

Parkinson's Australia National Conference

Sydney Olympic Park, 16 - 17 October 2008



Congratulations to Parkinson's NSW for conducting a first-rate world-class conference. I know that a tremendous effort was made by the Organising committee, Parkinson's NSW Council members, staff and many Parkinson's NSW members and volunteers. No aspect was ignored – from the venue, to the program, to the dinner! Please pass my congratulations onto all! I have attended a lot of conferences over the last 30 years and I think the "Buzz" associated with this conference was extraordinary. It was great to see so many people with PD having a go – whether it be tai chi, tango or circuit class exercises! *Dr Colleen Canning*



President's Report

This is the last edition of Stand By Me for 2008: an exciting year that has been characterized by major upgrading of all areas of operation.

Some highlights of the past quarter are:

PNSW hosted the National Parkinsons Conference in October. It proved to be an exceptional occasion; informative and energizing. I wish that each and every one of you could have been there to hear first hand the excellent speakers, network with each other and feel the positive energy from every quarter. There will be a DVD available so that the information can be circulated throughout the State. A wonderful footnote that I'd like to share with you is about two of our speakers, Drs. Abe & Ina Lieberman. They had enjoyed their experience at the conference so thoroughly that they took the time while on the plane returning home to send not only written "Thank You" but they also included a financial gift for use for People with Parkinson's. A wonderful compliment to the quality of the speakers and the thrust of the conference - a conference aimed at providing information for People with Parkinsons, rather than the medical and research community.

The second Annual 'Putting For Parkinsons' Golf Day was held at Monash Country Club this year. Again, it was a successful fund raising event and a worthwhile, fun day for all who participated. The support from outside the Parkinsons community served to remind us once again that people do care about their fellow man. One of the best would have to be David Samer, who I am thinking of renaming 'Mr. Golf'. His hard work in sourcing auction items and prizes is responsible for a large part of the day's profitability.

We have been very fortunate to have had the support of generous benefactors over the years, none more so than our resident Poet Laureate. Don Willcox, It was a great pleasure for the Council to award him Honorary Life Membership in recognition of his outstanding support for PNSW.

Traditionally, this is a time of year for review. I'd like to look at some of the achievements of the past three years and forward to what may lie ahead.

Services

We have seen an expansion in all areas of our organization, from our offices, to our staff and to our service provision. There always seems to be something happening at PNSW. The info line is running full time and is such a professional well run service that we tend to forget that it wasn't always there. We now have two counsellors available for one on one counselling, as well as clinics and outreach programs. The feedback regarding their excellence is marvellous.

NSW Government Acknowledgement

Our persistence in lobbying the Government for funds has met with limited success but a dialogue has slowly been developed and this gives us a base to build on. We have received a small grant from NSW Health, as well as some assistance for people to attend the Conference from both the Health Department and the Department of Disabilities. Free transportation to the Unity Walk from the Department of Transport was appreciated and underscored the importance of PWP. Small steps, but certainly signs of an awareness that had been eluding us.

Fundraising

Fundraising has always been a major need. From my first term of office, when a committee met with our fundraising Consultant, Marty Rhone, to formulate a considered plan to meet our objectives, fundraising has been a priority. We have put into place two major fundraising events that are envisioned to continue annually; the Unity Walk and the Parkinson's Golf Day. These fundraising efforts have been the driving force behind over \$250,000 in grants for research, our Medical Student program and our support program for PhD Students in the last three years.

Awareness

Community awareness and, through it, greater understanding of the needs of People Living with Parkinsons, is constantly looked at. Before every major event PR opportunities are explored and through Polka Dot, our PR consultants, we have been seeing much more media coverage. As I have discussed at length, the Unity Walk had a marvellous side effect of raising awareness, as do any of our activities that involved the general public.

Togetherness

Our meeting of Support Group Leader/Representatives was a wonderful occasion to share our needs, aims, ambitions and concerns on a face to face basis. Being able to connect in this fashion was invaluable and it is something that we intend to continue. Our Support Group network continues to grow - currently there are 57 Groups throughout the State.

The Future

We hope to build on the success of the Unity Walk - target for 2009 is 2000 walkers so let's all dust off those walking shoes!

Our aim is for even more research funds from our fund raising efforts and from endowments and we continue to look at ways to grow our services to address quality of life issues for our members.

The push for more and more Parkinson's nurses will continue. As well as in hospital settings, their value in rural clinics and in home visits will be highlighted. The postgraduate course at Notre Dame University's Sydney School of Nursing begins in 2009 and we will chart its success with enormous interest.

The developing course for Rural & Remote Physicians should be an excellent tool for better understanding and treatment of PWP in those areas. There is potential to expand this course to Urban Doctors.

Neurological Alliance is a term that we may soon hear more about. The government is starting to talk in terms of the 'Neurological Diseases' being under a specialized umbrella. This has a ring of realism about it. Working together with other organizations, such as Alzheimer's, as a Neurological grouping may well be the way forward.

Being President of PNSW has been challenging, interesting, and busy beyond belief. As 2008 draws to a close, let me say a heartfelt "Thank You" on behalf of myself and the Council, to our CEO, staff and volunteers; they have given 'above and beyond' so often this year and with such good will. How lucky we are!

Best wishes for a Happy, Healthy, and Safe Holiday Season - and remember - 2009 is the 30th Anniversary of PNSW and PA!

John Silk



CEO's Report

Parkinson's National Conference

I would like to thank our hard working staff and volunteers who have helped to make the National Conference (reported elsewhere in this issue), a great occasion. A special thanks to our sponsors, the

presenters (international, national and local), and of course to the delegates.

We received a wonderful response including feedback sheets, calls and letters, to advise how much participants personally enjoyed and valued the Conference and information. People also indicated that they felt very comfortable and welcomed at the Conference.

As one delegate said:

"The Conference was not only about helping people live almost a normal life with Parkinson's Disease, but also reporting on the progress of finding a cure. We all felt very confident with the results to date being on the right road to make Parkinson's Disease an affliction of yester year."

It was also wonderful to hear from the guest speaker Dr Abraham Lieberman, Head of Muhammad Ali Clinic, Arizona, who in a note of thanks referred to "this worthy organisation - Parkinson's NSW".

Kilkeary Foundation

With the support of the Kilkeary Foundation, we have been able to introduce two new programs:

New Program 1: Traffic Lights

The Traffic Lights Program aims to provide guidelines to nursing homes and their staff in caring for people with Parkinson's. We have regarded this as important, as not all nursing homes or their staff have been familiar with best practice.

If you would like to nominate nursing homes in your area that might be interested in receiving the training program please contact Susan Tait the co-ordinator of the program on 1800 644 189 or her email address susan@ parkinsonsnsw.org.au.

