



Stand By Me

New support group



Dr Sue Hodgkinson, Neurologist at Liverpool Hospital, with members of Parkinson's NSW at the public meeting to establish a Fairfield/Liverpool Parkinson's support group.

The Fairfield-Liverpool support group held its inaugural meeting on March 9 at Liverpool Hospital.

Late in 2005, Parkinson's NSW Council noted the lack of support groups in Sydney's western and south-western suburbs. It asked Council member Neil Sligar to be responsible for increasing support groups in this region.

Neil nominated Fairfield-Liverpool as the first target. Miriam Dixon, CEO, and Trish Morgan, support group co-ordinator, heard that people in the neurology unit at Liverpool Hospital had also identified a need for a Parkinson's support group. Planning toward the new group was shared between PNSW and Liverpool Hospital. Siobhan Langford, senior social worker at the hospital, led the hospital's involvement.

Seminar booked out!

Over 275 people attended the Parkinson's Awareness Seminar at Wagga Wagga, which was organised by the local support group under the leadership of John Allen.

People travelled from Nowra, Forbes, Albury, Griffith, Finley, Deniliquin, Cowra, Yass, Queanbeyan, ACT, Tumut and all points in between to the seminar.

The Mayor of Wagga Wagga, Kerry Pascoe, officially opened the seminar and spoke of the very successful activities of the support group.

Three top speakers were flown in from Sydney (courtesy of Rex Airlines) to join Wagga Wagga's local neurologist. The presentations covered four main topics.

Dr Mahant gave an introduction to Parkinson's disease –

Liverpool Hospital neurologists were told of the planned Parkinson's support group meeting. Fairfield Hospital and Liverpool City Council were also informed. Three articles, along with photos, appeared in the local press.

Around 50 people, including about 25 people living with Pd, gathered at Liverpool Hospital for the first meeting of the Fairfield-Liverpool Parkinson's support group. Parkinson's NSW President, John Silk, welcomed those attending. Trish Morgan described how support groups operate, indicating that activities differ according to members' preferences.

Miriam Dixon outlined features of Parkinson's disease, highlighting and dispelling myths that have grown about the condition. Miriam described how Parkinson's NSW keeps members informed about developments relevant to people with Pd.

Siobhan Langford discussed the network of social workers, occupational therapists, and other medical specialists at the hospital. This considerable resource would be available to provide information to the Fairfield-Liverpool Parkinson's support group.

Dr Sue Hodgkinson, head of Neurology at Liverpool Hospital, spoke generally about Parkinson's medication and its interaction with food. Whether or not to take L-dopa with food, and L-dopa's interaction with protein, was of great interest to attendees. Sue mentioned that her mother has Parkinson's disease.

Those present elected to meet at Liverpool Hospital on the second Monday of each month at 10.30am. The availability of a room at this time is still to be confirmed. All members will be advised. It was agreed that the first meeting of the Fairfield-Liverpool Parkinson's support group had been a great success.

what to look for and what to do about it; Professor G Halliday spoke on current research on Pd; special Pd clinical nurse instructor, Laraine McAnally, spoke on the aspects of caring for the Pd patient; and Wagga Wagga's local neurologist Dr M Jude's presentation looked at medical therapy – the why, what, when and how.

Features

- Meet Parkinson's NSW new council members page 2
- Latest research news page 4
- Workshop and support group for adult children of PLWP page 8

DIARY DATES/SPECIAL EVENTS

- April 11** **World Parkinson's Day**
(Tuesday)
- June 7** **Coffee Morning** at Concord (Building 25)
(Wed 10.30am)
Come and meet staff and volunteers of Parkinson's NSW and talk to others living with Pd
- June 23** **Parkinson's Fundraiser**
(Friday)
Organised by the Chinese community.
Tickets through Parkinson's NSW
\$60 each (table of 10) 7.00pm for 7.30pm
- August 23** **Coffee Morning** at Concord (Building 25)
(Wed 10.30am)
Come and meet staff and volunteers of Parkinson's NSW and talk to others living with Pd
- Sept 4 - 10** **Awareness Week**
- November 8** **Coffee Morning** at Concord (Building 25)
(Wed 10.30am)
Come and meet staff and volunteers of Parkinson's NSW and talk to others living with Pd

COUNCIL

John Silk
President

Allen Cropp
Vice President

Peter McWilliam
Treasurer

Dick Babb
Secretary

Council Members

Margaret Byron
Patricia Barkley
Dr Kay Double
Bruce King OAM
David King
Dr Sarah Mott
Rebecca Silk
Neil Sligar
Robert Young

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Gabrielle Chariton
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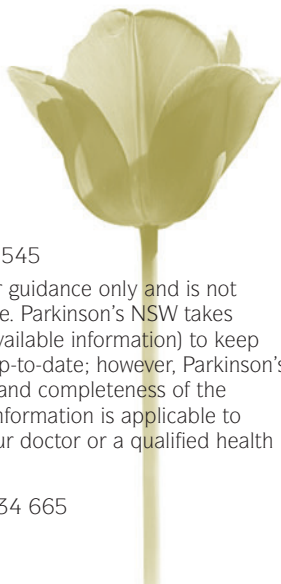
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Disclaimer: The information provided is for guidance only and is not a substitute for professional medical advice. Parkinson's NSW takes reasonable care (in the context of freely available information) to keep the information it provides accurate and 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.

