



PARKINSON'S NEW SOUTH WALES INC. NEWSLETTER – Issue 104, Spring 2008

*Ease the Burden and Find a Cure*

# Stand By Me

**Australia's 1st Unity Walk for Parkinson's**  
Sydney Olympic Park, Sunday 31 August 2008



Unity Walk Photos can be viewed – <http://www.parkinsonsnsw.org.au/assets/attachments/events/UnityWalk2008/>

**ALERT** PNSW has become aware of a company which is advertising treatment for PD based on cord blood stem cells in Australia. We advise members that this approach is untested for both safety and efficacy in PD, and thus we do not recommend it. An article on this topic will feature in the next issue of SBM.



## President's Report

Congratulations to Verlie Sullivan and Peter McWilliam – how wonderful to see the recognition of their work for the Parkinson's community in June's honour list. More is said about these worthies in the body of this edition, but let me just add that both of them well

deserve the accolades which followed the announcement.

My theme this edition is responsibility and awareness.

Our first Unity Walk for Parkinson's was held on August 31st. The response for a first time event was sensational, and our twin goals of raising funds for research and for our support services received an encouraging boost.

A most important and interesting 'unintended consequence' of the efforts that we all put into the walk was the great increase in awareness that it generated. Last year's survey of our readers clearly indicated that community recognition was a top priority for our members. Supporting the Unity Walk required each of us to interact with our friends, family, workmates, and acquaintances in a manner that highlighted our Parkinson's – it was a way of saying "Hello world, I am here!" Their response was a resounding "Now we that we know you need us we will support you!"

We are beginning to see the effect of professional PR assistance in the flow of stories, TV appearances and magazine articles that are appearing. In a steep learning curve we soon found out that the lead time for a story in the press was about two to three times longer than anticipated!

Now I am calling on all of us to accept responsibility, each in their own way, for raising awareness of the realities of PD. We must ensure that PD stays firmly in the public domain to give us the potential to break the stalemate for Government recognition and consistent recurring funding.

There are many ways for you to stand up and be counted. The walk experience showed how far the ripple effect can reach. Everyone who participated saw this, as friends and 'friends of friends' were drawn into the circle. How easy it was! Each of us is different, so pick the way for you, but do something so another person becomes aware of your condition:

- Acknowledge your PD
- Speak up at a family function and ask the rest of the family to spread the word
- Tell some one you know with PD about PNSW's services
- Join our speakers' group
- Volunteer to help at support groups or the PNSW office
- Attend your first support group meeting
- Attend a seminar
- Write to your local member regarding Parkinson's issues
- Write poems or articles about PD
- Tell a new acquaintance

**Do Something** – I am asking all of you in your own way, to pick up the cudgel and spread the word.

There is a lot happening over the next few months in the Parkinson's world. We begin with Awareness Week in September and two PNSW functions at Parliament House. In October Parkinson's NSW will host Parkinson's Australia's National Conference and I look forward to seeing as many of you there as possible. And don't forget 'Putting for Parkinson's', our annual golf day in November.

Welcome to spring!



John Silk

## Australia's 1st Unity Walk for Parkinson's

Sydney Olympic Park, Sunday 31 August 2008

The weather cleared just in time and the throng began to arrive at the Overflow, Sydney Olympic Park; some courtesy of the free transport kindly provided by the State Government and **Transport Minister John Watkins**.

Each walker was handed their Unity Walk t-shirt, and then it was off to have a snag at the **Lions Club BBQ**, munch on a delicious **Krispy Kreme** doughnut, send a hero message to a Paralympian via **Telstra Big Pond**, visit a sponsor tent, have their face painted in their favourite team colours or just wait until midday ticked over and the Unity Walk commenced.

League greats **Steve Mortimer** (Bulldogs) and **Brian James** (Souths) joined young Parkinson's sufferer **Nerissa Mapes** at the balloon festooned starting line. The honour of cutting the ribbon went to former Panthers NRL star **Brett Lobb** who, like Nerissa, was diagnosed at the young age of 32. Then the 1,000 plus walkers set off to on the 4kms around the Olympic Park stadia; some in their Unity Walk t-shirts, and others in their NRL team colours. It gladdened the hearts of people with Parkinson's to look back from the leading bunch and see a train of walkers stretch 400 metres long.

Half way around the course, **Presenting Sponsor, Bendigo Bank**, provided a drink station which ran dry before the last walker had passed. Less than one hour from the start, the first of the Unity Walkers arrived back at the start/finish and moved on to collect their bag of goodies and be entertained by rock band **'My Future Lies'** - unplugged. Lead singer Lukey, whose father and grandfather contracted Parkinson's donated his services and sales of the band's CD, whilst **Krispy Kreme, Lions and Telstra Big Pond** donated their proceeds.

Many stayed for lunch, soaking up the good music and talking in little communal gatherings, especially our **Support Groups** who had come from as far away as Coffs Harbour, Port Macquarie, Wellington, Dubbo, Cowra and the south coast. There was especially strong representation from the St George and Kuringai areas.