New Program 2: Living Life with Parkinson's

This edition of "Stand by Me" has a separate article on this new program, and I invite you to participate in it.

The Keven Williams Trust

The trustees of the Keven Williams Estate have given a substantial donation to assist Parkinson's NSW to provide services for people living with Parkinson's Disease. We are truly indebted to the estate for its continued assistance.

"Drugs to be Used with Caution" Brochure

You should receive with this edition of **"Stand by Me"**, a new copy of the "Drugs to be Used with Caution" brochure. The Pharmacy Guild of New South Wales has funded this. We particularly thank Carlene Smith for her efforts.

A Fantastic Fundraising Effort

Ann Smallmon was diagnosed with Parkinson's Disease on 21 November 2007, the day after her birthday. She is an artist living on the Far North Coast of NSW. She decided to fight back by fundraising and by raising awareness through publicity in the local press. Ann organised a music event at the Lennox Head Hotel in August. Four local bands entertained the crowd.

The Lennox Head Lions Club and the Ballina-on-Richmond Rotary Club helped with other fundraising events.

Altogether Ann was able to raise and forward a cheque for \$15,040.00 to Parkinson's NSW Inc to be used towards research and for support services.

Ann is already planning fundraising events for next year. She hopes to hold a golf day and is hopeful of another musical afternoon.

If you have been inspired by Ann's story and would like to arrange a fundraising event, we would love to hear from you. Just call our 1800 644 189 InfoLine.



Regional Support Group Visits

I have recently had the pleasure of visiting the Central Coast and Goulburn Support Groups. It has been wonderful to see the enthusiasm of the members and to hear their stories. One of the people we met was Alan Arnold, who is a gentleman living with Parkinson's who creates the most beautiful fine cross-stitch. He has donated two works for our office.

Parkinson's Artisans Show

We have been granted permission to hold an art exhibition in the Fountain Court of State Parliament House from 31 August 2009 to 25 September 2009. We would be delighted to hear from you if you would like to take part in this exhibition. Please call our 1800 644 189 to register your interest.

Season's Greetings

From all of us here at Parkinson's NSW, we wish you and your family season's greetings and all the best for the New Year.

Yours in Parkinson's friendship

Miriam Dixon CEO

National Conference – October 2008

Parkinson's New South Wales was pleased to host the Parkinson's Australia 2008 National Conference on 16 and 17 October 2008.

The themes for this year's Conference included:

- New directions in therapy for PD
- Exercise and its benefits
- Coping with Parkinson's
- Sexuality & Parkinson's live a full life
- Dealing with Depression
- Training for rural doctors and for nurses

We had 23 presentations over the two day period, some in plenary sessions and others in simultaneous sessions. We will be putting up on our website biographies of the presenters and abstracts of the papers presented.

Two hundred and forty delegates attended the conference.

Many of the comments showed an appreciative audience, including:

- (i) "I have had Parkinson's Disease for over 12 years and have really not had a full understanding of PD as I live in the country and this information is not available to us. I would like to thank Parkinson's NSW for bringing all these people together to enlighten us. I leave here today with a lot more knowledge and understanding".
- (ii) "An excellent conference and very informative two days".

- (iii) "An excellent range of information, it put a lot of things in context for me, increasing my knowledge".
- (iv) "Thank you all for the very informative two days, the speakers were great and gave knowledge and hope for the future; with this we can now go back to our groups and share. The greatest gift it gave was the knowledge that you are not alone and that help and friendship is but a phone call away. It was a bonus being able to speak face to face with the Doctors not only from Australia but America too who are doing the surgery and research, plus the allied health workers, in an informal situation over coffee and lamingtons or lunch. Our thanks to them for giving us their valuable time".

As well as the presentations, we had a lively time engaging in physiotherapy exercise, tai chi and a salsa workshop. Free hand massages were provided by Sydney College of Skin Care, contributing to the relaxation of those who took part.

The message that came through loud and clear, emphasised by many of the speakers, was keep active, exercise and stand up as straight as possible. Some of the talks on this theme included John Ball's "Living Well and Running Hard", Abraham Lieberman's "Exercise", and Renée Goossens' "Enhancing your Life to the Fullest".

DVDs of the conference will be available prior to Christmas for \$35 incl p&h. Please call 1800 644 189 to order your copy.

"TULIP PARADE"



This Lovely quilt has been donated by the Cowra Parkinson's Support Group 2008

Designed and pieced by: Meryl Lees Quilted by: Betty Field

Raffle tickets priced at \$2 each or 3 for \$5 The raffle will be drawn on World Parkinson's Day on the 11th April 2009.

Good morning, one and all

Thank you all for the very informative two days at the National Conference, most of the speakers were great and gave knowledge and hope for the future, with this we can now go back to our Groups and share. The greatest gift it gave was the knowledge that you are not alone and that help and friendship is but a phone call away.

We met new friends from all over, even some from across the Tasman, and have promised to keep in touch. It was a bonus being able to speak face to face in an informal situation over coffee and lamingtons or lunch with the doctors, not only from Australia, but America too, who are doing the surgery and research, and also the allied health workers. Our thanks to them for giving us their valuable time.

Our thanks also to the people – many of whom were volunteers – who organised the whole thing, and the people who were there to give us help and a smile on the two days, to you we are indebted.

I also want to give you a big thank and huge hugs to the ladies at Ryde office that have been so good to my daughter Amanda. Through working with them as a volunteer while suffering work related depression, she has now found new projects to work on and has a new family of friends. Amanda always comes away from that office with a smile and says that if all offices were like that there wouldn't be any work related depression.

Regards, Yvonne Blake (spouse to a "Parky")

Dr Abraham Lieberman talks about posture

The Parkinson's Australia National Conference was held at the Sydney Olympic Park on 16th and 17th October this year. It was an outstanding success with speakers from the United States and Australia, bringing us up to date on the latest therapies available.

One of the Keynote speakers was Dr Abraham Lieberman. He is a renowned neurologist, head of the Muhammad Ali Parkinson Clinic and chief of the Movement Disorder Clinic, Barrow Neurological Institute in Phoenix Arizona. On the Friday he spoke about the importance of good posture and keeping the spine straight.

Suggestions and tips from Dr Lieberman's presentation:

- Practice sitting with hands on hips it lifts the shoulders and straightens the spine.
- The way you stand matters, hands on hips raises the shoulders.
- Yoga sitting position lifts the pelvic girdle. Buddha sits like this.
- Swallowing and speaking are linked to a straight spine. Posture is important for breathing.
- Extend the wrist when you are carrying something it allows your fingers to function better.
- Talk with the chin raised like Obama.
- Practise blowing up a balloon (30 times a day). It makes you tighten your lips and use your lungs to blow.
- Lift your chin and eyes to eat. Put your elbows on the table it raises your shoulders and your chin.

