



Ease the Burden and Find a Cure

Stand By Me

“Shaking Up Parkinson’s” Seminar

The Hon. Reba Meagher receives the Access Economics Report on behalf of the NSW Government and announces a one off grant of \$50,000.

The Health Minister opened our Seminar “*Shaking Up Parkinson’s*” on 12 September at State Parliament House. She congratulated Parkinson’s NSW on their work in supporting people living with Parkinson’s disease.

Parkinson’s NSW is pleased to receive this one-off grant from NSW Health. The money will be used to assist us in providing information services to over 20,000 people living with Parkinson’s in NSW.

We are grateful for the recognition from NSW Health of the financial and emotional cost for people living with Parkinson’s, their families and the entire community. We look forward to increased cooperation with NSW Health in the future.

Our Seminar provided an opportunity to hear from leading researchers and clinicians in the field of Parkinson’s:

- Prof. George Mellick from the Eskitis Institute of Cell and Molecular Therapies, Griffith University, Brisbane, spoke about a multidisciplinary research approach to understanding the complexities of Parkinson’s disease;
- Assoc Prof Antony Cooper, from Garvan Institute of Medical Research, highlighted his research on transport defects within cells as an underlying cause of Parkinson’s disease;
- Dr Paul Silberstein, Movement Disorders Specialist Neurologist at North Shore Private Hospital, and staff specialist at RNSH, spoke about surgery for Parkinson’s – present and future;
- Dr Michael Hayes, Senior Staff Specialist Neurology, Concord Hospital, spoke about clinical trials and new medications;
- Rachel Miles, Speech Pathologist in Charge, War Memorial Hospital, spoke about optimism communication; and
- Dr Colleen Canning, senior lecturer Discipline of Physiotherapy University of Sydney, showed us exercises to produce BIG voices and LOUD voices.

The day concluded with a panel of three people living with Parkinson’s who have achieved extraordinary feats:

- Eddie – sky diver and bungy jumper;
- Anne – Harley Davidson bike rider;
- Ray – City to Surf participant.

DVDs of “*Shaking Up Parkinson’s*” are available by contacting the office.



Support Group state wide meeting

Support groups from across NSW sent a representative to Sydney to attend a two day meeting in July. At the meeting they heard from:

- Marty Rhone, our Fundraising Consultant;
- John Silk presented the Access Economics Report;
- Alan Cropp demonstrated how to raise awareness for individuals living with Parkinson’s; and
- our PR consultants, Polkadot PR, shared tips and advice on how to engage with the media.

Representatives also had the opportunity to hear the feedback from our recent membership survey. Support group leaders appreciated the opportunity to share experiences and stories from their group with others from across the State.

Parkinson’s NSW acknowledges the generous support from Regional Express Airlines who provided 15 return flights for our leaders to attend the meeting. This allowed Colleen O’Brien and Barbara Gillespie from Broken Hill to meet other people with Parkinson’s Disease. In August, Lorna and Brian White from Dubbo, called in for breakfast at Broken Hill during a one hour stopover of the Indian Pacific train.

We would also like to acknowledge the generosity of Novartis Pharmaceuticals for allowing us to use their meeting room and for providing exceptional catering for our two day meeting.

FEATURES

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President's Report

Spring is a time of renewal and optimism; an appropriate time for all of Parkinson's NSW to have a look at what is new and hopeful for our organisation and for all PLWP.

In July, 40 of our Support Group leaders and/or representatives, attended what proved to be an excellent two day meeting. The highlight of this meeting was undoubtedly the communication and interaction between everyone; city and country leaders, staff, councilors, and the management team at Novartis.

Rex Airlines and Novartis both earned a well deserved 'thank you' from us for their generous support of this conference. Novartis made us feel very welcome in their marvellous facilities, and they provided indulgent catering on both days.

The longer term outcome from the meeting will be a better understanding of the role each of us in PNSW has to play in getting Parkinson's understood by the wider community and accepted as an 'important disease' by Government. The aim is to create a climate that will give us a financial 'leg up' so that we might find a cure and improve the lives of this current group of sufferers.

On 16 August, Greg Pynt, Pat Barkley, Miriam Dixon and I attended a breakfast meeting in Parliament House Canberra hosted by Joanna Gash, the convener of Friends of Parkinson's in the Federal Parliament. John McDonald, the President of Parkinson's Australia, was

given the opportunity to present the Minister for Health, Tony Abbott, with a copy of a report prepared by Access Economics, regarding the economic costs and effects of Parkinson's on the Australian population. The Minister, on receiving the report, noted the number of people affected and looked forward to seeing some fleshing out of the recommendations.

With the oncoming Federal elections we can but hope that both sides of politics take heed of the report's recommendations, and develop a better understanding of what is necessary to fight this affliction.

