PARKINSON'S NEW SOUTH WALES INC. NEWSLETTTER
Ease the Burden and Find a Cure

Stand By Me

ISSUE 95 – Winter 2006

Fundraising dinner and book launch in Chinese Community


From left: Rosanna Ng, co-author of the Parkinson's Bi-lingual Exercise Booklet; Julia Fry, President of the Parkinson's Chinatown Bi-lingual Support Group; Alice Dong, co-author of the Parkinson's Bi-lingual Exercise Booklet and Dr Victor Fung, Neurologist, Department of Geriatrics and Aged Care Westmead Hospital, holding copies of the booklet.
Photo courtesy of Australian Chinese Daily.

A fundraising dinner, which incorporated the launch of the bi-lingual booklet, *Exercises for People Living with Parkinson's,* was held on June 23 at Zilver Chinese Restaurant, Haymarket.

The evening was a huge success, with almost 300 guests raising over $20,000. It was the first time Parkinson's NSW had held a joint effort with an ethnic community to raise funds and awareness of Parkinson's disease.

Event Chairperson Samuel Chu opened the night, and our two MCs, Monica Chu (Sydney Pacific Lions Club) and Cr Ernest Wong (Burwood Council), kept the evening running smoothly.

In his address, John Silk, President of Parkinson's NSW, said that although Parkinson's NSW has been established for 27 years, it has yet to receive government support. He appealed to guests to sign the petition to the Legislative Council of NSW about the lack of funding for Parkinson's-specific support services and for safe and adequate premises for Parkinson's NSW.

Guest speaker, the Hon. Henry Tsang OAM MLC, acknowledged his support of Parkinson's NSW and said he would forward the petition to Parliament House.

Dr Victor Fung, Neurologist at Westmead Hospital, formally launched *Exercises for People Living with Parkinson's,* congratulating the authors Rosanna Ng and Alice Dong and publisher Chinatown Bi-lingual Support Group. He said that the exercises have the potential to improve motor function and mood disturbance, which have a major influence on quality of life.

An auction was held with Robert Ho as the auctioneer, and a landscape oil painting generously donated by Wang Xu, finalist in the 2005 Archibald and 2006 Sulman Prize at the Art Gallery of NSW was sold. A bottle of Brandy XO Rare in Australia, donated by Hardy Wines was also sold. Many generously donated items were raffled and sold by silent auction. A special donation of $5000 was made by Elain Mah from the Hydro Majestic Hotel, Blue Mountains.

The evening's entertainment included a zheng (Chinese harp) recital by Patricia Chung, and a performance from singer Kristy Walker. The Pei Lei Chinese Wushu Association held a Tai Chi demonstration, and our special guest performer Elizabeth Tse generated large donations from her supporters when she was asked to sing first in English and then in Chinese.

Zilver Restaurant provided a beautiful Chinese banquet, including ginger shallot crab, a cold plate of combination duck, pork and chicken and fresh steamed barramundi. The wine accompanying the meal was donated by the Hardy Wine Company.

The VIP guest list included Gladys Berejiklian MP, State Member for Willoughby and Shadow Minister for Community Services; Dr Colleen Canning, Senior Lecturer in the School of Physiotherapy, the University of Sydney; Cr Le Lam from Auburn Council; Cr Clifton Wong of Hurstville Council; and Katie Young and King Fong, Chinese Community Elders.

The event attracted quite a bit of media coverage, with TVBA (Chinese television), Radio 2CR and SBS Cantonese, *The Australian Chinese Daily, Sing TAO News Daily* and *Australian New Express Daily* all attending.

Parkinson's NSW would like to thank all the guests for their incredible generosity, and the organisers for making the dinner such a memorable and enjoyable evening.

STOP PRESS

Funding for Parkinson's disease specialist support services and safe and adequate premises for Parkinson's NSW. Have you signed our petition yet? Call 1800 644 189 to receive your copy.

Features

DIARY DATES / SPECIAL EVENTS

August 11 (Fri 10.00am)	**Information Seminar on Deep Brain Stimulation** Speaker: Dr Paul Silberstein Organised by: St George/Sutherland Support Group Contact: David & Maureen Morrison 02 9525 4002 *Disability Access - Lunch provided - Gold coin donation
August 19 (tbc)	**Tweed Heads Support Group Seminar**
August 23 (Wed 10.30am)	**Coffee Morning** at Concord (Building 25) Come and meet staff and volunteers of Parkinson's NSW and talk to others living with Pd
Sept 4 - 10	Awareness Week
October 19 (tbc)	**Shoalhaven Support Group Seminar**
October 25 (tbc)	**Coalfields Support Group Seminar**
November 6 (tbc)	**Tamworth Support Group Seminar**
November 8 (Wed 10.30am)	**Coffee Morning** at Concord (Building 25) Come and meet staff and volunteers of Parkinson's NSW and talk to others living with Pd
November 23	**John Hunter Hospital, Newcastle Pd Workshop**
December (tbc)	**Parkinson's NSW Christmas Party** Kokoda Picnic Area, Killoola St, Concord Further details in the next issue of *Stand By Me*

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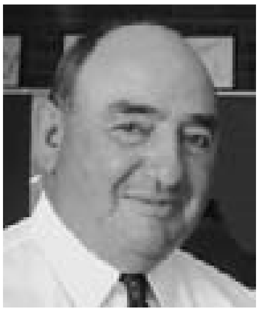
President's report



At a time when we are focused on our future goals it is important not to lose sight of what is already happening within the Parkinson's family. To this end, I'd like to share with you my thoughts about some people who do so much within PNSW – they come from many areas, from support groups to our volunteers, councillors, and staff – and I am going to be blatantly sexist and particularly discuss our LADIES.

