



Stand By Me

ISSUE 96 – Spring 2006

NSW Health Minister John Hatzistergos launches Awareness Week



Minister for Health John Hatzistergos.

The Parkinson's NSW awareness seminar, *Stem Cells to Sex and Other Things*, held at NSW Parliament House on September 6 2006 was well received, and attracted a record crowd.

At the seminar, NSW Health Minister John Hatzistergos officially launched Awareness Week and congratulated Parkinson's NSW for distributing *Get it on time* kits to hospitals, nursing homes and hostels across NSW.

The national *Get it on time* campaign is focused on medication management and highlights the importance of people with Parkinson's disease getting their medication **on time – every time** in order to prevent their condition from getting out of control.

The kits, which include posters and a brochure setting out our campaign message, were sent to:

- All staff working in hospitals and aged care facilities, to give them a better understanding of Parkinson's and why administering medication on time, and the correct dose every time is crucial.
- People living with Parkinson's, their carers and families.

- Hospital pharmacists, to make sure they always stock a broad range of Parkinson's medication, which is also easily accessible.

The Minister also received petitions signed by over 18,000 people from across the state supporting Parkinson's specific support services for NSW, and safe and adequate premises for Parkinson's NSW Inc.

Other speakers included:

Professor Alan Mackay-Sim – Stem Cell Researcher from Griffith University, who has undertaken history-making medical research in adult stem cell research and Pd. Under Professor Mackay-Sims' leadership, a National Adult Stem Cell Research Centre will be established. This is part of the Federal Government's \$22 million funding for adult stem cell research. He spoke on adult stem cells and Parkinson's.

Professor Meg Morris – Chair of Melbourne University School of Physiotherapy and Director of Allied Health Clinical Research in the Rehabilitation and Aged Care Program, Kingston Centre. Professor Morris heads up the team which received over \$800,000 from the Michael J Fox Foundation. She spoke on physical therapy approaches to prevent and treat falls and enhance mobility.

Dr Colleen Canning from the School of Physiotherapy, University of Sydney, spoke on her research projects and led the audience in a vigorous exercise session after the lunch break. She proved that exercise can and should be fun!

Dr Sarah Mott from the School of Rehabilitation Nursing, University of Western Sydney, provided a very entertaining talk on Parkinson's and sexuality.

Dr Greg DeMoore, a psychiatrist with Westmead Hospital, spoke on mood and Parkinson's, engaging the audience with stories of his patients. He responded to enthusiastic questioning from the audience.

And, in the final presentation of the day, Parkinson's specialist counsellor **Janine Rod** spoke about fears and expectations.

DVDs are available for purchase – see ad on page 6 for further details.

STOP PRESS

- Membership offer (see CEO's report) page 3
- Dr Kay Double receives research award page 6

FEATURES

- Parkinson's and sex page 5
- New support group is born page 7
- Counsellors Couch – confused carer page 10

DIARY DATES/SPECIAL EVENTS

- October 25** Coalfields Support Group Seminar
- November 2** Parkinson's NSW Stall on the Green
(Revesby Ladies Group – crafts)
- November 8** Coffee Morning at Concord
(10.30am)
(Building 25)
Come and meet staff and volunteers of Parkinson's NSW and talk to others living with Pd
RSVP - 6 November 2006
- November 14** Men's Parkinson's Network (MPN)
(see page 6)
- November 23** John Hunter Hospital,
Newcastle Pd Workshop
- December 9** Parkinson's NSW Christmas Party
Poetry and Movement
on the Green
RSVP - 25 November 2006
- February 27 2007** AGM - Further details in the next issue of *Stand By Me*

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Leanne Trupiano
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Stand By Me Editor

PARKINSON'S NSW INC.

Building 25, Concord Hospital,
Hospital Road, Concord, NSW 2139
Toll Free No: 1800 644 189

Phone: 02 9767 7881
Fax: 02 9767 7882
Email: pnswn@parkinsonsnsw.org.au
Web: www.parkinsonsnsw.org.au

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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President's report



Spreading the word

The Council, with your magnificent help, has spent a great deal of time getting the message out to the rest of NSW about who we are, our numbers, and why the community and government should know and understand us better.

First, there was the remarkable response to our 'call to action' on funding and premises. Over 18,000 citizens of this state – from Tweed Heads to Albury, Sussex Inlet to Broken Hill – supported and signed our petition. Politicians of all colours were briefed and asked to send letters to the relevant Ministers.