Our seminar on 12 September at Parliament House heralded a third piece of promising news. Reba Meagher, the Minister for Health in NSW, announced a one-off grant of \$50,000 to PNSW, to be used for information and education regarding Parkinson's. To my knowledge this is the first major amount of money we have received in NSW from the Government, and on your behalf, I had great pleasure in thanking the Minister. The Minister also accepted a copy of the Access Economics report, and we hope the NSW Government will be encouraged to consider on-going support of PLWP in our State.

To summarise, our 'PNSW' Spring:

The Support Groups are working with the Staff and the Council to better our lives and inform the populace about PD.

The Federal Government received a meaningful document to judge the effect of PD – and hopefully will be acting upon it.

The State Government acknowledged that we need help – and for the first time are giving us some help and hope for the future.

Let's dream on!

PS – Thanks to all those who ran in the Sydney City to Surf to raise funds for Parkinson's NSW, especially Miriam Dixon, our CEO.

Diary Dates

OCTOBER

- 24 Putting in for Parkinson's NSW Inaugural Golf Day
- 26 Trivia night at Randwick Labour Club at 7pm sponsored by Coogee Lions Club. All proceeds to Parkinson's NSW.

NOVEMBER

- 13 Life Members' morning tea
- 20 Young Men's Parkinson's Network
- 20 Partners of Young Men's Parkinson's Network Coffee Group

DECEMBER

- 8 Parkinson's NSW Christmas Party at the Vincent Fairfax Family Visiting area Cox's Road, North Ryde Starts 11.00am RSVP before 30th November
- 18 Young Men's Parkinson's Network
- 18 Partners of Young Men's Parkinson's Network Coffee Group

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

Surfers helping Surfers

Have you been a surfer? Would you like to experience the wind in your hair and the sea spray on your face again? Disabled Surfers Association of Australia will help you experience surfing again, or help you experience surfing for the first time even if you are wheel chair bound.

Contact Graeme Samuels on mobile 0408 605 280 or visit their website: www.disabledsurfers.org

Further Out Of My Mind

Poems by Dennis Smith

Contains 100 poems, including a number of poems about Parkinson's Disease

ALL PROCEEDS WILL BE DONATED TO PARKINSON'S ACT INC

\$10.00 per copy plus **\$4.50** postage (packed securely in cardboard box).

Contact Dennis on (02) 6247 8003 or 0414 997 102 or dandismith@netspace.net.au



CEO's Report

Staff Changes.

Sadly, Nancy Tung has resigned from the Information and Resource Officer's position, and Linda Matheson, our Office Manager has left us to move to Queensland.

I am delighted to let you know that Claerwen Armstrong and Lyn Smith are jointly sharing the Information and Resource Officer's position. Claerwen has a counselling background, and Lyn Smith has been an active member of the eastern suburbs group, and has a nursing background.

Beulah Barker has accepted the Office Co-ordinator position. Beulah has worked for the American Chamber of Commerce, and more recently held the position of Administration/Reception for a large wholesale travel company.

Awareness Week

Many of our support groups have been holding stalls in their local shopping centres. Many have reported contact with people newly diagnosed with PD, and have gained new members to their support groups, as well as making referrals to our InfoLine and counselling services.

Our support groups have also been instrumental in helping to raise awareness at the local level through contacts with radio, press and TV. WIN TV, SUZIE program interviewed Cherie Rice (past President, a young woman living with PD) and Anne Grey (a woman living with PD who is a Harley Davidson rider, featured in a previous edition of *Stand By Me*). This program reaches over eight million viewers.

Glen Wheeler, on 2UE, generously took the time to interview me on Sunday 2 September. Glen's Dad is living with Parkinson's, and he has been a great supporter of Parkinson's NSW, helping to raise awareness through his radio programs.

The Royal NSW Bowling Association featured a story on Parkinson's Awareness Week in their publication, *Bowls NSW*. They also ran an advertisement for our Christmas cards and raffle.

Our Awareness Seminar at State Parliament House was again a sell-out, with over 170 attendees. It was pleasing to have Jonathan O'Dea, member for Davidson, attend the presentation of the Access Economics Report by Health Minister Reba Meagher. Another special guest representing the Pharmacy Guild of Australia was Carlene Smith. Carlene was instrumental in writing our brochure "Drugs to be Given with Caution".

A highlight of the seminar was meeting so many members, and hearing about how they are meeting the challenges of living with Parkinson's Disease.

Our three panellists at the seminar were people who have maintained their sense of adventure while living with Parkinson's Disease. In particular, Ray Groves spoke about how calling our 1800 number, and utilising our counselling service had helped to turn his life around.

A big thank you to our staff and volunteers who worked so hard leading up to the seminar, and assured everything ran smoothly on the day.