Designed by New Age Graphics – 0412 334 665



President's report



Hello everyone,

As I begin to write my first message to you, the 'wish list' presented for your consideration before the last election is uppermost in my mind. Papers, notes and lists of things to do surround me. A scant two days after the AGM, the Executive met to look at the budget and to begin formatting strategies to present to Council for the coming year.

The Councillors are considering their areas of interest and expertise and our first Council meeting will see the establishment of new sub-committees for Support Groups and Fundraising to pursue and develop ideas.

It was with great pleasure that the CEO and I attended the opening meeting of the Fairfield-Liverpool Support Group, an initiative of Councillor Neil Sligar. Well done, Neil.

I would also like to congratulate John Allen for the **outstanding success** of the seminar he organised in Wagga Wagga. You will find a full report on page 1, so let me just say, we have already budgeted to help other support groups present similar events during the year.

The enthusiasm and interest of the Executive and Council members has already established an atmosphere of optimism and co-operation. We hope to entice as many members as possible to share their skills with us.

This edition of *Stand By Me* goes to press with a new team at its helm. Welcome to Gabrielle Chariton. Volunteering to use her expertise for Parkinson's NSW, while holding a full-time job, is more than appreciated. Our thanks to Gabrielle and to our CEO and the team at Head Office for the 'new generation' *Stand By Me*.

Here's to a productive year ahead for Parkinson's NSW!

Thank you for making me your President.

John

Parkinson's NSW Council Members 2006

John Silk – President



John is a husband, father, grandfather, friend, rugby fanatic, and three-times-a-week golfer. He hopes to provide the kind of constructive leadership to PNSW that engages as many members as possible. "We have a marvellous team on council and I'm looking forward to fully utilising their skills and ideas," says John.

Allen Cropp – Vice President



Allen obtained a senior management position in a major retail establishment, where he spent 26 years. He also operated as an international loss prevention consultant. Allen is married to Hiroe and has major involvement in the lives of his four talented grandchildren.

Peter McWilliam – Treasurer



Diagnosed with Pd on his 50th birthday in 1992, Peter retired on an ill health pension from the Reserve Bank of Australia two years later. Initially a volunteer with Parkinson's NSW, he was appointed first Treasurer then Deputy President before being elected President in 2001.

Dick Babb – Secretary



Dick Babb is married to Dorothy and they have two children and three grandchildren. He worked for the Commonwealth Bank for 40 years. He is a keen golfer, enjoys reading, gardening and travel.

Margaret Byron – Council Member



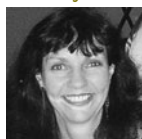
Margaret became involved with Parkinson's NSW through her mother-in-law, who was diagnosed with Pd thirteen years ago. Margaret has held all executive positions in her support group. She has a background in teaching and office administration.

Patricia Barkley – Council Member



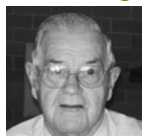
Patricia was diagnosed with Pd in 1995 and her husband was diagnosed in 2005. She has three sons and one granddaughter. Patricia, who promotes the Pd cause whenever and wherever she can, and will continue to do so as long as she is able, was recently named Shoalhaven Citizen of the Year at the 2006 Australia Day Awards.

Dr Kay Double – Council Member



Kay is a neurochemist at the Prince of Wales Medical Research Institute in Sydney, focusing on researching the causes of Parkinson's disease and developing new treatments. Kay also works to raise awareness of Parkinson's disease and the needs of PWP within the general community.

Bruce King – Council Member



Bruce, who leads the Manning/Great Lakes Support Group, spent his early years in the accounting profession, concluding as a Company Secretary. In 1958 he began service in the Baptist Church in administrative, pastoral and advisory roles. He retired in 1999.

David King – Council Member



David was diagnosed with Pd over three years ago. He regularly attends four support groups and is currently approaching retirement after a career in the financial services industry.

Dr Sarah Mott – Council Member



Sarah, a practising nurse since 1970, specialises in chronic and complex disabilities. Her professional interests include quality of life issues for people living with disability. Her personal life is enriched by her 16-year-old son and three dogs.

Rebecca Silk – Council Member



Interests: the arts and literature, gardens, food and rugby. Bridge is a necessity of life. Loves: people – family, friends, and particularly, husband John. She has seldom met a child or a puppy that she hasn't found interesting.

Passion: to try to make a difference for People With Parkinson's.

Neil Sligar – Council Member



Neil is a member of the Campbelltown Support Group. He was diagnosed with Pd in 1998, and continues to work as a certified financial planner. Neil's pastime is vigorous exercise, which he feels greatly assists his health.