The top corporate fundraising team, **PD Fit from the University of Sydney** enjoyed a catered corporate box at the St George/Eels game. **Ella Martin** won the giant plasma TV screen from **Harvey Norman** for having her registration and money in by August 25, and as we go to print we are still awaiting the announcement of the top individual fundraiser who will be off on a six day holiday to Hawaii, staying at the magnificent **Sheraton Keauhou Resort and Spa** courtesy of **Hawaiian Airlines and the Sheraton**.

It was a hugely successful day, especially when compared to the first American Unity Walk which drew just 200 to New York's Central Park.

A special thank you to all our volunteers, our sponsors, support groups and you for making Australia's First Unity Walk such a resounding success.

*Thank You Sponsors:*

**Presenting – Bendigo Bank**

**Supporting – Telstra**

**Hawaiian Airlines; Sheraton Keauhou Resort & Spa; Medtronic; NRL; ANZ Stadium: SOPA; Novotel & Ibis Sydney Olympic Park; Krispy Kreme Doughnuts; Harvey Norman; 2GB; Pharmacy Guild of Australia; Artisse Organic Food Bars; Sunday Telegraph.**



## CEO's Report

Dear Friends,

I would like to update you on recent and upcoming activities.

### Parkinson's Accredited Speakers Program

The Accredited Speakers Program was launched on Thursday, 31 July at our North Ryde office.

Doug Malouf, a gentleman living with Parkinson's and a member of the DBS Network (Support Group) has been instrumental in the establishment of the program. Brett Lobb, an ex-NRL Panthers player is the Chair of the program.

Doug has been both an international speaker and author, and is the CEO of a high profile training company, DTS International. He now works with many people every year on the international public circuit, and has authored 8 books and 5 audio cassette programs. Doug also shows people how to improve their performance, sales, management and communication skills.

Training for those interested in taking part will be offered by Doug's team. Program members will receive a PowerPoint presentation to assist with raising awareness. If you would like to take part in the Accredited Speakers group please call the 1800 644 189.

### Awareness Seminar

Our September Awareness Seminar this year was Parkinson's Management: "A Team Approach" which was held at State Parliament House. The Seminar featured the role of allied health staff from the Concord Parkinson's clinic, Janine Rod our Parkinson's Specialist Counsellor, and Carlene Smith, Pharmacist from the NSW Pharmacy Guild. Joan Perkins, the physiotherapist on the Concord team led a fun session on Tai Chi. Presentations from the seminar will soon be available on our website.

### Unity Walk

Our first ever unity walk was such an exciting day. The publicity leading up to the event was fantastic in raising awareness. Brett Lobb, ex NRL Panthers player who has PD, was featured on morning television along with Nerissa Mapes, a young woman diagnosed with Parkinson's Disease. With almost 1,000 walkers on the day and despite the threatening rain, our Parkinson's community felt very supported. It was great watching the sea of white t-shirts stretching way down the road as the walkers proceeded around the Olympic precinct. Some walkers had traveled from Wellington NSW, Coffs Harbour, Port Macquarie, Cairns and other locations. Our support groups from across NSW were well represented.

Many people with Parkinson's achieved their personal best, having completed the 4km walk.

Participants were entertained by "My Future Lies" a modern band. The lead singer's dad and the base player's Nan have Parkinson's.

### National Conference

Our next big event will be the Parkinson's National Conference at the Novotel Olympic Park on 16 and 17 October. This is the first national conference in Sydney for many years, and is a unique opportunity to hear from local and interstate researchers and clinicians. It will be a great opportunity for people living with Parkinson's from across Australia to find out more and ask questions. During the Conference you will be able to try out Tai Chi and gentle exercise. Please call 1800 644 189 now to find out more. Looking forward to seeing you there!

Yours in Parkinson's friendship,

Miriam

## Coffee Information Morning

Come and meet staff and volunteers at Parkinson's NSW

Talk to people living with Parkinson's  
10.30am start – 25 November 2008

25 Khartoum Road, North Ryde

RSVP – 18 November 2008

**Ph 1800 644 189**

## Diary Dates

### OCTOBER

16 & 17 National Parkinson's Conference  
"Reaching for Our Goals"

### NOVEMBER

13 Putting in for Parkinson's Golf Day  
25 Information & Coffee Morning Tea  
29 Volunteers "Thank You" Christmas Lunch

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



The University of Sydney,  
Faculty of Medicine

## Volunteers Required for Nerve/Muscle Research

We are conducting a study on nerve activity in Parkinson's disease. The test uses small electrical pulses to stimulate nerves, takes approximately one hour and has no lasting effects on your nerves.

If you would like to participate, you will need to attend the laboratory at 92 Parramatta Road, Camperdown.

For more information please call  
Stacey on 0409 405051.