We will be hosting the National Parkinson's Conference at the Novotel Sydney Olympic Park on 9 and 10 October 2008. Our next Awareness Seminar at State Parliament House will be in September 2009.

Access Economics Report

It was my pleasure to attend a Parliamentary breakfast on the 16 August at Federal Parliament, where the Hon. Tony Abbott accepted the Access Economics Report on behalf of the NSW Government. I was also able to meet up with my colleagues from around Australia, and Norman Marshall CEO Parkinson's Australia.

New Offices

I am thrilled to be able to report that we have finally received development approval to build our counselling and InfoLine offices. Work commenced early September and we hope to have an official opening in early November.

Speakers Group

Would you like to raise awareness of Parkinson's Disease? The Speakers Group are volunteers living with Parkinson's Disease (people with a diagnosis, partners and carers). Parkinson's NSW provides training on presentation skills and an information kit. If you are interested please call the office and speak with Beulah Barker. We would love to welcome you to the group.

Calling all Poetry Writers

Many of our members send us poems. We have been unable to include these poems in *Stand By Me*. We would love to share these poems with our members and the wider community, therefore we have created Poet's Corner on our web page. If you would like your poems to be included on our website, please forward them to the office. Emailed poems would be much appreciated – pnsw@parkinsonsnsw.org.au. To visit Poet's Corner on our website, click on the link at the bottom of the Home Page.

Handy Hints and Good Ideas

One of our members, Brian from Bowral, was inspired by **Allen's Triple A – awareness, acceptance, activity** section in our last *Stand By Me*. Brian has suggested that we encourage members to write in and share their tips and ideas for helping to live with the challenges of Parkinson's. Please forward your suggestions to Beulah at the office or email – pnsw@parkinsonsnsw.org.au.

InfoLine

Our InfoLine (1800 644 189) is often the first point of contact for people living with Parkinson's disease. It provides access to tailored accurate up-to-date information on living with Parkinson's and, where appropriate, a referral to support groups and our counselling service.

Please call our InfoLine as you travel along your journey with Parkinson's Disease to gain support and information. We would also love to hear from you about any concerns or difficulties you encounter, be it with supply of medication, accessing community services, or experiencing discrimination in the workplace.

We would appreciate any comments regarding your concerns, or appreciation of our services at Parkinson's NSW. Please feel free to raise these with our InfoLine staff or myself.

Miriam Dixon
CEO

Research

SEXUALITY AND PARKINSON'S DISEASE – WHAT ARE THE ISSUES?

by Sandra Lever

Sexuality Clinic Coordinator, Royal Rehabilitation Centre Sydney – Tel: 9808 9347

Sexuality is a central aspect of being human, and is linked to a person's quality of life. This article looks at common sexuality issues, the impact of sexual problems on people with Parkinson's Disease (PD) and their partners, and information on strategies for managing of sexual problems.

Sexuality

Sexuality is a highly complex human phenomenon that is individualistic, and incorporates a broad range of behaviour and feelings (LeMone & Jones, 1997). It is a holistic notion that includes more than the physical act of sex and is closely interwoven with the total health of the person (LeMone & Jones, 1997; Smith, 1999). Sexuality encompasses gender identities and roles as well as other components of self concept including body image and self worth (Greco, 2002). Most importantly, sexuality incorporates sexual orientation, eroticism, relationships, intimacy, reproduction and the ability to give and receive pleasure (Greco, 2002).

Changes to sexuality that may occur with PD

PD and its treatment may have a significant impact on a person's ability to function as a sexual being. Orna, Gila & Nir (2006) outline potential sexual problems in PD as being:

- decreased sexual desire;
- increased sexual desire;
- arousal problems;
- orgasmic problems;
- sexual dissatisfaction;
- role changes;
- difficulties in giving intimate touch;
- restrictions in sexual positions;
- difficulties in sexual communication;
- reduced vaginal lubrication in women;
- painful intercourse in women;
- erectile dysfunction in men; and
- premature ejaculation.

Impact of sexual problems

While some people easily accept changes in their sexuality, for others the changes can be very distressing. Feelings of frustration, sexual inadequacy and loss of self esteem may occur (Orna, Gila & Nir, 2006). Sexual activity can be a powerful source of comfort, pleasure and intimacy and a way of feeling "normal" when so much else has changed (McInnes, 2003).

Communicating about sexual concerns

It may be difficult for a person with PD to talk about sexuality concerns, and health professionals often do not raise the topic. However, it is important to talk about sexuality concerns because effective treatment is available for many sexual problems (Orna, Gila, & Nir, 2006). When talking to a health professional about your sexual concerns, you might start by saying: *"I have heard that ... people with PD experience changes in their sexual function. Can I discuss this delicate issue with you?"* (Orna, Gila, & Nir, 2006). If the health professional is

unable or unwilling to discuss sexual issues with you, ask them to refer you to a specialist (Orna, Gila, & Nir, 2006). It is important to remember that this is a very important issue and you are entitled to receive appropriate interventions to address your concerns (Orna, Gila, & Nir, 2006).