Women who often have medical or family problems to deal with and yet cheerfully, day in and day out, support our cause with unflinching loyalty. As I travel to the support groups and meet some of these Remarkable Women I often pause to think that without them – nothing!

I would like to mention a small sample of these 'assets' of ours that I have met or spoken with over the past four months:

- **Verile Sullivan,** who has been involved with the Newcastle group for 25 years, ably assisted by **Karen Begley**
- **Vera Heil** in Coffs Harbour, who I regard as my conscience, as she will both support and criticise without fear nor favour as long as it helps PWP
- **Julia Fry** of the Chinatown Bi-lingual Group, who gets on with the job of supporting, fundraising and making all information available to her group in Chinese
- **Diana Rynkiewicz,** President of the Hornsby-Ku-ring-gai Support Group, who never stops recruiting and advocating for PWP
- **Sarah Lines,** whose involvement in the Young Onset Group – whilst raising a young family and helping to balance the household budget – is extraordinary
- **Pat Barkly,** whose desire to be involved despite many hurdles keeps us all on our respective toes
- **Myra Chalmers** and **Maureen Morrison** of the St George group whose participation, in spite of major health problems, knows no end
- Our staff at the **Head Office** who are all much more than paid employees – many have involvement in their own support groups
- **Miriam Dixon,** our CEO, who keeps my ambitions at a level that is nearly achievable
- **Becky Silk,** who edits, enthuses, critiques, is my constant companion and still maintains a calm demeanour.

To all these women of remarkable human skills and the hundreds of others out there in NSW, a heartfelt "Thanks" from all of us mere mortals.

I would commend to all members our petition and letter-writing campaign. We know that our aims are necessary and realistic. With your support, we hope to make them POSSIBLE. Parkinson's NSW should not be the 'poor relation' of government funding.

Yours truly
John Silk

CEO's report

A big thank you to all those who responded to our *Stand By Me* reader survey. You indicated that reading research articles was a first priority. You also liked 'This might help you: tips and information for living with Parkinson's', and you also loved reading personal stories. The majority of you appreciated national and international news on Parkinson's. There was a great interest in carers' articles and stories about our support groups.

By far the majority shared your *Stand By Me* with at least one other. There was overwhelmingly support for our new layout as easier to read.

Your feedback on *Stand By Me* will help us to create a better newsletter.

Thank you for the response to our 'call to action'. We have been delighted with petitions coming back into the office and some of you have taken the time to copy in letters you have forwarded to local members.

I would like to quote from one of our members who forwarded us a copy of the letter she sent to her local member, the Hon. Carmel Tebbutt, Minister for Education, Member for Marrickville. In the letter she informs Ms Tebbutt that she has just turned 50 and was diagnosed with Parkinson's two years ago. She says her neurologist was very competent at giving advice on medication but she needed other advice on how to cope with a degenerative neurological condition.

> ... I then discovered Parkinson's NSW and the Parkinson's unit at Concord Hospital. By this stage I was not coping emotionally ... I visited the Parkinson's NSW counsellor a couple of times ... she was fantastic and since then I have got my life together and rarely see the counsellor but I know she is there, she keeps in contact with me. I am now hardly a drain on the health system; I do yoga, massage and swimming (which of course I have to fund myself). I am in fine form. I do, however, rely on information from Parkinson's NSW to keep me up-to-date with research. I will continue to be able to maintain my health, but this is largely due to the kick-start I got from Parkinson's NSW.

She goes on to say that she sees NSW Government funding as essential to allow those with Parkinson's to live with hope and dignity.

Letters from the heart such as this one really have an impact. Minister Tebbutt has forwarded the letter on to the Hon. John Hatzistergos, Minister for Health. We can highlight our needs through personal stories.

Please keep your petitions coming in, as you know every signature counts. Feel free to photocopy the petition form or please ring the office, and we would be only too happy to forward you more copies. Our petition will now be presented in the lower house by Angela D'Amore, Local Member for Drummoyne (including Concord) and in the upper house by the Hon. Henry Tsang.

Members of the Chinese community, together with the Parkinson's community, came together on Friday June 23 to launch the bi-lingual Parkinson's exercise book. The Chinese community have been extremely generous and supportive of our Parkinson's community, as you will see from the story featured in this issue of *Stand By Me*.

Yours in Parkinson's friendship
Miriam

SURVEY WINNERS

We had such a fantastic response to our *Stand By Me* reader survey that we decided to give three prizes away.

Congratulations to Tricia Burns from Edgeworth, Sandra Clifford from Lennox Head and Anthony Hogan from Goulburn, who have all won a signed copy of *Keep the Bastards Honest* by former senator Don Chipp.

Parkinson's NSW Sporting Expo – April 11

At least 60 people attended the Sporting Expo as part of Senior's Week 2006. Held in Kokoda Park, adjacent to Concord Hospital and on the banks of the Parramatta River, it is an ideal venue with a weatherproof pavilion and amenities close by.

Participants could try their hand at lawn bowls, boules, quoits, Tai Chi, badminton, horseshoe throwing, ball catching, seated Greek dancing and a seated parachute and ball game. This was all under the guidance of Concord Hospital Parkinson's Clinic physiotherapist, Joan Perkins and skilled trainers provided by Sally Castell from the Northern Sydney Health Promotion who was a major coordinator for the day.

The Tai Chi demonstration, performed by the Pei Lei Martial Arts Association, began with a routine of exercises for people with Parkinson's with Julia Fry, the very proactive President of the Chinese Bi-lingual Parkinson's Support Group, encouraging members to participate.

The booklet, *"Yes you can! Play Lawn Bowls"*, written by former Council member and keen lawn bowler Les Norris, was also launched and is available from Head Office.