## Research

### **MORE THAN BRAIN DONATION – PARTICIPATION IN CUTTING EDGE MEDICAL RESEARCH INTO PARKINSON’S DISEASE**

*From the Prince of Wales Medical Research Institute’s Tissue Resource Centre*

*By Glenda Halliday (Director) and Heather McCann (Manager)*

Have you ever wondered how an “everyday” person can participate in state-of-the-art medical research looking into Parkinson’s Disease and other Parkinson’s-like syndromes? By becoming a brain donor, individuals become an integral part of the research process. The Brain Donor Program at the Prince of Wales Medical Research Institute accepts donors with many different neurological diseases: movement disorders such as Parkinson’s disease, progressive supranuclear palsy, multiple system atrophy, corticobasal degeneration, Huntington’s disease and dementia disorders including Lewy body dementia, Alzheimer’s disease and frontotemporal dementia. Of course, unaffected subjects are also highly regarded as all research projects need to compare their affected cases with unaffected ones for a study to be valid.

At the Prince of Wales Medical Research Institute, we have been able to complete and internationally publish the following types of research studies, but only with the assistance of people with Parkinson’s Disease and Parkinsonian syndromes:

- Research projects identifying the localisation and severity of cell and tissue loss (atrophy) in the brain are used to determine the areas of focus of the disease process;
- We have comprehensively studied the dopaminergic systems, revealing that only one of the three main dopamine regions is vulnerable to Parkinson’s Disease, suggesting that neuronal dopamine synthesis per se is not causative;
- Counting of the cells in another major regulator of corticostriatal activity, the intralaminar thalamus, found that cell loss occurs here early on in the disease process;
- Regional brain atrophy studies revealed hippocampal and frontal atrophy associated with Lewy bodies in cortical regions, prompting further neuropathological studies on diffuse Lewy body disease and studies to determine associated clinical features.

These studies led to our participation in the initial International Consortium on Dementia with Lewy bodies and in the new international diagnostic criteria for dementia with Lewy bodies (now with significantly changed pathological criteria). We described the first case of corticobasal degeneration in Australia, and performed a number of studies comparing the pattern of cell loss between progressive supranuclear palsy and Parkinson’s Disease.

These studies on progressive supranuclear palsy revealed more substantial neuronal loss in basal ganglia output regions, with eye movement problems correlating with the degree of neuronal loss in the substantia nigra pars reticulata. Regional brain atrophy studies showed that the degree of pallidal atrophy related to the onset of falls, and that more substantial frontal atrophy occurred in progressive supranuclear palsy compared with Lewy body disease, with this atrophy relating to the severity

of dementia in progressive supranuclear palsy. In Lewy body dementia, we found that the severity of both cortical Lewy bodies and amyloid plaques related to the severity of dementia. Increased densities of Lewy bodies in the amygdala and temporal cortices were found to be related to the presence of well-formed visual hallucinations.

Our imaging studies showed abnormalities in the substantia nigra in association with motor slowing prior to the onset of Lewy body disease, and current analyses suggest significant early dysfunction of the presupplementary motor cortex. Linking clinical symptoms with cell and tissue loss enables researchers to not only better understand the cause-and-effect nature of the disease, but also concentrate their future efforts on certain regions of the brain.

The assessment of clinical symptoms in disease is also important in early detection, diagnosis and treatment. Using clinical assessments of non-motor symptoms in Parkinson’s Disease, we confirmed early, selective olfactory deficits (average onset 1 year prior to motor symptoms), but later sleep disorders (average 3-5 years after motor onset). A simple test of visuospatial skills did not prove predictive for dementia.

We have also been working on the development of objective diagnostic tests for Parkinson’s Disease with Dr Kay Double, a researcher at the Prince of Wales Medical Research Institute. Treatment-focused studies include the identification of a novel immune mechanism that is important for the late neuronal targeting for degeneration in Parkinson’s Disease. Studies on multiple system atrophy showed that pallidal stimulation may be beneficial for certain patients, and identified an early protein change in myelin could be targeted for treatment. Neurosurgery is one of the current treatment options for severe movement disorder and an assessment of its impact showed limited neuronal consequences unless placed in a region of ongoing neurodegeneration (when it increases such degeneration).

Other collaborative studies with Dr Double include identification of early changes in the neuromelanin within the substantia nigra dopamine neurons and detailed studies to determine important characteristics of neuromelanin. Studies to determine changes to neuromelanin in Parkinson’s Disease associated with transition metals and oxidation are ongoing.

In more recent years we have performed a number of genetic studies on Parkinson’s Disease and Lewy body dementia. We characterised the first Australian family with the A53T  $\alpha$ -synuclein mutation and have participated in the national collections of clinical and genetic material for research studies (the Australian Parkinson’s Project).

Our genetic studies identified the prevalence of autosomal dominant mutations in Australians with Parkinson’s Disease, and that genetic anticipation (the disease affecting subsequent generations at an earlier age) is common. Several families with autosomal dominant disease were identified following genetic

## **MORE THAN BRAIN DONATION – PARTICIPATION IN CUTTING EDGE MEDICAL RESEARCH INTO PARKINSON’S DISEASE** *continued*

screening of patients with Lewy bodies in the Brain Donor Program.

