



Stand By Me

Petitions presented to Parliament



Petition presented by our local member for Drummoyne, Angela D'Amore to the Legislative Assembly on Wednesday 11 October.



Dr Henry Tsang presented the petition to the Legislative Council on Tuesday 14 November. There was bi partisan support within the house.

We are hopeful that the Government will make funds available for specialised Parkinson's services.

Parkinson's NSW position statement on stem cell research

Parkinson's NSW was established in 1979 to enhance the quality of life of all people living with Parkinson's. Currently Parkinson's disease cannot be cured and current treatments are of limited benefit. A major focus of our work is to facilitate the development of treatments which will optimise management of the symptoms of Parkinson's disease and ultimately to find a cure for this disorder. It is the opinion of Parkinson's NSW that **stem cell research** represents a promising avenue for such advances and, as such, we endorse and encourage stem cell research in Australia and in other countries.

Parkinson's NSW acknowledges that stem cell research raises ethical and moral issues and respects the views of individuals and community groups on this matter. One of the primary ethical issues raised is the possible use of both human **adult stem cells** and **embryonic stem cells** in this research. Parkinson's NSW believes that there is insufficient scientific evidence currently available to support the claim that stem cells sourced purely from adults will result in therapeutic advances. We thus support the use of stem cells from both adult and embryonic sources until this question is resolved.

Parkinson's NSW endorses research into **therapeutic cloning** with the goal of developing more effective treatments and ultimately cures for Parkinson's disease and a range of other diseases and supports changes to current legislation in Australia to facilitate this research. This view is in line with the recommendation of the 2005 federal review committee into stem cell research known as the **Lockhart Review** (www.lockhartreview.com.au).

Therapeutic cloning is currently prohibited under Australian law. After wide consultation within the Australian community the federal review committee concluded that the current legislative framework covering stem cell research should be augmented to allow therapeutic cloning and related research under strict ethical and scientific regulation. Parkinson's NSW does not support human **reproductive cloning** and, together ▶

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Parkinson's NSW position statement on stem cell research *continued*

with the Lockhart Review, endorses current **Australian federal law banning this process.**

(See www.comlaw.gov.au/ComLaw/Legislation/Act1.nsf/all/search/AC8A3C16E54D5C1FCA256F72000FA3BC for this legislation.)

For information about the science of stem cell research and current Australian legislation regulating this research, visit:

- National Health and Medical Research Council of Australia (NHMRC) at www.nhmrc.gov.au/embryos/index.htm
- Coalition for the Advancement of Medical Research Australia at www.camra.org.au

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Stand By Me Editor

President's report



This is my final message to you for 2006. It's been quite a year!

PNSW is 'on the move' both literally and figuratively and optimism is spilling out all over.

As more than 18,000 petitioners attested, our need for safe and adequate premises has been pressing. As yet there has been no meaningful response from the

Government to our request for assistance. However, independent of Government aid, Council has approved a move to new offices and we hope to be there early in the New Year! Our new address will be 25 Khartoum Ave, Macquarie Park, North Ryde. This building is also home to Alzheimer's Australia NSW. We will have our own entrance, car parking and signage. The accommodation will provide easy, safe access for visitors, space for all of our staff, privacy for counselling, InfoLine booths, and space for our volunteers, storage and meeting rooms when needed. This is an exciting initiative that meets both our current and foreseeable needs, allowing our services to grow in both quality and quantity.

Our connection with the clinic at Concord Hospital will remain and use of the clinic facilities will continue.

As I write, the Senate has just passed the Patterson bill to allow therapeutic cloning. Your Council has been a strong advocate for the adoption of the Lockhart committee recommendations regarding therapeutic cloning. As members of CAMRA – Coalition for the Advancement of Medical Research Australia, and by independently stating our view via our website, we have put our position to the wider community that any research that offers hope to people living with Parkinson's – providing the ethical safeguards are in place – **must be allowed to proceed.** Joanna Knott, the Convener of CAMRA, despite severe physical impediments, has worked tirelessly to put the issue in perspective for all. She deserves our commendation.

By early in the New Year our Seed Grant winners will be announced and close to starting work on their proposed research projects, hopefully to uncover some positive new approaches for helping people living with Parkinson's.

Medical alert bracelets or necklaces inform ambulance officers and other medical personnel of a person's special needs at a time when rapid response could be critical. My visit to Wagga Wagga for a combined meeting with the Griffith Group pointed out, yet again, the need for us all to 'think ahead'.

The meeting was addressed by an officer from the local ambulance service who explained that officers are trained **not** to give certain drugs to people living with Parkinson's. However, they need to be **aware** that the patient has Parkinson's in order to follow the correct protocols. Since medical personnel are trained to look for Medic alert jewelry, I urge every member to acquire a Medic alert bracelet or pendant as soon as possible.

Peter McWilliam has stepped down as Treasurer. We can all thank him for a job well done and will continue to rely on his insight and intellect both within the executive and Council.

PARKINSON'S NSW INC.

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

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President's report *continued*

It is with great pleasure that I announce Greg Pynt has accepted appointment as Treasurer. Greg has a background in merchant banking and has held board positions in both charitable and social organisations of considerable size, thus bringing both experience and expertise to the position. I know you will join me in welcoming him to the executive.