A raffle for Easter baskets, sausage sizzle lunch and special song and dance performance by Kristy Walker kept members, family and friends entertained.

Parkinson's NSW would like to thank our volunteers and The Department of Aging, Disability and Home Care (DADHC) for providing a grant for the day.

Attendees try the seated parachute and ball game.

GAMBLING AS A SIDE EFFECT OF ANTI-PARKINSON MEDICATIONS

by Dr Kay Double, Prince of Wales Medical Research Institute

A short while ago the *Sydney Morning Herald* ran an article about an American man with Parkinson's disease who blamed his anti-Parkinson medication for triggering obsessive behaviours, especially uncontrolled gambling, which resulted in him becoming unemployed, bankrupt and his wife divorcing him.

Changes in behaviour are not generally recognised as a possible side-effect of drugs taken to treat Parkinson's disease symptoms but can, in fact, occur. The authors of an article published in the *Archives of Neurology* in September 2005 reported that they identified 11 Parkinson's disease patients in their Movement Disorders clinic who had developed a gambling addiction. Several of these patients also developed other obsessive behaviours, such as a marked increase in their sexual appetite, compulsive drinking and eating behaviours and obsessive shopping. In all cases, these compulsions became evident shortly after beginning treatment with dopamine agonists for their Pd.

For most patients, decreasing the dose of the dopamine agonist, or stopping agonist treatment altogether, resulted in the behaviours returning to a normal level within a short time.

Further research revealed a number of reports about gambling problems in Pd in the medical journals, and dopamine agonists are implicated to be the underlying cause in all but one case.

Anti-Parkinson medications work by interacting with or stimulating dopamine receptors in the area of the brain responsible for movement control. However, because these drugs are taken orally, they affect the whole brain and therefore can also interact with other dopamine receptors.

It is believed that obsessive behaviours develop when anti-Parkinsonian drugs stimulate the dopamine receptors in the limbic system – the area of the brain which is responsible for the pleasurable 'reward' feelings experienced when engaging in activities such as gambling. The extra stimulation is thought to increase the 'reward' system, causing some people to constantly repeat behaviours that bring this pleasure 'rush'.

Because some dopamine agonists, including the two implicated in this study*, stimulate the type of dopamine receptors found in the limbic system even more strongly than those in the motor areas of the brain, it is possible that these drugs pose a greater risk for obsessive behaviours.

Obsessive gambling has been associated with all of the commonly prescribed dopamine agonist drugs, including carbergoline (Cabaser), bromocriptine (Kripton, Parlodel) and pergolide (Permax). There is also one case where a gambling obsession developed after L-dopa treatment alone.

The likelihood of developing a compulsive behaviour when beginning treatment with a dopamine agonist is unknown, but clearly it is low. Nevertheless, given that uncontrolled behaviours can have catastrophic consequences for both patients and their families and that the development of these behaviours appears to be easily and quickly reversible, it is wise to be aware of this possibility.

*In this study all the patients who developed a gambling problem were taking either pramipexole or ropinerole, two dopamine agonists not sold in Australia.

DO WE NEED AN AUSTRALIAN PARKINSON'S DISEASE DNA BANK?

by Dr Carolyn Sue, Director of Neurogenetics, Royal North Shore Hospital

The cause of Parkinson's disease (Pd) is currently unknown, although current research suggests that both environmental and genetic factors play a role.

In the past decade, genetic mutations in genes have been found to be associated with Pd and at least five cause Pd. Some genes increase a person's risk of developing Pd; others protect against it. Genetic mutations are probably only present in about 10 per cent of people with Pd. However, even though genetic forms of Pd only account for the minority of Pd in the general community, knowledge about the function of these genes has greatly enhanced our understanding of what happens to the brain in the patients who suffer from the commoner forms of this disease.

How can a DNA bank help?

It is hoped that by understanding more about what happens to the brain in Pd, new treatments can be developed to prevent or treat Pd. Established DNA banks in both the United States and Europe have been able to provide many benefits already. Firstly, accurate information about how common certain genetic mutations are in the 'local' community can be determined. This knowledge provides accurate information to the families and caring physicians about an affected individual's risk of genes causing their form of Pd and also their risk of passing the disease on to other family members.

Secondly, a Pd DNA bank could potentially allow the early detection of gene abnormalities in affected participants as soon as the discovery of a new gene has been reported (if the individual so desires). Such early diagnosis is often delayed or typically unavailable given our current health system.

If paired with clinical information, DNA banks can provide prognostic information on how an individual's disease might progress, what their response to treatment with conventional therapy might be and whether side-effects to the medication might be expected or avoided. DNA banks also facilitate research to determine the effect of genetic factors of subjects suffering from Pd.

How does a DNA bank work?

DNA banks require the consent of participating individuals to provide a blood sample so that DNA can be stored for genetic analysis. In some circumstances, DNA may be extracted from other tissues such as saliva or mouth swabs. The patient's treating doctor is usually involved as clinical information about how Pd affects the specific individual is important to how the data is analysed. All results are kept confidential, and research workers must apply to the Pd bank to be able to use these samples. All research is subject to the scrutiny of approved Human Ethic Research committees.

▶

MINERAL BATHS AND BELLADONNA: A BRIEF HISTORY OF ANTI-PARKINSONIAN THERAPY

by Paul Foley, Prince of Wales Medical Research Institute

James Parkinson conceded in his now-famous booklet of 1817, in which he described the disease which now bears his name, that there was no possibility of a rational therapy which might cure the disease until the cause of the disorder was determined.