To assist with further genetic studies, 46 families have been identified for detailed examination. Specific genetic anomalies that may decrease the age of onset and increase or decrease the risk of developing Parkinson’s Disease have been found. Our most recent unpublished findings have come from examining the proteins implicated in hereditary forms of Parkinson’s Disease: a-synuclein, parkin and LRRK2. Higher levels of these proteins have been found in the glia, which are the support cells of the brain, rather than the neurons as was expected. This would help to explain the relatively slow progression of most cases of Parkinson’s Disease as the support cells are more able to adapt to the build-ups of abnormal proteins than the more sensitive neurons (they have the ability to move around and clear toxic substances). This may have implications for the cells to be targeted in the development of future treatments.

As you can see, only by collaboration between our research teams and people with Parkinson’s has it been possible to determine some of the mechanisms behind this disease and search for possible ways to improve treatments or even perhaps find a cure in the future. We currently have approximately 150 people with Parkinson’s actively participating in our research studies, and over 150 people with Parkinson’s who have already donated their brain tissue after death. A lot can be achieved when individuals decide to assist us with our Brain Donor Research Program.

Once an individual decides to become a brain donor, they are asked to fill in questionnaires providing us with information on past and current health and lifestyle

as well as family history of neurological disorders. Any family doctors or medical specialists are also contacted to provide their opinions and medical data. Histories are updated at regular intervals to ensure that information remains current and to know what is happening to people over time.

The point of all this tedious paperwork is to be able to look at the many variations that occur in individuals with the disease, so that we can then identify the underlying causes of those variations. It is also essential to have this information to be able to make a final diagnosis after death. Which brings us to the “D word”. One other reason for us asking lots of personal details upfront is so that when the time comes, the actual brain donation can be carried out with minimum disruption to the activities that normally occur upon the death of an individual. Our aim is to not add to any of the distress that family and friends are feeling. In fact we hope that the knowledge that breakthroughs are being made may help alleviate some of the sorrow.

To maximise the use of the very valuable brain tissue that we store for research, the Prince of Wales Medical Research Institute holds many of our samples in a Tissue Resource Facility. Here tissue samples are fixed in formaldehyde in the conventional way but also held frozen for biochemical and molecular studies and DNA extracted and stored for future use. Researchers from around the world, after satisfying strict ethical criteria, are able to request samples for use in their studies. So not only can becoming part of the Brain Donor Program help with Australian research into Parkinson’s Disease and similar disorders, but it may become part of a global effort to help improve the understanding of these life-changing diseases.

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## **BRAIN DONOR PROGRAM PRINCE OF WALES MEDICAL RESEARCH INSTITUTE, RANDWICK NSW AUSTRALIA**

*by Heather Grimmett*

It was not a difficult decision to make, to authorise my husband’s brain tissue to be donated to research following his death in February 2008.

My husband had severe Parkinson’s Disease for 15 years. His grandfather had it and an older brother of Michael’s has it. My mother and three of her siblings had died with Parkinson’s Disease and recently a first cousin was diagnosed with it. I also have a number of close friends who suffer with this disease.

You could say that I have been surrounded by Parkinson’s Disease since I was 10 years of age.

It was because of this that I felt an urgent need to support the research into this debilitating disease and other neurological diseases in our society. While my husband and I were keen to donate our bodies for research, and we had never discussed brain tissue donation, we did not have the brain tissue donation in place at the time of my husband’s collapse.

### **How Did I Go About the Procedure?**

I was able to speak to my husband’s neurologist and

Parkinson’s specialist nurse about the program and I duly procured the necessary forms.

From the outset I was impressed with the sensitivity of the letters from the professors who manage the Brain Tissue Donation Program at the Prince of Wales Medical Research Institute in Sydney. The forms were clear and straightforward. Assistance was given to simplify the process for the donors. Letters were already prepared and supplied to send to the local doctor and specialist to release medical information to the program and for them to receive the results of the microscopic and macroscopic reports, thus minimising the work for the donor’s family.

The procedures for advising the hospital, and for me to carry out at home should my husband die at home, were very clear. You need to advise your funeral director and your local doctor of the need to comply with the requirements. Again this was set out clearly in the donor program correspondence.

There were other comprehensive questionnaires to be completed after the donation. Once again they were clear, and gave you an opportunity to add anything you wished

**BRAIN DONOR PROGRAM****PRINCE OF WALES MEDICAL RESEARCH INSTITUTE, RANDWICK NSW AUSTRALIA** *continued*

to add about the person's health and symptoms, that you had observed and noticed over the years of caring for them.

I was particularly impressed to know that I would receive reports of the findings within three months of the donation. The promise was duly fulfilled and clear comprehensive reports were provided.

With the reports was a letter which provides a phone number you can ring if you wish to ask questions about the reports. I was again impressed, when I rang that number, and was able to speak directly with a Senior Professor within the program.

The costs for Brain Tissue donation were cost neutral to the donor's family, they were covered by the Research Institute.

At all times the program personnel expressed their gratitude for the brain tissue donation.