- When exercising, make the slow side keep up with the fast side.
- Turning affects your stride length and velocity. "Cueing" helps to maintain your stride length and velocity.
- Do what exercise you like, for example running, (spine should be straight).
- Breaststroke is good because it opens up your lungs.
- When using an exercise bike put the TV up high.
- Rocking chairs are good as the arm rest raises the shoulders.
- To generate power in your legs and hands, you must have a straight spine.
- The brain has a brake and an accelerator when you have dyskinesia, the brake is not working.
- Dr Lieberman ended his presentation with this take away message.

Nothing is irreversible until you are dead!!!

Maureen Morrison

The following is from Dr Abraham Lieberman's soon to be published book, which will be one of the subjects of his lecture. The book is the Muhammad Ali Parkinson Center's 100 Questions and Answers for Parkinson Disease, the 2nd edition of 100 Questions and Answers for Parkinson Disease.

Question 39: I Fall Often. Are There Exercises I Can Do?

Some PD patients have difficulty keeping their balance. They walk well but they fall. And when they fall they don't react quickly, they don't catch themselves and break their fall.

When you trip, but before you hit the floor, while your body's falling through space, information about the changing position of your body in 3-Dimensional Space is relayed to your brain, subconsciously, through sensors in your feet, your inner ears, and your eyes. Before you realise you're falling, your body takes corrective measures to break your fall. These corrective measures are called **righting reflexes**: reflexes that "right" or correct your position in space.

Walking on two legs, while freeing our hands, came at a price: animals who walk on four legs have better balance and are less likely to fall.

You can't climb as high or be as sure-footed as a mountain goat, you can't turn or whirl or prance like a horse. Some two-legged animals and, birds, can balance on tree-tops or telephone wires. But humans lack a bird's tail (a stabiliser) or a bird's wings. **To keep their balance, humans depend on their eyes, on sensors in their inner ears: sensors that monitor how fast (or slow) they turn, sensors that monitor their position in 3-D space.** Although blind-men can't see with their eyes, they can "see" with their feet and inner ears. Learning, under supervision, to walk blindfolded, is a way to train the sensors in your feet and inner ears.

Sensors in your feet monitor your position on the ground, in 2-D space, as well as your stride length and velocity, while sensors in your inner ears monitor the position of your body in 3-D space.

The sensors transmit their information to your thalamus (part of your basal ganglia) and then to your parietal and temporal lobes, the conscious parts of your brain that tell you "where you are". In your thalamus something happens. Either the information's distorted or it's not synchronised – think of what happens when you're watching a movie and the sound and pictures aren't synchronised. Part of improving your balance consists of re-programming your sensors. This may include activities such as, under supervision, walking backwards, or "walking backwards" on your hands and knees.

The balance difficulty, because it may result from several causes, must be analysed before a training program can be devised. The analysis may, like in the Muhammad Ali Parkinson Clinic, consist of placing you on a "Balance Master", a platform that allows you to see and "re-direct" your centre of gravity while the platform's shift back-and-forth or up-and-down. This happens while you're hooked-up to a harness so you don't fall. Balance training at home should be done under supervision to minimise falls. An adjunct to balance training is to have an occupational therapist come to your home and point-out and correct points and places where you're most at risk for falling.

Research

STEM CELLS AND PARKINSON'S DISEASE: THE FACTS

Ms Francine Carew-Jones, Prof Glenda Halliday, Prof Cynthia Shannon Weickert and Assoc Prof Kay Double Prince of Wales Medical Research Institute

Stem cells and their potential for the treatment of a wide variety of medical conditions, including Parkinson's Disease (PD), are often in the news. Yet many people are unsure what the term "stem cell" refers to, nor whether stem cells might offer new treatment methods for PD. In this brief article we will describe in simple terms what constitutes a stem cell and the potential of stem cells for new PD treatments.

What is a stem cell?

Stem cells can best be thought of as a type of immature "template" or unspecialised cell (similar to a blank artist's canvas). A stem cell has two important properties; firstly it has the ability to divide itself into two identical cells many times over, thus reproducing identical copies of itself. Secondly, a stem cell can also divide to produce one or two more mature cells (known as progenitor cells), which, under the right conditions, can develop into a neuron or other brain cell, or into a cell in another part of the body (see Figure 1). The division and development of stem cells is crucial for the normal growth and development of the brain and the body in babies and young children, but as the child grows to adulthood stem cells gradually become less numerous in most parts of the body. Nevertheless, even in adult life. stem cells can still be found in some organs, such as the intestine, where they are responsible for the continual replacement of the gut lining throughout the entire life span. Since this article is concerned only with the role of stem cells in the brain, we will restrict our discussion to stem cells in the brain.

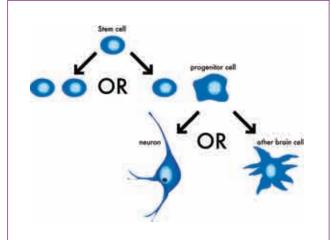


Figure 1: A stem cell can either produce two identical copies of itself, or one or more progenitor cells. A progenitor cell is a slightly more developed cell that is no longer a stem cell, and can develop into a variety of mature cell types.

Figure by Heidi Cartwright

Where are stem cells found in the adult brain?

For most of the last century it was believed that brain cells (neurons) in the adult could not reproduce themselves, and therefore were not able to be replaced. In 1998 researchers were able to demonstrate that the adult human brain contains a small number of stem cells which are able to divide, thus giving birth to new brain cells. This process is known as *neurogenesis*. Rather than occurring throughout the brain, however, neurogenesis appears to occur only in two specialised areas of the brain, a narrow border of tissue on the edge of the caudate called the *subventricular zone* (SVZ), and also in a small area called the *dentate gyrus* within the brain's memory area, the hippocampus. Astonishingly, some of these new brain cells don't remain in the place of their birth but have the ability to move to other regions of the brain where they develop into cells with specialised functions. So, for example, in the adult rat, brain cells born in the SVZ move a considerable distance along a special pathway to an area of the brain important for the detection of odours. A similar migration process also occurs in the olfactory system in the human brain.

What might stem cells offer People with Parkinson's (PWP) Disease?