He noted that bleeding the patient’s neck might relieve unwanted pressure on the brainstem, which he presumed to be involved in the disorder, and added that mercury would do no harm and might actually help. Nevertheless, Parkinson was confident that “some remedial process may ere long be discovered, by which, at least, the progress of the disease may be stopped”.

> A number of therapeutic approaches were tried in the 19th century, including cannabis, strychnine, arsenic, morphine, electrical therapies, nerve stretching, and mineral baths.
>
> The ‘Bulgarian cure’ included the administration of a special belladonna root extract.

A number of surprising therapeutic approaches were used to treat Parkinson’s disease in the 19th century, including cannabis, strychnine, arsenic, morphine, electrical therapies, nerve stretching, and mineral baths. But a family of plant chemicals known as alkaloids gained increasing attention following the isolation of what were regarded as the active principles from a number of plants traditionally employed in medicine, including the opium poppy and belladonna.

The first widely-used alkaloid was hyoscyamine, a drug isolated from several plants, including the Australian corkwood tree (Duboisia myoporoides). This treatment was considered to be relatively successful, although its main effect was to sedate the patient.

After the outbreak of the ‘sleeping sickness’ (encephalitis lethargica) in Europe in 1916, many new approaches were desperately examined, including extracts prepared from cattle brains designed to compensate the losses detected in the parkinsonian brain.

In the 1930s folk herbal therapist Ivan Raev caused a sensation with his ‘Bulgarian cure’, which consisted of a precisely defined therapeutic program and the administration of a belladonna root extract. Popularised in Italy by Queen Elena, the method spread to Germany, where the importance of vegetarianism and abstinence from alcohol and tobacco was also stressed. In English-speaking countries, specific belladonna alkaloids such as Rabellon were the preferred treatment.

The 1950s saw the introduction of a variety of synthetic anti-parkinsonian agents. Two major classes of agent were developed: anti-cholinergics, the most successful of which was Artane, which is still employed to a limited degree today; and anti-histamines, the most successful being Benadryl (now used in cough mixtures) and Disipal.

The synthetic agents, which were considered more effective than the older methods, dominated antiparkinsonian therapy until the end of the 1960s. Other approaches employed by doctors at this time included high-dose vitamin B6; energizers including the amphetamine Ritalin; barbiturates; and even drug cocktails of, for example, apomorphine, strychnine and amphetamine.

None of these alternatives, however, found the broad acceptance enjoyed by the synthetic anti-cholinergics … until the arrival of L-DOPA.

In the Spring issue of *Stand By Me* Paul Foley will look at the development of L-DOPA therapies.

Donors could elect to be informed of any result that affects them as individuals, or they can choose to simply donate the DNA to allow ongoing research. Participating individuals could also elect to be informed of any ongoing research findings that arise from working with the Pd DNA bank.

Currently, no such DNA bank exists in Australia, although the benefits are clear and the establishment of such a resource seems timely. If you are interested in participating in the establishment of the Australian Parkinson’s disease DNA bank please contact Parkinson’s NSW on 1800 644 189.

Coffee Morning

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

Talk to people living with Parkinson’s

10.30am, 23 August
Building 25, Concord Hospital

How do you feel about your Parkinson’s treatment?

We’d like to hear what you think.

The medical research division of DDB Remedy is currently seeking people with Parkinson’s disease to take part in a Patient Focus Group. We are conducting this group to find ways of providing better support for people undergoing treatment for Parkinson’s disease. If any of the following statements describe your situation we would like to hear from you:

- You have just begun treatment for Parkinson’s or are about to begin treatment
- You are currently undergoing treatment for Parkinson’s

The research will take part in Ultimo, Sydney.
Date and time is yet to be advised.

To apply to take part in this group, please email your name, age, gender, contact phone number and current stage of treatment to pd@syd.ddb.com

If you are selected to participate you will receive remuneration for your time.

For further information please call 8260 2883.

Good Health and Beauty Expo, Darling Harbour, June 16-18

Close to 9000 people visited the Good Health and Beauty Show, and we had a steady flow of visitors to our stand keenly requesting information. There were many inquiries from people as to whether they or their partners were experiencing symptoms of Parkinson's disease.

People were keen to sign the petition for funding and better premises for PNSW. The petition will be taken to both houses of State Parliament in August.

Making life easier

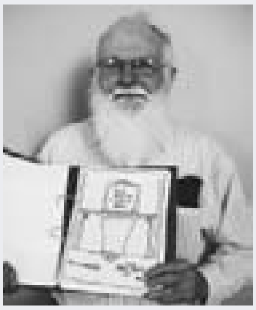
Retired engineer Brian McCauley is making life easier for PWP by creating simple yet inventive aid devices and furniture for people with disabilities.

His pieces, made from polyurethane-coated pine, are all custom-designed. They include:

- Bath seats which are made-to-measure to fit the bath. Brian's bath seats can be made higher than standard models, making them easier to get in and out of the bath
- Wide toilet benches, which can be built to the height you find most comfortable
- Where steps are too steep Brian can use treated pine to turn one step into two shallow steps, and three steps into four or five shallower steps
- Blocks to lift the level of beds and lounge chairs to the height that most suits you
- Ramps for wheelchairs
- Handrails and grabrails

Brian doesn't charge for labour and transport, he says, because he enjoys having something to occupy his time.

"Before starting a job I provide a scaled sketch of what I propose and the cost of materials. Naturally the client has most of the say. I just develop ideas into simple, practical and economic solutions. Sometimes the first attempt is not successful but I'm happy to keep trying. There is no obligation."


Brian showing one of his custom designs.

If you would like Brian to build some furniture pieces for you, call him on 02 4861 5535.