I recommend this remarkable research program to you. It would be much easier to put these plans into action while you are well enough to make the decision to donate, if you feel that you can, than before you are faced with a critical situation.

We need to continue research for a cure and a cause for the many neurological diseases that are prevalent in our community, which create such suffering and distress to so many people around the world.

If you wish to become a brain tissue donor contact the Prince of Wales Medical Research Institute, Barker Street, Randwick NSW 2031 Australia or PO Box 82 St Pauls NSW 2031 Australia. Telephone: 61 02 9399 1000, Facsimile: 61 2 9399 1005 or visit the web site at <http://www.powmri.edu.au>

**Personal Best** *by Linda Christison*

It is an Olympic year and the media has turned its attention to athletics, swimming and other quadrennially famous sports, every athlete is a medal hope. I know the press are fickle and will soon judge these potential heroes harshly, but I enjoy this pre-Olympic hype, it reminds me of the optimism of marathon eve, and although reality seldom meets expectation, that does not diminish the delights of anticipation.

The TV counts down to the Beijing opening with memorable moments: Cathy Freeman's slight frame carrying Australia's dreams an archer's flaming missile against the night sky and then Muhammad Ali, a symbol of determination and concentration as he struggles to control his arm tremors to light the Olympic Cauldron, the commentator's voice full of emotion as he describes Ali's battle with Parkinson's Disease.

I watch transfixed, even though I have seen this footage many times before, but now Ali's story is mine. I flex my fingers, tonight calmly at rest, and reflect on the Athens Olympic Games which are linked in my memory to my diagnosis with Early Onset Parkinson's Disease, and to the end of my own pursuit of personal bests. I watch Ali and tell myself how well my medication is working, and how all my friends say I don't look any different - but I also know that appearances are deceiving.

I am different to my pre PD self. I write like a five year old and stumble without my medication. I sleep just a few hours a night and could write a thesaurus for the word tired. Sometimes my food falls off the spoon, my keyboard hand stutters and my muscles become painfully rigid. My body has its own agenda, and it is a waste of time becoming irritated or impatient with its decisions. I am not the person who ran 64km in a training run, or regularly counted off 13 x 1km, my Boston Marathon is a memory and my marathon goals have changed.

I am more patient than I used to be, and I am grateful for the opportunities I have had in the past and what I can still do. I take nothing for granted. I am stunned by the continuing generosity of people - friends, family, work colleagues, the Parkinson's community, strangers... modern society is often said to be uncaring, but I have found unstinting support. There will be good and not so good days, but I know there are still happiness, adventure and success to be lived.

To our athletes please be proud of what your bodies can do, make the most of every opportunity, but find pleasure in the attempt rather than results that may or may not meet your expectations. Don't measure yourself against the standards of the press or gold medal ghosts. Every action you perform is a small miracle and a gift that should not be scorned.

If just for a few hours my co-ordination was restored and I could run smoothly and not jerk or stumble, I would not wear a stop watch or draw a finish line or see myself through another's critical eyes. I would run until I burnt the feeling of running into my soul forever, and the memory was mine and could not be erased and I would be proud of every beautiful step.

## On the groupvine *by Trish Morgan*

August visits to support groups in stunning coastal areas.

**Tomaree** support group in Port Stephens has new leaders - Heather Grimmett, Ann Canham and Margaret Ball. The meeting was well set up with microphones and projector for an excellent presentation about the local community transport service. Ian Canham, long term President, will provide support to the new Committee. Ian, his wife Ann and Patricia May, who has led the group on her own for the past 18 months, are typical of the great volunteers who maintain support groups. The future looks bright for Tomaree with six new members responding to advertising and contact with other community organisations.

**Port Macquarie** support group came together for lunch in Panthers Coffee Club. Members feel positive about the group which is led by Pat Stephenson. The "Facing the Future" seminar in June drew 70 people and brought new members to the support group. They were keen to hear about the Unity Walk, Awareness Week with its community service announcements, the new poster and the National Conference. Regional 'walks' were suggested for next year's Unity Walk.

**Manning/Great Lakes** support group meet on the last Monday in the month in the Baptist Church Hall at Forster. Members enjoy the monthly quizzes sent with the newsletter and will travel from Taree, Gloucester and Wingham to win a chocolate. A grant of \$300 from the Great Lakes Council and the skill of a member of the Baptist Church produced a display cabinet on wheels for brochures, books and videos. Well done to all for raising \$200 for the Cancer Council at the Biggest Morning Tea. Members are keen to buy the latest Christmas cards and plain cards showing a field of tulips and the Parkinson's rose.

### New Groups:

**Blacktown** support group started on a very wet Thursday - 24 July, at Glenwood Community Centre. The meeting was well supported by members of Dundas-Parramatta support group and the Young Men's Parkinson's Network. Several local residents were keen to be involved in a support group and the venue was very suitable. Dr Neil Mahant, neurologist from Westmead Hospital, addressed the August meeting on the medical and surgical management of PD. People came from The Hills, Plumpton, Seven Hills, Silverdale, Glenwood and Blacktown. Members were impressed with Dr Mahant's 'down-to-earth' approach which helped to dispel some of their concerns about treatment regimes. Blacktown support group meets on the 4th Thursday of the month at 10am. Ring 1800 644 189 for information.