As the symptoms of PD are caused by the death of brain cells that produce the chemical dopamine, researchers have suggested that stem cells might be coaxed into developing into new dopamine-producing neurons which could replace those dying in the PD brain. There are two ways this might be done. Firstly, stem cells in the brain might be encouraged to reproduce in greater numbers and to travel to the pertinent areas of the PD brain where they would be encouraged to develop specifically into mature dopamine-producing neurons. This would likely be achieved by manipulating the chemical environment of stem cells to encourage them to multiply, to migrate within the brain and to develop into dopamine cells. Secondly, stem cells could be used to produce new dopamine cells outside the body harvested from human embryos or from a variety of body tissues during life, such as from the umbilical cord or the nose. Recently it has also become possible to produce stem cells in a laboratory by genetically manipulating other body cells, such as skin cells. Stem cells from any of these sources would then be multiplied and grown into dopamineproducing neurons within a laboratory, before being surgically reintroduced back into the brain. Either of these approaches would aim to replace brain cells dying in PD with new dopamine-producing cells, thus increasing the amount of dopamine in the brain's motor circuits and restoring normal movement.

What are the hurdles in achieving such treatments?

Like the brain, the biology of stem cells is very complex and we are in our infancy in understanding these cells. We need to understand how stem cells are born, how they move, how they develop and how they are regulated. To ensure that any therapy for PD based on stem cells will be safe and effective we need to achieve a much greater understanding of all these processes than we have to date, and this is likely to take some years to achieve. While one of the current problems with experimental transplantation of cells into the brain in animal models is often the low survival rate of the cells, it is also important to ensure that the cells do not survive and divide *too* well, as uncontrolled cell division can result in brain cancer, another common problem in these experiments. In the 1970's, long before stem cells were discovered in the human adult brain, dopamineproducing neurons harvested from the brains of human embryos were transplanted into the brains of a number of patients with PD. These early attempts at a "restorative" therapy have given us some further clues regarding the benefits and problems associated with the introduction of dopamine cells into the human brain. While some patients enjoyed a reduction in their PD symptoms following the surgery, a considerable proportion also developed uncontrollable movements (dyskinesias) after transplantation, a side-effect attributed to the inability to control how much dopamine the new cells produced. This unforseen complication, together with the considerable ethical and practical issues surrounding the use of human embryos for this therapy, eventually to the abandoning of this approach. More recent analyses of the brains of several of these transplantation patients who have subsequently died revealed other unexpected phenomena. We do not yet have a complete understanding of how a brain cell knows it is supposed to be a brain cell - or more specifically a dopamineproducing cell. Clearly, just being in the brain does not necessarily result in an immature cell developing into a brain cell, as in the early transplantation trials some of the transplanted brain cells were found to have developed into other cell types in the brain, such as bone or hair. Another important factor to be considered is the fact that dopamine itself is known to control new cell birth in babies and children. It is likely therefore that dopamine is an important regulatory factor for stem cells in the adult brain, but we know little about how this works, nor do we know how PD, a disorder in which brain levels of dopamine are significantly reduced, affects new cell birth. We also need to understand the effects of dopaminebased anti-parkinsonian medication on new cell birth in the PD brain.* Of course the replacement of brain cells can only reduce the symptoms of PD but does not cure the disorder, which would still progress within the brain. This is relevant as it appears that newly transplanted brain cells are not immune to the effects of PD, as several recent reports describe transplanted embryonic cells developing Lewy bodies, abnormal accumulations of

protein characteristic of the PD brain. This suggests that newly born, or transplanted, stem cells, while possibly offering a temporary improvement in motor function, may also be eventually damaged by the progressive nature of PD. Even if this is the case, it is hoped that stem cellbased therapies may one day be able to provide effective relief from PD symptoms for time periods measured in years, rather than the hours currently provided by most anti-parkinsonian drugs.

How close are researchers to trying stem cell-based treatments in PWP?

Stem cell transplants are already being successfully used in the clinic to treat spinal lesions and in leukaemia, where stem cells are replaced during stem cell-containing bone marrow transplants. These treatments demonstrate the potential of stem cells and intensive research is being performed all over the world to improve our understanding of stem cells and how these can be used therapeutically for PD. Research has progressed to a point where stem cell-based approaches are being used in experimental models of PD in monkeys, usually the last step before promising approaches are tried, albeit cautiously, in a small number of human subjects. As we write, however, human trials of stem-cell based treatments have not been attempted nor published in the medical literature. As a result, no stem cell-based treatments for PD patients have been approved by the Australian Therapeutic Goods Administration, which monitors the safety and efficacy of medical treatments in this country, nor by any similar organisation in any other major Western countries. While Parkinson's NSW is aware that some such "treatments" are being advertised, unproven and at great cost, via overseasbased websites which can be accessed in Australia, we do not recognise or recommend these approaches. While the slow progress of research is frustrating (also to those of us who do it!) past experience has taught us that this is an area where caution – and knowledge - is advisable. Like many other researchers, patients and their families, we too hope that one day stem cells might provide new, more effective PD treatments, but let's do the research first

*The effects of aging, PD and PD medications on stem cells are currently being investigated by the authors and their colleagues.

Parkinson's, employment and quality of life

If you have been diagnosed with Parkinson's and are still working, researcher Louise Parker is keen to hear from you!

Louise's research project, Parkinson's, Employment and Quality of Life, which is being conducted through Swinburne University is an opportunity for working people with Parkinson's to tell how it really is. Given the increasing prevalence of Parkinson's in people of working age, and the myriad of challenges and concerns that this raises, it's vital that health professionals, rehabilitation specialists and employers have access to information that will optimise working conditions for people with Parkinson's. In addition, greater understanding of the workplace and Parkinson's situation will lead to improved information and support for those living with the condition, enabling them to make better decisions about the future. The main aim of the project is to identify where support and education is needed.

The Swinburne team is currently seeking participants to complete a short online survey about their experience as a person with Parkinson's in the workplace.

The online survey can be accessed at http://opinio.online.swin.edu.au/s?s=4356.

The outcome of the study will be made available through Parkinson's Victoria in late 2009.

Research

BRAIN DONOR PROGRAM, Prince Of Wales Medical Research Institute, Randwick NSW Australia

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

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

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

It was because of this that I felt an urgent need to support the research into this debilitating disease and other neurological diseases in our society. While my husband and I were keen to donate our bodies for research, and we had discussed brain tissue donation, we did not have the brain tissue donation in place at the time of my husband's collapse.

How Did I Go About the Procedure?

I was able to speak to my husband's neurologist and Parkinson's specialist nurse about the program and I duly procured the necessary forms.

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

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

BE A PERKY PARKIE

By Valerie Leyden, inspired by Dr Lieberman's

Presentation at the National Conference

Put your elbows on the table, place your hands on your hips, Practise saying "Mama" and use those lips.

Take a balloon out with you, wherever you may go – Now, 1, 2, 3 – blow, blow, blow!

Lift up your head and better you will chew, If your gait's a problem, there's a cue or two.

Concentrate on exercise to straighten up your spine; Don't be afraid, you really will be fine.

