PARKINSON'S NEW SOUTH WALES INC. NEWSLETTER – Issue 99, Winter 2007

Ease the Burden and Find a Cure

Stand By Me

Carers in the Nepean and Blue Mountains

Two seminars were recently held by the Nepean Support Group for carers in the Nepean and the Blue Mountains.

Sr Laraine McAnally, the Pd specialist nurse at Westmead, gave an overview of Parkinson's disease, its progress and details of medications. PNSW specialist counsellor Deborah England addressed the issues that carers can face.

Representatives from Centrelink and Carelink also gave presentations on what their organisations offer, and PNSW Support Group Coordinator, Trish Morgan, outlined the benefits of joining a support group.

Almost 100 people attended the two seminars. To help carers plan for the future, each participant was given a kit containing plenty of helpful information to take home.

Many positive comments were received on the day indicating that the carers' special needs were successfully met. Perhaps one of the most positive outcomes of the seminars was the establishment of a new support group in the Blue Mountains. Within a month of the seminars, Trish organised a public meeting for the new group and now the Blue Mountains Support group is up and running.

Edna Beddall

Edna Beddall received a 2007 NSW Seniors achievement award for community service, in recognition of her work as a volunteer with the Concord exercise group, Concord office and the Canterbury support group.

John Silk

On May 4, Dr. Brendan Nelson presented PNSW President John Silk with a Bradfield Community Service Award, in recognition of outstanding contributions made in the area of community service.

Blue Mountains Parkinson's Support Group

A warm and friendly welcome was given by Hazel and Tom Tolhurst to those who attended the first meeting of the Blue Mountains Parkinson's Support Group. Twenty-three people were there and several sent apologies.

'The feeling was one of a group anxious and willing to share their happiness and problems plus hints,' says Hazel. 'It was amazing the number of people who volunteered to help in various ways, for instance having contacts that may help or talk to us, people willing to print things and some who would help with morning tea, a very important job as far as I'm concerned! So it went on happily bonding over a cuppa.'

The group will meet on the third Thursday of each month at the Baptist Church Hall, corner of Orient Street and Great Western Highway, Lawson from 10.30am - 12noon.

There will be gentle exercise, guest speakers from health and community services, a library of books, videos and CDs and plenty of time to chat and provide mutual support.

Parkinson's support groups are open to anyone affected by Parkinson's or interested in learning about it.

News Flash

Embryonic stem cell research and therapeutic cloning legislation

The NSW Legislative Council voted overwhelmingly 26:13 in favour for stem cell conscience vote for the Human Cloning and Other Prohibited Practices Amendment Bill 2007

FEATURES

President's Report

In my message to you this quarter I am going to single out VOLUNTEERS.

Recently we required volunteers to put a mailer into envelopes and we were able to cobble together an assorted group of people; some had a particular interest in Parkinson's, others were 'professionals' from Volunteer Australia and a third group were friends of some Council members. All had a great fun for three hours, finished the mailer early and proceeded to pack up cards for resale. A saving of over $1000 for us!

This got me thinking about the thousands of hours of free service donated each year to PNSW, which enable us to EXIST.

There are committees in the 50 support groups, people who man the front desk in the office, those who help out at functions, guest speakers at seminars and support group meetings and many others, including the Council.

Also there are people like Gwen Bowen of the Southern Illawara Support group who received an Australia Day Citizen's award in recognition of her work at the Kiama hospital and with her branch of PNSW.

We take some of these for granted and I am as guilty as the next person of sometimes not acknowledging them as often as I should.

Their unswerving support for all of us makes the 'Ease the burden' part of the equation just that little bit easier. My thanks to them – one and all!

Early July will see the Support Group leaders or their representatives come together for a meeting where we will have some interesting insights to share about Parkinson's in Australia. A wonderful opportunity for folk from the whole spectrum of PNSW – Support Groups and Council, city and country – to meet and share information and ideas and foster understanding. I would like to acknowledge the sponsorship that Rex Airlines have provided our regional members with free flights and Novartis for the use of their rooms and their generosity in catering for the two day meeting.

Vice President Allen Cropp has spent a great deal of time compiling information for PWP and carers alike. This issue of *Stand By Me* features some of Allen's positive philosophy that encourages us to take a refreshing look at ourselves. Useful and enjoyable reading.

As I always ask in my talks, 'Have you taken your meds?' Keep well.

John Silk

My Health Record

The NSW Health department produces *My Health Record – Keep well, keep track.* For more information on this book please call 1800 644 189, contact your local support group leader or you can order directly from the NSW Health, Better Health Centre on 9816 0452.

Allen's Triple A – awareness, acceptance, activity

If you have time on your hands it is possible that you are vulnerable to increased stress levels. Keeping busy is very beneficial. If you have to, get a hobby. Keep your brain ticking over. It is very important to keep busy. Does not matter what type of 'busy'.

