



Ease the Burden and Find a Cure

Stand By Me

Major boost for research

Parkinson's NSW is thrilled to announce it has awarded \$164,000 in the form of research grants, seed grants and stipends for 2009.

The \$50,000 Unity Walk Research Grant went to **Prof Glenda Halliday**, Professor of Neuroscience and principal research fellow at the Prince of Wales Medical Research Institute, to work on the effects of Parkinson's disease on neurogenesis. Currently, PD cannot be cured but intensive worldwide research is working to develop treatments based on the use of replacement brain cells. Drug treatments act by increasing levels of dopamine, a substance known to influence the birth of new cells in the brain. This project will investigate whether the brain's ability to produce its own new cells is affected by PD or by common treatments for this disorder, critical for the development of safe, effective treatments.

The Fahey/Walker Research Grant of \$50,000 was given to **Assoc Prof Carolyn Sue**, Director of Neurogenetics at the Royal North Shore Hospital. The research will use a novel human cell model to investigate how neurons degenerate neurons in PD.

Seed Grants

Seed grants of \$20,000 each went to **Dr Stuart Smith**, senior research officer at the Prince of Wales Medical Research Institute, and **Dr Natalie Page**, hospital scientist at the ANZAC Research Institute. Dr Smith's project will evaluate the use of a recently developed device for monitoring indices of neuromotor function, such as reaction time and fine motor control. Dr Page will work on developing a new method for affordable, efficient detection of known mutations in PD genes.

PhD Scholarships

Three PhD scholarships of \$6,000 per year to be paid over three years were awarded to **Claire Stevens**, who aims to understand the molecular factors and cells involved in the inflammation associated with cell death mechanisms in PD and their role in disease progression; **Jie Zhang**, who will seek to provide an understanding of how neurogenesis is altered in sufferers of PD and the effects of L-dopa on neurogenesis in the Parkinsonian brain; **Natalie Allen**, who will study the effects of exercise on the risk of falls in PD and to **Stefanie Reyes** for the second year of her research into whether differential expression of tyrosine hydroxylase in the substantia nigra underlies cell vulnerability in PD.

Judging Panel

The Parkinson's NSW council unanimously agreed with the recommendations of the judging panel who were: Dr Paul Lockhart, Murdoch Children's Research Institute; Professor Malcolm Horne, Howard Florey Institute; Dr Natalie Gasson, Curtin University and panel coordinator Dr Sarah Mott, Australian College of Health Service Executives



Prof Glenda Halliday



Assoc Prof Carolyn Sue



Dr Stuart Smith



Dr Natalie Page



Claire Stevens



Jie Zhang



Natalie Allen

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President's Report

Dr Sarah Mott has tendered her resignation from Council to pursue new challenges in SA. She has contributed enormously to PNSW with her humour and vast experience as a nurse and educator and while we will miss her

immensely, she goes with a heartfelt 'God-speed'.

It is a great pleasure to welcome Dr Simon Lewis and Mr John Hassett to the Council. They bring with them excellent skills and their appointment brings the Council up to full membership.

Along with Council members, Support Group Leaders and Members at large I am often asked the question "What do I get out of being a Member of Parkinson's NSW?" As we get down to hard work again after the summer holidays, it seems an appropriate time to look at who we are and what our organisation represents and yes, what we gain from membership.

I am reminded of John Kennedy's paraphrasing of John Dunne's famous poem, For Whom the Bell Tolls: "Ask not what your Country can do for you, but what can you do for your Country."

In joining an organisation such as PNSW, whether one makes use of many or none of its services, an individual is lending their support to **all** People Living with Parkinson's by participating in:

- the fight for recognition of Parkinson's Disease by both the State and Federal Governments
- the financial support of our local research scientists
- the provision of information, counselling services and education for PWP, professionals and the general public
- increasing the awareness of Parkinson's in local communities
- the establishment and continuity of Support Groups

What does all this mean in 'real terms'?

Well, it means that our profile with both the NSW and Federal government has improved dramatically. We have received grants over \$65k in NSW during the last 12 months and over \$100k federally. This Federal money is funding an online information course for Rural & Remote Physicians to be launched at Parliament House Canberra in March. PNSW has managed the project and will continue in this role. I am convinced that having an established Secretariat in Canberra with a full time CEO lobbying for us is a huge step forward.

It means that our members and friends have supported our organization by making donations and bequests and have been totally behind our fundraising efforts; the now annual "Putting for Parkinson's" Golf Day and our marvellous first Unity Walk, which saw over 1000 people participating and raised \$100k for research and services. Over the last 3 years we have distributed over \$300k for research, PHD Scholarship's, and Rural Undergraduates living allowances (to date in Coffs Harbour, Port Macquarie and Albury).

It means that our Infoline is fully staffed and equipped to answer questions, provide support and send information packs to the newly diagnosed. It means

that anyone, anywhere in the state, can access confidential counselling services from well qualified and compassionate professionals free of charge. It means that we have continuing programs to educate and inform.