Donations and fundraising

Enthusiastic Dundas-Parramatta Support Group member, Kathryn Castelletto, recently held a breakfast and ended up raising $550! Friends and family feasted on bacon, eggs, sausages, toast, tea and coffee as Margaret Byron, Parkinson's NSW Bequest Officer, gave a talk. Kathryn requested that the money be put towards Parkinson's awareness. "I believe the more people know about Parkinson's the better," she said. In the past, Kathryn held a chicken and champagne night raising $500.

Parkinson's NSW member Edda Davis raised $875 at a trivia night she held for Parkinson's NSW. She said she hoped it would be the first of many to come.

Speeding Vibrations

by Sarah Lines

Our last lunch, held at the Vikings Sports Club at Dundas on April 23, was very successful and, I hope, enjoyed by all. It was a lovely location – quite a new club, with great food and great service.

We also welcomed some new faces – Keith and Lyn who travelled down from Taree, and David was also a new addition to our group.

Our next lunch will hopefully be 'Christmas in July' in the St George area. I am still checking on locations, and will advise ASAP.

If you haven't heard from me for a while, it's because our computer has conveniently 'lost' my email and postal address book! If you were receiving mail or emails from me and haven't been, please call or email me – I have managed to track most people down but there may be some that I have missed. What a disaster!

As I have mentioned earlier in the year, I am now working again, and have just stepped up to five days a week, which will soon turn into six with every second Saturday. So my spare time isn't what it was, and I don't have the opportunity to maybe write to you all as much as I would like, but I will still do my best and definitely keep up our lunch dates!

Look forward to hearing from you all.

Contact Sarah Lines:
PO Box 1294, Campbelltown NSW 2560
Or call 0404 032 419 or 02 4627 5632

A close shave for Parkinson's NSW

Hey! My name is Winey.

I'm 19 years old and I'm currently studying a Bachelor of Engineering/ Arts at the University of Sydney. This is a picture of me with my Dad, who has had Pd for 10 years (and is still strong!).

Over those years, Parkinson's NSW has been super awesome. We have attended information nights, social gatherings, fundraising events and we are also part of the very cool Chinese Support Group.

Anyway, now that I am older, I think it's time to start giving something back!

I also think it is time for young(er) people to start getting to know more about Pd.

I am currently producing and performing in a hilarious stage comedy called the Sydney Uni Engineering Revue – a fantastic all-singing, all-dancing cabaret style comedy sketch show held during National Engineering Week this year. After the final show, on August 20, I will shave off all my nice long hair (that I have had my whole life) in an event to raise lots of money for Parkinson's NSW.

The show will be held at Manning House, Sydney University on August 18, 19 and 20, 2006. Tickets are $20 (A-reserve) and $15 (B-reserve).

If you would like to come and support me in my Shave for Parkinson's NSW or watch/support the show, bookings are available by email: winey@student.usyd.edu.au or by calling the Producer (me) on 0425 334 173.

On the group vine

Casino Support Group maintains a close network by telephone contact when members cannot attend meetings. They also benefit from the ongoing support of the staff at Casino Day Therapy Unit and Neurologist, Dr Geoffrey Boyce.

Goulburn Support Group. Nineteen people from the Goulburn area met on Friday 30 June at the Goulburn Workers Club to form the new support group. They were full of enthusiasm and will meet on the second Thursday of the month at 10.30am. The local paper printed an article about Mick O'Connor who, with his wife Gillian, recognised the need for a support group locally. If you would like further information about the group please phone (02) 4822 6732.

Gunnedah Support Group is up and running, thanks to the initiative of local pharmacist Lisa Hagley. Lisa was interviewed by the local paper but the resulting story was not published in time for the May meeting, so Lisa is hoping for a better response next time. Lisa had spread the word herself and seven local people attended, including a local GP and his wife, and seven members of Tamworth support group. Lisa said the support of Tamworth members and their ideas were very helpful. The group will meet on the second Tuesday of each month from 11am-1pm in the Education Centre, Gunnedah Hospital. A package of resource books, videos and back issues of *Stand by Me* is on its way to Gunnedah.

Orange Support Group has decided to close after 15 years. The few remaining members, most of whom are carers/close friends, are no longer able to maintain the group and there is a shortage of younger members to take their place. Isabel Mitchell and Doreen Sherring are commended for their service and support to others. We hope the group may re-form in the future.

Southern Highlands Support Group is open to new ideas and included poetry and community singing at its meeting on April 18. Trish Morgan also read a poem from Don Wilcox's book, *Shaking Stanzas & Vibrating Verses,* which was very entertaining. In May, the group hosted a very successful Sausage Sizzle at the Mt Eymard Retirement Village, where there are several residents with Pd. John Babister gave a talk on the history of Mt Eymard to the 26 members present who were able to tour the village.

Yass Support Group coordinator Peter Wells was featured in the *Weekend Australian* magazine on June 10. In the article entitled *Good times, Bad times*, Peter talked about his experience of living with Parkinson's disease and his decision to undergo deep brain stimulation.

Trish Morgan visiting country support groups.

- 3/7/06: Cowra SG.
- 4/7/06: Yass SG.
- 13/7/06: Muswellbrook

Parkinson's NSW would like to announce that Julia Fry, President of the Chinatown Bi-lingual Support Group, received a 2006 Seniors Week Achievement Award for her tireless commitment to improving the life of PLWP from the Chinese Bi-lingual community. Julia is pictured with King Fong OAM, 2006 Seniors Week Ambassador.

Eastern Suburbs Parkinson's Support Group

by Marion Welch

The Eastern Suburbs Parkinson's Support Group meets at 2pm on the second Friday of each month at the Mill Hill Centre, 31-33 Spring Street, Bondi Junction. John Silk, President of Parkinson's NSW, was guest speaker at the June meeting.