Get rid of that narrow, illegible scribble, printing is easy and readable. The only thing that requires running writing is your signature. You will feel less frustrated if you can read what you have written.

Diary Dates

SEPTEMBER

2 - 9	Parkinson's Awareness week
3	Cowra Awareness Seminar
12	Seminar – Parliament House *featuring George Mellick*

OCTOBER

10	PNSW Coffee Morning
24	Putting in for Parkinson's NSW Inaugural Golf Day

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

You are cordially invited to attend the:

Virgin atlantic

Parkinson's NSW Golf Day

"PUTTING IN FOR PARKINSON'S"

Proudly supported by Sydney Markets

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

For a great fun day out, put together a team of 4 or we'll gladly put you in one. It's open to male and female golfers of all standards - Greg Norman to Greg Normal.

To register as an Augusta Gold or St Andrews Silver Sponsor or as one of the Huntingdale Hitters go to our website www.parkinsonsnsw.org.au and click on Parkinson's Golf Day and download a registration form

or call us on 02 8875 8900 for more information.

Prizes – Plenty of them including 3 overseas return airfares flying Virgin Atlantic.

The Cause - The most important consideration of the day

See you there!

Sydney Airport

Cromwell

CEO's Report

NSW Stem Cell Legislation

Many of you will be aware that legislation to allow stem cell research and therapeutic cloning (as recommended by the Lockhart Committee) was passed by the Commonwealth Parliament in December 2006. Mirror legislation was passed by the Victorian Parliament in April 2007. Similar legislation was recently introduced to the NSW Parliament

Before the Bill's introduction to the NSW Legislative Assembly, the Honourable Verity Firth, Minister for Science and Medical Research and Minister Assisting the Minister for Health (Cancer), arranged two parliamentary information sessions for members of Parliament. We were asked to participate on a panel, along with key researchers and fellow consumer organisations that are members of the Coalition for the Advancement of Medical Research Australia (CAMRA).

Neil Sligar (a former Council member) attended the Wednesday evening session and I attended the Thursday morning session. We were both able to draw the Parkinson's NSW position statement on Stem Cell Research to the attention of MPs and their advisers (this is available on our website).

We have also been in contact with members of both Upper and Lower Houses encouraging them to vote in favor of the proposed legislation. On June 7, the legislation was passed in the NSW Legislative Assembly by a vote of 65-26.

Member's Survey Results

A big thank you to all our members who responded to the survey in April. We were delighted with the number of surveys returned to the office and the response we received. I would like to share with you some results from the survey.

The majority who responded to the survey reported a diagnosis of Parkinson's disease. Almost 83% were in the 61 and over age group.

Our *Stand By Me* was rated as excellent by 44.4% and another 50.3% rated it as good.

The most commonly used of our services, amongst our members who responded to the survey, are our support groups. Over half of the respondents attended monthly meetings. The respondents rated our support groups as either excellent or good.

If you have never been to a support group, perhaps your fellow members might inspire you. You will find a list of all support groups on page 11 or please call us on 1800 644 189.

The respondents who have used our face-to-face and telephone counselling services rated these services as excellent or good. Our counselling service is free and confidential. To make an appointment please contact the office on 1800 644 189.

We asked a question on currently used complementary/alternative therapies. The two main therapies currently in use by respondents were eating foods containing dopamine and using an exercise program. None of the other possible therapies listed (including taking vitamins A and E, co-enzyme Q10, glucosamine antioxidants or using massage, Reiki, Bowen, Alexander technique, tai chi or aromatherapy) received a greater than 50% confirmation of use.

We were keen to hear your views about the priorities for Parkinson's NSW Inc. Increased public awareness was voted as the top priority followed by seminars and support for research. This will assist our Council and staff with determining priorities.

Living alone with Parkinson's

Parkinson's NSW received a grant from a private foundation to hold seminars for people living alone with Pd. The program was designed to give specialised information and support and to offer strategies to help those people living alone face the uncertain future.

The one-day seminars, multiple morning seminars and weekly teleconferences have all featured guest speakers covering details of Pd, including symptoms and medication, by a neurologist or Pd specialist nurse; representatives from Centrelink and Carelink, a legal practitioner and a Pd specialist counsellor.

The first seminar was held in Wagga Wagga then Newcastle, Concord and Dapto. The Community Outreach Team in Gosford are kindly allowing us to join with the workshops they are conducting at Erina. The final series of five morning sessions in Parramatta were underway as Stand By Me went to print.

For people unable to reach the venues there have been three groups of teleconferences, each over five mornings and with the same professional speakers. Local Centrelink representatives talked about services and payments available. Local solicitors explained about wills, enduring power of attorney, enduring guardianship and advanced directives. Carelink representatives discussed maintaining independence at home.

