentley  
 Bonham & Goodman  
 Stephen Brooks  
 Kris Bruckner  
 Andrew Bunting  
 Ian Burningham  
 Mr & Mrs Burke  
 Stephen Carmichael  
 Christine Chan  
 Michael Cole  
 John and Annarella Coppens  
 Scott Curley  
 Dapto New Vogue/ Old Time Dance Group  
 Andrew Davidson  
 John De Ravin  
 Brad Dean  
 Adam Douglas  
 Dough Dueppen  
 Rhys Edmonds  
 Caroline Fairlie  
 Andrew Falconer  
 Mr & Mrs Fennessy  
 Mark Falwasser  
 Steven Faulkes  
 John Fitzpatrick  
 Sarah Fogarty  
 Andrew Fogarty  
 Peter Fogarty  
 Heath Francis  
 Mr & Mrs Frensham  
 Raymond Garnsey  
 Matthew Gibbs  
 Andrew Godwin  
 Rikki Gold  
 Elizabeth Graham  
 Mr & Mrs Hansford  
 Andrew Harford  
 Mark Heffernan  
 Bruce Howe  
 Bhrett Hughes  
 Illawarra Combined Seniors' Dance Groups  
 Elfriede Johnson  
 Brian Jones  
 Gregory Jones  
 Duriye Kandemir  
 George Kassis  
 Elke Kaus  
 Tony Khoury  
 Matthew Korf  
 Benoit Laganiere

Lions Club of Coogee  
 Henry & Odette Lobelson  
 L MacDonald  
 John Mahar  
 Iain McDonald  
 John Melano  
 Christine Michaelis  
 Jane Mikulandra  
 Andrew Mooney  
 Jon Murphy  
 Richard New  
 Andrew Orrell  
 Phil Osman  
 George Pandleon  
 Jim Parkes  
 Michael Pennell  
 Darren Pereira  
 Tobias Pfau  
 Vu Pham  
 Ed Pike  
 D E Plumb  
 Matthew Reid  
 Revesby Ladies Group  
 Ritchies Stores  
 John Schilt  
 St Albans Sovereign Chapter No 128  
 George Stav  
 Greg Stevens  
 Pablo Storniolo  
 Sophia Symeou  
 Jeff Thorpe  
 Geoff Trahair  
 Darren Turner  
 Brian Vowels  
 David Walker  
 Geoffrey Walker  
 Sean Walsh  
 Jane Warburton  
 Guy Watson  
 Neil Weeks  
 Michael Wehinger  
 John Williams  
 David Xu  
 Rukshana Yates

#### IN MEMORIAM

Edward Brown  
 Merle Chuck  
 Mervyn Clark  
 Peggy Crews  
 Raymond Downie  
 Ian Evans  
 Janette Fawkes  
 John Fitzgerald  
 Peter Gilmore  
 Patricia Goodie  
 Margaret Graham

Elizabeth Gready  
 Jean Hatt  
 Louis Higgins  
 Stephen Holmes  
 Martin Huber  
 Mick James  
 Merle Jones  
 Alexander Kelly  
 Robert Kirby  
 Douglas Knight  
 Thelma Lee  
 Dante Maniscalco  
 Gordon McKillop  
 Harold Oliver  
 Betty Quinne  
 Trevor Rann  
 Margaret Robinson  
 Bessie Scott  
 William Spencer  
 Hilda Thornton  
 Myfanwy Vaughan

#### RESEARCH

Gwenda Falconer  
 Carol Hand  
 Lynne Hawke  
 Anita Lawrence  
 S Lee  
 Lions Club of Tumut Inc  
 PJ & MJ Meers  
 G & MD Porter  
 The Grafton Senior Citizens Euchre Players

#### SUPPORT GROUPS

St George/Sutherland Parkinsons Support Group  
 Cowra Parkinson's Support Group  
 Castle Hill Support Group

#### MEMBERS

James Renwick  
 Margaret Sharp  
 Paul Teychenne  
 Dennis Gibbons  
 Jos Agius  
 Allan Maroney  
 Ella Martin

#### DONATIONS WERE RECEIVED IN CELEBRATION OF:

The wedding anniversary of Peter and Maria Wong  
 Max and Gwenda Falconer

## Thank You to

# Harvey Norman

Parkinson's NSW Inc would like to thank Harvey Norman Head Office and Gordon Branch, for their generous donation of a two seater sofa for our reception/waiting room. The new Counselling Rooms are now complete and the sofa has made a wonderful addition to our waiting room.

## Diary Dates

### MARCH

18 Young Men's Group

### APRIL

4 Facing the Future with Parkinson's Seminar – Dubbo  
 10 Goulburn Awareness Seminar  
 11 World Parkinson's Day

### MAY

7 Facing the Future with Parkinson's Seminar – Albury  
 13 Facing the Future with Parkinson's Seminar – Narrabri  
 31 Facing the Future with Parkinson's Seminar – Grafton

### JUNE

3 Coffee/Information Morning  
 14 Facing the Future with Parkinson's Seminar – Port Macquarie

### AUGUST

29 Pride for Parkinson's Walk

### SEPTEMBER

1 - 7 Parkinson's Awareness Week

### OCTOBER

16 & 17 National Parkinson's Conference – Novotel, Olympic Park

### NOVEMBER

13 Parkinson's NSW Golf Day – Monash Golf Club

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

## Coffee/Information Morning

Come and meet staff and volunteers at Parkinson's NSW

Talk to people living with Parkinson's  
 10.30am – 11.45am, 3 June 2008  
 25 Khartoum Road, North Ryde

RSVP – 30 May 2008

**Ph 1800 644 189**

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

by Margaret Byron, Bequest Officer

If I won a million dollars in a lottery next week, I wonder what I'd do with the money? My imagination is running riot at the thought! Did you know that one of the things I should do after I have distributed and allocated the cash is to update my Will?