To date we have not had a direct response from the government but your Council is still hopeful of a positive outcome. Angela D'Amore, the Member from Drummoyne and our champion in Parliament, has just given birth to a son and this will cause some delay – for the happiest of reasons. We wish Angela, her husband and the new baby all the very best from everyone at Parkinson's NSW.

Second, were the many activities associated with Parkinson's Week. The highlight in Sydney was the opening of the Annual Seminar by the Minister for Health. Perhaps recognition of how we have penetrated the walls of Macquarie Street. The week also saw the launch of the James Parkinson Society. Our Bequest Officer, Margaret Byron, was introduced to the 60-plus people attending this inaugural luncheon. Ray Browning has the honour of being the first member of the James Parkinson Society and as such was presented with the first badge of the society. His response was to express how pleased he was to be able to assist PWP in the future. Well done Ray.

Third, under the guidance of our VP Allen Cropp, Council has been spreading the word and visiting support groups all over the state – with more visits planned for September and October. Many groups have now received Allen's compilation of the do's and don'ts of running a support group – this manual should simplify things considerably for new leaders.

Alongside this activity, a very successful seminar on surgical treatments highlighting Deep Brain Stimulation was run by David and Maureen Morrison and the band of workers at St George. Further seminars are planned for both Bombaderry and the Coalfields at Maitland in October.

All of this shows a picture of a positive organisation going forward. As a consequence we have been given more opportunities by charitable foundations and Trusts to bid for monies that they might have available.

We must at this stage thank and publicly acknowledge The Myer Foundation, Perpetual Trustees, the Cecila Kilkeary Foundation and other anonymous individuals for their financial and moral support. It is easy to ask but much nicer to receive and say *thank you*.

So we are spreading the word. Thanks to all involved.

John Silk



Grants for Parkinson's Research

Parkinson's NSW is a non-profit organisation formed to promote, disseminate and fund research into all aspects of Parkinson's disease. Parkinson's NSW is calling for applications worth up to \$20,000 each (exclusive of GST) for biological/non-clinical and clinical/psychosocial research.

The Grants Guidelines and Application Format can be obtained from our website http://www.parkinsonsnsw.org.au/research_grants.htm or please contact Ms Linda Matheson on (02) 9767 7879 or linda@parkinsonsnsw.org.au

Closing date for applications is
19 October 2006.

Those magnificent men ...

By Margaret Byron

Do you remember the President's Report in the last issue of *Stand By Me*? John Silk championed some of the ladies he knows who do so much for Parkinson's NSW.

I would like to take up the baton for all the Magnificent Men throughout the state, who give of their time and effort to further the cause.

David King has spent hours on the telephone contacting service clubs to ask if they would like a speaker to raise awareness of Pd. He then speaks at most of them.

Les Norris, not content with leading the Central Coast Support Group, wrote a booklet, *Yes you can! Play Lawn Bowls*.

Muralitharan Somasunderam, who in his quiet and unassuming way donates generously of his time as a volunteer in the office.

John Allen, leader of the Wagga Wagga Support Group, worked so hard to organise a most successful seminar this year.

John Carlton – he with the twinkle in his eye, donates his professional services to inspire people to stand in front of audiences, great and small, and raise the Parkinson's awareness flag.

There are many more Magnificent Men, some high-profile but others also working hard with their support. Thank you to you all.

CEO's report



We have reluctantly bid farewell to Kay Messiter, our information officer, after 10-plus years of service to Parkinson's NSW. Kay leaves us to start a new life on the Central Coast. Sadly Bev Aronstan, our Parkinson's specialist counsellor, has left us, and Heather Noakes has also moved on to take up a position closer to home.

I am pleased to let you know that we have been able to welcome Janine Rod as our new Parkinson's specialist counsellor, and Nancy Tung, our full time information/resource officer. Funds raised from the Chinese community dinner have been used to assist in the employment of Nancy, who speaks fluent Cantonese and Mandarin. And welcome to Linda Matheson, who joins us as our new office manager.

The Council, ever mindful of the need to increase membership, is undertaking a special membership drive. We are offering free membership until June 30 2007 to all members of support groups who are currently not a member of Parkinson's NSW. **Current members are being offered life membership at a discounted rate of \$165 (including GST) until December 31, 2006. Please call the office if you would like to take up this special limited offer.**

The Council has also announced two seeding grants of up to \$20,000 each to encourage research into Parkinson's. These grants have been advertised extensively through the research community.