> Now be a Perky Parkie, don't be filled with gloom and doom; There's still a life there for you, don't restrict it to your room.

There were other comprehensive questionnaires to be completed after the donation. Once again they were clear, and gave you an opportunity to add anything you wished to add about the person's health and symptoms, things that you had observed and noticed over the years of caring for them.

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

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

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

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

I recommend this remarkable research program to you.

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

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

Heather Grimmett

If you wish to become a brain tissue donor contact the Prince of Wales Medical Research Institute Barker Street Randwick Sydney NSW 2031 Australia or PO Box 82 St Pauls NSW 2031 Australia. Telephone: 61 02 9399 1000, Facsimile: 61 2 93991005 or visit the web site at http://www.powmri.edu.au

The Winston Churchill Memorial Trust

Established in Australia in 1965 – the year of Churchill's death – to perpetuate and honour the memory of Churchill by the awarding of Churchill Fellowships to Australian citizens. There is an opportunity to apply for Fellowships in health and medicine for 2009.

Dr Dorothea Sandars

For medical/veterinary parasitology or Parkinson's Disease, or advances in medicine in general.

Contact the National Office to receive your application package or download it from the website.

Applications open 1 November 2008 and close 27 February 2009.

Tel: 1800 777 231 or (02) 6247 8333 www.churchilltrust.com.au

Brain & Mind Research Institute launches a new clinic for Parkinson's Disease.

Researchers at the University of Sydney Brain & Mind Research Institute (BMRI) have launched a specific Research Clinic for people with Parkinson's Disease (PD). The Clinic will investigate many components of the underlying neurobiology of PD but in the first instance, they will investigate why people with PD vary markedly in the pattern of symptoms they experience. It is hoped that this disease *heterogeneity* may help them to unravel many of the issues that confound the management of PD.

The PD Research Clinic has been established by Neurologist, Dr Simon Lewis, and is currently supported by a team of Psychologists and Neuropsychologists. He also has collaborations with scientists and other researchers who have extensive experience in looking at the neuropathology of PD. In his presentation, Dr Lewis stated that this 'joined-up research' will help to ensure that findings are translated "from the bench-side, to the bedside and beyond".

Dr Lewis has extensive clinical and research experience in PD. Through collaborations with leading international researchers in PD, he has published extensively in this area. In particular, his work has identified that certain patterns of disease are associated with a less favourable prognosis and that such patients are more likely to encounter difficulties with the troublesome non-motor features of disease such as mood and memory. Dr Lewis would now like to extend this work, by targeting other features such as anxiety, depression and sleep disturbance; known predictors of quality of life and caregiver burden. Investigators hope to use these assessments to select and recruit specific sub-groups of patients into future studies that will capitalise on the facilities within the BMRI, such as the Circadian Studies Sleep Laboratory and the Ramaciotti Imaging Centre.

The new PD Research Clinic at the BMRI is looking to assess patients at all stages of the disease, collecting data across clinical, cognitive, psychiatric and behavioural domains in an annual 3-hour visit. The PD Research Clinic will take place at the Brain & Mind Research Institute in Mallett Street, Camperdown. Anyone suffering with PD who would like to become involved or receive further information should contact the Parkinson's Disease Research Clinic (see details below).

The Parkinson's Disease Research Clinic at BMRI Phone: 9351 0702 Email: pdclinic@med.usyd.edu.au

Speeding Vibrations

Speeding Vibrations members met on Sunday 23rd November at Zita's Restaurant, Woy Woy. They travelled from Newcastle, Earlwood, Ultimo, Blacktown, The Hills, Georges Hall, Asquith and the Central Coast.

The food and service was excellent and the venue was very pleasant, as Zita's overlooks the channel at Woy Woy ferry.

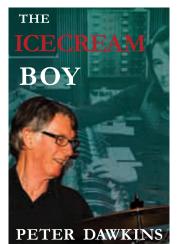
Kel and Jill Healy, the Stamp People, live on the Central Coast and were invited by Ron and Melanie De Jager, who organized the lunch and who live at Woy Woy.

28 people attended, including longstanding members Kay Messiter, Harley and Dianne Holman, Hanneke and Howard Dobson, Maree and Nick Klafas, Sue and Phil Rance with their friend, Susan Asplind, Peggy and Stewart Macfarlane, Bob and Lyn Macfarlane. The Young Men's Network was represented by Gary and Val Cearns, Ray Groves, Roger, Lyn and Renee Finlayson. The Macfarlanes and the Rances belong to both groups.

Sandra Way and her husband Mark Hurden representated Hornsby/Ku-ring-ai support group. Gerald Ganglbauer, who is leader of the Ultimo support group, attended the last Speeding Vibrations lunch at St George Motor Boat Club in June,2007.

Next lunch for Speeding Vibrations will be held on Sunday 1 March 2009 at Ben Roberts Café, Honour Avenue, LAWSON, in the Blue Mountains at 12 noon.

Please ring Trish Morgan at PNSW Phone 1800 644 189 or 02 8875 8903 for information.



The Icecream Boy

Book and CD package for just \$24.95 (GST incl.), plus \$6 postage and packaging

Peter Dawkins, who had a stellar career in music production, has suffered from Parkinson's disease now for some 20 years and he has been through the mill. He fought hard to keep working in the face of increasingly severe symptoms, but had to stop. Peter was one of the first patients in Australia to undergo deep brain stimulation, but it had limited success for him and, after a couple of years, he had the surgery re-done, this time successfully.

Peter has written his autobiography, published by Parkinson's NSW, titled The Icecream Boy. It's a ripping yarn about being immersed in music, as well as coping with PD. The book, a 110-pp paperback (with colour illustrations), is being offered by Parkinson's NSW at \$24.95, including GST, plus \$6 for postage and packaging. A compilation of some of Peter's most famous music productions, on CD, is included in the price, so the package is a snap.

Parkinson's Annual Golf Day

Monash Golf Country Club, Ingleside

November 13, 2008

One of the Peninsula's most picturesque Golf Club's was looking a picture on a fine but blustery Spring day when well over 100 golfers of varying standard, mounted their carts for the Shotgun Ambrose start.

Yamaha provided every player with transport whilst Tooheys and Cadbury Schweppes ensured everyone stayed refreshed. After 18 holes of missed opportunities, missed hits and misdemeanors, most adjourned to the clubhouse for the evening meal, auctions, raffles and lots of 'if only' stories. Guests dined with fine McGuigan Wines and were entertained by the man who hit 100 before tea, and that was just his golf! Cricketing legend Doug Walters ensured everyone forgot their ordinary game and listened to his fun game.