It means that with a support group network of 60 (and growing) no one should have to travel the Parkinson's road alone. PNSW is the umbrella for our support groups providing an operating framework, insurance policies and on-going assistance and practical advice. Our bi-annual meeting of support group representatives in Sydney this coming July is highlighted on my calendar.

So when you are again asked the question "What do I get out of being a member of PNSW" – this is my 'short answer' – you don't have the time to read my long one!

Stay well one and all.

John Silk

Treasurer's Report Formation of Trust

by Greg Pynt, Treasurer

Phil Maundrell and I have long held the view that charitable organisations such as Parkinson's should always develop sufficient reserves to enable them to operate on the income from those reserves. If this is achieved the security and continuity of the organization and the services it supplies are assured. The usual structure to ensure that the capital is both generated and preserved is a trust, sometimes called a foundation.

To date Parkinson's NSW has lived hand to mouth with little left over at the end of each year. Fortunately 2008 has been a very different year, thanks mostly to the efforts of our president, John Silk and our fund raising consultant Marty Rhone. While we are not wealthy we do have sufficient cash to provide services for 2009.

We have also had the great good fortune to have received a substantial bequest from the Estate of the late Daphne Jean Fahey. This will form the basis of the new trust.

This money will be used to seed the new trust, the trustees of which are presently John Silk, Chris Davies, Phil Maundrell and Greg Pynt. Under the trust deed, and in accordance with the wishes of M/s Fahey and her partner, income from the capital will be available to the trustees for expenditure on research into Pd and for general purposes of Parkinson's NSW. It will not be possible to remove capital from the trust and it is intended that the purchasing power of the capital be preserved by only taking out a portion of the income and leaving the balance as a protection against inflation.

The trustees are appointed as representatives of Parkinson's NSW. It is our intention that they be replaced from time to time to ensure new ideas and they may not always be councilors of PNSW. The funds of the trust will be managed by a professional fund manager to ensure appropriate investment strategies.

The trust will operate in perpetuity and is open to bequests and gifts from anyone provided that the sum involved is of a substantial nature. An application has been made to the Australian Tax Office for charitable status.



CEO's Report

In Appreciation

Gwen and Malcolm Evans were both Life Members of our organisation. Malcolm served for some years as a vice president and Gwen served as a secretary, as well as being a founding and very active

member of the St George support group. Together they devoted many years service to our organisation. Malcolm was diagnosed with PD at 41 and suffered with it for 27 years. He died in May 2000. Gwen, like many other carers, continued supporting the organisation at support group and State level. She died late last year and our best wishes go to her family.

We also mark the passing of Robert Young this year. Robert was for many years a member of the Council of PNSW, as well as being very active with the Hornsby support group. Following his retirement with PD, he brought his publishing knowledge to the assistance of the organisation, as well as helping in other ways.

John Hassett and Dr Simon Lewis



John Hassett



Dr Simon Lewis

In this edition of *Stand by Me*, our president John Silk welcomes John Hassett and Dr Simon Lewis to the Council. John has extensive background in management and consulting within the financial services sector, including as a managing director. He was diagnosed with PD in May 2002 and continues to work actively in management consulting.

Dr Simon Lewis is a Consultant Neurologist, and will bring specialist expertise to the Council. He trained at the University of Cambridge and the National Hospital for Neurology and Neurosurgery, Queens Square, London, and has recently been appointed to the University of Sydney and the Royal Prince Alfred Hospital as the Senior Lecturer in Cognitive Neuroscience. He is also a director of the newly established Parkinson's Disease Research Clinic at the Brian & Mind Research Institute. He has a particular interest in education for PWP and Health Professionals.

Advocacy

We have been strongly lobbying federal members of parliament to have additional Parkinson's treatments listed under the Pharmaceutical Benefits Scheme. These treatments are available in a number of countries. We would like to widen the range of treatments that doctors can prescribe for their patients in Australia.

Living Life Program

From May we will be running again the Living Life with Parkinson's Program, which allows people living with Parkinson's Disease to phone in to a group phone line, where they can share their experiences, and have access to experts. It's often like speaking to friends over the phone. It is also a great way of sharing ideas and experiences with others, when it is not easy to get out. For more information, and to register for this, please contact the InfoLine 1800 644 189.

Art Show

As part of our September awareness activities, we will be having an art show at New South Wales Parliament House, showcasing art by people living with Parkinson's. If you would like your artwork to be considered for exhibition, please contact me on the InfoLine, 1800 644 189.

Yours in Parkinson's friendship

Miriam Dixon
CEO

Coffee Information Morning

Come and meet staff and volunteers
at Parkinson's NSW

Talk to people living with Parkinson's

10.30am start – 16 June 2009
25 Khartoum Road, North Ryde

RSVP – 9 June 2009
Phone 1800 644 189



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Parkinson's no barrier **Geoff Townsend: Living life to the fullest**

In 2005, Geoff Townsend's life was changed forever. The music teacher was diagnosed with Parkinson's disease, a disorder he now concedes he suffered for some years prior to his diagnosis.

"You learn your limitations – but you don't let those limitations stop you from living a fulfilling life," he says.

