



PARKINSON'S NEW SOUTH WALES INC. NEWSLETTER – Issue 103, Winter 2008

*Ease the Burden and Find a Cure*

# Stand By Me

## Come and join us for Australia's 1st Unity Walk



**Join Australia's  
1st Unity Walk  
for Parkinson's**

Sunday August 31st, 2008  
Sydney Olympic Park

On Sunday 31st August, we invite everyone, including NRL club supporters, people with Parkinson's and their families and friends to wear their League team colours with pride and join with former playing greats and celebrities as we take the "Olympic Walk" around all the magnificent sporting stadiums at Sydney Olympic Park that made our Olympics **'the best ever'**.

The Parkinson's Unity Walk has the potential to become our biggest yearly fundraiser and we especially invite people with Parkinson's, their families and carers to join us to help raise funds for Parkinson's research and to help those with Parkinson's. This is a chance for all of us in the Parkinson's fraternity to unify in the common goal of finding a cure for Parkinson's disease. For every dollar raised 50% will go towards research. The other 50% will fund support services for people with Parkinson's, their families and carers.

The Parkinson's Unity Walk started 15 years ago in New York's Central Park and this year more than 15,000 participated. This is Australia's inaugural Unity Walk and your chance to be a part of history as we join with NRL team fans in also celebrating the Centenary of Rugby League. This will be a great family fun day and there will be food stalls and amusements for the children.

To find out more or to register visit [www.unitywalk.com.au](http://www.unitywalk.com.au) or [www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au) and click on Australia's First Unity Walk for Parkinson's. You can then create your own sponsorship page for your family and friends to support your walk. If you would like to register a team you can do that on the website also.

You can also register or donate by completing your details on a registration form which is available from Parkinson's NSW in North Ryde. For more information email [unitywalk@parkinsonsnsw.org.au](mailto:unitywalk@parkinsonsnsw.org.au) or phone 1300 889 751.

***Be a part of Australia's 1st Unity Walk for Parkinson's.***

# In order to maximise our fundraising income, it has been decided that only t-shirts will be issued to participants in the Unity Walk.

## NEWS FLASH

Peter McWilliam & Verlie Sullivan, members of PNSW, have both received awards in the Queen's Birthday Honours List.



## President's Report

As I put pen to paper, uppermost in my thoughts is the Grand Old Man of Parkinson's NSW, Allen Cropp – immediate past Vice President who recently passed away. There is much to say about him but for

me, two memories are outstanding: Allen's passionate championing of the needs of PWP and Allen's insistence that with Education, Understanding, Support and Optimism a PWP could both cope with the challenges of Parkinson's and continue to live a full life.

His cheerful assertion "I'm all right" even at the worst periods of his illness typified his "never let it get you down" approach to life.

God saw that he was weary and did what he thought best. He put his arms around him and whispered "come and rest".

I think it is timely to devote this column to a discussion of PNSW's involvement with Parkinson's Australia and the medium to long term advantages for our support of PA. At this year's AGM I announced a rise in annual fees for PNSW. A major contributor for this increase was our contribution to the Secretariat in Canberra, which has risen to approximately \$20 per member.

PNSW has historically supported the idea of a strong national organization representing PWP throughout Australia. It is a fact that large scale fund raising for specialized projects needs a national approach, as does funding from the Federal Government for large scale projects and research. Additionally, and of critical importance, is a Federal approach to obtaining recognition and funding for the special needs of Parkinson's sufferers.

In 2005 the decision was taken by PA to employ a fulltime CEO in Canberra to take advantage of the momentum to be gained by the Access Economic Report. Norman Marshall has been in this role for nearly a year and in this short time has established himself as the face and voice of Parkinson's in Canberra. He is proving to be an effective lobbyist and we hold high hopes for the future. To date, he has succeeded in:

- Gaining access to the relevant Ministers and their advisors at both State and Federal levels
- Obtaining funding for the printing of brochures for GP's
- Obtaining top up funding of \$90,000 for a Rural and Remote training program for doctors to help diagnose and treat PD
- Organizing the Parkinson's Day in Martin Place
- Obtaining funding from Beyond Blue, with the help of PVIC, in all states to help deal with depression
- Assisting PSouth Australia in obtaining funding for two Parkinson's Nurses

There is real benefit to be seen in the cooperation amongst states in various projects; an example of which is the Rural and Regional online Teaching course to help the Doctors in the field recognize and treat PD. The project is funded by a grant from a Victorian

based Charitable Trust and the Federal Department of Health. The working committee, headed by Dr. Victor Fung, is made up of Neurologists from NSW & QLD, and representatives from The College of Rural and Remote Doctors, and the Australian College of General Practitioners. The course is being developed by the University of Queensland's Medi-Serve organization and will be run on their Computers

All this is being managed by PNSW on behalf of PA.