The Eastern Suburbs Support Group's first meeting was held on April 12, 1991 at War Memorial Hospital. By 1992 the group had become self-supporting and monthly meetings were held at the Bowen Library at Maroubra. Paddy Bastic, Muriel Naylor and Joyce Markham organised the meetings and speakers, publicised the group and provided support to members.

In 1993 a small group of staff at War Memorial Hospital – Dr John Ward (Geriatrician), Philippa Maher (Social Worker) and Gloria Piccoli (NUM) – met regularly to discuss the idea of setting up a special clinic to cater for the specific needs of Parkinson's patients. The multi-disciplinary clinic was set up in 1994 and is now led by Dr Nick Brennan (Geriatrician).

In 1997 Muriel Naylor began to find it difficult to continue as Secretary and the group moved to the Mill Hill Centre at Bondi Junction. Marion Welch, a Social Worker at War Memorial Hospital, was asked to be the Group Co-ordinator, and still holds this position today.

Hans Wurzer is Chairman of the Eastern Suburbs Support Group, Lyn Smith is Secretary and William Berman is Treasurer. There are also six committee members including Paddy Bastic.

Volunteers required for research on reflexes and joint stiffness in Parkinson's patients

Your assistance is needed in a research project studying joint stiffness and reflex activity in Parkinson's patients. The study aims to improve our understanding of the movement disorder and to provide improved diagnostic techniques and methods for assessing it's response to medication. The knowledge gained may ultimately contribute to improvements in therapy.

Patients may attend the Movement Disorders Lab, Neurology Unit, Westmead Hospital or the School of Biomedical Sciences at the Lidcombe campus of the University of Sydney. Assistance with transport (taxi fare) is available.

Patient volunteers

- Must be diagnosed with Idiopathic Parkinson's disease
- Should be able to follow simple instructions
- Should not have gross, uncontrolled involuntary movements
- Should be on medication.

We are grateful for your assistance in this program.

For more details please contact,

Vimal Stanislaus
The University of Sydney
Phone: 0433 561 978
Email: J.Burne@fhs.usyd.edu.au

Dr John Burne
The University of Sydney
Phone: 9351 9316

Keep it simple in the kitchen

If you're living with Parkinson's disease, chances are you're trying to simplify most things in your life and around the home.

One room that PWP may start to have difficulty with is the kitchen. Turning on the tap or lifting a heavy pot out of the oven might become harder as your symptoms progress, so some modifications (or a complete renovation) taking the following tips into account will help make the kitchen a safer and easier place to work in.

Ensure the kitchen is fuss-free, uncluttered and easy to clean. Look out for ovens, microwaves and cooktops with large, straightforward controls. Choose easy-clean finishes, such as glass splashbacks (easier to wipe down than tiles-and-grout) and white, rather than stainless steel, for appliances. An undermount sink (which is fitted under the benchtop) and ceramic cooktops eliminate the nooks and crannies in which dirt can accumulate.

Ergonomic placement of appliances is critical. Fit ovens and microwaves at bench height, to reduce the amount of bending required to get things in and out. Include bench space on at least one side of the oven so you don't have to lift hot pots and pans too far. Also include a section of heat-resistant material beside the cooktop to slide hot saucepans onto. You may find two drawer-style dishwashers, installed side-by-side, easier to access than standard models.

Make storage space more accessible. Install large drawers rather than cupboards under the bench, and fit the middle shelves of the pantry with pull-out drawers. This eliminates the need to get in and hunt around for items. Install a carousel unit or pull-out rack in awkward corner cupboards. Food storage is particularly important for PWP, who may find it less convenient to visit the shops. If there's space, a big walk-in pantry will allow you to change your food purchasing patterns.

Adequate lighting is very important in the kitchen. Install strip or two-way directional task lights underneath the overhead cupboards, so the benchtops are well-lit at all times. Install a rangehood fitted with lights over the cooktop.

Non-slip floor tiles can help improve the safety of your kitchen, especially if you are prone to spilling things.

Make things easier to open and close. Handles and taps may become difficult to grasp as your dexterity decreases. Make things easier by selecting D-shaped handles for cupboards and drawers, or choose the style that will open with a little push. On the kitchen door, go for a lever rather than a doorknob, which can be difficult to grip and twist. Similarly, lever-style or ceramic disc quarter-turn taps are the simplest to operate.

For more information about making your kitchen more user-friendly, call the Independent Living Centre of NSW on (02) 9890 0940 or visit www.ilcnsw.asn.au

Take care with alternative therapies

by Sue Mercer

As the nurse coordinator in the Parkinson's Disease Clinic at Concord Hospital, I have been aware for some time that many people with Parkinson's use non-prescription remedies in conjunction with their prescription drugs/medications.

While I don't profess to know much about non-prescription remedies, I am aware that they can sometimes react with the 'mainstream' Parkinson's medications. I am therefore encouraging patients to provide a comprehensive list of everything they use, including herbal remedies and vitamin and mineral supplements, to their neurologists and GPs.

Treating Parkinson's can be very expensive for patients and their families, so it may be helpful to evaluate the financial cost versus the benefits in terms of symptom relief of some of these products. For example, it may be cheaper to follow a well-balanced diet than take a vitamin supplement. If the diet provides the recommended daily allowance of any given vitamin, then any further supplemental vitamin intake would be of no additional benefit.