Couples may also find it difficult to talk to each other about changes in sexuality and intimacy. Open communication between couples about your fears and concerns can be a good starting point in coping with difficulties (Orna, Gila & Nir, 2006). Key points that may be useful for communicating include:

- listening to each other without "butting in";
- not being afraid of tears or a discussion that may cause them;
- choosing the right time to talk, for example when no other distractions are present;
- using "I" statements, for example "when this happens, I feel..."; and
- checking that you have heard what your partner is saying (Sandowski, 1989).

Potential sexual concerns in PD

The following paragraphs will provide a brief overview of some of the options available if sexual concerns should arise.

In a research study by Bronner, Royter, Korczyn & Giladi (2004), 87.5% of men with PD reported erectile dysfunction. A number of options are available for erectile dysfunction. These include sexual counselling, medications (Cialis, Viagra, Levitra), penile injection therapy (caverject), external devices (vacuums and rings) and surgical treatment (penile implants) (Lever, 2003). It is also possible to have sex with a half erect penis, usually with the partner on top to guide the penis inside. It is also important to remember that a full erection is not required to have an orgasm and that orgasm can be reached with other sexual activities other than penetration.

Premature ejaculation was also a concern reported by men with PD (Bronner et al, 2004). Many factors affect control of ejaculation including anxiety and time since last ejaculation (King, 1998). Options for gaining greater control include focusing on non-intercourse love making activities rather than intercourse, using self-stimulation more often and/or before sexual activity with your partner, and learning relaxation techniques (King, 1998). Antidepressant medications may also be prescribed by your doctor to delay ejaculation. Numbing sprays or creams from chemists or adult shops may also be used, although numbing the penis may defeat the purpose of making love (Orna, Gila & Nir, 2006; King, 1998).

Difficulties with arousal was reported by 87.5% of women with PD in Bronner et al (2004) study. Discussing feelings, concerns and preferences with your partner can help improve your sexual experience as well as setting the mood and atmosphere, ensuring that you will not be disturbed, taking time with physical stimulation and positive communication about areas that arouse

Research

SEXUALITY AND PARKINSON'S DISEASE – WHAT ARE THE ISSUES? *continued*

you. Sexual fantasies which are normal and used by lots of people (Schnarch, 2002) may also be helpful in distracting from negative thoughts.

Reduced lubrication due to arousal difficulties, anxiety, poor self concept and/or lack of oestrogen, as occurs with menopause, may cause painful intercourse in some women (Schnarch, 2002; Zawid, 1994). Using a water soluble lubricant such as K-Y jelly may be of benefit in reducing this type of pain (Greco, 2002). It is not recommended to use an oil based lubricant such as baby oil as these can increase the risk of vaginal infections (Greco, 2002). Sexual pain may also be positional so it may help to try different positions, particularly positions which enable the woman to control the amount of penetration.

People with PD often need to adopt alternative sexual positions for sharing sexual experiences. For example, a large amount of body strength and balance is required in the position where the male is on top (Greco, 2002). Couples may need to experiment with different sexual positions to find one that is comfortable.

The use of sensate focus exercises may also be useful in helping re-establish comfort with each other and identifying what feels good and what feels unpleasant. This technique involves taking turns in gently touching, stroking, massaging and/or kissing each other's bodies and telling each other in a positive way what feels good and what does not (Greco, 2002). The focus of the exercise is not on orgasm or intercourse but if this should occur and you both enjoy the activity, then great.

If hormone levels are low, oestrogen and progesterone replacement therapy for women, and testosterone replacement therapy for men may help the body respond to sexual stimulation (Orna, Gila & Nir, 2006; Schnarch, 2002).

Many medications also contribute to problems with sexuality. Some medications may cause a decrease in sexual desire such as anti-depressants, some blood pressure medications, benzodiazepines and anticholinergic medications (King, 1998, Greco, 2002). Medications used for the treatment of PD may cause a reduced sexual drive, erectile dysfunction, difficulties with orgasm, premature ejaculation or even hypersexuality (Orna, Gila & Nir, 2006). Whilst hypersexuality is more common when a person is on subcutaneous apomorphine, it also occurs with levodopa and oral dopamine agonists (Giovannoni, Sullivan, Turner, Marison & Lees, 2000). In hedonistic homeostatic dysregulation, inappropriate sexual behaviour such as exhibitionism,

excessive use of sex-phone-in lines, prostitution services and adult shops may occur (Giovannoni et al, 2000). Hedonistic homeostatic dysregulation is a syndrome that may occur in males with early onset Parkinson's Disease when increasing quantities of dopamine replacement therapy is taken despite increasingly severe drug induced dyskinesias. If you think that your medications may be causing sexual problems, then discuss this with your doctor.