All the seminars, whatever form they took, provided the opportunity to share experiences with others in a similar position. Feelings of isolation diminished, encouragement was fostered, information and ideas were exchanged. These helped people come to terms with the diagnosis of Pd and empowered participants to face the future with a renewed positive attitude.

YOUNG MEN'S PARKINSON'S NETWORK

Are you under 60? Living with PD?

Are you looking to meet other men who share similar experiences?

Monthly Meetings
every third Tuesday from 10.30am – 12.00noon
25 Khartoum Road, North Ryde

Contact: Garry Cearns
Mobile: 0418 648 835
Phone: 9871 1853
Email: cearns@netspace.net.au

Research

RESEARCH PROGRESS IN PARKINSON'S DISEASE

by Dr Kay Double and Francine Carew-Jones

Parkinson's disease (PD) is estimated to affect four-and-a-half million people worldwide with that number expected to double within the next 23 years. Intensive research efforts are underway to improve current treatment and management of the disease, develop earlier, more accurate methods of diagnosis of PD and ultimately to develop strategies to delay or prevent the onset of this disorder.

Diagnosis

Worryingly, post-mortem studies demonstrate that PD is wrongly diagnosed in approximately 20-25 per cent of patients. This is because PD is currently diagnosed by observation of symptoms (which also occur in a range of other disorders) and response to drug treatments, a highly subjective method reliant on the experience and skill of the physician.

Post-mortem and imaging studies have also revealed that when a patient develops the first symptoms of PD, the disease is already well underway, with approximately 70 per cent of the cells in the part of the brain that is most affected, the substantia nigra, already having been lost. Researchers are aware of the urgent need for accurate and objective methods to diagnose PD in its earliest and most rapid stages.

Recent research advances in this area includes the launch of a new PD 'gene chip' in February 2007 by researchers at the Howard Florey Institute in Melbourne. This chip will allow abnormalities in six genes which can cause inherited PD to be tested simultaneously, providing considerable savings in time and money. While this new technology will primarily benefit those patients with the rare and inherited forms of PD in the short-term, the chip will also allow researchers to study the contribution of a range of other genes to the development of the disease, knowledge which will ultimately benefit the majority of patients with the common non-inherited form of the disease.

Our research group is well aware that it will be vital to develop diagnostic methods to identify patients before the onset of symptoms, and possibly even persons at high risk of the disorder before the initiation of brain cell death, so that treatments aiming to slow or halt cell death can be initiated at a time point where they can have the most benefit.

As a commercial partnership with a pharmaceutical company in Germany we are developing a blood test based on changes in the immune system, which we hope will identify people in whom brain cell death has begun prior to the development of symptoms. We are also working with our international colleagues to develop a diagnostic method using ultrasound imaging of the brain which appears to identify people who are at increased risk of developing PD.

Treatment

Every year thousands of research articles appear in the scientific literature on PD, and panels of clinical experts in movement disorders publish up-to-date information regarding the best management of PD in major neurology journals so that the medical community can keep up with the newest information available.

The most recent of these, published in November 2006, confirmed that the best medication for symptom management in PD is still Levodopa (l-dopa), a replacement for naturally occurring dopamine, the chemical which is reduced in the PD brain. L-dopa has been used for the past 47 years, and research has improved our understanding of how it gets into the brain and how it is metabolised. This has led to the possibilities of new delivery systems, such as infusion systems and patches which are hoped to improve symptom management.

The report also looked at some of the so-called complementary management methods. Some l-dopa-containing foods, such as *mucuna pruriens* (cowhage) and broad beans, can result in short-term improvements in symptoms, while vitamin C can prolong the actions of l-dopa. No symptom improvement was seen, however, in studies using folic acid or vitamin E supplements. Other complementary treatments shown to be beneficial include acupuncture, the Alexander Technique (a way to develop awareness of posture and hence improve it) and speech therapy. It must be noted, however, that these complementary therapies have been studied in only a few, small studies and more research is required.

A complementary therapy which has been looked at in more depth is exercise. All studies utilising exercise to date have shown improvements in movement in persons with PD, although it is not yet clear how much and what sort of exercise is required, nor how long-lasting these effects are.

A new approach to treatment for PD includes a vaccine against the abnormal protein deposited inside the vulnerable brain cells and a trial of this approach is underway. Cell replacement therapies are also still under investigation. Early work in this area showed some promising results but the safety of cell transplants, either from stem cells or other sources, is still unknown, and only extremely low numbers of stem cells have survived transplantation in animal studies. Stem cells sourced from bone marrow or umbilical cord blood (but not human embryos) are currently being used in humans to treat some disorders, including ischemic heart disease and spinal cord lesions but as yet this has not yet been tried in PD.