Geoff spoke to the Tribune about how to live a fulfilling life in spite of the often cruel Parkinson's disease.

In April 2005, Music Director at Yass High School, Geoff Townsend, was filled with relief. Neurologists had diagnosed the degenerative illness, Parkinson's disease. How could a man who had just been diagnosed with Parkinson's possibly feel relieved?

"It could've been a lot worse. For years I presented symptoms and I feared I may have had a brain tumour or muscular dystrophy," Geoff said.

For the next three years, Geoff Townsend continued to teach aspiring musicians at local schools throughout Yass. He would go on fishing trips, attend Parkinson's support group meetings and raise money for research into finding preventatives for the disease. Parkinson's disease has proven no barrier for Geoff.

In 2000, a throbbing left arm pain woke Geoff from his sleep in the late hours of the night. Try as he might, the then 51-year-old couldn't move his distressed arm. It was the beginning of long series of symptoms that would convince doctors Geoff Townsend was a new addition to the growing list of 80,000 Australians with Parkinson's.

A short time later, the school teacher began striding around with his left arm tucked under his right – for no apparent reason. When people started to raise an eyebrow at Geoff's bizarre stance, he glanced down and stared in amazement, realising he was totally oblivious to how he had been standing. Alarm bells began ringing when Geoff discovered such behaviour was subconscious. Something was wrong.

Over the next few years, life continued as normal for the Bowning resident, with a minor hiccup or two feeding the slight anxiety in the back of his mind.

There was one event, however, which was the catalyst for Geoff to rush to his GP and asked to be referred to a neurologist.

"I was fishing out at Burrinjuck... something I've done many times," Geoff explained. "I pulled the boat up so I could do a bit of fishing. I went over and tied the front of the boat to a tree – instead of the back of the boat. Water started gushing on board and I fell into the water as I started to panic. I clung on for 40 minutes until I was rescued... I nearly got hypothermia."

The incident sparked concern among family and friends. Soon after, Geoff Townsend was diagnosed with Parkinson's and suddenly, the long list of bizarre occurrences made sense.

Parkinson's is known for throwing a few surprises at those who suffer from the disease. Geoff has had his fair share of strange incidents. "I remember looking down at a keyboard one day thinking, 'I need to type T for Townsend', but all I could see was a whole keyboard full of Ts."

While Parkinson's is a degenerative illness, there are a number of practices people can carry out to slow the rate of deterioration. "Gym work is great for Parkinson's," Geoff explained. "I tend to do lots of crosswords and sudokus to keep my brain active."

Yass Parkinson's Support Group strives to ensure sufferers and their families have a great quality of life, while community members become more aware of Parkinson's disease. Last week, the group raised in excess of \$1800, all of which will go towards research. Yass Parkinson's Support Group would like to thank the community for their generosity.

While the disease continues to hamper Geoff in many ways, the 59-year-old remains very optimistic about the future. "I'm looking forward to the next few years of my life... I'm enjoying my retirement. I would like to travel and I look forward to seeing my daughter and grandchildren in Norfolk in England."

Life is there to be lived, and Geoff plans on packing a lot into his living.

To find out how you can help those suffering from Parkinson's in your community, by phoning the InfoLine 1800 644 189.



Geoff cuts his farewell cake during a dinner last year, recognising his contribution to music in Yass.

NSW wish to express thanks to the YASS TRIBUNE for allowing this article to be reproduced in this issue of SBM.

Our new women's group

It took two years of talking, and much determination. Finally on Wednesday 25th February we held our first meeting for women, under the age of 50, diagnosed with PD. Getting such a lively and motivated group of women together was a means to widen their circle of friends, and develop a support system that extended beyond their immediate family. We shared personal experiences, practical information and resources for living well with PD.

We will continue to meet every third Wednesday of the month at our offices in North Ryde. We welcome any newcomers and their female family members or carers, and look forward to our continued growth.

For further details, please feel free to contact Janine or Trish on 8875-8900

Using telehealth technology to monitor Parkinson's Disease from within the comfort of your own home

Dr Stuart Smith, Senior Research Officer, Prince of Wales Medical Research Institute

The quality of life of individuals living with Parkinson's disease depends on a number of key physical and neuropsychological characteristics of their disease and upon our ability to detect and act upon significant changes in those characteristics. However, most people living with the disease may only get to see their doctor on an irregular basis, particularly those living in rural or remote Australia. It is not uncommon for 6 months or a year to go between assessments by a medical practitioner. As yet, science knows relatively little about the day-to-day or week-to-week progression of the disease. Telehealth technology, which combines digital data acquisition and communication technologies to monitor health status on a daily basis, is gaining attention as a promising strategy for acquiring accurate and reliable measures of Parkinson's disease in the comfort of people's own homes.