Wills need to be updated after every major lifestyle changes, such as winning the lottery, getting married or divorced, or after the death of a spouse. Even if life has been trundling along smoothly for a while, it's good policy to check your Will every 3 to 5 years.

If it has been sometime since you made your last Will, why not pick up the phone and make an appointment with your solicitor for next week? Please also consider making a bequest to Parkinson's NSW. Whilst a cash bequest is good, a percentage or the residue of your estate (after gifts to loved ones have been made) allows for the all the unknowns that may lie in the future. For further information please phone Margaret on 9876 5351 between 8am and 8pm. Always be guided by your solicitor.

Making a bequest to Parkinson's NSW allows the vital work of supporting people living with Parkinson's to continue. Though we trust it will be many years before your bequest comes to us, it will eventually help us to reach our goal: a community free of Parkinson's disease.

## Facing the Future with Parkinson's

During 2008 Parkinson's NSW is running the Facing the Future with Parkinson's program that helps participants enhance their life-coping skills and make the most of the future with Parkinson's Disease. It is for people with Parkinson's Disease, their carers, family & friends. Seminars will be held at a number of venues in regional and metropolitan NSW.

For those who don't live near one of the venues, or who find it difficult to travel to a seminar, we are pleased to be able to offer Teleconference Groups. You can participate in the comfort of your own home. It involves one hour a week on the phone, for five weeks. They will be run on a Tuesday morning or Thursday morning, starting at the end of April. There is no cost for participants.

The program will provide education, practical advice and emotional support to meet your specific needs. Some of the things you will find out about are: professional support, specialist community services and information to help you plan for the future. You will have the opportunity to talk to others in similar circumstances and to give and receive mutual support.

To find out more or to register, please phone Parkinson's NSW on 1800 644 189. Early registration would be appreciated.

## Support group contact details

GROUP	CONTACT	PHONE
Albury/Wodonga	Valerie Leyden	02 6040 6153
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown	Trish Morgan	02 8875 8903
Bathurst	Jennifer Mannell	02 6332 8963
Blue Mountains	Hazel Tolhurst	02 4757 4214
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	02 6341 3692
Deniliquin/Finley	Glenis Gordon	03 5881 3295
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta		02 9876 4284
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla		02 4472 2037
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	02 4822 6732
Grafton	Cathy Eggins	02 6642 2156
Griffith	Joyce Giacomelli	02 6966 9900
Gunnedah	Lisa Hagley	02 6742 0018
Hawkesbury	Jill Sykes	02 4730 4302
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South		02 4232 2807
Lower North Shore		02 9412 2740
Macarthur	Maree Sinclair	02 4626 4959
Manly/Mosman	Trish Morgan	02 8875 8900
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
Parkes	Con Diamond	02 6862 1925
Pittwater/Warringah	Margaret Smith	02 9913 7745
Port Macquarie	Patricia Stephenson	02 6584 0212
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	Patricia May	02 4981 0641
Tweed Heads		07 5524 9417
Wagga Wagga	John Allen	02 6925 2713
Yass	Peter Wells	02 6226 2233
Young Onset	Sarah Lines	02 4627 5632

**PARKINSON'S NSW INC.**

PO Box 71  
 NORTH RYDE BC NSW 1670  
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 Fax: 02 8875 8999  
 Email: pnswn@parkinsonsnsw.org.au  
 Web: www.parkinsonsnsw.org.au

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## Parkinson's NSW Raffle Prize Winners

- 1<sup>st</sup> Prize Winner:** Panasonic 127cm Plasma Screen  
 Yamaha Home Theatre System  
 Panasonic 160Gb HDD DVD recorder  
*Margaret Morrow*
- 2<sup>nd</sup> Prize Winner** Toshiba IT Notebook P200/602 Intel  
 Tech Pacific Multifunction HP Printer  
*Janet Heenan*
- 3<sup>rd</sup> Prize Winner** Canon Digital Camera SLR 10.1 MP  
*Florence Gill*
- 4<sup>th</sup> Prize Winner** BrightPoint Navman GPS F20  
*Melanie Leahy*

## Parkinson's... ...with personal experience

A special education session for those wanting to learn about  
 Deep Brain Stimulation (DBS)

program  
 details

9.30 Registration  
 10.00 Dr Paul Silberstein  
 Parkinson's disease and deep brain stimulation  
*followed by*  
 a Panel Discussion with people who have  
 experienced DBS

When: Wednesday 2 April 2008  
 Time: 9.30am  
 Where: Conference Centre  
 North Shore Private Hospital  
*Paid parking is available on hospital grounds*  
 RSVP: Friday 28 March 2008  
 1800 644 189

*~ refreshments will be provided ~*



This is a continuing educational program proudly  
 sponsored by Parkinsons NSW and Medtronic

## 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.

## Parkinson's Artists Group

Are you a person living with Parkinson's who paints, creates prints or sculpts? Would you like to meet with others sharing similar talents?

Our first group will meet on the Thursday, 10th April @ 10am

Level 1, 25 Khartoum Road North Ryde

RSVP by ringing 1800 644 189 by the 3 April

## To become a member, visit our website:

[www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au)

or

Call InfoLine: 1800 644 189

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

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

Parkinson's NSW Inc. ABN 93 023 603 545

Disclaimer: The information provided is for guidance only and is not a substitute for professional medical advice. Parkinson's NSW takes reasonable care (in the context of freely available information) to keep the information it provides accurate and up-to-date; however, Parkinson's NSW does not guarantee the correctness and completeness of the information. You should confirm that the information is applicable to your circumstances by checking it with your doctor or a qualified health care professional.

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