Research has lead to a better understanding of how brain cells die in PD and the development of possible neuroprotective agents (substances which slow down the rate at which brain cells die). A number of possibly neuroprotective drugs currently being used in human clinical trials for PD including creatine and minocycline. Iron-binding agents are hoped to be trialed soon. There is already some clinical evidence that coenzyme Q10, another possible neuroprotective, can slow the progression of disability in PD and further trials of this substance are underway. In addition, a synthetic form of coenzyme Q10 called mitoquinone (MitoQ) has been developed which has several advantages over natural coenzyme Q10. A human trial of MitoQ for PD is underway in New Zealand and Australia.

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Research

RESEARCH PROGRESS IN PARKINSON'S DISEASE *continued*

Research into PD must seem frustratingly slow for patients and their families, but keep in mind that researchers are motivated by a desire to help, not harm, patients, thus we are neccessily cautious when testing new ideas in the clinic. Research has resulted in a much better understanding of what happens in the parkinsonian brain and as a result treatment options should soon be available which will, for the first time, modulate the disease process. Until this time we will continue to develop ways to improve symptom management.

Patients should be mindful that complementary medicine substances and therapies are not covered by the Therapeutic Goods Administration, and are thus generally not well studied and are uncontrolled. Before beginning any form of complementary approach, investigate what is known about the treatment, its benefits and risks and discuss these with your doctor.

This article is a summary of a presentation by Dr Double at the Eurobodalla Parkinson's Support Group seminar on March 16 2007.

Speech pathologists learn to *say it loud*

by Rachel Miles, Speech Pathologist in Charge, War Memorial Hospital, Waverley

In May 2007, 68 speech pathologists from all around the state converged on Bondi Junction to participate in a two-day workshop on the Lee Silverman Voice Treatment (LSVT®) program.

The workshop was run by certified LSVT trainers, Dr Deborah Theodoros and Dr Liz Ward, from the Division of Speech Pathology at the University of Queensland. LSVT is a proven effective voice and speech treatment for people with Parkinson's disease who are experiencing communication difficulties. This speech pathology treatment is intensive, requiring four therapy sessions per week for four consecutive weeks, plus a healthy dose of home practice.

Research has shown that more than 75 percent of individuals with Parkinson's have voice and speech disorders, often characterised by reduced loudness, reduced pitch variation, breathy and hoarse vocal quality and imprecise articulation, to varying degrees.[1]

The LSVT program has been scientifically studied over 15 years and concentrates on a straightforward set of tasks designed to improve voice and respiratory functions.[2] The approach centres on a very specific therapeutic target: increased vocal loudness. This key target acts as a trigger to increase effort and coordination across the speech production system. The speech pathologist instructs and constantly encourages individuals with Parkinson's to produce a louder, healthy voice by using increased effort.

Studies have shown that Parkinson's disease may change an individual's ability to monitor and filter sensory information.[3] This may explain why individuals with Parkinson's who have reduced vocal loudness often report that their voices are not reduced in loudness, but rather, suggest that their spouse or friends 'need a hearing aid'. When prompted to 'speak up' to appropriate volume, they comment that they 'feel like they are shouting'.

A key component of the LSVT is for individuals to be continually reminded to monitor the loudness of their voice and the effort it takes to produce appropriate loudness. During the course of daily treatment, they learn that what feels too loud to them is actually an appropriate level that helps listeners hear and understand them.

Thanks again to the members of the Eastern Suburbs Parkinson's Support Group and St George/Sutherland Support Group who volunteered their time to assist the speech pathologists with their training. Your time and effort was greatly appreciated. Many thanks to Parkinson's NSW for their sponsorship of this event, which enabled the training to be accessible to so many speech pathologists across the state, raising the profile and availability of effective communication therapy to individuals with Parkinson's.

More information about the LSVT programme is available on the internet at www.lsvt.org. This website will also soon include contact details of the speech pathologists who participated in the recent training.

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[1] Trail, M., Fox, C., Ramig, L., Sapir, S., Howard, J., & Lai, E. (2005). Speech treatment for Parkinson's disease. Neurorehabilitation, 20, 205-221.

[2] Ramig, L. O., Sapir, S., Fox, C., & Countryman, S.(2001). Changes in vocal intensity following intensive voice treatment (LSVT) in individuals with Parkinson disease: A comparison with untreated patients and normal age-matched controls. *Movement Disorders,* 16, 79–83.