One 'dead eye dick' managed to sink his putt in the Putting Competition and the de Vries Tayeh team from Parramatta won the day as did Parkinson's NSW, which raised over \$40,000 net for the second year in a row. This makes it one of the most successful charity golf days after only two years.

A new initiative saw Parkinson's NSW create the President's Cup trophy, to be played for every year by teams from the Sydney Markets and Fish Markets. The inaugural competition was won by Sydney Fish Markets and for Sydney Fruit and Vegetables it was a case of the one that got away.

Parkinson's NSW would like to sincerely thank our Platinum sponsors – Sydney Airports Corporation and Cromwell (see ads below and next page); Gold sponsors – Bulldogs, People Bank, Sydney Markets and Yamaha, plus all other sponsors and everyone who participated. We hope to see you again in 2009.







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In addition to accessing Phoenix's stock selection capabilities, the Fund features **no entry or exit fees**, **quarterly distributions payments**, **daily liquidity**², **a diversified portfolio** of approximately 20 securities and **capital growth potential**³ from a historically low base. Minimum initial investment \$20,000 with an option to reinvest distributions to compound growth.

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(1) S&P/ASX 300 A-REIT Accumulation Index. Historical performance figures are not necessarily an indication of future performance. (2) Withdrawals paid within a week in normal circumstances. (3) Capital growth is not guaranteed. Units in the Cromwell Phoenix Property Securities Fund ARSN 129 580 267 (the Fund) are issued by Cromwell Property Securities Limited ABN 11 079 147 809, AFSL 238052 (DFS). Before making an investment decision in relation to the Fund investors should read Product Disclosure Statement dated 14 April 2008 (PDS), which is available from www.cromwell.com.au or by calling Cromwell Investor Services on 1800 334 533. This information is provided by CPS and has been prepared without taking into account your objectives, financial situation or needs. Therefore, in deciding whether the product fits your objectives, financial or taxation advisor, whether the product fits your objectives, financial situation or needs.

Woman to woman Parkinson's support group

If the person you are talking to doesn't appear to be listening, be patient. It may be that he has a small piece of fluff in his ear.

Pooh's Little Instruction Book , Inspired by A.A. Milne

This Winnie the Pooh quote, although not very scientific, is true in many ways. We do a great deal of listening here at PNSW and have heard the demand for a women's support group. So we are now initiating this new support group for women with PD under the age of 50.

We strongly believe in the unique power of support groups. This new group will be a gathering of women diagnosed with PD, who will share information, common experiences, situations and problems. Members will have the opportunity to offer each other emotional and practical support based on the unique perspective only available to those who have shared experiences. They can give each other reassurance that their reactions are normal, and that they are not alone. It is going to be a group run by and for women with PD under the age of 50.

Through mutual support, women can gain self-esteem and courage to take on the disease and the difficulties that may lie ahead. This new group will provide a warm and supportive environment, a place where women can be themselves, release anxiety and tension, ask sensitive questions and tackle day-to-day problems. It will also allow women to access new ideas to help deal with difficulties in their daily lives. Knowing that others are coping with similar problems produces a sense that one is not alone.

WHEN: Wednesday 25 February 2009TIME: 10.30 am - 12.00 amWHERE: 25 Khartoum Road, Ryde

Please RSVP to Janine on 8875-8900

Bright Ideas For Blue Days Blue days are more common when it's wet or windy

Why do I feel like this today? Luv yourself for WHO you are Show emotion – 'let it out', you will feel better Eat well and enjoy it Exercise regularly Identify supportive people Stay involved in life Plan something enjoyable a coffee/take a movie/meet with friends/plan a holiday Be normal – Think normal

Funds raised on our charity golf days support Parkinson's counselling services.

Building Better Airport

> We're building for the future. We're building a better airport for Sydney and NSW.



On the groupvine by Trish Morgan

It's time to celebrate new groups and the diversity that exists in our support groups.

Yamba has a support group following monthly meetings for coffee in homes and cafes. Publicity in the Daily Examiner and Coastal Views followed by a public meeting brought 21 people together. Heather and Graeme Wilson, Iris and Ross Neuendorf, Pat and Rex Waghorn,

are the initial members. They have developed a 'charter' or Aim which includes 'to be supportive, understanding and encouraging of each other – Socially – Emotionally – Practically'.

They also aim to 'continue to contribute to others – family/friends/community'. See Heather's

"Bright Ideas For Blue Days". What creativity is out there in our membership!

Bega Valley will have a support group in 2009, thanks to Sue and Phil Nelson who raised the idea at the National Conference. They have been meeting with Bob McDonald and Jean Nicholson and the proposal for a support group will be raised at a seminar "Living with Parkinson's" to be held there on 6th February next year. Margaret Byron, Deborah England and Trish Morgan will be participating in the seminar.

Diversity:

Some groups including, **Central Coast, Coalfields** and **Lower North Shore**, held stalls for Charity Day, which was sponsored by their local councils.

Blacktown support group are attending Blacktown Meals on Wheels centre for a 3-course meal, preceded by morning tea and bingo. There is plenty of time for chatting and some board games after lunch before the bus returns people home. This is available on Thursdays to those who live in the Blacktown Council area. Cost is \$5 for the meal and \$3 for the bus. Members are making new friends and their carers can choose to join in, stay home or have a day out elsewhere.



Maroubra support group took up the challenge to learn the Argentine Tango. Members followed the steps with increasing confidence. The class was led by Sandy Grant, who is a professional dance teacher. Members enjoyed the lesson which stimulated the brain and the body. Norma Doyle from Wagga Wagga support group was visiting her daughter, Katie Thornton. Sandy with Walter Orski, Vince and Margaret Faure show how it's done.



Newcastle support group held a BBQ/meeting to celebrate the 80th birthday of their leader, Verlie Sullivan OAM. It has been a very big year for Verlie. Evelyn Collins, P arkinson's Specialist nurse, gave an excellent powerpoint presentation of the National Conference. About 50 members enjoyed a delicious lunch.

Group changes:

Deniliquin support group is closing as its leader, Glenis Gordon, is getting married and moving back across the border to Victoria, where she grew up. Glenis still intends leading the Finley group bi-monthly meetings. We send our congratulations to Glenis and best wishes for her future happiness. Glenis has done a wonderful job of coordinating 2 support groups since the loss of her husband in 2000. Murry Druitt will be the contact person for Deniliquin and Finley areas while Glenis settles into her new home.

Shoalhaven Shakers with branches in Nowra and Ulladulla have decided to form 2 separate support groups. Jonathan Morgan has taken over as leader of Shoalhaven Nowra and he has some energetic helpers. Barry Mitchell supported by his wife, Irene and Alan Graham, will continue to lead the Shoalhaven Ulladulla support group.

News flash!