Conclusion

Sexuality problems are an important contributor to stress. The unhappiness and conflict that these problems may cause can have a devastating effect on the person with PD as well as their partners. It is hoped that this article has provided some useful information about this important topic. There are also people who can provide support and advice in this area. If you have sexual problems, don't let embarrassment stop you from seeking assistance.

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Speeding Vibrations

YOUNG ON-SET NETWORK

Diagnosed under 60?

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

ALL WELCOME!

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

COOGEE LIONS MAROUBRA LIONS

Trivia Night

In Support of Parkinson's NSW

When: Friday 26 October 2007

Time: 7.00 pm for a 7.30pm start

Where: Randwick Labor Club, 135 Alison Road, Randwick

Cost: \$15 per person – Drinks at Club prices.

**Please contact Wendy
for delivery of your tickets on 9664 9467.**

Profile: Lucelle King



Lucelle King is the wife of Bruce King, Council Member and Leader of the Manning-Great Lakes support group. Lucelle's career was full of variety including ticketwriter, signwriter, choirmaster, Sunday School teacher, and mother of four children.

Lucelle has used her creative skills to design banners for Australian Church Women (NSW);

a logo for Christian Women Communicating International (CWCI); and covers for World Community Day.

Lucelle has held administrative roles in support of women through the Baptist Church and its organizations. She was President of NSW Baptist Women's Fellowship

(1977-80); President of Baptist Theological College Ladies' Auxiliary (1981-89); and the Director of the Church's children's camps from 1945-1958.

In the commercial world, Lucelle worked as a ticketwriter/signwriter for 13 years at Bankstown Square, for Lend Lease Management. Her musical and choral skills saw her present The Christmas Story at Bankstown Square and at Carlingford Court. She was conductor of the CWCI Women's Choir for six years.

Lucelle was awarded Life Membership in 2000 for her work at State and National level for Australian Church Women (NSW). She was diagnosed with Parkinson's Disease in 2001 and re-diagnosed with Gait Dyspraxia in 2005. She currently resides at Kularoo Gardens Centre in Forster and attends the local Parkinson's Disease support group. She and Bruce celebrated her 80th Birthday in July with over 30 family and friends.

Revesby Ladies' Group *by Trish Morgan*

A phone call in November 2005 from Phyllis Aldridge, of the Revesby Ladies' Group, started a wonderful relationship with Parkinson's NSW. This group has met weekly over thirty years for mutual support, and to fundraise for worthy causes.

The Ladies had already chosen PD for their charity for 2006, and had opened the fund with a raffle. Since then, they have held stalls, bus trips and raffles and have raised over \$8,000. Phyllis works tirelessly at seeking donations from shops and business houses for the raffles. The Ladies held 2 stalls at Concord Hospital Market to sell their knitted goods, bric-a-brac and second hand clothes. Travelling from Revesby to Concord in peak hour traffic, in a car loaded with goods, was no mean feat. Phyllis was ably assisted by Cathy Don and Brenda Grant.

Revesby Ladies' Group deserves our heartfelt thanks for a magnificent effort to "Ease the Burden and Find a Cure".



Revesby Ladies Group.

Cowra Parkinson's Support Group holds successful seminar

To mark the beginning of Awareness Week, the Cowra Support Group hosted a Wellness Seminar. Their seminar featured Dr Kay Double, Sister Laraine McAnally, local physiotherapist Mark Gillham, Occupational Therapist Stacey Whiley and Dr Simon Hammond. John Silk provided a short presentation on the Access Report, while Miriam Dixon spoke about Parkinson's NSW support services. The seminar was attended by people from the surrounding districts of Orange, Bathurst and Parkes as well as the Cowra region itself.



Ray Heilman, President Cowra support group with Jennifer Mannell, Leader Bathurst support group.

On the groupvine

by Trish Morgan

Awareness Week: Thank you to all our members who worked so hard to put the cause of Parkinson's NSW before the public. Slowly, people will learn what living with PD is all about. Some groups swing into promotion mode with great skill, such as:

- Coalfields;
- Coffs Harbour;
- Hornsby/Kur-ring-gai;
- Newcastle; and
- Wagga Wagga.

Castle Hill held Awareness stalls over six days at five shopping centres. Illawarra North ventured into Wollongong Mall, and Illawarra South tried a new venue at Warrawong. Many groups, like the Central Coast, approached the media for TV and radio interviews. Laraine Rowland gave her story to educate second year medical students at Newcastle University. Maureen Morrison spoke at Sutherland Library, and there were displays of Parkinson's information throughout the library. The Goulburn Post gave front page lead in to a story about Michael O'Connor's experience with PD which prompted him and his wife Gill to establish the Goulburn support group.