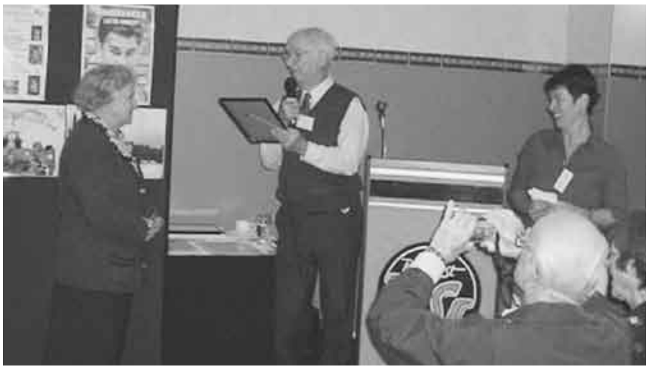
[3] Fox, C., Morrison, C., Ramig, L., & Sapir, S. (2002). Current perspectives on the Lee Silverman Voice Treatment (LSVT®) *American Journal of Speech Language Pathology.* 11, 111-123.

On the groupvine

by Trish Morgan

The Bathurst Regional Support Group meeting brought together 45 members from Bathurst, Cowra, Dubbo, Narromine, Orange,Wallarawang and the Blue Mountains. John Silk addressed the group and presented certificates of service to Isabel Mitchell and Doreen Sherring, who have led the Orange support group for many years. The afternoon saw a presentation by Allen Cropp on Awareness. This covered an extensive list of symptoms and how Allen has coped with his illness. The members responded with close attention and enjoyed the musical approach to Awareness. Bathurst RSL provided tea, coffee and lunch free of charge. Allen Cropp presented the manager, David Veness, with a certificate of appreciation. Certificates were also presented to Patricia Sparkes for producing the Bathurst support group pamphlet, which was launched on the day, and to Jennifer Mannell for years of service as leader of Bathurst Support Group.

The Goulburn Regional Support Group meeting brought together 22 members from Bowral, Queenbeyan and Yass. Allen Cropp delivered his Awareness presentation. Members contributed their own experiences from living with Parkinson's and enjoyed the musical session. Everyone enjoyed lunch from the bistro at Goulburn Workers' Club where the group meets. The club provided tea and coffee and the members supplied refreshments. Both these meeting showed the value in bringing support groups together to make new friends and learn more about Pd.



Cowra Support Group received the major award in the Community Group category at the 2007 Cowra Australia Day Award Ceremony. This was for the support and friendship offered to sufferers of Parkinson's disease and also to their carers. It made the group very proud to be recognised in this way and we congratulate them. It is a wonderful year for Cowra Support Group as their planning for an Awareness Week Seminar on Monday September 3 is well in hand. Guest speakers will be local neurologist from Orange, Dr Simon Hammond; Dr Kay Double, researcher Prince of Wales Medical Research Institute; Sr Laraine McAnally, Parkinson's specialist nurse Westmead; Deborah England, Parkinson's counsellor PNSW; and Stacey Whiley, carer support officer from Orange. For information contact President Ray Heilman on 0428 639 850 or Secretary Joy Dwight 02 6345 3217 after 7pm.

Illawarra South Support Group has reason to celebrate. Leader, Gwen Bowen, was awarded the 2007 Australia Day Citizen Award by Kiama Council (see President's Report). The group has also been successful in their submission for the Volunteer Small Equipment Grants. They purchased a laptop from Harvey Norman, Warrawong, and are looking forward to having it as a valuable source for information and communication.

Other groups who have been successful are Chinatown, Central Coast, Coffs Harbour, Grafton, Hawkesbury, Hornsby/Ku-ring-gai, St George/Sutherland, Wagga Wagga and Yass. Items purchased included laptops, projectors, DVD players, PA systems, stereo/CD player, multi-function printers as well as equipment and software to provide the Lee Silverman voice training in the home (Yass Support Group).

Port Macquarie Support Group has seen a growth in numbers and an increase in services for their members. Dr Geoffrey Boyce, PD Specialist Neurologist from Lismore, will run a clinic in Port Macquarie once a month on a Tuesday and Wednesday. Dr Boyce was guest speaker at a special meeting on May 22. Thirty-nine people attended and the group kept Dr Boyce busy with questions. There are group members coming from as far as Kempsey. A member with Parkinson's spoke to the local Carers Association in Port Macquarie earlier this year. Two years ago this group was in recess due to health reasons. Congratulations to the leader Patricia Stephenson for working hard to revive it.

New group news

- Blue Mountains Support Group is featured on page 1.
- Mudgee Support Group is in the planning stage and should start very soon. Thanks to the interest of Rev Terry Cahill and other interested parties, who travelled to Dubbo Support Group and came back with lots of ideas and information.
- Manly/Mosman may soon have a support group, thanks to the Carex Expo at Rosehill where Allen Cropp met Jacqui Enright, a registered nurse with extensive management experience in aged care who is keen to start a group.
- A survey to determine the interest in new support groups has been sent to members in Manly/Mosman, Maroubra and Blacktown/Seven Hills. The response has been very positive and it is heartening to have the good wishes of our members for successful outcomes.

New brochure

Parkinson's disease and hospitalisation guidelines.