The Council is completing an exceptionally productive period and there are many ideas, plans and projects that will continue on into next year. With the AGM slated for February, why not give some serious thought to nominating for a place on the 2007 Council? Please see nomination form enclosed. There is a lot of work to do and lots of satisfaction in the 'doing'.

Becky joins with me in wishing each and every one of you peace and happiness and especially health as we approach the festive season. May you have a wonderful New Year!

A bigger and better InfoLine

By Nancy Tung

Since this is the first time I write wearing my headsets, of course I want to talk about the InfoLine.

InfoLine is a toll-free telephone information service provided by Parkinson's NSW. If anyone has any questions about Parkinson's disease, they can simply call the InfoLine on 1800 644 189.

Recently I enlisted the help of the St George/Sutherland Support Group to start the ball rolling on the task of making our InfoLine bigger and better. I asked them to complete a questionnaire on what they thought of the service and how it might be improved.

Jane Wiseman, Editor of *Chit Chat*, wrote to the members of her group encouraging them to return the questionnaire. Following is part of her letter:

The free telephone number for the InfoLine (1800 644 189) is published in the phone book and may be the most accessible way for some people to have their questions answered, perhaps after being recently diagnosed.

An opportunity has arisen to make relevant changes to what presently happens when the phone is answered when this number is called. This is to make this system 'user friendly'.

Perhaps a recently diagnosed person may feel let down by the interaction they had had with the doctor who gave them minimal information and they have more questions. Every opportunity should be given to the people within NSW to have access to something like an InfoLine whenever they have questions that they need answered. The InfoLine is there to give access to whatever assistance is available.

Thank you Jane for a comprehensive summary of the main role of the InfoLine. If anyone else who would like to pick up the ball, please contact me on 9767 7881 for a copy of the questionnaire.

CEO's report



Dear Friends

Thanks again for your support in having our petitions signed by over 18,000 people. These were presented by Angel D'Amore to the Lower House in October and by Henry Tsang to the Upper House on 15 November (see photos on front page).

We would like to think these may have an impact, particularly with the election next March, and we are seeking further meetings with the relevant Ministers.

One of our recent initiatives, suggested by our Vice President Allen Cropp, has been to distribute brochures for Parkinson's NSW across 1,700+ pharmacies in NSW, for handing to customers who have prescriptions filled for Pd-specific medications. We have appreciated the assistance of the NSW Pharmaceutical Guild in this initiative.

We are also completing another project with the Guild, namely publication of a brochure entitled *Drugs to be Given with Caution*, which indicates which drugs should be used with caution while on Parkinson's-specific medication. The brochure has now been accepted and adopted as a national brochure by Parkinson's Australia. We have pleasure enclosing a copy of the brochure. We would love to hear your feedback about the brochure – please drop us a line or email your comments to pnswn@parkinsonsnsw.org.au

Our latest seminar for Allied Health Staff was held on October 17 with fantastic feedback from participants.

Our central focus remains on Member Services and we are pleased to advise that with the Perpetual Trustees Baxter Charitable Foundation Grant we have been able to expand our professional counselling service to five days a week. We look forward to Deborah England, our newest psychologist, joining the counselling team and complementing the work of Janine Rod in November.

The Keven Williams Trust has once again very generously made a substantial donation to Parkinson's NSW to support our ongoing work.

On behalf of the Parkinson's NSW staff and volunteers I wish you season's greetings and all the best for 2007.

Yours in Parkinson's friendship

Miriam

EXPRESSIONS OF INTEREST

Parkinson Pals Network

Would you be interested in meeting, for social contact, other couples living with Parkinson's who live near you?

If so, please contact Sue Rance for further information and to register your contact details:

Parkinson's NSW – Tel: 9767 7881

Stem cell research – the facts

What are stem cells?

When an egg is fertilised by a sperm to make a human embryo, that single fertilised egg cell divides millions of times to form the six billion or more cells that make up our bodies.

Most of these cells have undergone a process called differentiation and become specialised for a certain function.

Stem cells differ from other cells in the body in three main ways:

- They are **unspecialised**, which means they have not developed into cells that perform a specific function.
- They can **differentiate** – i.e. divide and produce cells that have the potential to become other more specialised cell types or tissues. These new cells and tissues are used to repair or replace damaged or diseased cells in the body.
- Unspecialised stem cells are capable of **self-renewal**. Stem cells are able to divide and produce copies of themselves.

Once a cell has become specialised (has differentiated) it has a limited capacity to produce new cells. Thus, if a muscle or blood cell is damaged it cannot replace itself. Stem cells therefore play a critical role by providing new cells for growth and for replacing and repairing used and damaged tissues.

Types of stem cells

There are three main types of stem cells that are being investigated for their potential use in medicine. They differ in their degree of differentiation and ability to self-renew.