**Ultimo** support group was born on 4 June at the Ultimo Community Centre, corner of Harris Street and William Henry Street. The members came from the local area and staff of the University of Technology. Chris Davis, Vice-President of PNSW, and Gerald Ganglbauer will share the leadership of the group. Numbers are small but the group was very fortunate to have Dr Simon Lewis, Neurologist from Royal Prince Alfred Hospital, speak at the second meeting about the different drugs available for Parkinson's Disease. Gerald is promoting the group through 'The City News' and as a member of the community centre. The Ultimo support group meets on the 1st Thursday of the month at 10.15am.

### Support group snippets!

**Shoalhaven** support group will visit **Eurobodalla** (Moruya) support group in October, and they donated to the Unity Walk.

**Eastern Suburbs** reports that the Parkinson's Clinic at War Memorial Hospital, Waverley, is going well, with information and therapy programs provided.

**Bingara** support group raised over \$600 towards the Unity Walk from the raffle of a State of Origin jersey. Well done!

**Tweed Heads** support group held a mini seminar with Neurologist Dr Geoffrey Boyce in August, with donations to the Unity Walk.

*Thank you* to all our support group members who supported the Unity Walk!



*Coffs Harbour and Nambucca Valley Support Groups at Unity Walk.*



*Fairfield-Liverpool Support Group at Unity Walk.*



*Goulburn Support Group at Unity Walk.*

Unity Walk Photos can be viewed -  
<http://www.parkinsonsnsw.org.au/assets/attachments/events/UnityWalk2008/>

## Verlie's support



Verlie Sullivan has been recognised in the 2008 Queens honours list for service to people and carers of Parkinsons disease with an Order of the Medal of Australia (general division).

Verlie Sullivan would rather be back stage than in the spotlight. But when you start a Parkinson's support group, and have remained its president for 24 years, you can hardly expect to stay backstage forever. But at 79, she has no plans to quit the group.

Mrs Sullivan's late husband, Geoff, was diagnosed with Parkinson's disease when he was 55. With no local support, they went to the NSW Parkinson's Association in Parramatta. On the drive home, Mrs Sullivan decided that she would start a support group in Newcastle. And so she did.

In July 1984, Mrs Sullivan advertised for people living with Parkinson's to come and share their story over a cup of tea. About 15 people came along and so the support group started. The group, now numbering 50 regulars, meets monthly at the Charlestown Multi-Purpose Centre.

Mrs Sullivan's role has included providing support for members; visits to nursing homes; connecting with patients at the Parkinson's Exercise and Evaluation program at Rankin Park Day Hospital's Parkinson's Clinic; raising funds for Parkinson's NSW Inc and raising awareness of Parkinson's disease. She is also a life member of Parkinson's NSW Inc.

A few years ago the support group helped to secure a Parkinson's specialist nurse at John Hunter Hospital.

Mrs Sullivan is quick to tell you that none of this would have been achieved without the support of family and friends and the wonderful people at the support group.

"It has been my dream come true to help people with Parkinsons and their carers.

It's the people who make it all worthwhile."

*With thanks to "The Star" and Nellie Hejduk, journalist for permission to reprint this story. (Abridged)*

## Pioneering Parkinsonian



Mr McWilliam was awarded the Medal of the Order of Australia (OAM) for service to the community in the Queen's Birthday honours.

When Peter McWilliam was diagnosed with Parkinson's disease on his 50th birthday in 1992, he turned to Parkinson's NSW for information, counselling and support. In gratitude, two years later the Pennant Hills man became a volunteer with the not-for-profit organisation, and has since gone on to devote the last 14 years to Parkinson's NSW and other Parkinson's support groups. Mr McWilliam (pictured above) started *Parkinson's Australia Magazine* and helped establish the Parkinson's Australia website and the support group 'Speeding Vibrations'. Mr McWilliam told the *Advocate* he hoped a cure would be found. "Failing that, more government funding is needed for services for Parkinsonians," he said.

"I consider it a recognition of the work done by all the support groups and volunteer staff," Mr McWilliam said.

*With thanks to the "Hornsby Advocate" and Steve Graham, journalist for permission to reprint this story.*

### Young Men's Parkinson's Network

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](mailto:Cearn@netspace.net.au)

## Important safety information about Cabaser

Pfizer Australia has informed us about important safety changes to Cabaser® (cabergoline) in the treatment of Parkinson's Disease, and the availability of one of the strength variants. These changes will come into effect on 1 November 2008.

The safety changes are due to an ongoing review of clinical studies that looked at the development of serious side effects affecting the heart, lungs and kidneys in patients taking certain medicines, including Cabaser, for Parkinson's Disease.