Robert Young – Council Member



Robert, a member of the Hornsby-Ku-ring-gai Support Group, has been associated with Parkinson's NSW for four years. Married with four children and one grandchild, he worked in book publishing, retiring at the age of 70.

CEO's report



Dear friends,

The last month has been an exciting time as the office team began working with the new Council to develop the plans for this year.

One of the changes will be to put more resources into member services. For example, we have increased counsellor hours. You will notice immediately the decision to reduce the size of *Stand By Me*. Our

new-look newsletter costs significantly less to produce, which means more funds can be channelled into member services. The new *Stand By Me* still aims to be more informative than ever, with research reports co-ordinated by new Council members Dr Kay Double and Dr Sarah Mott; all the latest Parkinson's news; book reviews; and more.

Readers are encouraged to send in their own stories and ideas to be considered for inclusion in the newsletter. We would also be grateful if you could take time to fill in and return the enclosed readers' survey.

As part of NSW Seniors Week, we held a Parkinson's Sporting Expo on Saturday April 1, and we are encouraging our support groups to hold other sporting activities. Research has shown exercise may have beneficial effects for people living with Parkinson's. The theme for NSW Seniors Week is 'Live Life'.

One of our goals this year is to increase fundraising, and we would welcome your ideas. We would love some additional volunteers, whether regular or on an occasional basis. Assistance in these ways increases our ability to provide member services and advocacy for the Parkinson's community.

The Chinese community are holding a fundraiser for Parkinson's NSW on Friday 23 June – moneys raised will go towards employment of a bi-lingual resource worker. We would be delighted to see you all there. For further details see Diary Dates.

Yours in Parkinson's friendship
Miriam

Coffee Morning



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

Talk to people
living with Parkinson's

10.30am, 7 June

Building 25, Concord Hospital

See you there!

GENE THERAPY TRIAL: FIRST RESULTS

by Dr Kay Double, Prince of Wales Medical Research Institute

In September 2005 Neurologix, Inc., an American company developing new treatments for diseases of the nervous system, announced preliminary results from a gene therapy trial in Parkinson's disease patients.

The aim of gene therapy is to introduce genes into cells of the body or brain to modify the production of certain substances within those cells. Modification of the substances of interest, for example an enzyme or a protein, is then hoped to cure or symptomatically treat the targeted disease.

The Neurologix study attempted to introduce the gene for an enzyme called glutamic acid decarboxylase, or GAD, into the brain cells of 12 patients with advanced Parkinson's disease. This approach is based on the fact that the loss of dopamine in the brain of Parkinson's disease patients results in other areas of the brain becoming overactive, ultimately disrupting normal motor control. The GAD enzyme synthesizes a brain chemical called gamma-aminobutyric acid (GABA) which inhibits the activity of brain cells.

In this study, the GAD gene was introduced into a brain area which is overactive in Parkinson's disease called the subthalamic nucleus (STN). Reducing the over-activity of the STN with a surgical lesion or by electrically stimulating this area using Deep Brain Stimulation has been shown to reduce the symptoms of Parkinson's disease in many patients. The idea behind the gene therapy approach is to increase the amount of GABA-producing GAD enzyme in the cells of the STN. The subsequent increase in the amount of inhibitory GABA dampens the over-activity of the STN, thus restoring the activity of the motor pathways towards a more normal state.

A unique feature of the study is the way in which the gene was introduced into the brain. The human GAD gene was first incorporated into a virus (the adeno-associated virus or AAV), and it was this viral messenger or 'vector' that was injected via a hair-thin catheter into the patient's brains. Viruses can be used to introduce genetic material into cells because of their ability to incorporate their own genetic material and artificially added genes, such as the GAD gene, into the recipient cell's own genetic material. This study is the first time a viral vector has been used to treat an adult neurological disease. While directly injecting a virus into the brain sounds risky, this human trial follows 10 years of basic research which suggested that the AAV virus is a safe and effective vehicle to transport genes into the brain. Most importantly, the virus has never been associated with any human disease.

This small study was specifically designed to demonstrate only the safety of introducing genetic material into the human brain to treat Parkinson's disease (a so-called Phase I study). To date there has been no evidence of adverse effects from the introduction of the gene up to one year following the treatment.

The researchers have also been able to gather some data regarding the effects of the gene treatment on the patient's symptoms and the initial data looks promising. The STN is found on both sides of the brain but all the patients received the gene therapy only on one side of the brain. The untreated

STN on the other side of the brain could therefore be compared with the treated side. One year following treatment, patients showed a 27 per cent improvement in motor function on the side of their body which corresponded to the treated STN, but no improvement on the untreated side.

Another standard measure of Parkinson's severity – the 'activities of daily living' scale which is assessed by the patients themselves – also indicated an improvement on the treated side, although this is not statistically significant. In support of these symptomatic improvements, data from imaging studies of the brain showed that abnormal glucose metabolism – an indicator of decreased brain function – increased on the untreated brain side, but the increase was significantly smaller on the treated brain side. This suggests that the clinical improvements observed reflect more normal brain function on the treated side.