We are celebrating **International Disability Day** and the **Festive Season** at our annual Christmas function, which will be held on December 9 at Concord. This year we are featuring poetry and entertainment along with our traditional barbecue. We hope to produce a special Parkinson's poetry book – if you would like to submit poems please forward them to the office. We would love to see you there.

Please call 1800 644 189 to book your place.

Yours in Parkinson's friendship
Miriam



Nancy Tung, Janine Rod and Linda Matheson.

WALKING RESEARCH

By Dr Colleen Canning, School of Physiotherapy, the University of Sydney

Over the past few years many Parkinson's NSW members have volunteered for studies conducted by Dr Colleen Canning from the School of Physiotherapy at the University of Sydney – thank you for your support! Two of these studies are complete and we can provide you with the results of your efforts. Both studies have been recently published in international journals.

The effect of directing attention during walking under dual-task conditions in Parkinson's disease

(Canning CG. Parkinsonism and Related Disorders 2005; 11:95-99)

Many day-to-day activities require people to perform more than one task at a time, for example walking while carrying a drink. People with Parkinson's disease often find it difficult to do two tasks at once.

In this project, 12 people with mild to moderate Parkinson's disease were studied while walking and carrying a tray of plastic wine glasses. They were either instructed to concentrate on taking big steps while walking or to concentrate on balancing the tray and glasses.

When participants were asked to concentrate on balancing the glasses, they walked slowly, with short strides and slow footsteps. However, when they were asked to concentrate on taking big steps, they walked faster and with longer strides and, in most cases, the glasses remained upright on the tray.

These results suggest that when people with Parkinson's are walking and doing another task at the same time, they may concentrate on the second task more than necessary. Since walking safely is very important, it may be best for people to concentrate, first and foremost, on their walking.

As this study showed that walking performance could be improved temporarily by concentrating on taking big steps, it may be possible (with enough practice) for people with mild Parkinson's disease to improve their ability to walk while doing another task.

It may be possible for people with mild Parkinson's disease to improve their ability to walk while doing another task

Walking capacity in mild to moderate Parkinson's disease

(Canning CG, Ada L, Johnson JJ, McWhirter S. Archives of Physical Medicine and Rehabilitation 2006; 87:371-375)

When people with Parkinson's disease walk a short distance, they typically walk slowly with lots of short steps. It was not known, however, whether these problems worsen when walking over longer distances.

Sixteen people with mild to moderate Parkinson's disease and 22 people of similar age without Parkinson's disease

participated in this study. Their walking was measured over a short 10-metre walkway and then during a six-minute walk test (where participants walk as far as they can in six minutes).

This study aimed to answer the following questions:

- **Is walking capacity (measured as the distance walked in six minutes) reduced in people with Parkinson's disease?**

The people with Parkinson's disease did not walk as far as the control group (an average of 546 metres compared to 619 metres).

- **Is comfortable walking speed (measured over 10 metres) maintained throughout a test of walking capacity?**

Comfortable walking speed measured over a short distance was slower for the people with Parkinson's disease than for the healthy people. During the six-minute walk test, both groups were able to walk faster than their comfortable speed. Surprisingly, the 'fast as possible' walking speed for the people with Parkinson's disease was about the same as for the control group. However, the people with Parkinson's could only walk at an average of 76 per cent of this speed during the six-minute test, whereas the healthy people could walk at 84 per cent of their 'fast as possible' speed.

- **Do the problems of slow speed, short steps and frequent steps get worse during the test of walking capacity?**

No – the pattern of results for both groups is similar. People tend to begin walking quickly, then slow down in the middle of the test, with another burst in speed toward the end.

Even though the people with Parkinson's disease could walk as fast as the healthy people over short distances, they could not maintain this speed over six minutes. It's possible that consistently walking at lower speeds results in decreased fitness, which further reduces walking capacity. Exercise programs designed to help sustain walking at fast speeds might help improve this.

Studies currently underway

There are two research projects currently being conducted by the School of Physiotherapy at the University of Sydney and the Department of Neurology at Westmead Hospital:

- Can home-based lower limb strengthening exercises reduce falls in people with Parkinson's disease?
- Does home-based treadmill training improve walking capacity and quality of life in people with early to mid-stage Parkinson's disease?