These serious side effects are not new, but are more likely to occur when taking Cabaser at higher doses and for a prolonged period. It is expected that the chances of experiencing heart valve, lung and kidney problems will be reduced by limiting the maximum daily dose of Cabaser.

The maximum daily dose of Cabaser will therefore be reduced from 6 mg a day to 3 mg a day, and patients will no longer be prescribed the 4 mg tablets from 1 November 2008.

**Cabaser 1mg and 2 mg tablets are not affected by these changes and will continue to be available on the Pharmaceutical Benefits Scheme. Cabaser remains an important treatment option for patients with Parkinson's Disease and Pfizer Australia is committed to patient safety.**

Pfizer Australia is letting healthcare professionals know about these important changes.

If you are taking Cabaser please see your doctor to discuss the best treatment options. If you are unable to see your doctor before 1 November 2008, you should continue taking Cabaser tablets as you would normally until your doctor reviews your treatment.

The Consumer Medicine Information for Cabaser advises that Cabaser may cause heart valve problems or may affect lung and kidney function. It also states that it is important that patients have the tests that their doctor has ordered while they are taking Cabaser. These tests include chest x-rays, physical examinations, blood tests and heart monitoring. Further information on these tests is included in the Consumer Medicine Information.

If you wish to seek further clarification of the information contained in this article, please contact your doctor, pharmacist or Pfizer Australia Medical Affairs on 1800 675 229. A copy of the **revised** Consumer Medicine Information for Cabaser will be available from pharmacists on 1 November 2008.

### Speeding Vibrations

YOUNG ON-SET NETWORK

Planning a luncheon in November  
at Woy Woy

**ALL WELCOME!**

Please ring Trish Morgan for details  
02 8875 8900



### 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
- Medication Reminders
- Transport
- Respite & Convalescence Care
- Early Stages Dementia and Alzheimer's Care



[homeinstead.com.au](http://homeinstead.com.au)

Sydney North West: (02) 9816 1599  
Sydney Northern Suburbs: (02) 9144 2322  
Sydney Eastern Suburbs: (02) 9387 4800

## Special Thanks



The Penrith Taxation Office Sporting & Social Club held a Trivia Night on Friday 16 May 2008 with proceeds from the night going to the Parkinson's NSW Nepean Support Group. Joe Golding, who heads up the support group, fielded the aptly named team Movers & Shakers. While they didn't finish among the placegetters, they had an enjoyable night and, according to Joe, are still coming up with the answers.

Thanks to Jeff Townsend from Penrith RSL who organised for the room to be provided free of charge. Of course, helping to make the night a success were local South Penrith businesses, Ardi from Car Surgeons in South Penrith who donated two free car services, and Betta Electrical who donated a DVD player. Special thanks to the Tax Office Social Club committee and staff who organised, and attended and made the night a success. The end result saw the Nepean Support Group presented with a cheque for \$939.20.

## Donations

### \$50 and over received between 1 June 2008 and 31 August 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.

#### IN MEMORIAM

Mr Bell  
 Patricia Blake  
 Martin Blake  
 Bunny Bradley  
 Beatrice Bunn  
 William Burrows  
 Betty Cameron  
 Brian Campbell  
 Alan Canings  
 Peter Darton  
 Maureen Dening  
 Frank Finlayson  
 Hugh Floyer  
 Phylis Hotz  
 John Hynard  
 Nita Laing  
 Brian Lamont  
 Alan Leitch  
 Cyril Long  
 June Mackie  
 Robert McGarvey  
 Shirley Middleton  
 Helen Morris  
 David Muller  
 Roy Norman  
 Joan O'Donohue  
 John O'Kane  
 Mamas Polycarpou  
 Pasquale Prete  
 John Ryan  
 Ronald Scobie  
 Alex Shaw  
 Michael Shying  
 Tom Silva  
 Barrie Stewart  
 Antonino Tesoriero  
 Piera Verzeletti  
 Ross Wagstaff  
 Molly Walker  
 Sidney Wheeler  
 Aubrey Winton  
 James Wright  
 Robert Young

#### DONATIONS WERE RECEIVED IN CELEBRATION OF:

50th Birthday of Katie Thornton  
 60th Birthday of John Milston  
 60th Birthday of Hedy Parady  
 70th Birthday of Faye Moran  
 The birthday of Melanie America

#### SUPPORT GROUPS

Cowra Parkinson's Support Group  
 St George/Sutherland Parkinsons Support Group  
 Wagga Wagga Parkinson's Support Group  
 Canterbury Parkinson's Support Group

#### DONATIONS

Helene Anderson  
 Alan Baikie  
 Walter Bailey  
 Lucy Baldry  
 Norma Rae Barker  
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 Ken Beenie  
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 Barry Snowball  
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 Katie Thornton  
 Mavis Thorpe  
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 Vince Vetrivano  
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 Anthony White  
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 Marie Williamson  
 Terry Zadro

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 Edmond Antaki  
 Bernard Atkinson  
 John Bamford  
 Peter Baulman  
 Shirley Beckett  
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 Peter Yeend  
 Doris Yum

## Special morning tea

by Margaret Byron, Bequest Officer

Some Very Special People enjoyed a sponsored Morning Tea in the Jubilee Room at State Parliament House on 4 September. Amongst the Very Special People were those who have made a bequest to Parkinson's NSW. We are so pleased to be able to acknowledge their generous giving and welcome them to *The James Parkinson Society*. This Society has been formed to recognise our valued supporters and is at no further cost to them. Some people prefer that their action remains anonymous and we respect this. If you have made a bequest to Parkinson's NSW or are considering it and need some questions answered, please phone me (Margaret) on (02) 9876 5351 any time between 8am and 8pm or ring 1800 644 189 and leave a message for me to contact you.