Quirindi is ready to start a support group. An email received from Les Howard on Saturday 22nd November, says he is supported by the local Councillor Colleen Wills who has offered the CWA rooms. Members in the area can ring PNSW on 1800 644 189 for information. Letters will be sent out re the initial meeting.

Bequest

Heath Ledger, the young actor, didn't do it. Peter Brock, the racing car driver, didn't do it. What didn't they do? Update their Will after a major lifestyle change. Heath had become a father, and Peter moved in with a new partner, but both died before adjusting their Wills. Actually, Peter Brock started a "do it yourself" Will kit, but hadn't got around to getting signatures from witnesses, so the Will had to go through court proceedings before it was finally accepted.

Putting off updating our Wills can cause a lot of heartache for our loved ones. Just making a phone call for an appointment with our solicitor can avoid so much distress. Updating our Will gives us reassurance that everything is in order. If you need to update your Will, please don't put it off any longer.

Would you also consider making a bequest to Parkinson's NSW at the same time? There are various types of bequests. If you would like more information, please phone Margaret on (02) 9876 5351 any time between 8am and 8pm or ring 1800 644 189 and leave a message for me to contact you.

Margaret Byron, Bequest Officer



Welcome to Koala T Care the number 1 mobility, rehabilitation and healthcare supplier.

We are very pleased to offer ALL Parkinson's NSW members the opportunity to receive **10% discount** on ALL Koala T Care products (excluding spare parts, freight & hire equipment).

Koala T Care – Laurieton & Tuncurry are owned and operated by Gary & Linda Clarke.

The Laurieton store is the holder of the DVA contract on the mid north coast.

At Koala T Care we pride ourselves on superior service and very competitive pricing. If we do not have the requested product in stock, we will order it in for you.

Koala T Care also hires various products for those who only have short term needs.

So if you require any mobility or rehabilitation equipment please call Koala T Care for a no obligation free quote and allow us to make

"EVERYDAY LIVING MADE EASIER"

Contact details for Koala T Care

Head Office 4/16 Laurie Street, LAURIETON. NSW 2443 1/62 Manning St, Tuncurry. NSW 2428

Phone: (02) 6559 5911 or Freecall 1300 780 750 Phone: (02) 6555 2322 or 1300 780 750

> Fax No: (02) 6559 5922 Fax No: (02) 6555 2344

Mobile: 0424 199 750 - Gary Clarke Email: koalatcare@tsn.cc

Web: www.koalat.com.au

Stamp Volunteers

Wanted:

Postage stamps for fundraising

Jill & Kel Healy and their helpers are still actively seeking mint and used postage stamps in small or large donations, Australian or foreign.

We rely on stamp donations without which we can do nothing.

We would like to thank all the wonderful Support Groups who have generously donated their time in collecting used stamps over the past seven years.

Our thanks also go to all the other donors, Probus and other Service Clubs, business firms, retirement villages, friends and relatives of Parkinson's, not only in NSW but also in Victoria, Queensland and Western Australia.

We are indebted to the wonderful effort of David King who in "Stamping Out Parkinson's" not only spreads the word but collects and trims many of the stamps.

We do not venture to Sydney often these days. so we would be happy to have the stamps sent direct to us. Please remember to include your name and address so we can thank you.

Jill & Kel Healy Villa 931 Henry Kendall Gardens Maidens Brush Road Wyoming NSW 2250



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Living life with Parkinson's Program

North, south, east, west; Doing what we know is best.

Reaching out to you all with support and information. To give you courage to walk tall through nice 'n' easy education!

We're waxing lyrical because we've again got funding to hold information seminars throughout the State in 2009. Some of the comments made at the seminars this year were:

All speakers were excellent and I enjoyed the seminar.

I found every topic very interesting and valuable. You were all very good.

Personal contacts with other Parkinson's sufferers was very valuable.

Explaining some unanswered questions I have had.

People with Parkinson's, carers, family and friends will all gain something from the Living Life with Parkinson's seminars. We hope you will be able to come along to the seminars to be held in Armidale, Auburn, Bathurst, Bega, Mittagong, Mona Vale, Parkes, Penrith and Taree (see dates below). Refreshments will be provided and all of the seminars will be free.

Can't come to a venue? Then sit in the comfort of your own home and join a Teleconference Group. Like the seminars, you will hear from specialists about PD and professional and community services to help you live life to the fullest.

There are no limits on the number of people attending the seminars but the Teleconferences will be popular, so it's a case of "First in, best dressed". And that's a joke because although you need to register early, you can participate in your pyjamas if you want – nobody will know!

Please come to a seminar and register as soon as you can. We look forward to meeting you and having a rewarding time together.

Phone 1800 644 189 to register or find out more.

SEMINARS							
F	EBRUARY	ſ	MARCH		APRIL		MAY
Bega	Fri 6th	Mittagong	Tue 3rd Fri 6th	Parkes	Sat 4th tbc	Mona Vale	Tue 5th tbc Thu 7th tbc
Penrith	Tue 10th Fri 13th	Auburn	Thu 12th Tue 17th			Taree	Mon 11th tbc
Bathurst	Thu 26th	Armidale	Wed 18th				

		TELECONFERENCES		
GROUP 1	GROUP 2	GROUP 3	GROUP 4	GROUP 5
Tues 17th Feb	Tues 17th Feb	Thur 19th Feb	Tues 5th May	Tues 5th May
10.00am - 11.00am	11.15am - 12.15pm	10.00am - 11.00am	10.00am - 11.00am	11.15am - 12.15pm
Tues 24th Feb	Tues 24th Feb	Thur 26th Feb	Tues 12th May	Tues 12th May
10.00am - 11.00am	11.15am - 12.15pm	10.00am - 11.00am	10.00am - 11.00am	11.15am - 12.15pm
Tues 3rd Mar	Tues 3rd Mar	Thur 5th Mar	Tues 19th May	Tues 19th May
10.00am - 11.00am	11.15am - 12.15pm	10.00am - 11.00am	10.00am - 11.00am	11.15am - 12.15pm
Tues 10th Mar	Tues 10th Mar	Thur 12th Mar	Tues 26th May	Tues 26th May
10.00am - 11.00am	11.15am - 12.15pm	10.00am - 11.00am	10.00am - 11.00am	11.15am - 12.15pm
Tues 17th Mar	Tues 10th Mar	Thur 19th Mar	Tues 2nd Jun	Tues 2nd Jun
10.00am - 11.00am	11.15am - 12.15pm	10.00am - 11.00am	10.00am - 11.00am	11.15am - 12.15pm

To find out more or to register, please phone Parkinson's NSW on 1800 644 189. Early registration is appreciated.