- Embryonic stem cells come from a four to seven-day-old embryo. They have the ability to form virtually any type of cell found in the human body, but cannot develop into a whole new organism. Embryonic stem cells are taken from embryos created in IVF (in vitro fertilisation) clinics. Spare embryos that are not required for implantation are used. They are donated for research purposes only with informed consent from the donors. It is illegal in Australia to conduct any type of research on embryos that are conceived naturally, and embryos cannot be specifically created for research purposes.
- Embryonic germ cells are derived from the part of a human embryo or foetus that will ultimately produce eggs or sperm (gametes). This is called the gonadal ridge found at 6 to 9 weeks of gestation when the embryo is developing into a fetus. These cells do not appear to be as versatile as embryonic stem cells.
- Adult stem cells are more specialised than embryonic stem cells. They are found in the majority of tissues and organs in our body and generate the mature cell types within that tissue or organ. They have a restricted ability to produce different cell types and to self-renew.

Potential uses of stem cells

Stem cells have potential uses in many different areas of research and medicine.

Adult and embryonic stem cells could be used in the generation of cells and tissues for cell-based therapies – i.e. treatments in which stem cells are induced to differentiate into specific cell types that are then used to replace damaged cells within the body.

Stem cells could be used to treat a range of conditions including heart failure, spinal injuries, diabetes, Parkinson's disease and other diseases that involve cell damage or loss. It is hoped the introduction of undifferentiated or differentiated stem cells into damaged tissue will lead to the regeneration of the cell types within that tissue.

For example, haematopoietic stem cells (blood stem cells found in bone marrow) are transplanted into Leukaemia patients to generate new blood cells. In the future, neural stem cells may be able to regenerate nerve tissue damaged by spinal cord injury, brain cells destroyed in Parkinson's disease or stroke, or insulin-producing islet cells that are destroyed in Type 1 Diabetes.

Embryonic stem cells could also be used to study early human development and how cells differentiate and function. This may help identify why cells become cancerous and what causes some birth abnormalities.

Stem cells grown in the laboratory may be used for identifying potential new drugs for treatment of diseases such as Alzheimer's or Parkinson's, and for testing drugs and chemicals before they are trialled in animals and people. This may make drug testing safer, cheaper and more ethically acceptable to those opposed to pharmaceutical testing on animals.

Stem cells may also be useful in screening potential toxins in substances such as pesticides; and may assist in the development of new methods for gene therapy for those suffering from genetic illnesses.

The above information was kindly provided by the Australian Stem Cell Centre. For more information visit www.stemcellcentre.edu.au

Notice of Special General Meeting and Annual General Meeting

A Special General Meeting to discuss the review of the Constitution will be held at
10.30 am, February 27, 2007
and will be immediately followed by the
Annual General Meeting at 11 am.

Guest speaker Dr Kay Double, Parkinson's NSW Council member and researcher who was featured in the National Health and Medical Research Council's *Ten of the Best* booklet, will speak on her groundbreaking research into the disease process of Parkinson's.

WHAT IS PROGRESSIVE SUPRANUCLEAR PALSY?

By Dr Nicholas Cordato, Department of Geriatric Medicine – Westmead Hospital, and the University of Sydney

Progressive supranuclear palsy, or PSP, is one of the most frequently encountered movement disorders after Parkinson's disease. PSP is often misdiagnosed, especially in early disease. Contributing to this diagnostic confusion is that, as with Parkinson's disease, no reliable laboratory or radiological tests have been developed to accurately diagnose PSP during life. Therefore, identification of PSP requires recognition of key clinical attributes. Accurate differentiation from Parkinson's disease is important, as PSP carries a poorer prognosis, and response to currently available medications is generally disappointing.

In common with other neurodegenerative movement disorders such as Parkinson's disease, at some point during their disease course, almost all PSP patients will exhibit both bradykinesia (slowness of movement) and rigidity. However, two other key clinical features have emerged as being the most reliable in helping to diagnose PSP during life. These are:

- early loss of balance with falls within the first year of disease onset, and usually a bit later in the disease, and
- progressive impairment of eye movements or so-called gaze palsy, from which the disorder derives its name.

Although impairment of balance does also occur in Parkinson's disease, falls do not become a problem for Parkinson's patients until after more than nine years of disease on average. Gaze palsy does not occur in Parkinson's disease at any stage of the disease.

The impairment of balance progressively worsens and the falls become more frequent as PSP progresses, with many patients eventually becoming immobile and suffering injuries from their falls. The exact cause of imbalance in PSP remains unclear, but as the disease advances, the evolving gaze palsy certainly does contribute. The most severely involved eye movements are those in a downward direction. PSP patients will therefore often complain of difficulties looking down at their food whilst eating, reading books or going down stairs. Eventually eye movements in all directions become impaired.

Although identification of early imbalance/falls and gaze palsy is very helpful in making a diagnosis of PSP, only 50 to 75 per cent of patients with pathologically proven PSP at postmortem will have both these clinical features by three years of disease.

In collaboration with Professor Glenda Halliday at the Prince of Wales Medical Research Institute; Professor John Morris at Westmead Hospital; and Professor Christos Pantelis at the University of Melbourne, we have been seeking ways in which to more accurately identify and to better understand PSP.

Our group has recently published work detailing numerous additional clinical attributes of PSP, which are either infrequent or absent in Parkinson's disease, and may therefore assist with diagnosis. These include the sustained contraction of a specific facial muscle (the

frontalis), the presence of so-called primitive reflexes and the substantial disturbances of behaviour, especially the presence of apathy or inertia.