Dr Stuart Smith, in collaboration with colleagues at the Prince of Wales Medical Research Institute, Griffith University and Southern Cross University, has recently been awarded a seed grant by Parkinson's NSW to evaluate the use of telehealth technology for monitoring motor function in people living with Parkinson's disease. "We are working with a US-based organisation called the Kinetics Foundation who are supporting research into Parkinson's disease", says Dr Smith. The Kinetics Foundation was set up by Dr Andy Grove, ex-CEO of the Intel Corporation who himself has Parkinson's disease. The Foundation is supporting researchers working on technological innovations in Parkinson's research. "Over the next 12 months, the Foundation will supply us with a number of devices for monitoring motor characteristics (hand movement, arm and vocal tremor) of Parkinson's disease that can be used in a person's own home", reports Dr Smith. "With this device we will be able to learn more about the progression of Parkinson's disease and will be able to make an individual's own data available to them via an internet interface."

Dr Smith and his colleagues are particularly interested in recruiting participants for their study from regional and rural NSW. "In Australia we have relatively few people distributed over a large land mass. It may often be very difficult for people living in rural areas to make it into their regional centre to see a Parkinson's specialist who may have flown up from Sydney for the day. With the kind of telehealth technologies we are exploring, we hope to be able to provide clinicians and individuals with Parkinson's disease alike weekly access to characteristics of their disease", says Dr Smith. This research will be the first trial of the technology in an Australian context and will provide important information that can be used to guide subsequent, large-scale implementation of the technology.

"Using the device is really quite straight forward", reports Dr Smith. "All that a person needs to do is follow a series of instructions presented on the screen of a small electronic device that is about the size of a hardback book (See figure1). The test takes about 20 minutes and should be taken once per week over a twelve-month period. Missing a week or two will not matter too much.

If the study participant has the internet at home then they will be able to upload their data onto our central database and be able to view progression of their own data in a password secured website. For those people without the internet at home, we have put in place a postal system to return the data keys to us here at the Institute". Dr Smith plans for the study to begin in June of this year and run for twelve months. "We are really very excited about testing the device. We think that by people with the technology that can monitor their state of health in their own homes, we will empower them to take a more active role in their health management", he concludes.

Dr Smith and his team are currently seeking to recruit anyone diagnosed with Parkinson's disease within the last 5 years, who are living independently in their own home and who are preferably living in rural/regional NSW. A small number of participants will also be recruited from the Sydney metropolitan area. While an internet connection in your home is ideal, the study will not exclude people who do not have access to the internet. If you would like to take part in the study or receive further information please contact Dr Smith.



Hydrotherapy research for Parkinson's Disease!!!

Hydrotherapy on site exercise programmes
in a heated pool (34 degrees)

at the

War Memorial Hospital Waverly

If you have been diagnosed with PD by a
neurologist and can walk, please join us.

**Contact Vikki Sharock or Anouk Furst
Ph.9369 0297**

between 8.30am and 5.00pm Monday to Friday.

How does DBS work?

The apparently miraculous effects of deep brain stimulation (DBS) have been known for about 15 years. Yet there several unanswered questions, one of which is “How does DBS work?” There are a few steps to answering this question.

Parts of the brain are overactive in Parkinson’s disease (PD)

The loss of dopamine producing cells in the substantia nigra is responsible for many of the movement-related symptoms of PD. Dopamine is a chemical that the brain uses to regulate the activity of networks of brain cells, and this is the key to understanding the benefit of medications such as L-DOPA (which helps cells to make dopamine) and dopamine agonists (which act in the same way as dopamine).

The lack of dopamine means that many networks are poorly regulated, and some parts of the network become overactive.

Destruction of overactive areas can improve symptoms of PD

Deliberate destruction of parts of the brain is called lesioning surgery, and includes pallidotomy (targeting the globus pallidus) and thalamotomy (targeting the thalamus). For many decades, neurosurgeons have been using lesioning surgery to try to help people with PD. Lesioning surgery was all but forgotten when effective medication (L-DOPA) was identified in the late 1960s, but made a resurgence 25 years later. By this time, many patients developed medication-related side effects such as dyskinesias, which in some cases were severe enough to undergo pallidotomy. Fortunately, our understanding of brain networks had advanced considerably in this time, as had surgical techniques. Pallidotomy was widely used, and measurements of nerve cell activity in the brain during the procedure helped to improve our understanding of brain activity. Yet several issues limit the benefit that can be attained – it is difficult to treat both sides of the brain without causing severe side effects, and it is not possible to reverse or adjust a lesion once it has been made.

High frequency stimulation mimics lesioning

One of the key parts of lesioning surgery is ‘test stimulation’, where electrical pulses are used to activate (stimulate) the part of the brain that is about to be lesioned. If there are untoward effects of the test stimulation, the probe needs to be moved so that permanent damage is not inflicted in an unintended location. If stimulation produces the desired effects, the lesion is made at that location.

Once a lesion has been made, it cannot be altered. If the lesion is too small, there will be insufficient benefit, but if it is too big there will be permanent side effects. In contrast, stimulation can be adjusted, and can even be turned off.

Advances in technology in the late 1980s and early 1990s meant that cardiac pacemakers could be modified to deliver continuous electrical stimulation via implanted electrodes. Prof Benabid did just that, and in doing so pioneered the field of DBS. More than 50,000 patients have since had the procedure worldwide.