This is a blue print for the future – the state organizations working together to achieve a strong PA. Unfortunately this doesn't come for free. So whilst we've had to increase our annual fees, it will benefit all of us in the long run.

John Silk



*The President of the Rotary Club of Burwood, Peter Moore (left) presented a cheque to John Silk, President PNSW, for \$6000.*

## Diary Dates

### JUNE

14 Facing the Future with PD – Port Macquarie

### AUGUST

31 Parkinson's Unity Walk

### SEPTEMBER

1 - 8 Parkinson's Awareness Week  
2 Information & Coffee Morning Tea  
3 Parliament House Seminar (A Team Approach)

### OCTOBER

16 & 17 National Parkinson's Conference  
"Reaching for Our Goals"

### NOVEMBER

13 Putting in for Parkinson's Golf Day  
25 Information & Coffee Morning Tea

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



## CEO's Report

On 11 April 2008 we celebrated World Parkinson's Day with a breakfast in Martin Place.

I express our appreciation to the volunteers (including many living with Parkinson's), who were there from 7.00am making breakfasts for the

public, and handing out free tulips, bulbs and other awareness material.

We also attracted the attention of commuters by providing entertainment, including music and dancing. The performers included three grandchildren of our late Vice President, Allen Cropp, who are continuing to support Parkinson's NSW in memory of Allen. Allen was absolutely committed to being active and to being involved in community life and helping others, regardless of his Parkinson's. It is wonderful to see that he has passed that commitment on to his grandchildren. We will miss him.

One of our ongoing projects on the political advocacy front has been to advocate for the release and PBS subsidy of a wider variety of Parkinson's drugs and devices, to give medical practitioners a greater choice in selecting the right affordable treatments for each of their patients. We have, for example, been concerned that even where an appropriate drug is available, the devices to administer it may not be subsidised. Our recent

work has included writing and speaking to members of parliament, seeking added support.

On 16th and 17th October 2008 we will be hosting the first Parkinson's National Conference held in New South Wales for several years. We are pleased that we have been able to attract top speakers from around Australia and internationally, all keen to share with our members and guests their knowledge as to the latest developments and ideas. Details are included in an insert in this edition of Stand by Me, and I would encourage everyone to book early, as places are limited.

I look forward to catching up with many of you at the conference, if not before.

Yours in Parkinson's friendship

Miriam Dixon  
CEO

*Hiroe Cropp and family would like to thank all members for their kind expressions of sympathy and their generous support.*



## Walk to Fly

Thanks to Hawaiian Airlines we are offering the individual who raises the most sponsorship money for the Unity Walk a holiday of a lifetime in Hawaii.

Hawaiian Airlines have been serving the Hawaiian Islands for over 75 years. Flights depart Sydney to Hawaii and connect from Honolulu to ten west coast US cities with no charge for stopovers in Hawaii. Genuine island hospitality, complimentary meals, beverages and entertainment are just a part of Hawaiian Airlines award winning service. Visit [HawaiianAirlines.com.au](http://HawaiianAirlines.com.au) or phone 1300 669 106 for more information.



## Join Australia's 1st Unity Walk For Parkinson's

The biggest event in our history!

Sunday 31st August 2008 – Sydney Olympic Park

HELP US TO RAISE MUCH NEEDED FUNDS  
FOR RESEARCH AND SUPPORT SERVICES  
FOR PEOPLE WITH PARKINSON'S

Bring your family and friends and be a part of the fun  
REGISTER TO WALK NOW!

[www.unitywalk.com.au](http://www.unitywalk.com.au)  
or phone 1300 889 751 for more information

## TAMWORTH PARKINSON'S PUSH SUCCESS

## Ben proves the power of one



## Ben Cross' story is one of determination.

A 68-year-old Tamworth resident in the advanced stages of a battle with Parkinson's Disease, Mr Cross is responsible for starting a chain of events which will help develop greater research into the degenerative neurological condition that afflicts him and tens of thousands of other Australians.

Diagnosed with Parkinson's in 1992, Mr Cross had no severe symptoms of the disease at the time.