If you would like to find out more or be involved in either of these studies, contact Natalie Allen, Physiotherapy Research Officer on 9845 5538, or Dr Colleen Canning on 9351 9263 or email: c.canning@fhs.usyd.edu.au

INTERESTED IN SEX?

By Dr Sarah Mott, Royal Rehabilitation Centre Sydney

Did the title of this article attract your attention?
If so, read on ...

In our recent study of 444 people with Parkinson's disease (Pd),¹ 52 per cent of participants reported that sexual limitations affect their lives. To understand these results, a review of the research literature was undertaken and is presented, briefly, below.

Sexual activity is considered to be a normal and healthy part of most people's lives. However, whilst sexual activity tends to decline with increasing age, decreased sexual functioning may be accelerated in Pd.^{2,3}

Sexual limitation in Pd has many causes – autonomic nervous system dysfunction, psychosocial changes, medication side-effects and motor disabilities.

Autonomic nervous system (ANS) dysfunction affects 70 – 80 per cent of people with Parkinson's. This can lead to altered libido, vaginal tightness and delayed ejaculation.⁴ In men, erectile dysfunction is often the first symptom of Pd reported and usually pre-dates the onset of other neurological symptoms by several years.⁵

The motor symptoms of Pd, including decreased agility and the limitations of bodily movement, may also make sexual intercourse difficult. Sexual arousal and orgasm can increase the rigidity, tremor and bradykinesia of Pd.⁶

Anti-Parkinson medication can affect both libido and the sexual response. Most studies report problems such as impaired erection and delayed ejaculation in antidepressant and anticholinergic drugs.^{7,8}

Research investigating the impact of chronic disorders has shown that psychological and social factors are also significant. For example, depression, anxiety, and frustration provoked by the very fact of being ill may sharply curtail libido. Jacobs, Vieregge and Vieregge⁹ found depression in people with Pd to be more relevant to the subjective sense of dissatisfaction with their sexuality than their physiological dysfunction.

Stress is also a factor: as symptom severity increases, partners, who are predominantly the carers, typically face increased levels of emotional, physical and financial stress.¹⁰ Time pressures, concern about the future and finances, and a lack of knowledge about Pd add further stress.^{11,12}

People living with Pd often experience reduced self-esteem as a result of receiving care, increased dependency and premature retirement.¹³ In younger people with Parkinson's, unemployment seems as important as depression in determining satisfaction with sexuality.

Changes in body image, tremor, bradykinesia, lack of facial expression, skin texture and smell (drugs may cause a change in body odour) may make a person seem less attractive to their partner.¹⁰ The effect of these factors on your sex life will depend on your ability to discuss the problems. Be aware that Parkinson's disease may compromise interpersonal communication, with some

sufferers having a reduced range of verbal, nonverbal and emotional expression.¹⁴

This review of the literature provides insight as to why so many of the participants in our study reported sexual limitations. So what can be done to help? It is important to speak with your general practitioner or neurologist about the effects of anti-Pd medication – there may be alternatives or strategies that can alleviate the problem.

On a personal level, looking after yourself, avoiding fatigue, talking with your partner and exploring various ways of giving and receiving intimacy are all useful.

If you would like more information, contact the following organisations:

- The Family Planning Association has professionals who specialise in sexuality issues for people with a disability. The FPA can also provide details of local Sexual Health Centres. (www.fpahealth.org.au; 1300 658 886)
- Impotence Australia provides information on impotence and other male and female sexual problems. (www.impotenceaustralia.com.au; 1800 800 614)

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Research

INTERESTED IN SEX? – *continued*

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Early warning test for Parkinson's receives national recognition

The research of Dr Kay Double, a National Health and Medical Research Council (NHMRC) Senior Research Fellow at the Prince of Wales Medical Research Institute, has received the nation's highest commendation through her inclusion in the NHMRC's 2006 '10 of the Best' booklet.

Dr Double's research into Parkinson's disease looks at the function of neuromelanin, a pigment unique to human brains. In the brain cells of a person with Parkinson's disease, this pigment disappears.

Based on her findings, Dr Double and her team have developed a new blood test which will provide early detection for the loss of neuromelanin and this may predict the onset of Parkinson's.