Final results from this trial are expected in mid-2006. While these results must be considered very preliminary and there is still much more work to be done, the scientists involved are excited about this research because, while it does not represent a 'cure' for PD, it may lead to improved therapy options for drug-resistant symptoms for some patients. Further, the 'viral vector' technology developed in this research may be useful in future to deliver treatments to the brain which may slow disease progression.

Professor Eric J. Nestler, a member of the Neurologix Advisory Board and Professor and Chairman, Lou and Ellen McGinley Distinguished Chair in Psychiatric Research at the University of Texas Southwestern Medical Center at Dallas explained: "If the efficacy demonstrated here is replicated in a definitive trial, it would represent a fundamentally new platform for the treatment, not only of Parkinson's disease, but of a large number of neurological and psychiatric disorders as well. Such a replication would make viral-mediated gene therapy for brain diseases a reality."

The Aged-care Rights Service

The Aged-care Rights Service (TARS) is a community legal centre that provides advocacy for the residents of Commonwealth funded hostels and nursing homes, self-care retirement villages and recipients of in-home aged care in NSW. We also give information on the costs associated with entering an aged care facility and give advice on retirement village contracts.

TARS provides education for the residents and staff of aged care facilities and retirement villages, professional groups that work in aged care as well as carers and community groups of seniors interested in learning about the rights of people receiving aged care services.

TARS is funded by Commonwealth and NSW government departments.

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Research

THE MEDICATION MANAGEMENT PROTOCOL RESEARCH PROJECT

By Professor Lynn Chenoweth, South Eastern Sydney Area Health Service/University of Technology

Dr Sarah Mott, Royal Rehabilitation Centre Sydney

Lorraine McAnally, Westmead Hospital

Dr Yun-Hee Jeon, South Eastern Sydney Area Health Service

Anecdotal evidence from Parkinson's NSW members and preliminary findings of Australian studies on people with Parkinson's disease (Pd) identifies a number of concerns with the administration of medications during hospital care.

These respondents claim that staff generally lack the necessary knowledge, understanding of, and sensitivity to the importance of individualised medication regimes for persons with Pd and, therefore, do not always administer these medications as prescribed by the patient's neurologist or GP. As well, the hospital pharmacist may alter this prescription without referral to the patient's neurologist or GP, or indeed the patient and their family carer. These actions can lead to poor health outcomes for patients, distress for patients and their family carers, and difficulties for health staff when medication mismanagement leads to delirium, confusion and deteriorating health for the person with Pd.

Patients, family members and specialist Pd staff report the occurrence of increased 'freeze' periods for the patient, contributing to falls and other injuries, and increased lengths of stay in hospital. The reliance on specialist medical

consultations is also more likely to occur as a result of medication mismanagement, adding to the cost of care services.

Within the current acute health care climate of staff shortages and increasing reliance on agency and pool staff, a Pd medication protocol may increase the quality, safety and therapeutic value of Parkinson's medications for the patient. A Pd medication protocol may also increase hospital staff's knowledge of Pd medications and thereby prevent many of the errors in management.

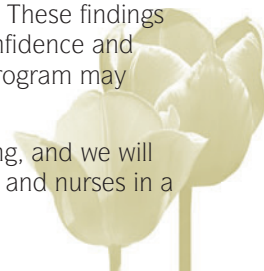
A Pd medication protocol may increase the quality, safety and therapeutic value of Parkinson's medications for the patient.

These findings indicate that nurses can improve their confidence and knowledge quite a lot.

This Pilot Study aims to develop and evaluate a Parkinson's Disease Medication Protocol (PDMP) and compare this with Usual Medication Protocols (UMP). Nurses will be educated about Pd medications and will be tested on their knowledge and confidence of Pd medications before and after the education program.

So far, we have findings from the nurses who have been recruited from the five participating hospitals. The cumulative results at pre-test indicate that the nurses (n = 110) have about 50 per cent accuracy in actual knowledge about Parkinson's disease, Parkinson's medications and use; and about 50 per cent level of confidence in knowledge about Pd and Pd medications. These findings indicate that nurses can improve their confidence and knowledge quite a lot. The intervention program may influence this pre-test score at post-test.

The next stage of the project is in full swing, and we will report on the results from people with Pd and nurses in a later newsletter.



Hermann Eisenberg – Australia Day Award

PARKINSON'S CARER HONOURED



Mr Herman Eisenberg, who has been a carer for his wife who has had Parkinson's for many years, was awarded an AM in the Australia Day honours.

Mr Eisenberg, immediate past president of the Great Synagogue, was honoured for his service to the community, particularly through the Great Synagogue, the Wesley Mission and Rotary International.

For 28 years Mr Eisenberg has been deeply involved with Rotary. During this time he has been a director and team leader of Sydney Rotary, the largest Rotary club in Australia.