Also, a better understanding of brain networks focussed attention on the subthalamic nucleus (STN). The STN is

only a few millimetres across and was largely neglected by neurologists and neurosurgeons, but it was placed in the centre of a model of movement related brain networks. A few monkeys with experimentally induced PD had STN stimulation, and improved dramatically, so it was only natural to move on to humans.

This leads to the paradox: stimulation mimics the effect of lesioning, as though that part of the brain is ‘turned off’ rather than destroyed. But how can this be? Stimulation of the nerves that leave the brain to control muscles causes muscle contraction, but lesioning those nerves causes muscle weakness. Stimulating the cells more than 100 times a second seems identical to destroying them.

Blocking cell activity will stop the flow of information through those cells, which is a good thing if that activity is the problem. This is exactly what current models of brain networks tell us: that the STN is a key site of increased activity in PD. This abnormal activity is ameliorated by L-DOPA.

How this kind of stimulation could inhibit nerve cells remains poorly understood. The most helpful insight came about a year ago, when it was found that stimulation of the nerves causes an increase in a chemical messenger called adenosine. Adenosine inhibits nearby cells, but does not harm them, suggesting that adenosine may act as a “brake” on the abnormally active cells. This is a preliminary observation, and more work is needed before we can truly understand how DBS ‘disrupts the disruption’.

Stimulation is reversible and adjustable

Unlike a lesion, it is easy to reverse DBS – simply turn it off. This can be unintended, for example if the battery suddenly fails, and can lead to a dramatic worsening of PD symptoms. Furthermore, there are several ways to adjust the effects of stimulation. Firstly, the wire has several stimulation points near its tip, and the pacemaker can be programmed to use any combination of contacts. Secondly, the amount of stimulation can be altered – increased if there is insufficient benefit, or reduced if there are side effects such as dyskinesias. It can take a lot of time to find the best stimulation settings. Finally, if the electrode is not in an ideal position, it is possible to remove it and place another in a different location to try to gain a better effect.

Limitations of DBS

DBS is not a perfect treatment and, although it can be life changing for some people, it is certainly not for everyone. There are risks, particularly in people over 70-75 years. DBS helps mainly movement-related symptoms of PD, and is less effective on other symptoms. DBS can only improve movement similar to a good dose of L-DOPA, and symptoms that do not respond to medication will not respond to DBS. The advantage of DBS is that it works continuously, without the ‘ups and downs’, improving the off periods as well as dyskinesias. The only symptom DBS can be better at treating than medication is tremor. ►

How does DBS work? *continued*

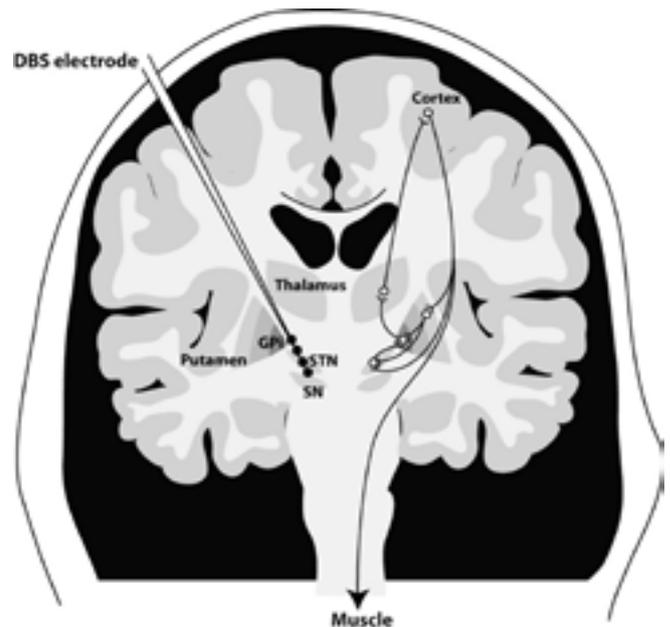
The future

There is still much to be learned about DBS. Clinical trials are currently underway to answer several key questions. When is the best time to have DBS – earlier or later? Which part of the brain is best – globus pallidus versus STN? Can DBS targeting other areas help balance? Does DBS slow the progression of PD?

Watch this space ...

Dr Neil Mahant
Specialist Services
Suite 3, Westmead Private Hospital
9687 0900

Dr Mahant is a member of the Scientific Advisory Board of Parkinson NSW.



Counselling Corner

by Deborah England

Like everyone else I watched the horror of the Victorian bushfires unfold, and when I witnessed the pain, shock and anguish on all those faces, like folk everywhere I felt powerless. We witness much that is confronting through the media. We watch wars, famines, floods, sieges, the list is endless, and they have an effect. We are all by various degrees subject to vicarious trauma. Life sometimes seems incredibly hard and cruel. Individual circumstance can also allow us to feel this way when things don't work out for us the way we think they should. I was then very moved and proud by the way Australia mobilised in response to what was happening and the relief effort that flooded into the affected areas. So that even amongst all that suffering there was evidence of the triumph of the human spirit and the value that we place on each other. The events surrounding that triumph were dreadful but the coming together of a nation with love and support was rather beautiful. It reminded me of a gift with terrible wrapping.