Dr Double's work investigated the vulnerability of the pigment in a Parkinson's disease brain, how it occurs in a healthy brain, why these changes occurred and the consequences of changes for the survival of the brain cells.

"We found that the pigment in the healthy brain protects the cells from free radical-damaging molecules and other toxins," she said. "But in the Parkinson-diseased brain, the pigment is changed so that instead of protecting the cells, it becomes toxic itself.

"Our research indicates that increased amounts of iron bound to the pigment cause the cells to be damaged and die.

"This research has also highlighted the potential to develop new treatments to slow down, or even stop altogether, brain cell death."

The blood test, currently being commercialised, will provide early detection and correct diagnosis of Parkinson's disease. At the moment, Parkinson's disease can be diagnosed only after signs such as slowness, stiffness and tremor appear.

Dr Double has been awarded a NHMRC Senior Research Fellowship to continue her research into the causes, diagnosis and treatments of Parkinson's disease.

Men's Parkinson's Network (MPN)

Are you under 60 and interested in meeting informally with other men diagnosed with Parkinson's?

Please call Trish or Janine on 9767 7881.

RSVP - 7 November 2006

First meeting planned for
Tuesday 14 November 2006
Concord RSL Club, Nirranda Street, Concord West
at 10.30am - 12.00 noon.

On the group vine By Trish Morgan

AWARENESS WEEK ACTIVITIES, Sept 4 – 10, 2006

Coffs Harbour had an action-packed programme with a static display all week at the RSL, free coffee and a chat all day at the Catholic Club on Tuesday September 5, 'Paint the Pinkie' by Coffs Harbour Hospital Payroll staff on Wednesday September 6 and a member's social afternoon with keyboard music on Saturday September 9. Vera's daughter organised a night of nail beauty with wine, games and prizes for her friends called 'Get Nailed'.

Coalfields were selling and raising awareness in a big way with the help of the Rutherford Lionesses. Hours of work went into the making of silk tulip pins, each carrying the message 'Ease the burden and find a cure'. These were sold at Cessnock Market Town and Stockland Mall, Greenhills.

Coalfields were also publicising their upcoming seminar on Wednesday October 25 at East Maitland Bowling Club.

Dubbo had an information stall with a fruit raffle to encourage people to stop and chat.

Hornsby/Ku-ring-gai were experienced promoters with stalls at St Ives Village Centre from 10am-4pm on the Thursday and Friday and at Hornsby Westfield on the Saturday.

Nepean invited their neighbours at the Senior Citizens where their meetings are held to come in for afternoon tea.

Newcastle held their usual information, craft and goodies stall at John Hunter Hospital and raised \$550.

Goulburn were selling in the community and needed more supplies before Awareness Week.

OTHER NEWS

Tweed Heads had a very successful seminar on Saturday August 19. People came from the Gold Coast and the Northern Rivers. Dr Geoffrey Boyce, Consultant Neurologist; Greta Wellm, Physiotherapist at Murwillumbah Hospital; and Dick Babb, Secretary PNSW were the guest speakers. Together with her family and friends, Shirley Rushton managed everything including the catering. This was a free seminar. Donations and new members were a bonus.

Wagga Wagga: John Allen has been talking to Rotary and trainee nurses. The group had a special dinner prize for a Father's Day raffle.

NEW GROUP By Neil Sligar

The Bankstown Parkinson's Support Group was born on Wednesday September 13 at the Bankstown Sports Club. The baby is small but healthy and appears likely to flourish.

Dr Cordato, neurologist from Bankstown Hospital, and Natalie Allen, research physiotherapist from Sydney University, assisted at the birth.

Nourishment was provided by Maureen Morrison from the St George-Sutherland group who secreted her home-made chocolate biscuits into the club.

Thanks to Trish Morgan for her pre-natal encouragement and effort.

The Bankstown support group will meet again at the Sports Club on the third Thursday in October at 10am. It will be a neighbour for the Liverpool-Fairfield support group, born in March and now a thriving child. These two groups give Parkinson's NSW a local presence in a catchment of around 600,000 people.

It's hoped that the Blacktown area will have a Parkinson's support group next year. A wide void we could see in 2005 in western and south-western Sydney on the Parkinson's support group map will then have been removed.

A hair-raising success



A light-headed Winey with her father.

Hi! My name is Winey Suen and I have been feeling rather 'light-headed' lately. That's because I just axed off about 300 grams of hair!