Thank you to all of those who offered their personal stories to the newspapers.

Castle Hill support group is being driven by the industrious Alex Bory. Alex feels strongly about fighting PD and about spreading awareness. He regularly speaks to organisations about PD. Alex has enlisted a band of helpers from his local church, St Andrew's at Crestwood, to help at shopping centres and to volunteer to do a mail out at PNSW.



Castle Hill Support Group – Alex Bory and Susan.

Castle Hill hosted a combined Arthritis and PD support group meeting in August through their leader Gayle Parker, who is an Occupational Therapist. The guest speaker was Danielle Fischer from the Garvan Research Institute, who spoke about research advances in Osteoporosis and Parkinson's Disease.

Chinatown support group hosted a very successful seminar on 4 July, which was attended by 150 people, half of whom were of Chinese speaking backgrounds. The speakers were Dr Michael Hayes, who talked about medication and PD; Dr Paul Silberstein, who talked about surgery; and Mr John Poon, a psychologist in private practice, who talked about psychological impacts and how to deal with them. There was an exercise interlude lead by physiotherapist, Rosanna Ng. Chinatown are to be commended for their work in delivering quality education using professional interpreters to reach people of several different languages.

Illawarra North celebrated the birth of a baby boy in May. Keiran was born to social worker, Emma Robinson, who has been leader of the group since 2005. John Coppens and Ian Squires are now sharing the leadership. This group has two bus trips each year, and will be off to Jervis Bay in October to visit the Lady Denman Museum and Gardens. They made 15 new contacts at the stall in Awareness Week.

Manning/Great Lakes has grown in the last three years to a membership of almost 50. Their leader, Bruce King, who is also a country representative on the Council of Parkinson's NSW, distributes a 'chatty' newsletter about the members' activities and includes jokes and brainteasers. They are a very happy bunch as their photo shows. Bruce's wife Lucelle is our Profile Personality for this issue.



Manning-Great Lakes Support Group.

Up and Coming Events

1. Update regarding Manly/Mosman support group. Meeting with Manly Council this week regarding a venue. Lots of enquiries. Members will be notified about the public meeting.
2. Update regarding Blacktown support group. This is likely to be the first project for 2008.

This might help you reprinted from Chit Chat

Myra Chalmers

Something Myra wants you to think about

As you would imagine, I have had a lot of legal and financial paper work to sort out following Ron's death on 12 June.

I have been very fortunate because of the organised way Ron had left things for me. I am aware of a good friend who also lost her husband, but the situation for her was very different. It made her loss a lot more difficult because of the strain imposed as she tried to organise her affairs.

What I would like to suggest that you give some thought to, is that this friend had never written a cheque, paid an account or even done any financial paper work. Her husband had always done these things. Now she has found that she doesn't know about running her financial life, including managing income tax and is quite worried about how she will manage from now on.

Ron made sure that all our accounts and the house were in both names (jointly) so that either of us could sign. When Ron died I could draw money in my own right, operate the bank account and write cheques. I had the experience of coping with the paper work that we had found necessary in the past.

I beseech you all, forget male or female chauvinism and make sure that you both have means of survival in the event that either you or your partner dies. I appreciate that I feel prepared to cope with this aspect of my loss

and I realise that some people who read this may also be prepared but some may not.

Work together on this and have an easy conscience. Don't leave your loved one high and dry like my friend.

At the very least, make sure that you both know how to write a cheque or fill out a form, how to do the income tax and know whether and how to pay bills.

Being prepared in this way is sure to save a great deal of heartache in the long run at a time when you don't need extra stress.

Myra Chalmers

These are wise words based on Myra's personal experience.

*A number of charity and community groups have courses based on a financial literacy program called "**Money Minded**". A variety of workshops are available or can be completed on-line. The Benevolent Society of NSW could be contacted for details about this course.*

Contact Susan Allen on 4627 2792.

The Money Minded website suggests that "Every Person's financial circumstances are unique and each individual requires a different level of support". One variation to be considered is whether or not someone is receiving whole or part pension or is self-funded.

Jan Wiseman

Community development and support expenditure (CDSE)

Three members of the Dundas-Parramatta support group are also members of the volunteer Parkinson's Speakers Group. Members of the Speakers Group go to service clubs like Rotary, Lions and Probus, to raise awareness of Parkinson's Disease. Recently the Support Group successfully applied for a Community Development and Support Expenditure (CDSE) funding from The Epping Club to purchase two lap tops, data projectors and a digital camera. This will enable speakers to use PowerPoint for their presentations about PD, with the visual enhancement giving greater impact.