I was also struck again by the concept that all we have is now. This is it! The life that is ours is the one we are living today. The more we try to hang on to what we think life should deliver us or to the life to which we feel we are entitled, the less time and energy we have to live the life we have.

One of the greatest challenges of our lives is to integrate the pieces of our lives as we live them. Living in the present means noticing. Noticing when we are tired, noticing when we are happy, and noticing the beauty and the people and relationships around us. These are the moments to be framed and used on not so good days. So live this day with awareness. Live in the moment with consciousness, compassion for yourself and others. Our lives are so precious and so too are we. When faced with adversity it can be really difficult not to put all our focus on the 'wrapping', but we need to try to also find the 'gift'.

Unity Walk 2009

We are growing and we want you to be a part of it.

On the back of the great success we had in 2008, this year's Unity Walk will be held in Australia's two largest cities on the same day – Sunday 30 August 2009.

Sydney's event will once again be held at Sydney Olympic Park but the Walk itself will take a whole new route, taking in some of the most wonderful sights surrounding SOP. It will include the 'Ring Walk' around the famous Brick Pit, across Wentworth Common and along Haslam's Reach. Melbourne's inaugural Unity Walk will start in Federation Square, in the heart of Melbourne's CBD, and run along the banks of the Yarra River in both directions.

The success of our first Unity Walk was very much due to the wonderful support we received from the Parkinson's community; our members and Support Groups. We need that support to continue because you are the rock on which this event will grow and grow to become what we hope will be one of the most significant charity events each year in this country.

The name Unity Walk was well chosen by our American colleagues some fifteen years ago. From humble beginnings the event has grown to the extent that over 11,000 attended last year in New York's Central Park and \$A2.5m was raised. Wouldn't it be wonderful if we could reach those dizzy heights in this country?

The Unity Walk is all about community; coming together in support of a common cause. A union of hearts and minds all supporting Parkinson's and a search for a cure. So please, everyone, put the date in your diaries and start spreading the word and organising your groups. We have assessed last year's event and come up with amendments and innovations that will make registration less challenging. We have done this with the assistance of the Everyday Hero website authors so that every dollar you raise will be there for the whole world to see. See you on August 30 at Sydney Olympic Park and to make things even easier we once again have secured free metropolitan bus and rail travel to and from the Park, thanks to the Minister for Transport's office.

On the groupvine *by Trish Morgan*

Cruising is the big word in travel! Some of our members are getting away to all kinds of places.

Brigitte and Ian Squires from **Illawarra North** support group reported flying to UK to join the Queen Elizabeth 2 in November on her final voyage from Southampton to Dubai, where she was to become a hotel convention centre. Her service history covered 40 years, including acting as a hospital ship during the Falklands War and more than 5 million nautical miles travelled. The Squires had had several trips on her previously and didn't want to miss the final journey.

Margaret and Robert Huckle from **Manly/Mosman** support group left on 26th February on the Queen Mary 2 from Garden Island, Sydney, as the ship was too big to tie up elsewhere in the harbour. Their trip was via Yokohama, Hong Kong and Bangkok to Singapore. The second part of the holiday was by train to Kuala Lumpur and by ferry from Butterworth to Penang. The last week will see them travel by coach overnight to Singapore then fly home to Sydney by 24th March.

Carer Respite! Barbara Malone from **Maroubra** support group is leaving on 1st May for a tour of Holland, Italy, Greece and UK with her good friend from days in the Girl Guides. Her friend came to Australia as a 4 year old and is going to have a family reunion with her elderly aunts and to research the family history. Barbara is taking this opportunity while her husband, Jim, is managing most of his own care. Jim acted as travel agent and booked everything on the internet.

Barbara will be in phone contact and her son James will take over her caring role.

Successful launch of Quirindi Support Group

Seventeen people attended a public meeting in the Quirindi CWA rooms on Monday 19th January 2009. Thank you to the **Tamworth** Support Group members who travelled in the heat to welcome people.

Mayor Cr Ian Lobsey opened the meeting, Cr Colleen Wills, Marie Blundell and Leah Weatherington from the CWA supported the group by providing the use of the rooms and afternoon tea which was most appreciated by those in attendance.

Federal Member Tony Windsor also attended and provided advice on how Parkinsons' groups could access funding to support their activities and offered to forward on any material PNSW could provide to Federal members of parliament.

Quirindi group has held its first meeting in February and enjoyed watching DVDs from the Blue Kit which is available from PNSW for people newly diagnosed. Ring 1800 644 189 for a kit.

Les Howard will lead the group and he has the support of the community and local paper, *The Quirindi Advocate*.

New Group at Bega!

Bega saw the first of the "Living Life with Parkinson's" seminars on Friday 6th February. (photo) Over 50 people attended from ACT, Cooma, Central Tilba, Narooma, Tathra, Cobargo and all places from there to Bega. Half were members of PNSW. At least 20 planned to attend the first meeting of the 'Bega Valley Bunch' on Monday 2nd of March. The seminar was a great success. The new group are calling themselves the '**Bega Valley Bunch**'.