How does it feel? One word: aerodynamic.

The Parkinson's disease charity shave at the University of Sydney Engineering Revue was an enormous success.

Aside from raising lots of money for Parkinson's NSW, I was surprised by the number of people who knew people with Pd, yet the extreme lack of knowledge about Pd and Parkinson's NSW. I was honoured to be able to raise a lot of awareness about Pd, its effects and certainly the work of Parkinson's NSW, especially to a lot of young(er) people.

The event was attended by over 300 people and a grand total of \$5602.95 was raised.

A massive thankyou to everyone who supported Parkinson's NSW, myself and my friend Stu during the charity shave. We had an awesome time.

Do you or a loved one live alone?

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Care Call is an activity of Bapco Community Services

Mum slipped in the shower. Luckily she was wearing her Care Call waterproof pendant. She pressed the button and help was there in minutes.

Push for Parkinson's support funding

Courtesy of the Gloucester Advocate



Gloucester's Bev Ridgeway has joined the campaign to lobby for state government support for Parkinson's support services.

Photo courtesy of the Gloucester Advocate.

Parkinson's disease support group member Bev Ridgeway is helping Parkinson's NSW in their bid to win state government funding for Parkinson's specialised services.

Bev has circulated a number of petitions throughout Gloucester, calling for people to sign and show their support for state government funding for Parkinson's NSW's 1800 freecall information line; the Parkinson's counselling service; the 48 statewide Parkinson's support groups and to provide information and education for health professionals and people living with Parkinson's.

Bev knows first hand what it is like to live with Parkinson's.

Her husband Bill was diagnosed with the disease in the mid 1970s, one of just 10 per cent of Parkinson's sufferers to be diagnosed with the disease before the age of 40.

The disease is most prevalent in people over the age of 60.

Until a little over two years ago Bev was caring for Bill at home, but she said as it became more difficult for her she had to make the very difficult decision to place Bill in hospital.

She said she has found the information and support provided through Parkinson's NSW has been invaluable since Bill's diagnosis.

"Support groups are pretty important things for carers and sufferers," she said.

Bev said one of the benefits was that you got to meet people who were talking the same language.

She said while there is no Gloucester support group, groups are located at Forster Tuncurry and in Newcastle.

"I'd also be pleased to help anyone, even to help them join the association so they can access information," she said.

At this stage there is no known cause, cure or diagnostic tool for Parkinson's disease.

Parkinson's NSW provides free of charge information, education, encouragement and support for people living with the disease, their families and carers.

Bev said she hoped people would support her in signing the petition for government support for Parkinson's NSW and their services.

The petition is available to sign at the Hospital Activity Centre, the Gloucester Medical Centre and the Gloucester Advocate office.

"I've collected quite a few signatures at the moment," she said.

Support needed in Broken Hill By Judy Marshall

Working in the Parkinson's NSW office on a Wednesday as I normally do, I mentioned I was going to Broken Hill for a holiday.

Miriam Dixon, our CEO, turned to me with her eyes lit up ... I know that look. I thought, 'I'm about to volunteer for something!'

Miriam asked me if I would agree to contact Colleen O'Brien while I was there. Yes, of course I would.

When I arrived in Broken Hill I contacted Colleen and we arranged to meet.

The day of our meeting was rainy, cold and windy. Despite this, five ladies arrived, and we spent the next two-and-a-half hours chatting. I explained how I became involved with Parkinson's NSW, then I told them about our

counselling service, our 1800 number and our clinic. I also talked a little of our fundraising events and the sporting expo. They were all very interested in any research.

They told me there is no support for them in Broken Hill. Their GPs are good but not expert; they have to travel to Adelaide for specialist treatment.

I asked them what would be their greatest wish. The unanimous vote was for a seminar for the local doctors and nurses (and patients).

Three of the ladies took out membership on the spot. I really enjoyed talking to them, but I felt sad at times that I could not help them more. They are so far away from any support. How lucky are we who live in the city.

How can we help them?

Bathroom basics

Hard floors, hot water, slippery surfaces ... a number of safety issues can arise in the bathroom, particularly if you experience reduced dexterity and become less mobile. There are a number of modifications that you can make to your bathroom to make it a safer place for you and your family. These range from simple changes like installing grabrails to a complete re-design of the floorplan.

And making your bathroom safer doesn't mean you have to compromise on style, either. Some of the safer design features listed below will actually improve the aesthetics of the bathroom.