He is also a Past Master of Lodge Mark Owen and has been a member of the Masonic Order for 29 years.

For many years a supporter of and financial contributor to the Wesley Mission, Mr Eisenberg was awarded the Wesley Corporate Citizen Award in 1992.



Ageing Research Centre

The Ageing Research Centre at the Prince of Wales Medical Research Institute, Prince of Wales Hospital, Randwick is looking for people aged 60-70, with early stages of Parkinson's Disease (Hoehn & Yahr stages 1 to 2.5) who are willing to come to the Prince of Wales Hospital on two occasions for approximately 2.5 hours each time.

The Study will include:

Visit 1: a medical assessment of movement, balance and speed; and a brain ultrasound

Visit 2: an MRI brain scan.

We are also hoping to recruit people 70-80 years of age, who do not have Parkinson's disease, to undergo similar assessments, to determine whether slowing of movement is a part of normal ageing or an early sign of a possibly preventable disorder. For this we are seeking to recruit people who walk normally and people who feel their movements are slowing up.

More information may be obtained from Stephen Duma on 9399 1000 during business hours (9.00am to 5.00pm).

Captain Starlight outback adventure

A personal experience related by Anne Kermode, a member of the Armidale Support Group



In August 2005 the *Australian Geographic Captain Starlight Expedition* followed the tracks of Henry Readford, the famous Australian cattle duffer, covering over 6500 km in two weeks.

I had hesitated going for fear that it would be too difficult, sleeping in a tent on the ground with the

need to get up on cold nights (helped by taking a small container) and morning stiffness (helped by weekly Pilates classes and weight bearing exercises over the past 12 months). My Pd has been progressing very slowly since it was diagnosed over nine years ago; because I feel well whilst taking medication – Madopar – on time, I sometimes forget to take it until symptoms develop. However, I was persuaded that this holiday would be too good an opportunity to miss.

Readford's tracks took us through the beautiful Widden Valley to our first camp at Dunn's Swamp, amongst the fascinating, natural sandstone rock sculptures, 'The Pagodas'.

Travelling north, up the Strezlecki Track in South Australia, the beauty of the desert in full bloom was breathtaking.

Abundant bird life was vocal but hidden amongst the yellow, white or pink flowers.

Rain in Brachina Gorge in the Flinders Ranges, a favourite place of painter Hans Heyson, enhanced the beautiful colours on the trees and patterns on the wet rocks.

Most memorable was the search for the site of Hill Hill Station, on the banks of Strezlecki Creek, where Readford sold Whitney the bull. It was real outback driving over endless sand dunes, then along the dry riverbed scattered with mature trees. There was great excitement when the ruins of a large mud-brick, cement rendered house were spotted! What a remote, lonely, barren place for a homestead.

Near Bowen Downs Station we explored the substantial remains of the cattle yards, expertly built, supposedly by Readford, in the 1860s. Here he allegedly mustered the 1000 head of clean-skin (unbranded) cattle and the white bull, before driving them south.

This special expedition, on remote outback tracks, took us to fascinating places we would never have ventured to on our own. Hardest was accepting the challenge of leaving my comfort zone. Few of those with us had had direct experience of someone with Pd and the few who had, showed they cared, whilst others were interested to learn about it. I am pleased I went on one of the biggest adventures of my life.

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Speeding Vibrations

by Sarah Lines

Speeding Vibrations is the NSW support group for people diagnosed under the age of 50, which I have also stretched to those under 60.

We have over 260 members state-wide from as far away as Coonabarabran (hello to Peter and Kim), Warialda (hello to Keith), down south to Sussex Inlet (hello to Pat and Ken) and Richmond (hello to Peter and Ruth), and Redhead (hello Howard and Hanneke).

Based on our coverage, we aren't the traditional support group that meets once a month, however we do meet at least four times a year for a Sunday lunch. The locations vary so that we can get as many people attending as possible.

Recent lunches have been held at Leppington and Birkenhead Point, and the last one, in November 2005, was at Dural Country Club.

Our Dural lunch had another successful turnout of 33 people. We also welcomed some new faces joining the group – Peter, Sandra and Fotih. Due to the rain we were relocated inside the bistro rather than in the courtyard, however our three tables and our own private coffee bar kept us all together. I hope everyone managed to speak to who they wanted to and hopefully met some new faces as well.

Another big thankyou for a special presentation made at Dural – I am now in proud possession of the original sign

made for Speeding Vibrations in its early days. For those who didn't see it, rest assured it will be a permanent fixture at all of our future meetings. So a humble thankyou to Harley, Kay and Leanne.

Here is an excerpt from Harley's speech for those that missed it:

On behalf of Kay, Leanne and myself, we would like to pass on to you for safe keeping this sign which was displayed at Speeding Vibrations functions. I designed it and a friend of mine got his tech students to make it, that was about 13 years ago I think.

What does it mean? A good question, as the years pass and we have changed with Parkinson's disease, I see different things in the little man and how he is trying to live with Young Onset Parkinson's disease. How did we come up with this name? I don't know... but it was better than some of the groups which were operating overseas at the time.