Volunteers sought for Parkinson's NSW Speakers Program

One of the problems with Parkinson's is that the general public doesn't really understand the disease and the impact that it has on the people with Parkinson's and their families.

For some time Parkinson's NSW has been attempting to rectify this lack of public awareness by having people go to local service clubs, such as Rotary, Lions and Apex along with other community organisations to spread the message about Parkinson's and the impact it has on the sufferer and their family.

Unfortunately the number of speakers has dwindled and Parkinson's NSW, in conjunction with Doug Malouf (a renowned public speaker, trainer and person with Parkinson's) have updated our support material. They are offering a revitalised speaking programme with the joint aims of significantly improving public awareness of Parkinson's disease and raising funds for providing services to people with Parkinson's and to undertake research into Parkinson's.

We would love to encourage people living with Parkinson's, their partners, families and carers across NSW to volunteer for the Speakers Program.

Equipment, such as a portable audio system and PC based support material, is available to assist you with your speaking engagements and training can be arranged to help you use the equipment. Training in public speaking and how best to get your message across can also be arranged.

If transport is a problem we hope we can help.

Please call Lyn, Claerwen or Sue on our InfoLine, free call, 1800 644 189 to register or if you would like to chat about this program. We are waiting for your phone call!

Parkinson's NSW needs your help.

Mates Race – 28 days around Australia



What is so special about that? You have to do it with no money, no car, no food – you rely on the generosity and hospitality of fellow Australians – all while raising money for charities.

Christian Reynolds and Max Rosenthal participated in this amazing and challenging event, with Parkinsons NSW as their charity of choice.

The guys left Sydney on Boxing Day 2008 and hitchhiked, begged bus rides, managing to get all around the country. On the way, they were stuck in 45 degree heat in north west WA on the side of the road for over 48 hours, got caught in floods in North Queensland and washed out in their tent in Tamworth.

Part of the challenge was to participate in charity events on the way – encouraging people to donate blood in Adelaide, “zincing up” beachgoers at Cottesloe Beach in Perth, working in a soup kitchen in Brisbane – all part of the journey.

They arrived home on the 28th day – happy to have a shower and a sleep in their own beds, check it out at www.matesrace.com



A Dream Ticket Offer

Saturday 16 May 8pm

Here is a very special opportunity for our Support Groups, members and readers of SBM to see our Fundraiser in his other life. Marty Rhone is presenting his hit show ‘Cliff & the Shadows & the Big O’ at the magnificent State Theatre on May 16.

He has spoken with the folks at the State Theatre and Ticketmaster and they have come up with the following exclusive offer for Parkinson’s.

VIP Premium – \$67 (Save \$12/ticket)
Groups 8+ \$65 (Save \$14/ticket)

A Reserve – \$57 (Save \$12/ticket)
Groups 8 +\$55 (Save \$14/ticket)

B Reserve – \$49 (Save 10/ticket)
Groups 8 +\$47 (Save \$12/ticket)

To book call 13 6100 or visit any Ticketmaster outlet and don’t forget to quote ‘Parkies’ to be eligible for your discount

Living life with Parkinson’s Seminars – teleconference dates

SEMINARS					
MARCH		MAY		JUNE	
Mittagong	Tue 3rd, Fri 6th	Taree	Mon 11th	Parkes	Sat 13
Auburn	Thu 12th, Tue 17th				
Armidale	Wed 18th				
Northern Beaches	Fri 27th, Tue 31st				

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

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

MEDIA RELEASE

New strength Stalevo 200/50/200 mg for Parkinson's Disease patients now listed on the PBS

From 1st December 2008, a new strength of Stalevo 200/50/200 mg (levodopa 200 mg / carbidopa 50 mg / entacapone 200 mg) is available on the Pharmaceutical Benefits Scheme (PBS) providing physicians with more dosing options and flexibility for their patients with Parkinson's disease (PD) who experience end-of-dose motor fluctuations.

A recent Australian study published in the Journal of Clinical Neuroscience suggests that end-of-dose motor fluctuations often go unrecognised

The study found more than one in two apparently stable PD patients may in fact, be experiencing end-of-dose motor fluctuations. The wearing-off patient questionnaire helped identify motor fluctuations in up to 57% of patients assessed. Furthermore, over 77% of investigators assessed the wearing-off patient questionnaire as either very useful or quite useful for detecting motor fluctuations.

Neurologist, Dr Andrew Evans from the Royal Melbourne Hospital, said this study reiterates the importance of careful monitoring for 'wearing off' symptoms, and believes the availability of the new strength of Stalevo 200/50/200 mg dose provides patients and healthcare professionals with an effective treatment regimen that can be adjusted to suit each patient's requirements as their disease progresses.

"Stalevo can improve overall patient care in improved motor symptom control, activities of daily living and quality of life. Stalevo is now available in four doses, providing both patients and healthcare professionals with a smooth transition of treatment through all PD stages," Dr Evans said.

Stalevo is an optimised levodopa therapy that significantly improves PD patients' ability to control body movements and the ability to perform basic functions, such as walking and dressing, compared with standard levodopa.