Donations IMPORTANT NOTICE regarding General Donations

All general donations will now be acknowledged in our Annual Report which will be published for the Annual General Meeting on the 29 September 2009.

There has been a significant increase in our general donations and as there is limited space in our newsletter, this decision has been made for all general donations received in this financial year. We will continue to publish in Stand By Me, donations made for In Memoriam and for Birthdays.

Thank you for your continuing support.

Donations have been received in memory of the following people between 1st September and 30 November 2008

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

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

IN MEMORIAM

Santo Alessi Marie Brown Edmund Clear Lex Couchman Colin Currey Tony D'Mello William Donnolley Gwen Evans Bernadette Fawcett Mary Hazlett Gracie Mauro Grasso Boris Grbevski Marta Kopecka Brian Lamont Stanley Laylim Cyril J Long Jack McGeorge Kevin Mitchell Jennifer Mock Harry Moore Trevor J Moore Colin J Newsome William Nixon Ronald G Puxtv Francesco Rossettin Val Rowlands Ray Ryce Francis Sadleir Ralph Sidman **Doug Sutton** Ted Temple Lillian Thew Margherita Trimboli

Maxwell Try Charles Urquhart Piera Verzeletti Gweneth A Vyner Viv Whittaker Gordon Wratten Ian K Young

DONATIONS WERE RECEIVED IN CELEBRATION OF:

81st Birthday of Herman Eisenberg 70th Birthday of Leigh Reading 65th Birthday of Joan Grimes The marriage of Therese Dyson and Geoff Cooper



Support group contact details

GROUP	CONTACT	PHONE		
Albury/Wodonga	Valerie Leyden	02 6040 6153		
Armidale	Julie Bowden	02 6771 4346		
Ballina	Gerri White	02 6628 8278		
Bankstown	Trish Morgan	02 8875 8903		
Bathurst	Jennifer Mannell	02 6332 8963		
Bingara	Joan Bush	02 6724 1976		
Blacktown	Bryan McAlister	02 9674 6827		
Blue Mountains	Hazel Tolhurst	02 4757 4214		
Broken Hill	Colleen O'Brien	08 8087 2175		
Casino	Dawn Dennis	02 6662 6141		
Castle Hill	Gayle Parker	02 9634 0578		
Central Coast	Les Norris	0418 607 684		
Chinatown Bi-lingual		0421 224 712		
Coalfields	Betty Rumbel	02 4931 5210		
Coffs Harbour	Vera Heil	02 6652 9959		
-	Ray Heilman	02 6341 3692		
Cowra	-			
Finley	Murry Druitt Lorna White	03 5881 1315		
Dubbo	Loma white	02 6882 7778		
Dundas/Parramatta	N.A. 1. 1. 1. 1.	02 9876 4284		
Eastern Suburbs	Marion Welch	02 9369 0250		
Eurobodalla	lan Parr	02 4472 2037		
Fairfield/Liverpool	Warwick Brown	02 9602 8231		
Glen Innes		02 6732 1252		
Goulburn	Mick O'Connor	02 4822 6732		
Grafton	Cathy Eggins	02 6642 2156		
Griffith	Angela Bortolin	02 6962 3289		
Gunnedah	Lisa Hagley	02 6742 0018		
Hawkesbury	Jill Sykes	02 4730 4302		
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092		
Illawarra North	John Coppens	02 4283 1346		
Illawarra South		02 4232 2807		
Lower North Shore	Jan Cumming	02 9412 2740		
Macarthur	Maree Sinclair	02 4626 4959		
Manly/Mosman	Bill Lindsay	02 9949 3991		
Manning/Great Lakes	Bruce King	02 6555 9409		
Maroubra	Trish/Lyn	02 8875 8900		
Nambucca Valley	Margaret Butcher	02 6564 8231		
Narrabri	Janice Holmes	02 6792 1468		
Nepean	Joe Golding	02 9670 5093		
Newcastle	Verlie Sullivan	02 4954 0338		
Parkes	Con Diamond	02 6862 1925		
Pittwater/Warringah	Margaret Smith	02 9913 7745		
Port Macquarie	Patricia Stephenson	02 6584 0212		
Shoalhaven/Nowra	Jonathan Morgan	02 4446 0514		
Shoalhaven/Ulladulla	Barry Mitchell	02 4454 0747		
Southern Highlands	Marj Webb	02 4434 0747		
	5	02 9525 7215		
St George/Sutherland	Myra Chalmers			
Tamworth	Pat Johnson	02 6765 6948		
Tomaree	Heather Grimmett	02 4981 4853		
Tweed Heads	Shirley Rushton	07 5524 9417		
Ultimo	Gerald Ganglbauer	0411 156 309		
Wagga Wagga	John Allen	02 6925 2713		
Yamba	Heather Wilson	02 6646 1369		
Yass	Clarrie Schlunke	02 6226 4150		
Young Onset	Trish Morgan	1800 644 189		

PARKINSON'S NSW INC.

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Diary	Dates			
JANUARY 2	2009			
19	North Ryde Office re-opens after holiday break			
FEBRUARY	2009			
6	Living Life with Parkinson's Seminar – Bega			
10 & 13	Living Life with Parkinson's Seminar – Penrith			
26	Living Life with Parkinson's Seminar – Bathurst			
18	Coffee/Information morning – North Ryde office			
MARCH 20	09			
3&6	Living Life with Parkinson's Seminar – Mittagong			
11	Coalfields Awareness Seminar			
12 & 17	Living Life with Parkinson's Seminar – Auburn			
18	Living Life with Parkinson's Seminar – Armidale			
APRIL 200	9			
4	Living Life with Parkinson's Seminar – dates and venue to be confirmed			
11	World Parkinson's Day			
MAY 2009				
5&7	Living Life with Parkinson's Seminar – dates and venue to be confirmed			
JUNE 2009)			
16	Coffee/Information morning – North Ryde office			
AUGUST 20	009			
11	Coffee/Information morning – North Ryde office			
30	Australia's Unity Walk for Parkinson's			
31	Parkinson's Artisan's Show – thru till the 25 September			
<u>SEPTEMBE</u>	R 2009			
1st week	Parkinson's Awareness Week			
2	Awareness Seminar – State Parliament House			
29	Annual General Meeting – venue tba			
NOVEMBER	2009			
24	Coffee/Information morning – North Ryde office			

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

To become a member, visit our website:

www.parkinsonsnsw.org.au

or

Call InfoLine: 1800 644 189

At the December Council Meeting it was decided that, from 1st April, all subscriptions and joining fees will be increased as follows:

- Individual Membership: \$35
 Professional Membership: \$75 • Organisations: \$100 • Life Membership: \$350
- Parkinson's NSW Inc. ABN 93 023 603 545

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