## Choice

by Deborah England, Parkinson's NSW Counsellor

I often think about the concept of choice. The choices we make can be quite simple, from what we put on to wear or what we'll have to eat, to more significant decisions that have greater consequences for us.

Sometimes, particularly when we don't recognise that we have a choice, it can distort our thinking. By this I mean, for example, a cause and effect sort of phenomenon. Let's say we say to someone 'He made me do it' or 'She makes me angry'. It implies that one person's behaviour can 'make' another person respond in a certain way. It certainly can elicit such a response, but only if the person chooses to let it happen. We can challenge this sort of thinking in ourselves, if we so choose, by asking ourselves some fairly easy questions. By asking ourselves exactly how one thing caused the other. By questioning how something happened and what other alternatives there were, we can begin to recognise our choices. It seems to me that a person is surrendering a lot of their personal power if they allow others to control their emotional state. Is it a reasonable expectation that someone else takes the responsibility for controlling how we are feeling?

To escape this trap is not to pretend to feel otherwise but to start looking at things differently. Upon reflection, we may discover that there is a different course of action that could be taken that may well have better emotional consequences for us.

We are free to choose how we perceive the world.

### Support for "Parkinson's Plus" Conditions?

PNSW would like to establish a register for people who have been diagnosed with Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), Corticobasal Ganglionic Degeneration (CBGD) or Dementia with Lewy Bodies.

Please ring Infoline on 1800 644 189, and help PNSW improve support services.

## 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
Bingara	Joan Bush	02 6724 1976
Blacktown		1800 644 189
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	Ian Parr	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	Angela Bortolin	02 6962 3289
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	Bill Lindsay	02 9949 3991
Manning/Great Lakes	Bruce King	02 6555 9409
Maroubra	Trish/Lyn	02 8875 8900
Nambucca Valley	Margaret Butcher	02 6564 8231
Narrabri	Janice Holmes	02 6792 1468
Nepean	Joe Golding	02 9670 5093
Newcastle	Verlie Sullivan	02 4954 0338
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	Heather Grimmett	02 4981 4853
Tweed Heads	Shirley Rushton	07 5524 9417
Ultimo	Gerald Ganglbauer	0411 156 309
Wagga Wagga	John Allen	02 6925 2713
Yass	Clarrie Schlunke	02 6226 4150
Young Onset	Trish Morgan	1800 644 189

**PARKINSON'S NSW INC.**

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

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# Parkinson's NSW Golf Day

**'PUTTING IN FOR PARKINSON'S'**

Proudly supported by Sydney Markets

*Money raised will go to the Parkinson's NSW Counselling Service*

Following on from the great success of last year's inaugural golf day, it is with great pleasure and excitement that Parkinson's NSW cordially invites you to our annual golf day and to **'Putt in for Parkinson's'**.

We had a significant number of Parkinson's players last year and we would like to see that number grow. Many who attended last year's inaugural event voiced their approval, commenting that it was one of the best golf days they had attended. We intend to keep up that standard, in fact exceed it. The proceeds will once again go to the Parkinson's Counselling Service; a vital service that helps take away much of the initial anxiety and uncertainty that confronts people with the disease, their carers and families.

Once again Virgin Atlantic is providing the "Hole in One" prize. Any golfer who jags a hole in one on the designated Par 3 will win 2 Upper Class return airfares to Hong Kong.

All players this year will have carts, courtesy of Yamaha, and in Monash Country Club you have one of the best courses you'll ever play on, so our goal is to ensure the day is a memorable one, lots of fun and that everyone walks away with something, including a broad smile on their face. As was the case last year, we will have a stack of prizes, fine food and hospitality provided by one of Sydney's finest golf clubs. Here are the details:

EVENT DETAILS	
When:	Thursday 13 November 2008
Where:	Monash Country Club, Powderworks Road, Ingleside
Cost:	Sponsorship Pebble Beach Platinum \$5000 Augusta Gold \$2,500 St Andrews Silver \$1,200 Team of 4 \$700 Individual \$200

EVENT TIMES	
11am	Registration, BBQ brunch
12noon	Ambrose Shotgun Start
6pm	Drinks, Dinner, Prizes, Auctions

**1800 334 533 [www.cromwell.com.au](http://www.cromwell.com.au)**

\* Dated 16/01/2007. Past performance is not an indication of future performance.



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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