Speeding Vibrations was the first group of its type in Australia and nearly the first in the world.

I look forward to hearing from any new people who would like to be part of our group.

Contact Sarah Lines – email jsl022@bigpond.com or call 4627 5632 or 0404 032 419.

PO Box 1294 Campbelltown NSW 2560

On the group vine

Cowra Support Group was formed following a public meeting in March 2003. The group has been very active in informing the public about its activities, with monthly reports in the Cowra Guardian and leaflets distributed in medical centres, pharmacies and the health centre. Cowra, with a population of 8000, supported the group's stall and concert in Awareness Week and \$2500 was raised for research.

Hawkesbury Support Group are very social. They enjoy outings with a formal meeting every three months. Last year's highlights were a cruise on the Nepean Belle followed by lunch at St Mary's Leagues Club, and a bus tour of the northern beaches with lunch at Palm Beach RSL. Several members received certificates of appreciation from PNSW for their work in the group.

New group news: See Neil Sligar's report on the public meeting to establish a Fairfield/ Liverpool Support Group (page 1).

Mick and Gillian O'Connor of Goulburn contacted Head Office asking how to start a support group! Trish Morgan will be

phoning PNSW members in Goulburn and surrounding areas to find out if they are interested in forming a group.

Please contact Concord about either of these groups and you will be put on the mailing list.

2006 looks very promising for growth of support groups.



Cowra Support Group members, Barry and Carol Doyle, Meryl Lees, Joy Dwight, Marion and Ken Bryant.



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2005 – Year of the T-shirt

by Trish Morgan

2005 was the year of the T-shirt – black cotton emblazoned with tulips.

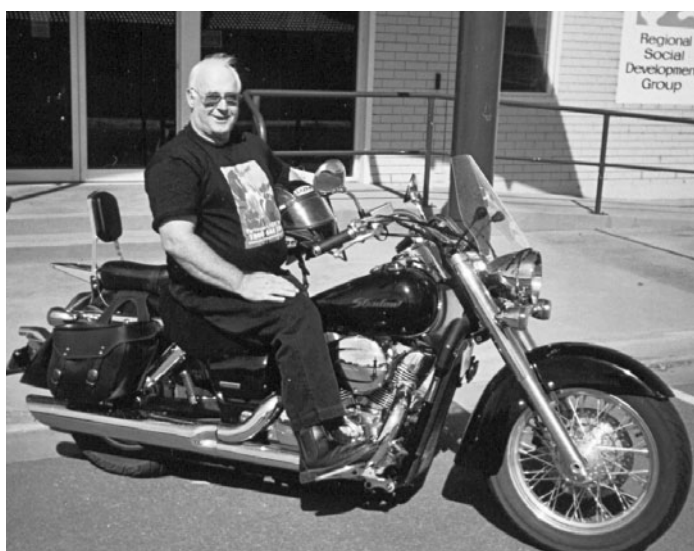
It arrived in time for the Daily Living - Homecare and Ageing Expo at Rosehill Racecourse in March. Members were seen wearing it at the Convention Centre, Darling Harbour at subsequent expos, including Seniors, Leisure and Lifestyle, Health and Beauty, and Nurses.

Support groups were excited to receive a package of five – one in each size. Margaret Byron greeted me at Dundas/Parramatta SG wearing hers – we were a match! Cathy Eggins from Grafton said she was proud to wear it during Awareness Week, especially as Miriam Dixon was wearing it as well as all the volunteers and staff of PNSW at Parliament House. The T-shirt united us all. Neil Sligar, PNSW council member, wore it to the first lunch for 2005 of Speeding Vibrations at Camden Country Club.

It was worn by members of the speakers group at talks to service clubs and other community groups. Newcastle support group appeared en masse in their T-shirts, in the Summer edition of *Stand by Me*, as they raised awareness with a stall at John Hunter Hospital.

Louise Sauvage, 2000 gold medal winner at the Olympics and Paralympics, has a T-shirt in appreciation of her signing an Olympic volunteers T-shirt which was auctioned at the fundraiser dinner for Rasheda Ali in November. Rasheda has taken a T-shirt home to the USA. Murry Druitt, motorcycle enthusiast, has been wearing his in the far south-west of NSW and wore it while on holiday in WA recently. In March, Murry wore a different T-shirt as organiser of volunteers at the Commonwealth Games.

The year of the T-shirt has brought unity to members of PNSW as they continue supporting one another and raising awareness in the wider community. It has been fun!



Murry on his motorcycle. He carried the Queen's Baton in the relay through the south-western border town, Moama, on February 19. Murry is a member of the Deniliquin support group and has given years of community service with the fire brigade and the Lions Club.

Workshop for the 'forgotten ones'

On February 18, the counselling service of Parkinson's NSW conducted a workshop for adult children of a parent living with Parkinson's disease.