Prescription treatments for Parkinson's disease

The commonly-prescribed medications for Pd include:

- Dopaminergic Agents (levodopa) such as Sinemet and Madopar.
  Sinemet is levodopa + carbidopa and
  Madopar is levodopa + benserazide.
  Stalevo = levodopa + carbidopa + entacapone.
  These medications come in varying forms and doses.
- Catechol-O-methiltransferaste (Comt) Inhibitors – (entacapone) Comtan.
- Dopamine Agonists such as (cabergoline) Cabaser, (bromocriptine) Parlodel, (pergolide) Permax, (apomorphine) Apomine.
- Anticholinergics such as (benzhexol) Artane, (benztropine) Cogentin.
- MAO type B Inhibitors (Monoamine Oxidase Inhibitor (MAOI's)) – (selegiline) Eldepryl.
- Amantadine Derivatives – (amantadine) Symmetrel.

Other medications commonly taken by Parkinson patients include antidepressants, anti-anxiety medications and antipsychotics.

Non-prescription treatments for Pd

These are some of the more commonly used alternative treatments for Pd which have the potential to interact with prescription medications.

Vitamin B 6 (pyridoxine) may interact with dopaminergics, e.g. Sinemet and Madopar as the levodopa is antagonised with pyridoxine.

St Johns Wort may interact with the following prescription drugs: Amitriptyline and Selective Serotonin Reuptake Inhibitor (SSRI) and related antidepressants such as sertraline, paroxetine, fluoxetine, citalopram, fluvoxamine and nefazodone.

Caffeine may interact with antidepressants, SSRIs.

Capsicum may interact with MAOI's.

Chaste Tree may interact with dopamine receptor antagonists.

Ginseng may interact with MAOI's.

Kava may interact with dopamine antagonists causing an increased risk of parkinsonism, extrpyramidal symptoms (various movement disorder, involuntary writhing movements).

Sympathomimetics (e.g. ephedrine and pseudoephedrine from Ephedra) may interact with antidepressants. Possible hypertensive crisis with MAOI's and hypertension and arrhythmias with tricyclics. Also may interact with dopaminergics and antipsychotics.

Yohimbine may interact with tricyclic antidepressants causing hypertension.

If you have any queries please consult with your doctor.

Reference: MIMS Issue No. 2 2005. MIMS Australia.

Talking to children about Pd

A diagnosis of Parkinson's disease can be hard enough to cope with, but when you have children or grandchildren, there are other issues too. Should you tell them? How will they react? And how will they cope as your Parkinson's progresses?

Telling children about your diagnosis

If you choose to tell your children or grandchildren about your illness, do it soon after the diagnosis. They are probably aware that something is not right, so it is usually better to be honest about having Parkinson's, rather than letting them draw their own conclusions or think something worse is happening.

Tell them as much as you think they want to know, but do not assume anything. You know Pd doesn't affect life expectancy and is not contagious, but are your children 100 per cent sure?

Make your explanations simple and appropriate to their age and maturity. Using a book with pictures of the brain may help explain things to a younger child.

Remind them that although you may not be able to do everything you used to do, you still love them the same. And tell them they can talk to you about it at any time.

Helping children cope

The fatigue and on-off fluctuations associated with Parkinson's may mean you can't spend as much time with your children or get involved with all their activities, so you will need to be aware of the effect this might have on their emotions, behaviour and academic performances.

It may help if your children could meet other children of PWP. It can be reassuring for them to know they are not the only ones whose lives are affected by Parkinson's. Contact Parkinson's NSW to find out about our Linking Program which may help put you in touch with other families with children.

It's also a good idea to let a child's teacher know what is going on, to help them understand why your child may be upset from time to time.

Family life

The roles and duties of family members may have to be re-negotiated as your Parkinson's progresses. Children are often keen to help, and remember to tell them regularly that you deeply appreciate their efforts around the house.

However, be aware of not depending on them too much, and try not to overload them with responsibilities. With everything that children, especially teenagers, have to cope with these days, Parkinson's can be a difficult extra burden to handle. And even though they may be helpers, they also need to be nurtured.

Try to lead by example – show them that life is still good and you are still the same person, despite Parkinson's disease.

Talking through the problems

Consider holding regular family get-togethers, to discuss how everyone is feeling and coping and find constructive solutions to family concerns.

Family or individual therapy or counselling may be an option if a child seems troubled or depressed. Children can sometimes keep their fears and worries to themselves, so parents may not recognise the fact that they are experiencing difficulties. It can be helpful for a child or young person to talk to a neutral party. If you think your child could benefit from counselling or therapy, talk with your GP or contact Parkinson's NSW who can refer you to the type of service you need.

The positive side

There are some benefits: living with a parent or grandparent who has Pd can make a child more responsible, independent, patient, mature, open-minded, and less self-centred. This independence and awareness can build confidence and self-esteem.

And remember ...

Children feel all sorts of emotions in relation to their parents' or grandparents' Parkinson's – grief, fear, rejection and embarrassment. Some may become weepy, obstructive or withdrawn.

Each family is unique, and with good communication and forward planning you can help children cope and live well with a parent or grandparent who has Parkinson's disease.

Sources:

- "Talking to Children about PD" by the APDA Young Onset Information and Referral Center, *Young Parkinson's Newsletter,* Spring 2006, p.7. Published by American Parkinson Disease Association Inc.
- Parkinson's Disease Society of the UK Information Sheet *Talking to your children about Parkinson's.*

Margaret Byron joins staff of Parkinson's NSW

I have recently been appointed as Bequest Officer for Parkinson's NSW. I think it's going to be the best job within the organisation! I look forward to keeping in touch with the many people who have supported Parkinson's NSW.

I will chat with people who want to continue to support the organisation, visiting them personally and encouraging them to think about making a bequest.

Bequests will help us to ease the burden for people living with Parkinson's and allow us to work towards a community free from Parkinson's.

An ongoing gift

When someone names you in their Will, they're placing you amongst their nearest and dearest.