Stalevo 200/50/200 mg will be available for patients with Parkinson's disease requiring higher doses of levodopa. This higher dose of Stalevo® may be prescribed for patients with Parkinson's:

- as a replacement therapy for current standard levodopa-decarboxylase inhibitor combinations (Sinemet® and Madopar®) when they experience fluctuations in motor function due to end-of-dose wearing-off.
- in place of standard levodopa and entacapone (Comtan®), thus reducing the pill burden for patients.

Stalevo targets end-of-dose 'wearing-off' experienced by patients by combining levodopa / carbidopa, with entacapone. While carbidopa reduces the side effects of levodopa, entacapone extends the delivery of levodopa, allowing significantly more levodopa to reach the brain, helping patients have better symptom control for longer.

The optimal daily dosage of Stalevo must be individually determined. Stalevo tablets are available in four strengths, each in 4:1 ratio of levodopa to carbidopa and combined with 200 mg of entacapone in a standard release formulation; Stalevo 50/12.5/200 mg, Stalevo 100/25/200 mg, Stalevo 150/37.5/200 mg and now Stalevo 200/50/200 mg.

For further information about the Stalevo range, call 1800 671 203 or visit www.novartis.com.au.

Parkinson's, Employment and Quality of Life

If you have been diagnosed with Parkinson's and are still working, researcher Louise Cooper 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>.

Louise Cooper, DPsych Researcher, Swinburne University of Technology

NB: The Access Economics' report, *Living with Parkinson's Disease: Challenges and Positive Steps for the Future*, commissioned by Parkinson's Australia and published in 2007, was viewed as pivotal in the move to address issues related to Parkinson's in the work place. This current study, which emphasises the psycho-social aspects of employment for people with Parkinson's, is further indication that the time has come to see Parkinson's as a question of quality of life rather than a set of medical symptoms, and to urge governments and policy makers to fund appropriate action.

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 December and 26 February 2009

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

John Anderson
Jim Bell
Allan Bible
Alan Campbell
Jim Chamberlain
Brian Christie
Peter Cole
Thomas Connolly
Noeleen Cox
Alda Di Leva
Rose Gaudry
Giuseppe Giuffrida
Matteo Giurini
Owen Glendenning
Max Heather
Donald Holmes
Hope Hood
Dusan Ivanson
Edna Jeans
Laurence Jenkinson
Rhonda Joblings

Shirley Lewis
Cecil Moore
Con Mulders
Rudolf Prokoph
Humberto Puglia
Win Richards
W A Ridgeway
Harry Smyck
Neville Stapleton
William Thompson
Jock Turner
Douglas Whitehouse
Robert Young

DONATIONS WERE RECEIVED IN CELEBRATION OF:

The Whitton
Family Christmas
The birthday of
Lydia Eisenberg
50th Wedding Anniversary of
Mr & Mrs David Samer

Bequests

Please consider leaving a bequest to Parkinson's NSW in your will. It is the ultimate gift you can make; to leave a lasting legacy in perpetuity and assist those with Parkinson's.

Alternatively, a living legacy will mean that you can personally experience the benefit your generous gift provides.

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

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
Bega Valley	Sue Nelson	02 6475 9932
Bingara	Joan Bush	02 6724 1976
Blacktown	Bryan McAlister	02 9674 6827
Blue Mountains	Hazel Tolhurst	02 4751 9903
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
Cowra	Ray Heilman	02 6341 3692
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta		02 9876 4284
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla	Ian Parr	02 4472 2037
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Finley	Murry Druitt	03 5881 1315
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
Quirindi	Les Howard	02 6747 1459
Shoalhaven/Nowra	Jonathan Morgan	02 4446 0514
Shoalhaven/Ulladulla	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	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
Young Men's Network	Garry Cearns	02 9871 1853

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Welcome to
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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).

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 4/16 Laurie Street, LAURIE TON. NSW 2443
 Phone: (02) 6559 5911 or Freecall 1300 780 750 Fax No: (02) 6559 5922
 1/62 Manning St, Tuncurry. NSW 2428
 Phone: (02) 6555 2322 or 1300 780 750 Fax No: (02) 6555 2344
 Mobile: 0424 199 750 – Gary Clarke
 Email: koalatcare@tsn.cc Web: www.koalat.com.au

Diary Dates

MARCH 2009

- 12 & 17 Living Life with Parkinson's Seminar – Auburn
- 18 Living Life with Parkinson's Seminar – Armidale
- 25 Young Women's Group with Janine Rod – North Ryde
- 27 & 31 Living Life with Parkinson's Seminar – Northern Beaches

APRIL 2009

- 11 World Parkinson's Day

MAY 2009

- 11 Living Life with Parkinson's Seminar – Taree
- 31 Speeding Vibrations lunch

JUNE 2009

- 13 Living Life with Parkinson's Seminar – Parkes
- 16 Coffee/Information morning – North Ryde office

AUGUST 2009

- 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

SEPTEMBER 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

DECEMBER 2009

- 5 Parkinson's Christmas Party – venue TBA

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**