The workshop, facilitated by the Parkinson's counsellor, was informative and gave group participants an opportunity to share their concerns and experiences of living with Parkinson's disease.

The Parkinson's NSW support group co-ordinator gave valuable advice regarding channels available to aid in the care of a patient with Parkinson's disease.

At the conclusion of the workshop, each participant completed an evaluation form. Comments from participants included the following:

I found the workshop very useful and informative – as it was a lot of sharing personal experience with Pd.

I feel that it would be good to have these sessions on a regular basis.

The informality made it easier to discuss personal stories and allowed for questions.

Thank you so much for providing a forum for the forgotten ones affected by Pd.

These comments further identified the need for a forum which will allow participants to share their experiences on a regular basis. In order to accomplish this, the counselling service has future plans to form a new group for the adult children of a parent living with Parkinson's disease.

If you are interested in attending this group please call 9767 7881 or freecall 1800 644 189.

Computer mice – who needs them!

Do you find a typical mouse difficult to use these days?

Don't worry – there are many other ways to use a computer.

For instance, you could use a trackball instead of a mouse. Or set up your Windows operating system to suit your particular needs – there are many choices available, such as 'sticky keys', using keyboard shortcuts and other accessibility features.

You could also use a voice recognition program to dictate your commands to the computer. Don't worry if your voice is weak – you can train it to recognise yours.

The Australian Seniors Computer Clubs Association's website on barrier-free access could help you. Go to <http://www.seniorcomputing.org/barrierfreeaccess/software.htm#Hand>. We can also refer you to a computer club for seniors in more than 100 locations if you are 55+.

For more information call (02) 9286 3871 or email office@seniorcomputing.org

Australian Seniors
Computer Clubs Association **ASCCA**

Book Review

Don Wilcox, our resident poet, has turned his skills to book reviewing. If you would like to purchase any of the books reviewed, please contact your local bookshop or the University Co-op Bookstore, Bay Street Branch 9212 2229.

“SHAKING UP PARKINSON’S DISEASE”

By Abraham Lieberman

This absorbing US book on Parkinson’s is subtitled “Fighting Like a Tiger, Thinking like a Fox”. It mingles information on the medical aspects of Pd and its treatments with comments from celebrity Parkinsonians, a range of case histories and every day problems and how to cope with them.

The book is attractive in appearance and well laid out. The language is clear and engaging. The tone is positive and interest-arousing. Particularly strong are the treatments of: autonomic problems (breathing, swallowing, drooling, bowels, bladder and sex), disease causes, anxiety, depression and dementia. Cabaser is not mentioned and some readers may find the book just a little technical.

Features include: Contents and index; good, clear, relevant pictures; diagrams and tables; large, clear print size.

ISBN 0-7637-1866-1 (Jones and Bartlett) 2002.
Paper cover. 275 pages ELSEVIER AUD 30.25

Teamwork

There were seven of them eleven of us
Including the doctor another big plus

First was Julia a jewel indeed
With a voice that ranged from slow to speed
Next came the ever jolly Rose
An extravert from head to toes

And Sister Therese, a most famous name
Occupational therapy is her game

Emma with her special flair
Gave us tempting ‘strawberry fare’
Fresh fruit with our morning tea
And best of all no GST

And full marks to Marilyn
With a hard row to hoe
The social worker who never says no

Written by Bob Bosustow, client of the Community Outreach Team (CORT) who attended the Living Well with Parkinson’s group program on the Central Coast. CORT is a division of Northern Sydney Central Coast Health (NSCCH).

Pirouetting with Parkinson’s

by Edda Davis

Dear Lord, please explain to me, as I am at a loss
To understand, why you have nailed me, to this cross?
Control and power over my legs and arms you took
Laying my emotions bare like an open book.

Now when stressed, my hands and legs do shake
As my brain attempts to control the first steps that I take
Struggling to lift my feet they rise to tippee toes,
Like a pirouetting ballerina holding a pose.

As the ‘freezing’ worsens I’m more likely to fall down flat,
In the club I hear voices say, “what the hell was that?”
I dust myself down and accept an extended arm,
Their kindness soothing me till I regain my calm.

At the moment my legs are rubbery and weak,
But I’ll fight this curse as I have a stubborn streak,
Pain and frustration we continue to endure,
In great expectation of that miraculous cure.

© September 2005

Parkinson’s NSW Counselling Service forthcoming events

MANAGING WORRY AND STRESS

A group workshop for individuals and/or family members living with Parkinson’s.

This program will be held each Monday for four weeks, starting on May 1, between 10.30am - 1.00pm at the Medical Library, Concord Hospital.

If you would like to register or need more information please contact Parkinson’s NSW on 9767 7881 or freecall 1800 644 189.

SUPPORT GROUP FOR ADULT CHILDREN OF A PARENT WITH PARKINSON’S DISEASE

Future plans are underway to start this group.

If interested please call Beverley or Trish at Parkinson’s NSW on 9767 7881 or freecall 1800 644 189.