David King accepts the cheque for \$7,277 for equipment for the Speakers Group.

Allen's Triple A – awareness, acceptance, activity

If you are talking to someone, and you are constantly being asked to repeat what you have said, then change the volume level ...

... SHOUT SOFTLY

You may think that you are already shouting, so up the volume level a little more.



NEWCASTLE PRIVATE
HOSPITAL

Newcastle Private Hospital is pleased to offer the

Lee Silverman Voice Treatment (LSVT)

Proven effective treatment for voice and speech disorders in individuals with Parkinson's.

- ENT assessment essential
- Health fund coverage or private payment options
- Intensive course of treatment

Enquiries to Kate Monk, Speech Pathologist
Certified LSVT – Phone: 4941 8442

Correct position for opening your bowels

<p>Step one</p> <p>Knees higher than hips</p>	<p>Step two</p> <p>Lean forwards and put elbows on your knees</p>
<p>Step three</p> <p>Bulge out your abdomen Straighten your spine</p>	<p>Correct position</p> <p>Knees higher than hips Lean forwards and put elbows on your knees Bulge out your abdomen Straighten your spine</p>

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THE BRISTOL STOOL FORM SCALE

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces ENTIRELY LIQUID

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Parkinson's NSW Inc. Raffle Tickets

\$5

1st Prize

- Panasonic 127CM Plasma Screen \$3288.00
- Yamaha Home Theatre System \$1499.00
- Panasonic 160Gb HDD DVD recorder \$649.00

2nd Prize

- Toshiba IT Notebook P200/602 Intel \$2999.00
- Tech Pacific Multifunction HP Printer \$229.00

3rd Prize

- Canon Digital Camera SLR 10.1MP \$1599.00

4th Prize

- BrightPoint Navman GPS F20 \$529.00

DRAWN – 8th December 2007

Please contact Parkinson's NSW for tickets

Free InfoLine 1800 644 189



Research into blood fat changes in Parkinson's Disease



We are investigating changes in blood fats in Parkinson's Disease to assist us in developing new, more effective treatments for this disorder.

We are seeking females who:

- are aged between 50-85;
- suffer from any stage of Parkinson's Disease; and
- who do not have high cholesterol levels, and do not take medications for high cholesterol (eg Lipitor).

We are seeking males who:

- are aged between 50-85; and
- who do not have high cholesterol levels, and do not take medications for high cholesterol (eg Lipitor).

Participants will be asked to:

- fast overnight before the appointment;
- have 20mL (one tablespoon) blood taken by a trained nurse; and
- undergo a motor examination to be conducted by a neurologist.

The **one-hour, one-appointment** study will be conducted at Concord Repatriation General Hospital (CRGH). Breakfast is provided on the day of the appointment. Transport can be provided in the form of taxi vouchers.

For more information, please contact:
 Ian Ng: (02) 9399 1102 mobile: 0405 996 141
 Dr Kay Double: (02) 9399 1056
 Sue Mercer: (02) 9767 7917

This study has been approved by Human Research Ethics Committee-CRGH

Donations

\$50 and over received between 19 June and 27 September 2007

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

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

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Bernard Acton
Gwendoline Bailes
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Charles Briers
Edward J Brown
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Gladys Davis
Daphne Duncan
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Parkinson's Support
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Eurobodalla Parkinsons
Support Group
Glenn Innes Parkinsons
Support Group
Grafton Parkinsons
Support Group
Newcastle Parkinsons
Support Group
Northern Rivers
Parkinsons Support
Group
St George/Sutherland
Parkinsons Support
Group
Tomaree Peninsular
Parkinsons Support
Group
Young On-set Parkinsons
Support Group

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

by Margaret Byron, Bequest Officer

The James Parkinson Society is not separate to Parkinson's NSW. On the contrary, it is an integral part of the organisation.

If you receive *Stand By Me*, then you are a member of Parkinson's NSW. Members who have included Parkinson's NSW as a beneficiary in their Wills, and have informed us about their generous intention, are part of a special group of members. This group is called the James Parkinson Society. Parkinson's NSW will receive their gift in years to come, therefore, these members are "... bringing hope for the future."

Since the launch of the James Parkinson Society in September last year, 17 people have informed us that they have made a bequest to Parkinson's NSW. We are grateful to be able to thank them for their action now and share with them bringing hope for the future.

Some people may have named Parkinson's NSW in their Will but choose not to tell us. We respect that choice and your gift is appreciated just as much.

There are different sorts of bequests. If you would like more information or would like to discuss any aspect of making a bequest to Parkinson's NSW please contact Margaret on (02) 9876 5351 any time between 8am and 8pm.