This brochure is designed to assist the person living with Parkinson's disease prepare for hospitalisation.

Hospital staff will also benefit from the information.

To obtain a copy please call 1800 644 189 or ask your support group leader.

Help us raise awareness

Are you willing to tell your story about the challenges of living with Parkinson's to the media? If you are please contact the office 1800 644 189 and speak with Nancy or fill in an *"Information for Media Interviews"* form online.

www.parkinsonsnsw.org.au

Profile: David Boyle – Port Macquarie Support Group

David Boyle and his wife Mavis moved to Port Macquarie when they retired in 1981.

David was in the Air Force until 1946 and then joined the ANZ bank and worked throughout Central Victoria and on the border of NSW. He was a teller in three branches and was a manager of five in places such as Ararat, Yarrawonga, Yackandandah and Stawell.

David and Mavis love to travel, and have made two year-long caravan trips around Australia. They also did the Grand Europe tour, and have visited Thailand, Bali, the western states of America and New Zealand.

Son Glen says that David had hip problems which required three hip replacements and these problems with mobility masked the underlying Parkinson's disease. Hand tremor was his Pd signal.

David has enjoyed golf and lawn bowls in his retirement. He continues a strong interest in Lions and Legacy.

Pictured are members of the Parkinson's NSW Illawarra South Support Group (L–R) Pam Drinkwater, Cherie Rice, Jimmy Drinkwater and (seated) support group leader Gwen Bowen with Harvey Norman Warrawong store manager, Peter Simmonds, and salesman Robert Chilton at the presentation.

Illawarra South Support Group

With the help of a grant from the Federal Government Volunteer Small Equipment Grant funding scheme, the Illawarra Support Group was able to purchase a laptop computer and printer.

The purchase of this equipment gives the group the ability to use the word processing functions, download and print recent relevant information/research findings from the internet, and create a computer based database of support group details.

Robert Chilton at Harvey Norman Warrawong was extremely helpful in matching our needs to available equipment within our budget. His assistance and the generosity of Harvey Norman were acknowledged with a Certificate of Appreciation presentation in-store.

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

Coffee Morning

Come and meet staff and volunteers at Parkinson's NSW

Talk to people living with Parkinson's

10.30am - 11.45am, 10 October
25 Khartoum Rd, North Ryde
RSVP – 8 October

Book Review

Parkinson's Disease and the Family
by Nutan Sharma MD and Elaine Richman PHD, 2005

Yes, *Parkinson's Disease and the Family* is another American title, but it looks at issues relating to living with Parkinson's disease within the family unit that often don't get addressed.

Family members with little knowledge or understanding of this disease often have great difficulty in knowing what to do, while the patient themselves is trying to decide what his or her best options are – will I volunteer to be part of a new drug trial, or will I be able to live on my own, and so forth.

As well as giving a thorough review of current treatments, those often 'glossed over' issues like sexual function and alternate therapies are also discussed.

Too often people within the caring role can find themselves playing medical interpreter, and patient advocate, as well. This book draws on the expertise of the authors in offering valuable suggestions for patient care from both latest research and clinical practice.

Waste matters

by Sarah Mott

Eliminating waste from our bodies via the bowel or the bladder is essential to feeling well. This article looks at common issues with these parts of the body as a result of Parkinson's disease (PD).

Bowel issues

Gastrointestinal dysfunction is a frequent symptom occurring in more than 50 per cent of people with PD (Winge, Rasmussen & Werdelin, 2003). Many contributing factors have been suggested, including lack of physical exercise due to postural instability, reduced fibre and fluid intake due to chewing problems (bradykinesia) and dysphagia.

As well, autonomic failure of nerves associated with the passage of faeces through the intestine and the act of defaecation have been associated with constipation in people with PD (Winge et al., 2003).

Antiparkinsonian drugs can slow the motility of the bowel (Pfeiffer & Quigley, 1999) contributing to chronic constipation. Complications of chronic constipation, such as bowel obstruction, perforation, volvulus, and paralytic ileus are more common in PD and can be fatal. It follows that people with PD need to take whatever measures they can to maintain good bowel (Calne, 2005).

Some suggestions to improve bowel habits include:

- Regular gentle exercise is essential. If the person cannot walk far, short frequent walks around the house or garden are preferred to no exercise at all.
- Ensuring that there is plenty of fibre in the diet. Fibrous food does not have to be chewy and unpalatable! Bananas, mangos and peaches, for example, provide fibre and are soft to eat, as are many vegetables. Changing from white bread to wholemeal or multigrain adds extra roughage to the diet. When baking breads, cakes, muffins etc, add some fine bran to recipes to provide fibre without altering the texture or taste.
- Adequate fluid is essential to keep the bowel working efficiently. Aim for at least two litres of fluid a day which can include tea, coffee, soup and soft drink. Diet soft drinks contain artificial sweetener that can have a laxative effect, helpful in moderate quantities.
- Regular use of an aperient or gentle laxative may be necessary. If in doubt, seek advice from your pharmacist or general practitioner.