Correction – Stand By Me, Issue 93, Summer 2005

Page 24, “MLAK for Access”, to be eligible for a MLAK (Master Locksmiths Association Key) you require a letter from a doctor or health professional.

Page 6, “Australian Chinese Charity Foundation Grant”, line 2 should have read “Chinese Charity Foundation”.

Donations

CHRISTMAS DISPLAY FOR RESEARCH

Gwenda Falconer presented Parkinson's NSW with a cheque for \$1300.00 for Parkinson's research. This money was raised from a spectacular indoor Christmas display at Gwenda and Max Falconer's home in Baulkham Hills.



(From left) John Silk, President; Rebecca Silk, Councilor; Gwenda Falconer; and immediate past president Cherie Rice.

PARKIES PANTRY

Carol Hand, a member living with Parkinson's, has cooked up a storm with her rocky road, Christmas cakes and handmade chocolates, and along with her Christmas cheer raffle, has raised \$2500.00 for Parkinson's research in memory of her late father, Henry Cupples. Carol hopes to open the Parkies Pantry in June/July with more rocky road and homemade sponges for sale.

Parkinson's NSW Fine Art Raffle



Win this painting donated by Edda Davis valued at \$1000 from her wildflower series.

Tickets are \$10 each and are limited to 100.

All proceeds to go to Parkinson's NSW.

To purchase a ticket contact

4997 3208 or 1800 644 189

Local shop supports Parkinson's



Balcony Living, a garden/home furniture and giftware store located in Concord, held an information evening on

Parkinson's. David King, Councilor and speakers group member; Kay Messiter, Parkinson's NSW Information Officer; and Miriam Dixon, CEO, shared information on Parkinson's and encouraged guests to support the Parkinson's cause. Owners and hosts of the evening, Tirrill Riley-Gibson and Andrew Gibson, are encouraging their customers to collect used stamps and drop them off at the store. Parkinson's NSW would like to thank them for their generous support.

www.balconyliving.com.au

TADAust Connect

Exclusively for people who have a Disability Support Pension, Aged Pension or DVA Entitlement Card. (Subject to conditions.)

\$5.50 per month for:

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For more information please call 1300 735 439.

Music CD 'cure' for Parkinson's?

Some of you may have read about or heard of Mr Peter English and his claim that he has cured himself of Parkinson's by listening to a music CD.

Mr English's pharmaceutical background and gift for self-promotion may make him attractive to patients looking for a 'cure', but according to Parkinson's NSW council member and neurochemist Dr Kay Double, his claims are completely unproven.

"There is currently no known cure for Pd, nor have there been any validated cases of patients going into remission, as Mr English claims in the *Northern Star* article," says Dr Double.

"Some patients find that alternative or complementary treatments, such as massage or acupuncture, used together with their prescribed medications, help them better manage the symptoms of their Pd, but this does not mean that they are 'cured'", explained Dr Double.

Parkinson's NSW new email address

Over the next six months we will be phasing out our old email address.

Our new address is pnswn@parkinsonsnsw.org.au

Donations

\$50 and over received between 24 September, 2005 – 15 March, 2006

We are always grateful for all donations as we still do not have Government funding. *Thank You.*

IN MEMORIAM

Ben Allen

Mr & Mrs D Hamilton

Bruce Beveridge

Mr Rod Beveridge

Bruno Braico

Mr Paul Braico

Mr Diquai

Laraine Risco

Brian Chick

Mrs Amy Chick

Sidney Clemesha

Central Coast SG

Harold "Bill" Coulter

Ms Yvonne Coulter

Henry Cupples

Mrs Carol Hand

Edith Dacey

Mr & Mrs T Hugh

Gladys Davis

Mr & Mrs F Christou

Mr V Coluccio & family

Mr Vincent Lagana

Ms Elizabeth Stubbs

Dr John Dowsett

Mr & Mrs R Fry

Patricia Grant

Mr & Mrs S Keen

I Johnstone

Patricia McGrath

Mr Colin McKeith

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R & P Harvey

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Ms Adrienne Kabos

Mr Gavin Laws

Mr John O'Halloran

Mr & Mrs K Quek

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Leo Orvieto

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Mr Robert Yeoh

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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
Bathurst	Jennifer Mannell	02 6332 8963
Campbelltown	Maree Sinclair	02 4626 4959
	Sarah Lines	02 4627 5632
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
Finley	Glenis Gordon	03 5881 3295
Glen Innes		02 6732 1252
Grafton	Cathy Eggins	02 6642 2156
Griffith	Joyce Giacomelli	02 6966 9900
Hawkesbury	Valmai Tuckerman	02 4575 1403
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
Manning/Great Lakes	Bruce King	02 6555 9409
Muswellbrook	Pat Moody	02 6543 3164
Nepean	Joe Golding	02 9670 5093
Newcastle	Verlie Sullivan	02 4954 0338
Orange		02 6365 8228
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	Jenny Meyers	02 9521 6502
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
Young Onset	Sarah Lines	02 4627 5632