Grabrails

The easiest way to improve a bathroom's useability and safety is to install grabrails. Generally, grabrails around the toilet are installed at 800mm above floor level, and are set at a 45 degree angle, or vertically 200mm in front of the toilet. If there is a wall on both sides of the toilet, grab rails on both sides may be appropriate. Grabrails should also be installed alongside and in the shower recess – about 800mm above floor level.

Flooring

Wet, slippery tiles can be very dangerous. Slip-resistant flooring in the bathroom is essential for everyone's safety. When renovating, select slip-resistant tiles – there are many now on the market. For a more economical solution, it is also possible to paint a slip-resistant treatment over your existing floor tiles.

Maximise floor space

If you are renovating your bathroom, bear in mind that you may one day need to manoeuvre a walking frame or wheelchair in the bathroom. So aim to free up more floor space, select a semi-recessed basin set into a half-width vanity, or a pedestal basin. A wall-hung toilet will have the same effect, and has the advantage of being able to be placed higher than normal.

Shower

Build a hobless shower, without a step up or down, which minimises the risk of tripping and will be more accessible for those with walking frames or wheelchairs. A shower curtain is much safer and easier to manoeuvre around than a glass screen (and easier to clean, too!)

Ideally, the shower recess should be at least 1100mm x 1100mm. A hand-held showerhead fitted on a vertically adjustable rail will provide more flexibility. And if you can, install the taps close to the edge of the shower recess, so you don't have to lean in to reach them.

Other considerations

Install plenty of storage shelves above the bench. This will save you having to bend down to reach soap, towels etc.

Some hot water systems can be fitted with water temperature controllers. This not only makes life easier, but can prevent the risk of scalding.

And throughout the bathroom, bear in mind that lever-mixer style tap fittings are easier to operate than knobs.

For more information about making your bathroom safer, call the Independent Living Centre of NSW on 1300 885 886 or visit www.ilcnsw.asn.au

The James Parkinson Society Launch

By Margaret Byron, Bequest Officer

On September 7, during Parkinson's Awareness Week, we launched the **James Parkinson Society ... bringing hope for the future**. This is a Society formed to recognise those who make the generous commitment of including a bequest to Parkinson's NSW in their will.

Senior members of Parkinson's NSW in the Sydney metropolitan area were invited to attend the inaugural lunch, a sponsored event which was held at the Ryde-Eastwood Leagues Club in West Ryde. Apart from the food and drink, the highlights were an entertaining talk by Dr Sarah Mott, a council member and a health professional with a special interest in Pd; and the induction of our very first member, Ray Browning.

Like many of our Parkinson's NSW members, Ray is a long-time supporter of the organisation, giving generously of his time before Bet, his wife who has Pd, became a resident of a nursing home. Ray says he hopes it will be years before we have the benefit of his bequest! (So do we, Ray.) His family supports his action and know that his gift will help Parkinson's NSW expand its services – *bringing hope for the future*.

We plan to have two or three sponsored lunches per year, one of which will be in regional NSW. The next one is planned for May 2007, when we hope to induct more new members.

If you would like to receive our brochure, *Leaving a bequest to Parkinson's NSW*, or if you have any questions about the James Parkinson Society and making a bequest, please contact Margaret Byron on 9876 5351.

All calls are confidential.



Have you got a birthday, wedding or family celebration coming up?

You might like to consider asking family and friends to make a donation in lieu of presents to mark your special occasion, just like Sue Rance recently did for her 60th birthday.

From our counsellor's couch

By Janine Rod

CONFUSED CARER

My mother was diagnosed with Parkinson's at the age of 82, only six months after my father had passed away. It was such a shock to us; not only did we have to come to terms with the loss of our father, but now we also had to deal with a parent with a chronically debilitating disease. As the eldest daughter, I took my mother in to come and live with us about two years ago. Even though I do love her, there are times that I find myself feeling resentful of her. I feel so guilty for having these feelings and for also feeling embarrassed by her behaviour. She drools and I don't want to take her out. I know it sounds selfish but I often feel that I've got no life and I'm not sure if I can cope with this anymore. It is having a terrible effect on my marriage and on my children.

Joan, NSW

Dear Joan

Parkinson's disease affects not only the person who has been diagnosed with Parkinson's but also their spouse, family and friends.