Another major focus of our group's work has been mapping areas of atrophy or shrinkage in the brain using MRI brain scans during life as well as post-mortem brain specimens. We were the first to have published evidence of specific damage in the frontal lobes of patients with PSP. Such frontal lobe atrophy is not present in Parkinson's patients. Most interestingly, frontal atrophy in PSP was found to statistically correlate with specific clinical features, including behavioural disturbances, suggesting these areas of brain damage are involved in producing key clinical features.

We are presently examining changes on brain SPECT scans to look at differences in brain blood flow in PSP and Parkinson's disease. Preliminary results similarly identify characteristic patterns of brain blood flow in PSP, with the frontal lobes again most significantly involved. We are now analyzing the relationships between these blood flow changes and specific clinical features.

It is hoped that research such as ours may assist with improving the accuracy of diagnosis of PSP during life as well as to help us better understand the processes underlying this disabling disorder. It is only through such knowledge that effective treatments will be developed.

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Research

RESEARCH INTO DRUG THERAPIES FOR PARKINSON'S DISEASE

By Dr Jasmine Henderson, Department of Pharmacology, University of Sydney

Our group is focusing on understanding more about Parkinson's disease and its treatment using animal models. The study involves surgically injecting a minute quantity of a toxin into rat's brains to induce Parkinsonism. The rats develop slowing of movements, muscle stiffness and abnormal posture. We then proceed to allocate groups of rats to various coded treatments. The rats are given the drugs for approximately one month and are regularly tested for Parkinson's symptoms. At the end of the month we perform detailed studies of the brain to confirm that the surgery was targeted correctly and to observe what effect each treatment had.

The main treatment used in Pd is levodopa, which replaces a deficiency of a chemical called dopamine in the brain. However, we know that other parts of the brain, which contain other chemicals, are also affected by Parkinson's. With time, as many people find they have to take larger doses of levodopa, they may also develop abnormal movements (called dyskinesias), problems with balance and movement progress. Some of these changes may relate to alterations in the chemistry of other brain regions.

One such change involves over activation of some brain regions containing the chemical glutamate. We have therefore been focusing on using drugs which block this overactivity using drugs called glutamate antagonists or blockers. Thanks to Parkinson's NSW funding, we have been able to demonstrate in our animal model that a 'non-selective' glutamate antagonist dextromethorphan, commonly found in cough syrup, does indeed reduce this overactivity by approximately 72 per cent. However, other symptoms were not improved.

Furthermore, small clinical studies have shown that while dyskinesia was improved, this drug has not been well tolerated by patients,¹ indicating a need for more selective drugs of this type. In our Rotary-funded research*, using a more selective glutamate (NMDA NR1/NR2B) antagonist given to the animals via drinking water, we found an even greater (95 per cent) improvement in glutamate overactivity. This was also reflected by marked improvement in the animal's posture and movement, with no obvious side effects at the dose studied. Some other studies have used similar types of drugs requiring injection,² whereas ours was quite effective when given by mouth.

These combined results are very encouraging as they support the use of highly selective glutamate antagonists as a future treatment for Pd. We expect to publish these results soon in international journals. Further work will identify how such drugs work in combination with levodopa and whether they can slow down the brain cell loss in Pd.

* Generously supported by Rotary Liverpool West & Australian Rotary Health Research Fund

1. Verhagen Metman L et al. Movement Disorders 1998; 13(3):414-7.
2. Kelsey JE et al. Psychopharmacology 2004; 175(2):179-88.

Second grant from Chinese Community

The Australian Chinese Charity Foundation has for the second year awarded a grant for Parkinson's NSW. At its annual dinner held at the Marigold Restaurant, Sydney on 21 October, Julia Fry representing the organisation accepted a cheque for \$6000 from NSW Health Minister John Hatzistergos.

Julia did a fantastic job as our ambassador. She wouldn't let go of the Minister's hand until she had finished her bit about our petition. Well done, Julia!

The function was also attended by Senator Amanda Vanstone – Minister for Immigration and Multicultural Affairs and Mr Vanstone; and Peter Debnam – NSW Leader of the Opposition and Mrs Debnam.

Men's Parkinson's Network

By Harley Holman – **Tuesday November 14**

I have been living with Parkinson's for the past 16 years or so. We all take a lot of things in life for granted, one of them is networking.

On Tuesday November 14, 12 young men, all with the same hunger for information, gathered together at Concord RSL to network and share their experiences.

We look forward to meeting again on Tuesday December 19 at 10am.

Please join us and stay for lunch – contact Janine or Trish at Parkinson's NSW on 9767 7881 or 1800 644 189.



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On the group vine

By Trish Morgan

Seminars held in Shoalhaven and Coalfields in October drew large attendances, and focused on people with Parkinson's disease and their special journeys.

SHOALHAVEN SEMINAR

Our members from Eurobodalla, Goulburn, North and South Illawarra, St George/Sutherland and Shoalhaven enjoyed the opportunity to gather at the Bomaderry Bowling Club to laugh, learn and make new friends.

There was plenty of laughter when Todd Barkley described living with both parents who have Pd. This was 'Aussie' humour at its best.