Bladder issues

It has been reported that people with PD commonly experience urinary difficulties (Olanow et al., 2001; Pepper & Goldstein, 1999). These are likely to be associated with symptoms of urgency and frequency as well as difficulty in micturition (Calne, 2005).

Incontinence is a problem affecting not only the ability of the person with PD to venture from home, it also impacts on self-esteem and creates physical difficulties such as urinary tract infections and sore skin.

Suggestions to manage urinary problems include:

- Do not restrict fluid intake, rather monitor the best times of day to drink. If you are going on an adventure (shopping, social event etc), you may like to restrict your fluid intake for one to two hours before you set off – remembering to empty your bladder as you leave. When settled, near a convenient toilet, you can make up for the lack of fluid earlier. You should aim for at least two litres of fluid a day.
- Try not to get into the habit of urinating frequently to save accidents. Unnecessary urination can cause the bladder to lose its tone and become inefficient.
- Watch out for signs of urinary tract infections, such as burning on urination, low abdominal discomfort, lethargy and feeling generally unwell.
- If urine is leaking, there is a chance of skin breakdown. Cream such as zinc and caster oil creates a good barrier between the urine and the skin. Avoid talcum powder as this becomes damp and acts like sandpaper against the skin and in the creases.
- If problems continue, seek advice from your general practitioner.

Calne, S. (2005). Late-stage Parkinson's Disease for the Rehabilitation Specialist: A Nursing Perspective. *Topics in Geriatric Rehabilitation. Motivation and the Older Adult,* 21(3), 233-246.

Olanow, C., Watts, R. & Koller, W. (2001). An algorithm (decision tree) for the management of Parkinson's disease. *Neurology,* 56(11 Suppl 5), S1-S88.

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Pepper, P. & Goldstein, M. (1999). Postoperative complications in Parkinson's disease. *Journal of the American Geriatrics Society,* 47(8), 967-72.

Pfeiffer,R. & Quigley, E. (1999). Gastrointestinal motility problems in patients with Parkinson's disease – epidemiology, pathophysiology, and guidelines for management. *Central Nervous System Drugs,* 11(6), 435-448.

Winge, K., Rasmussen, D. & Werdelin, L. (2003). Constipation in neurological diseases. *Journal of Neurology, Neurosurgery and Psychiatry,* 74, 13-19.

Counselling corner

by Janine Rod

Often when I visit my doctor I get flustered and can't remember everything I wanted to ask. Do you have any advice on making the most of appointments?

Many people find it helpful to keep a diary of their symptoms and how they are feeling, so that when they visit their GP or neurologist, they have a record of their symptom fluctuations day-to-day. It is also a good idea to be prepared with a list of concerns you want to mention, for example, are there any changes in symptoms? Do you need to review your medication? You can add to this list over time before your appointment, as and when you think of things you want to ask.

You might find it helpful to take someone with you to listen and prompt you, in case you forget anything or have trouble speaking. This can be helpful when there is a large amount of information to absorb from the doctor as well – you could ask whoever accompanies you to write down the answers to your questions so that you can concentrate on what the doctor is saying and explaining.

About Jesse

by Maureen Morrison

Nestled under the valley in the shadow of the Ilawarra escarpment lie the two small townships of Stanwell Park and Coalcliff. Early one March morning, Ruth Rendall, David and myself took the spectacular coastal drive to Stanwell Park's local public school.

You may by now be wondering what this is all about? Well it's about Jesse, that young man of 12 years mentioned very briefly in the last issue of *Stand By Me* who nominated Parkinson's disease as his charity of choice for his 2007 school fundraising activities. Together with the submissions of the other students, voting took place and no one was more delighted than Jesse when he was advised that his nomination for Parkinson's NSW had been successful .

As a member of the Student Representative Council, a swimmer and footballer, this young man has a smile that would melt the ice-caps off the Andes.

For Jesse it was a very special recognition, as his suggestion for Parkinson's was proposed in memory of his much loved grandfather (Ruth's beloved husband) who died in August last year from complications arising from this disease.

We often talk at times about 'making a difference' but do we do anything about it? Or do we just sit and talk?

You've done the street stalls, manned desks at exhibitions, all in the name of awareness and fairness, but in the meantime, while you are waiting for miracles to eventuate, could I suggest and encourage you all to give some thought to approaching your local schools, asking if you could come and visit a class at a time perhaps.

After all, these are the young ones who in the long term will be the recipients of that elusive Pot of Gold … the CURE.

St George-Sutherland SG members meet teachers and students.
(Left to right) SG member Ruth Rendall, her grandson Jesse who wrote the Parkinson's submission, SG member Maureen Morrison who spoke at the assembly, and teacher/librarian Terry Bailey.