*"I was at a pain centre in Royal North Shore Hospital when I was asked to stand on a balance ball/board,"* he said.

*"When I did I experienced a tremor in my right arm. A few months later I was diagnosed with Parkinson's Disease."*

Just over a decade later Mr Cross was inspired by the story of a fellow Parkinson's Disease sufferer, His Holiness Pope John Paul II.

He decided to establish a worldwide appeal in the Pope's honour which would raise money to support research into Parkinson's Disease.

It was Mr Cross' initial vision that the appeal would involve every member of the Catholic church in the World making a small donation to the same appeal, with all proceeds going to Parkinson's research.

Mr Cross began his appeal in November 2006 by sending a letter to the Vatican addressed to His Holiness Pope Benedict XVI. A short time later he received a reply from his local diocese in Armidale which directed him to the local Catholic priest.

In March 2007 Mr Cross wrote to the Michael J Fox Foundation in New York seeking support for his appeal.

Mr Cross, who is not a Catholic, also decided to send a letter via Parkinson's NSW Chief Executive Officer, Miriam Dixon, to the Catholic Archbishop of Sydney, Cardinal George Pell.

*"I began the letter by saying that if the oldest oak tree in England had grown from one seed then all I needed to do was plant the seed and see what the idea might grow to become,"* Mr Cross said.

Cardinal Pell believed Mr Cross's mission was a worthy one and, rather than seeking donations, he has contacted the Australian Campus of Notre Dame University.

A new postgraduate certificate in neurodegenerative disorders will now be established as a tribute to Pope John Paul II's memory.

Mr Cross said without the support of Kerry McMahon – the independent Member for Tamworth, Peter Draper's, electorate officer – Mr Draper himself and Parkinson's NSW he wouldn't have felt inspired to continue to push for the donation drive which, in turn, would not have led to the development of the Notre Dame postgraduate certificate course.

*"I am very pleased with the way things have turned out,"* Mr Cross said.

Chief Executive Officer of Parkinson's NSW, Miriam Dixon, said her organisation had been thrilled by what Mr Cross had achieved. *"The postgraduate course through Notre Dame will be the first of its kind in Australia, and will help to train specialists in the complexities of neurodegenerative disorders, including Parkinson's Disease,"* she said.

*"This will provide nurses with a key role in patient care and may also help people who suffer these diseases, particularly Parkinson's, to stay in their own home for longer."*

The postgraduate certificate in neurodegenerative diseases will become available through Notre Dame's Sydney campus as an external course beginning in 2009.

Studies shows between one and two people out of 1000 experience Parkinson's Disease. There is no known cure.

To coincide with World Parkinson's Day last Friday, Parkinson's NSW has made available a number of kits for newly diagnosed sufferers.

They are available by phoning 1800 644 189.

*By Jacqueline van Aanholt*

*The Northern Daily Leader – Tuesday, April 15, 2008*

## Guidelines for Nursing Practice in Caring for People with Parkinson's Disease –

### REVISED EDITION

The purpose of this publication is to provide a user friendly reference for nurses caring for people with Parkinson's Disease (PD).

It is the aim of this publication to assist nurses in bridging any theory and experience gap, and to guide them in understanding and anticipating the care needs of the patient or resident who has PD.

The Research Sub-Committee of Parkinson's Western Australia (PWA) has initiated the guidebook. The editors are Parkinson's Nurse Specialists with many years of experience in managing PD. The information and advice contained herein is based on the knowledge current at the time of publication, and references are included for those who wish to pursue more detailed information.

*Doherty, J (RN Cert. Gerontology B.N. M Nurse) (2007), Guidelines for Nursing Practice in Caring for People with Parkinson's Disease. Available from Parkinson's WA - \$110 + postage www.parkinsonswa.org.au*

## Internet Teleconferencing now a reality for Parkinson's People

Recently we had an article about the Young Men's Parkinson's Network wanting volunteers to help test an internet teleconference facility. Well, we can report that with the help of 7 volunteers we were able to hold a teleconference with 5 guys which lasted 1.5 hours for a cost of 50 cents in telephone charges. This first test used the internet to connect to all the participants by calling their home phones. The location of the guys covered a large geographical area from Sydney, Newcastle, Central Coast and the Far North Coast.