Peter Dawkins slipped some jokes into his account of his second DBS surgery.

Barry Mitchell received a surprise when he was presented with a special NSW Government Award for Community Services for the work he did to achieve a designated bed at Shoalhaven Hospital for people with Pd. The certificate and plaque were presented by Bruce Shaw, CEO of Parkinson's Australia.



Barry Mitchell receiving his award.

Keynote speaker Dr Kay Double presented on her latest research, which was reported in *Stand By Me* Spring 2006.

COALFIELDS SEMINAR



Members of Coalfields support group – left to right Neville Elphick, Russell Jobson and Evelyn Collins.

The Coalfields seminar, held at the East Maitland Bowling Club, was well supported by members of the wider community, including the Mayor of Maitland, Peter Blackmore, and the Lions Club of Rutherford.

An expo held at the same time included displays and talks by the Arthritis and Diabetes support groups, Community Transport, Australian Hearing, Educare – Department of

Health Carer Services, and Anstey Surgical home health care products.

There was also information about the Lions Spinal Cord Fellowship, which is funding three researchers at Monash University – the only privately-funded stem cell research in Australia.

Members came from the Central Coast, Newcastle, Manning/Great Lakes, Tomaree and the local Coalfields group to hear the guest speakers – Pd specialist nurse Evelyn Collins; and Dr Chris Levi, who is a senior staff neurologist at John Hunter Hospital, Newcastle.

Professor Lynn Chenoweth from the University of Technology gave a report on her research involving the education of nursing staff in hospitals about Parkinson's disease.

WHAT'S HAPPENING IN 2007

- Seminars at Tamworth and Cowra are planned for early next year.
- Eurobodalla Support Group will hold a mini-seminar in conjunction with their 15th birthday on March 16.
- Ulladulla Support Group will be starting on February 21, sponsored by the Shoalhaven Support Group under Margaret Graham and Barry Mitchell.

GOING ON HOLIDAYS THIS CHRISTMAS?

When travelling throughout NSW, why not make contact with the nearest support group? You may time your trip to coincide with a local meeting.

See the back page of *Stand By Me* for contact details of each group.

DIARY DATES / SPECIAL EVENTS

- | | |
|--------------------------------|--|
| December 9
(11.00am) | Parkinson's NSW Christmas Party
Poetry and Movement
International Day of People
with a Disability
Please come and celebrate Christmas with the staff, volunteers and friends of Parkinson's NSW!
Enjoy lunch, Tia Chi and Entertainment |
| address – | The Vincent Fairfax Building
Macquarie Hospital Campus
Cox's Road, North Ryde
(parking at Vincent Fairfax Building)
RSVP by Friday 1 December
1800 644 189 or 9767 7881 |
| February 21 | First meeting - Ulladulla Support Group |
| February 27 | Parkinson's NSW AGM |
| March 5 | Tamworth Seminar |
| March 7
(10.30am) | Coffee Morning at new premises
Come and meet staff and volunteers of Parkinson's NSW and talk to others living with Parkinson's disease
RSVP - 5 March 2007 |
| March 16 | Eurobodalla 15th Birthday/Seminar |

Donation update

Parkinson's NSW would like to thank the following members for their generous contributions:

Malcolm Davis

Malcolm Davis, whose wife has Parkinson's disease, has made a generous donation of \$5000 to Parkinson's NSW to assist other people living with the disease.

Thanks to Malcolm's assistance, we have been able to purchase a Lightwriter – which will be available for loan by members who have significant speech difficulties. The Lightwriter allows people with Parkinson's to communicate by typing their message and having it converted into speech.

If you know of anyone who would benefit from using the Lightwriter please call 1800 644 189.

Stamp collectors

A big thank you to all those people who collect used stamps for us – and to Kel and Jill, who have been able to donate \$1075 from their stamp recycling efforts.

Edda Davis

A big thank you to Edda Davis – her raffle raised \$1000.

Parky's Pantry

Carol Hand once again opened her delicious cake stall, Parky's Pantry. Carol is donating the proceeds of \$400 to Parkinson's NSW in memory of her dad, Henry William Cupples.

Carol is running a Christmas cheer raffle and the tickets are \$2 each. Please contact the PNSW office if you would like to purchase some tickets.

Coalfields Support Group

With the help of Rutherford Lionesses, the Coalfields Support Group made 700 silk tulip pins and painted them in beautiful colours. Each tulip carried the words '*Ease the burden & find a cure*' and sold for \$2.50 during Awareness Week.

They make a special gift for guest speakers and hard-working members!

To purchase some tulips, call Parkinson's NSW on 1800 644 189.



Mr Bill Boogaart

Bill Boogaart of Henry Kendall Village is a living example of the old adage "It is never too late". Following the death of his wife, Wendy, last year to Parkinson's and other illnesses, he decided he needed another outlet, as he missed Wendy "so terribly", so he enrolled with a local singing teacher and gave his first performance at just ninety. As his teacher told the local Central Coast News in July this year, anyone hearing Bill is immediately impressed with the strength and timbre of his rich baritone voice. On September 30 Bill held his first charity concert and raised \$220.00 for Parkinson's NSW, well done for a first time effort!