Run for Parkinson's NSW

The Sun-Herald held the first City2Surf fun run 37 years ago. The event now attracts people from all over Australia and is one of the biggest fun runs in the world. The 2007 City2Surf is being held on August 12.

The City2Surf is a great way to generate money for charity, and this year Parkinson's NSW is encouraging everyone to get involved.

You can help by joining in the City2Surf, and running or walking the 14km route from the City to Bondi. If that's not really your style, you may prefer to help with the fundraising effort by supporting other people who are participating in the event.

To join the City 2Surf

If you want to run – or walk! – in the City2Surf, you will need to register. You can register online by visiting **http://city2surf.sunherald.com.au,** or you can download an entry form and send it in by post. An entry fee of $38 applies for adults and $25 for children aged 5–17.

If you'd like to invite your family and friends to make donations to support your run, set up a fundraising page by clicking on the 'Run for charity' link– don't forget to select Parkinson's NSW as your chosen charity.

To help with the fundraising effort

If you're not so inclined to tackle the run, you can still get involved with eth City2Surf by making a donation and supporting those runners who have nominated Parkinson's NSW as their charity. Just go to **http://city2surf.sunherald.com.au** and select 'sponsor a friend' or 'make a donation' on the 'Run for charity' page.

Support Antonio

Antonio Borazio has chosen Parkinson's NSW as his charity for the 2007 Sun-Herald City2Surf.

'This charity, which funds research into Parkinson's disease and also assists people with the disease, holds a special place in my heart,' says Antonio.

'I was diagnosed with Parkinson's disease in April 2004. Although my case is only mild at present and is controlled reasonably well with medication, I realise that it can get worse with time. I'm sure a cure is just around the corner.

'Your support will go a long way into finding a cure. You are all my heroes! Thank you for your generosity!'

To support Antonio's run visit **http://city2surf.everydayhero.com.au/hero_pages/send_to_a_friend/18272**

For more information about the City to Surf visit http://city2surf.sunherald.com.au or call 1800 555 514.

2007 Awareness Seminar at State Parliament House

This year our seminar will be held on September 12, and will feature George Mellick – *The shaking palsy meets the 21st century: A multidisciplinary research approach to understanding the complexities of Parkinson's disease.* Also Dr Michael Hayes will speak on clinical trials and new medications. Could you please place this in your diaries.

Donations

$50 and over received between 10 March and 18 June 07

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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Edward John Brown
Albert Cork
Charles Coroneos
Fred Cowen
William Crawford
Henry Cupples
Gladys Davis
Daphne Duncan
Jessie Eaton
Geoff Foot
Maria Furnsby
Clive Gledhill
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DAVID & MAUREEN MORRISON 40TH WEDDING ANNIVERSARY

Rona and John Harris

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St George/Sutherland Parkinson's SG
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Correction Donations in Memoriam Autumn Issue 2007

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Myra Chalmers

Roy Gower
St George/Sutherland SG

Peter Joils
St George/Sutherland SG

Colin McCowan
St George/Sutherland SG

These were printed incorrectly. We apologise for any distress caused.

Bequest Lunch

On May 8, 83 people came together to renew old friendships, make new friends and enjoy great fellowship over a good meal at the Epping Club.

The occasion? To recognise some special people who had done something very positive for Parkinson's NSW – those who have told us that they have made a bequest to Parkinson's NSW.

We are so pleased to have been told so that we could thank them and acknowledge their generosity by making them a member of the *James Parkinson Society* – which has been formed to honour people who have made a bequest to Parkinson's NSW.

Are you aware that a Will should be reviewed every three to five years? If you are thinking about amending your Will, perhaps because circumstances have changed, please do consider making a bequest to Parkinson's NSW.

As one member said, 'It's money that you can't take with you.'

If you would like to know more, call Margaret, the PNSW Bequest Officer on 02 9876 5351 between 9am and 8pm for a confidential chat. (Or ring Nancy on 1800 644 189 with your details and Margaret will get back to you at a time that is convenient to you.)

Hopefully by the time of the next Bequest Lunch there will be another group of people with the foresight to give something they can't afford now but will be of benefit to people with Parkinson's disease in the future.

The Newcastle Bequest Lunch has been postponed to 2008.

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	0418 168 558
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
Parkes	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
St George/Sutherland	Myra Chalmers	02 9525 7215
Tamworth	Pat Johnson	02 6765 6948
Tomaree	Ian Canham	02 4994 9276
Tweed Heads		07 5524 9417
Wagga Wagga	John Allen	02 6925 2713
Yass	Peter Wells	02 6226 2233
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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Have you been diagnosed with Parkinson's? Yes/No

Date of Diagnosis __________ Date of Birth __________

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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

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