So we were very pleased when one of our Parkinson's NSW friends wrote to say that she'd recently updated her Will, and included Parkinson's NSW amongst her favourite charities listed as beneficiaries.

But we also felt pleased that this kind lady had informed us – because that gave us the opportunity to say a warm and sincere 'thank you' for this special act of long-term generosity.

The greatest blessing of all though, is that people care – enough to want to give to others, even beyond their own lifetime.

If you would like to find out how you can benefit people with Parkinson's disease in your will please give me a call on 02 9876 5351.

“There is life after Parkinson’s!”

by our counsellor Beverley Aronstan

I would like to tell you a story about one of my clients, a gentleman who was diagnosed with Parkinsons about four years ago.

At his first visit to me, just after the disease diagnosis, he was in a state of shock and about six months after diagnosis he was still struggling to accept this diagnosis. It took another six months of counselling before he would try the prescribed anti-parkinsonian medication. Slowly, he started walking, then began swimming – an exercise he had not been able to manage for 10 years due to tremendous pain in his arms. He also went for regular massage. In addition to this, he attended regular counselling sessions and learnt strategies to manage his anxiety and depression.

He went from being a man who never smiled or partook in social activities to a man who beamed and exuberated with health and vitality. He regarded Parkinson’s as a challenge, and the more he challenged life by addressing his physical, emotional and spiritual needs, the more energy and vitality he had.

Today, he is eager to partake in as many activities as he can fit into his day’s schedule. His attitude change has been the single most important factor in the management of his condition.

At the last medical checkup (four years after diagnosis) his neurologist was delighted, and said that he seemed to have not only halted the progress of his Parkinson’s but was actually fitter than before the diagnosis.

So I leave you with this thought:

Concentrate on what you can do and not what you can’t do!

Parkinson’s NSW Counselling Service – forthcoming events

MOVING ON WITH PARKINSON’S

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

This workshop will cover:

- Adjustment to diagnosis
- Nutrition/Exercise
- Stress management strategies.

This program will be conducted by our counsellor. Starting in August, it will run for four weeks every Wednesday between 9am–11am 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.

TELELINK GROUP PROGRAM

This program is linking people with Parkinson’s by telephone. Scheduled every Wednesday in August for three weeks from 3pm–4pm for individuals with Parkinson’s disease who, due to physical or geographical distance, cannot access our services in person.

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

Our Book Review will be held over till next issue.

Why Participate in the Arts? Accessible Arts speak up

> There is evidence that active participation in artwork can engender redemptive self-respect in those who feel excluded from society. This may be the result of gaining admittance to an activity that enjoys social and cultural prestige. But it seems also to reflect that standards of achievement in art are internal and self-judged, and allow for a sense of personal fulfilment …
>
> (Extract from *What Good are the Arts?* by John Carey)

Deciding whether to engage in arts and culture can be difficult for some people. Perhaps they compare it to looking at a blank canvas or falling asleep at the opera? However, as Carey has identified, involvement in the arts has shown marked improvements in health, wellbeing, self-esteem and, ultimately, feeling valued within our society.

Twenty per cent of the population – or an alarming one in five people – have difficulty fully experiencing and participating in arts activities and events. As the population ages and more people acquire a disability, access, participation and experience is projected to become an even bigger issue. Accessible Arts is the peak arts and disability advocacy body in NSW which provides opportunities for people with varying abilities to express themselves creatively.

Changing attitudes, developing a model for the future and refreshing public knowledge about these issues is where Accessible Arts leads the way. The organisation acts as a consultant to other cultural organisations, helping to make their events more accessible and enjoyable for all people. The vibrant and rewarding experience of taking a tactile tour at the Art Gallery of NSW or a person who is blind having a performance at the Sydney Theatre Company described to them in words can make all the difference to individuals and communities that experience barriers.

Accessible Arts regularly provides up-to-date information on accessible events and activities, an arts tutor list, arts resources, a library, funding information, room hire, training and volunteering opportunities.

Accessible Arts also offers a low-cost half-day TAFE-accredited Disability Awareness and Access Training course that helps to identify barriers faced by people with disabilities. The course looks at accessing venues and participating in events, and suggests ways of breaking down physical and attitudinal barriers.

Accessible Arts also celebrates how people with disabilities are involved in the arts via their monthly newsletter. They are keen to hear from people who have created an original artwork, poem, short story, played music or participated in a cultural activity.

For more information or to subscribe to the monthly Accessible Arts e-newsletter, contact Nadia de Ceglie on 02 9251 6499, email: ndeceglie@aarts.net.au or visit the website at www.aarts.net.au.

accessibleARTS
ARTS + DISABILITY NSW

OUR VISION

A society in which people with disabilities fully experience and participate in the arts and cultural life.

Donations

$50 and over received between 16 March – 27 June, 2006
We are always grateful for all donations as we still do not have Government funding. Thank You.

IN MEMORIAM

Judy Anderson
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Mrs Bobette Basham

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Mrs Marjorie Bush,
family and friends

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Correction from Autumn 2006 - Issue 94

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PLEASE FIND MY:
☐ CHEQUE ☐ MONEY ORDER ENCLOSED OR

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EXPIRY DATE: ________________

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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: ________________

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SUBURB: ________________

STATE: ________________ P/CODE: ________

PHONE: ________________

EMAIL: ________________

☐ Tick if you would like information on wills and bequests

Support Group contact details

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Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bathurst	Jennifer Mannell	02 6332 8963
Campbelltown	Maree Sinclair	02 4626 4959
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Casino	Dawn Dennis	02 6662 6141
Castle Hill	Pallavi Yarrapothu	02 9634 0578
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