Marion & Wally Organ

Celebrated their 50th wedding anniversary in July and guests were asked in lieu of presents to donate to Parkinson's NSW. Parkinson's NSW would like to extend a special thank you to the Organ family and friends for their generous donation of \$1550.00.

A remarkable man

By Melanie De Jager

My husband Ron was diagnosed with Parkinson's about 15 years ago. Initially the symptoms were mild and did not make a great deal of difference to our lives. He continued to work and nobody knew about his illness, but he withdrew socially because he didn't want people to notice his shaking.

In 2002 Ron started going to church with me and our four sons. He accepted Jesus as his Lord and the church now prays for his healing. He has become more social and is less worried about what people might think about him.

In 2004, his employer told him they didn't need him anymore. He was devastated to say the least, but devoted himself to finding the best investment for our retirement funds, betting on horses, and fishing, until one day a friend mentioned that he wanted to sell his laundry business.

On December 1, 2005 we took over the two laundry businesses. Ron has absolutely thrived; he says he has a purpose. He does all the accounting, the pickups and deliveries and helps out in the laundries. It has been challenging and hard work, but it's wonderful to work together, and after 30 years of marriage it has strengthened our commitment to each other.

People say that Ron looks better now than he did two years ago. My children and I admire him enormously, that he will not give in to Parkinson's disease and continues living life to the fullest.

He is a terrific example to everyone.



Melanie and Ron De Jager

Living with Parkinson's disease isn't easy for anyone. It is challenging enough for individuals living with a spouse or carer. But what if you are either widowed, or single, or separated? How do you deal with the physical, emotional, and social implications of the disease while living on your own?

Thousands of people living with Parkinson's find they can live happily and safely on their own – by maintaining supportive relationships, and taking the necessary safety precautions.

Each person living with Parkinson's is affected differently by the disease, so it is important to regularly do a realistic self-appraisal. Coping on your own can increase your stress levels, so take a look at where you are at – what are your stressors? Ask yourself: *How severe are my symptoms? How do they affect my quality of life? Am I coping? What adjustments do I need to make?*

Physical issues are more visible and sometimes easier to come to terms with than emotional ones. For some people living alone, loneliness and depression can prove more difficult to deal with than physical problems. Feeling down is common with Parkinson's, but it's important to remember that you're not alone. Organisations like Parkinson's NSW are just a phone call away, and can offer counselling and advice to help you cope, and can put you in touch with other people in your situation.

If you're living alone, make a point of reaching out to others as much as possible. In our society we are taught to be independent and self-reliant. However, try taking a different perspective. Allow people to have the gift of giving. Most people genuinely feel good in helping others through tough times – and if the roles were reversed, you would too. So if you need help getting to doctor's appointments, or to go shopping, ask someone. It is important to have someone to call in an emergency too. In addition to family and friends, it's a good idea to have the telephone numbers of your neighbors.

Getting help with the household chores can make a huge difference to your quality of life. Hiring someone to clean and vacuum once a week may be all you need. Simple home adaptations – such as installing support rails and ramps – can also ease daily living tasks. You may wish to arrange for an occupational therapist to visit your home and advise on how to arrange your furniture, adapt your bathroom or kitchen, and what gadgets will help you.

Most importantly, be kind to yourself. It is easy to get frustrated when you live alone with Parkinson's. Try and maintain a positive attitude. There will be some difficult days so there is no point in beating yourself up about it – but there will also be some good days – enjoy those. Accepting that you have the illness will go a long way toward coping.

Many people with Parkinson's live alone and manage very successfully. The single life has many benefits – such as freedom and flexibility – and there is plenty of support available to help people living by themselves feel safer, more positive and less alone.

Why not join our new program being offered by Parkinson's NSW – *Living Alone With Parkinson's*. This

innovative group support program, which has been made possible thanks to a generous grant from the Cecilia Kilkeary Foundation Ltd, will provide education, practical advice and emotional support tailored to participant's individual needs. The program will also put participants in touch with community services and give them the opportunity to meet others in similar circumstances and talk about the impact of living with Parkinson's disease.

The program aims to help participants accept their diagnosis, enhance their life coping skills, and make the most of living alone.

The Living Alone With Parkinson's program

If you a person living with Parkinson's who lives alone, join our new program to access:

- professional support
- links to specialised community services
- the opportunity to interact with others in similar circumstances; to give and receive mutual support
- information to help participants plan for the future
- long-term support.

Make the single life work for you

- Seek counselling when you feel your mood slipping – from Parkinson's NSW, your GP, or a friend.
- Visit friends and family regularly, or invite them over to your place. Join clubs, classes or church groups to widen your social circle.
- Stay active – swim, join a tai chi or yoga class, or just go for a walk. It will help keep you fit and you'll meet people along the way.
- Enquire about services that can make life easier. You can arrange to have your groceries and prescriptions delivered, or have someone help with the housework or gardening.
- Consider getting a personal response system such as VitalCall or Blue Phone, which allows you to access help in case of emergency just by pressing a button.