Belinda Mar, a registered Music Therapist, was the special guest at our most recent sponsored Bequest Lunch, held at Ryde-Eastwood Leagues Club, West Ryde, on 18 September. She told us about her work and how music therapy is successful in maintaining and improving the wellbeing of people. Three people were inducted as members of the James Parkinson Society at this lunch.

Do you have Parkinson's Disease?

We are looking for people who have Parkinson's Disease and who may be interested in participating in a clinical trial using a 24 hour patch to deliver an investigational drug. This trial is being performed by Dr Michael Hayes and his research team at the Neurosciences Department, Level 5 West, Concord Repatriation General Hospital, Hospital Road, Concord NSW 2139.

People who are suitable for this trial are those with Parkinson's Disease, who have difficulty getting going in the morning before their first dose of daily medication.

The study will be targeted primarily to those subjects who have disturbed sleep and have difficulty mobilising in the early morning as a result of Parkinson's Disease.

If you are interested in finding out more please contact: Rosie Portley, Study Coordinator on (02) 9767 5184 or (02) 9767 6416 to discuss the trial.

Support group contact details

GROUP	CONTACT	PHONE
Albury	Bruce Ockenden	02 6025 7147
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown	Trish Morgan	02 8875 8903
Bathurst	Jennifer Mannell	02 6332 8963
Blue Mountains	Hazel Tolhurst	02 4757 4214
Canterbury	Trish Morgan	02 8875 8903
Casino	Dawn Dennis	02 6662 6141
Castle Hill	Gayle Parker	02 9634 0578
Central Coast	Les Norris	0418 607 684
Chinatown Bi-lingual		0421 224 712
Coalfields	Carol Bateson	02 4930 8638
Coffs Harbour		02 6652 9959
Cowra	Ray Heilman	02 6341 3692
Deniliquin/Finley	Glenis Gordon	03 5881 3295
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta		02 9876 4284
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla		02 4472 2037
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	0428 226 732
Grafton	Cathy Eggins	02 6642 2156
Griffith	Joyce Giacomelli	02 6966 9900
Gunnedah	Lisa Hagley	02 6742 0018
Hawkesbury	Jill Sykes	02 4730 4302
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South		02 4232 2807
Lower North Shore		02 9412 2740
Macarthur	Maree Sinclair	02 4626 4959
Manning/Great Lakes	Bruce King	02 6555 9409
Nambucca Valley	Margaret Butcher	02 6564 8231
Nepean	Joe Golding	02 9670 5093
Newcastle	Verlie Sullivan	02 4954 0338
Parke	Con Diamond	02 6862 1925
Pittwater/Mona Vale		02 9997 1542
Port Macquarie	Patricia Stephenson	02 6584 0212
Shoalhaven/Ulludulla	Barry Mitchell	02 4454 0747
Southern Highlands	Marj Webb	02 4871 2615
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Tamworth	Pat Johnson	02 6765 6948
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Tweed Heads		07 5524 9417
Wagga Wagga	John Allen	02 6925 2713
Yass	Peter Wells	02 6226 2233
Young Onset	Sarah Lines	02 4627 5632

PARKINSON'S NSW INC.

PO Box 71
 NORTH RYDE BC NSW 1670
 Toll Free No: 1800 644 189
 Phone: 02 8875 8900
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 Email: pnswn@parkinsonsnsw.org.au
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Name (Mr, Mrs, Ms, Dr) _____

Organisation (if applicable) _____

Address _____

State Postcode

Tel (H) (W) (M)

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Have you been diagnosed with Parkinson's? Yes/No

Date of Diagnosis Date of Birth

Annual Membership (incl. GST)

- Individual Membership \$22.00
- Organisational Membership \$55.00
- Life Membership \$220.00
- I would like to make a donation of (tax deductible over \$2) \$ _____

TOTAL AMOUNT \$ _____

Pay online – www.parkinsonsnsw.org.au

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(Each member may nominate a joint member – at no cost. Please complete)

Name _____

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I am paying by: cheque money order

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Bequests

Please consider leaving a bequest to Parkinson's NSW in your will. It is the ultimate gift you can make; to leave a lasting legacy in perpetuity and assist those with Parkinson's. Alternatively, a living legacy will mean that you can personally experience the benefit your generous gift provides.

To make a bequest or living bequest please call 1800 644 189.

Parkinson's NSW Inc. ABN 93 023 603 545
 Disclaimer: The information provided is for guidance only and is not a substitute for professional medical advice. Parkinson's NSW takes reasonable care (in the context of freely available information) to keep the information it provides accurate and up-to-date; however, Parkinson's NSW does not guarantee the correctness and completeness of the information. You should confirm that the information is applicable to your circumstances by checking it with your doctor or a qualified health care professional.
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