I can understand your mixed feelings about your mother – these kinds of feelings are not unusual. People living with Parkinson's can become more dependant as the disease progresses and in some cases their symptoms may become more distressing.

It might be helpful for your mum to be re-assessed by a neurologist specialising in Parkinson's disease. If you need help finding a neurologist please contact our office.

Counselling can help you to cope with the emotional issues arising from caring for your mother

Counselling is also important. It can help you cope with the emotional issues arising from caring for your mother. It also allows you to work through the feelings you have and share your concerns in a safe, empathic and non-judgmental environment.

You might consider respite, which provides a breathing space not only for you and your family, but also for your mother. She may be feeling vulnerable, less valued and guilty about the way she is affecting you and your family, and may also want some time out.

Many of our members have found support groups invaluable. These groups give you the opportunity to share common experiences and gain practical support and information. The knowledge that you are not alone, that someone else understands and is going through a similar time, can provide you with much support.

I commend you for the strength and resilience that you have shown in this challenging situation.

Help is just a phone call away – call Parkinson's NSW on 1800 644 189.

Janine

Fathers and daughters stride out for Parkinson's

Two members of our Fairfield/Liverpool support group, Ivan Begonia and Joe Minter completed the City to Surf fun run, accompanied by their daughters, Leah Begonia and Joanne Minter.

Both Ivan and Jo have been runners in their past. Ivan is 66 and was diagnosed only 11 months ago. He said that he was fit enough to do the City to Surf "at a good power walk pace".

Joe is 81 and completed the City to Surf with his daughter in less than three hours. Both Joe and Ivan plan to enter the City to Surf next year.

Do we have other takers? We would love to form a Parkinson's NSW team for 2007. Please call the office to register your interest.



Joe Minter and his daughter Joanne Minter.

Coffee Morning



Come and meet staff and volunteers at Parkinson's NSW.

Talk to people living with Parkinson's

10.30am, 8 November
Building 25, Concord Hospital
RSVP - 6 November 2006

See you there!

Donations

\$50 and over received between 28 June – 30 September, 2006

We are grateful for all donations as Parkinson's NSW receives no government funding. Thank you.

IN MEMORIAM DONATIONS

Mr Benedossa

Mrs Maria Benedossa

Mr Rex Button

Mrs Judith Riches

Mrs Lois Stewart

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Ms Laraine Rowe

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Northern Rivers

Shoalhaven

St George/Sutherland

Wagga Wagga

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If you wish us to send you a membership form and information please fill in the address box below and send it to:

Parkinson's New South Wales Inc.,
Building 25, Concord Hospital,
Hospital Road, Concord NSW 2139

NAME: _____

ADDRESS: _____

SUBURB: _____

STATE: _____ P/CODE: _____

PHONE: _____

EMAIL: _____

Tick if you would like information on wills and bequests

Support group contact details

GROUP	CONTACT	PHONE
Albury	Jenny Shields	02 6042 1439
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown		1800 644 189
Bathurst	Jennifer Mannell	02 6332 8963
Canterbury	Trish Morgan	02 9767 7881
Casino	Dawn Dennis	02 6662 6141
Castle Hill	Pallavi Yarrapothu	02 9634 0578
Central Coast	Les Norris	0418 607 684
Chinatown Bi-lingual		0421 224 712
Coalfields	Carol Bateson	02 4930 8638
Coffs Harbour		02 6652 9959
Cowra	Ken Bryant	02 6342 4403
Deniliquin	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
Finley	Glenis Gordon	03 5881 3295
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	Emma Robinson	02 4223 8282
Illawarra South		02 4232 2807
Lower North Shore		02 9412 2740
Macarthur	Maree Sinclair	02 4626 4959
Manning/Great Lakes	Bruce King	02 6555 9409
Muswellbrook	Pat Moody	02 6543 3164
Nambucca Valley	Margaret Butcher	02 6564 8231
Nepean	Joe Golding	02 9670 5093
Newcastle	Verlie Sullivan	02 4954 0338
Parkes	Con Diamond	02 6862 1925
Pittwater/Mona Vale		02 9997 1542
Port Macquarie	Patricia Stephenson	02 6584 0212
Shoalhaven	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	Ian Canham	02 4994 9276
Tweed Heads		07 5524 9417
Wagga Wagga	John Allen	02 6925 2713
Yass	Peter Wells	02 6226 2233
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