Speeding Vibrations

YOUNG-ONSET 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





MedicAlert
NON PROFIT ORGANISATION

Gift Certificates Available

ANYONE OF ANY AGE WHO HAS A -

- medical condition
- drug or food allergy
- taking medication
- organ donation request
- personal request - eg. medical directive

OR NEEDS -

- Identification - eg. children/traveller
- Next-of-Kin Notification Service

SHOULD BECOME A MEMBER OF MEDICALERT®.

For a strictly Limited Time Only MedicAlert® is offering to Parkinson's NSW Members an exclusive discount on Gift Certificates and New Memberships

Now is your opportunity to give the gift that could save your life or someone you love

In an emergency when seconds count, being unconscious, injured or so confused that critical, accurate, personal or medical information cannot be given, puts lives at risk! In an unknown environment, eg. travelling interstate or overseas, attending school camps, or for persons who do not fully understand their medical conditions or identification details eg. Parkinson's, Alzheimers or young children, correct details are often impossible to ascertain. This may cause unnecessary panic and delayed identification and next-of-kin contact information. Not having this information available immediately can complicate diagnosis, delay vital treatment leading to extended recuperation and even fatal mistakes.

For over 35 years the non-profit Australia MedicAlert Foundation has been protecting and saving lives of its members by providing healthcare professionals with authenticated medical and personal information. MedicAlert® protects over 260,000 Australians 24hrs a day and over 4 million members worldwide. No other body-worn personal medical identification is more respected or trusted that can offer the vital protection and services of MedicAlert®. Endorsed by leading National Medical and Professional Organisations.

MedicAlert® should not be confused with the home security push button alarm systems which provide protection within the home environment only. Once outside this location the signal cannot be activated leaving you at risk. MedicAlert® protection is unrestricted and accessible 24hrs a day.

MedicAlert® does not simply provide bracelets and necklets but a complete 24hr Personal Emergency Medical Information and Identification Lifesaving Service.

Membership Includes:

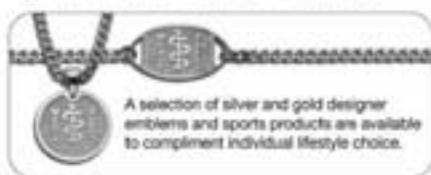
Universally recognised customised engraved emblem - bracelet/necklet with individual medical information, special needs or request etc., unique membership ID number and the 24hr emergency telephone number. All attending emergency personnel immediately read the information engraved on the back of the emblem and respond accordingly - **avoiding emergencies becoming tragedies.**

24hr Telephone Hotline - linked to the Confidential National Registry and attended by trained healthcare professionals.

Confidential National Registry - additional medical and personal information is held on this 24hr Database Registry including emergency contact details eg. next-of-kin, doctor and other "need to know" information.

Membership Card - listing personal, medical and emergency contact details which can be used as an instant verification resource when information is essential for accurate patient records.

Please see your discounted Application Form in this newsletter



Telephone 1800 88 2222

The James Parkinson Society Bringing hope for the future

By Margaret Byron

Members of the James Parkinson Society are a very select group within Parkinson's NSW. They are special because they have made a bequest to Parkinson's NSW.

While we hope it will be many years before we obtain the bequests, knowing about them enables us to plan to expand our services. This will help people living with Parkinson's disease in the future. How lovely it would be to promise them that we would be able to expand our services to ease the burden for them and their families in the years ahead.

A bequest is a gift of personal property such as cash, shares, works of art, jewellery, a house or other tangible property, transferred to a person or charity as nominated in a Will.

Parkinson's NSW would be happy to receive any of the above as a bequest. There are other sorts of bequests. To find out more, contact Margaret on 9876 5351 or freecall 1800 644 189.

Another sponsored lunch is being planned

Some of our senior members who live in metropolitan Sydney didn't get an invitation to the Inaugural Lunch of the James Parkinson Society held on September 7. Sadly, this was because we don't have your date of birth. We're already planning our next sponsored lunch.

If you didn't get an invitation last time, please let us know if you have had your 70th birthday. Contact the PNSW office or contact Margaret on 9876 5351.

We are planning a free lunch for senior members outside the metropolitan area next year. Details in the Autumn edition of *Stand By Me*.

Improving bathroom safety - Throne Toilet Rails

The support rails are a compact unit that attaches firmly to the existing toilet bowl. They fit approximately 90% of standard toilet bowls. (see flyer)

The rails are simple to install. They are fully transportable - ideal for people when holidaying or on respite.

Support is provided to both sides of the body. The user is able to safely lower down onto the toilet using the rail and then lever up from the seat, by pushing down on the rail.

Special offer for Parkinson's NSW members

Parkinson's NSW members can purchase the Throne Toilet Support System from a quality healthcare supplier, or directly from Throne. Send your receipt to Throne to receive a rebate of \$15 on powder-coated rails and and \$30 on stainless steel rails, with \$5 going to PNSW.

How much does it cost?

The RRP of the powder-coated rails is \$235 per unit and the stainless steel rails cost between \$370 and \$390 per unit, depending on the model chosen.

For more information

Call Throne Accessories on 02 6280 6851 or visit www.throne.com.au

Donations

\$50 and over received between 1 October – 15 November, 2006

We are grateful for all donations as Parkinson's NSW receives no government funding. Thank you.

IN MEMORIAM DONATIONS

Bob Aitken

Josey Pyne

Bill Coulter

Yvonne Coulter & family

Henry W Cupples

Carol Hand

Shirley Field

R Bland

Bruce Collins

Ray W Gower

Michelle Birse

Leo J Haley

B Haley & family

Ron Heil

Coffs Harbour

Support Group

John & Rebecca Silk

N Watts

Norma Jarrett

Edith Northcott

Peter King

John Swivel

George Manewell

V Manewell

Teresa Rayment

Frances Brasher

Bernard Fonti

M Hill

Kaye Morrison

Elizabeth Pooley

Cecil Rayment

P & J Rubie

S Trovato

G & S Vaccari

Kenneth Russell

Kenneth Russell

William B Smith

Peter Smith

The Pike-Woods families

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Frank Ingrati

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R Kerr

Rusy Byram Khursigara

David King

A Lechner

Miranda Congregational

Seniors Group

Maureen Morrison

National Seniors Hornsby

Shire Day Branch

Cathy Northey

J & A Pope

Port Macquarie Golf Club

Greg Pynt

Revesby Ladies Group

Ritchies Stores

John Silk

Neil Sligar

Barbara Stilwell

P Tattersall

The Rotary Club

of Dural Inc.

Doug Unmack

Otto Zeckendorf

SUPPORT GROUP

Dubbo Parkinsons

Support Group

Eurobadalla Parkinsons

Support Group

Illawarra South Parkinsons

Support Group

RESEARCH

AON Charitable Foundation

Val Bingham

J Blackman

B Nicholson

E Norris

Ross Shepherd

Social Club Committee of

Blue Haven Village

OTHER

Maureen Dening

Peter Donald

Dennis Gibbons

A Gorham

Michael Grainger

David Hain

Jasmine Henderson

Norma Jarrett

David King

Margaret Lui

H Martin

Roslyn Matthews

P Moller

R Mulroney

Donald Nicholson

D S North

Port Macquarie Golf Club

Revesby Ladies Group

Ritchies Stores

Leonard Rynkiewicz

Maria Sofianidis

Stamp Sales

Walter Steller

Patricia Swain

Peter Young

DECEASED ESTATES

Keven Williams Estate

RESPIRE

Rosalina Newman

FOUNDATIONS

Australian Chinese

Charity Foundation



Bluephone

Take the FEAR out of living alone

Bluephone is a medical telephone designed and manufactured in Australia by Smartcaller International Melbourne.

Bluephone enables you to safely stay in your home. It has the ability to alert your family and friends at the press of a button. The Bluephone is activated by a personal pendant or smoke detector. It will send a message to family or friends if you have not pressed the OK button.

Bluephone is a complete home security product giving you peace of mind; the Bluephone will become a friend of the family. In an emergency situation it gives a voice message to the you reassuringly telling you it is taking over. The **Bluephone** continues dialling up to eight telephone numbers of family or friends until one of them answers, relaying the alarm voice message. *No ongoing monitoring cost.*

Financially the Bluephone is not out of anyone's reach. Smart Caller International wanted to make the Bluephone affordable to all homes, not just a few. The Bluephone comes with a personal pendant, and if required smoke detectors and home security monitors at an additional cost.

Bluephone for only \$395.00 incl pendant

Parkinson's NSW special discount rate till the end of February 2007 Bluephone for only

\$375
INCL PENDANT

Call Bluephone NSW

On Free Call 1800 684422 for more information

I would like to make a donation of \$ _____

PLEASE FIND MY:

CHEQUE MONEY ORDER ENCLOSED OR

CHARGE MY:

VISA MASTERCARD BANKCARD

EXPIRY DATE: _____

CARD NO.: _____

NAME ON CARD: _____

ADDRESS: _____

SUBURB: _____

STATE: _____ P/CODE: _____

PHONE: _____



If you wish us to send you a membership form and information please fill in the address box below and send it to:

Parkinson's New South Wales Inc.,
Building 25, Concord Hospital,
Hospital Road, Concord NSW 2139

NAME: _____

ADDRESS: _____

SUBURB: _____

STATE: _____ P/CODE: _____

PHONE: _____

EMAIL: _____

Tick if you would like information on wills and bequests

Support group contact details

GROUP	CONTACT	PHONE
Albury	Bruce Ockenden	02 6025 7147
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown		1800 644 189
Bathurst	Jennifer Mannell	02 6332 8963
Canterbury	Trish Morgan	02 9767 7881
Casino	Dawn Dennis	02 6662 6141
Castle Hill	Pallavi Yarrapothu	02 9634 0578
Central Coast	Les Norris	0418 607 684
Chinatown Bi-lingual		0421 224 712
Coalfields	Carol Bateson	02 4930 8638
Coffs Harbour		02 6652 9959
Cowra	Ken Bryant	02 6342 4403
Deniliquin	Glenis Gordon	03 5881 3295
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta		02 9876 4284
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla		02 4472 2037
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Finley	Glenis Gordon	03 5881 3295
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	02 4822 6732
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	Emma Robinson	02 4223 8282
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
Muswellbrook	Pat Moody	02 6543 3164
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	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