After the success of the home phone conference we all agreed to try the next phase of conferencing using the Internet and Instant Messenger installed on each computer. The advantage of this method is that more people can participate, video of the meeting can be seen by everyone and it costs nothing for the service. The Instant Messenger software has now been installed on each volunteer's computer and by the time you read this, testing should have been completed and ready to go live at the June YMPN meeting where we are having a special guest speaker.

There are many YMPN people living with PD in the community that can't get to meetings because of geographic location, they are house bound or living in nursing homes.

The best example as to the impact of the conference facility was feedback from the people who benefit from these ideas. Here is a recently received email:

*Hi Garry*

*I am Dick's wife, Lucy, and just emailing a reply on his behalf. He would love to be involved in the teleconferencing facility! What a great idea. If you haven't had any other takers yet, we can be the trial version. I am a bit tech savvy so shouldn't have any probs setting it up with some good guidance – famous last words perhaps!*

*I think it is fantastic that you have set this up – Dick was very happy to talk to someone at long last who could relate.*

*I would be happy to do anything I can to help – I work 4 days a week but am happy to help with the computer side of things if you need – I am handy with databases, word, excel, email distribution lists and happy to learn anything. If I can help please let me know.*

*Thanks again and keep up the good work*

*Lucy (his better half, of course!)*

Using the Access Economics Report, the estimates would be that there are around 2,600 men in NSW living with PD who were diagnosed under the age of 60. The hope is to help as many of these people as possible by opening up avenues of communication and building camaraderie to make life better in some small way.

If you would like to be a part of the teleconference meeting, just contact PNSW and we'll send you all the manuals and give you all the help you need to participate. The process is simple, you don't have to be a computer expert. Should any other support groups be interested in this facility it can be made available to them.

## On the groupvine by Trish Morgan

### Country groups are coming together!

Goulburn support group hosted an Awareness Seminar on Thursday 10th April. This was fully sponsored with donations from The Mulwaree Trust, Goulburn Rotary and a bingo night organised by June Lang, a volunteer fundraiser for charities in Goulburn. The speakers were Dr Tuck, Neurologist from Canberra, Dr Kay Double, Parkinsons Research Scientist, Laraine McAnally, Specialist Parkinsons Nurse, and Deborah England, Counsellor Parkinsons NSW. The seminar was chaired by Barry Mitchell, leader of the Shoalhaven support group. Norman Marshall, CEO Parkinson's Australia, presented certificates to the sponsors and Goulburn Workers Club, the venue for the seminar. Members from Goulburn, Illawarra North and South, St George/Sutherland, Shoalhaven and Yass support groups attended this quality seminar.

Narrabri support group hosted the "Facing the Future" seminar on 13th May. 60 members from four support groups were there – Narrabri, Gunnedah, Bingara and Tamworth. The local "Courier" gave half a page spread with photos of the groups. They were treated to a first class seminar with speakers – Lisa Hagle, pharmacist and leader of the Gunnedah group, Deborah England, PNSW counsellor, Anne Marie Brewster, physiotherapist from Moree and Lauri Moss, solicitor from Narrabri. Three of the support groups had met for lunch in Gunnedah the week before, so they were already forming friendships. Tamworth and Gunnedah plan a similar gathering in Bingara.

Several couples are meeting in Wellington and Yamba for social support and coffee. Hopefully their numbers will grow and they will join the support group network.

## Stephanie's 50th Birthday Party Celebration

Stephanie put on a special party for her 50th birthday earlier this year.

Her mum, Mary, has PD and Stephanie decided to ask everyone to make a donation, in lieu of gifts, to Parkinson's NSW. Everyone made generous individual donations with a total of \$1790, being sent to PNSW along with photos of the happy day.

The Council and Staff at PNSW would like to express their appreciation to Stephanie Kavallaris and her family for their generous donation.

## Thank You

A Very Big Thank You to Mrs Meryl Lees for donating a lovely tulip quilt, in memory of her late husband, Mr Bob Lees. It is hanging in our North Ryde office.

She also presented a cheque from the proceeds of the sale of several other quilts that she and her daughter had made.

Your time and efforts are truly enjoyed by all who visit the Parkinson's NSW office. *Thank you.*

## Dopamine cell death in Parkinson's Disease:

### WHY DO SPECIFIC CELLS IN THE SUBSTANTIA NIGRA DIE FIRST?

Chief investigators: Dr Kay Double (Prince of Wales Medical Research Institute), Dr Phillip Dickson and Professor Peter Dunkley (University of Newcastle); Research Staff: Ms Stefanie Reyes

#### Background

The symptoms of Parkinson's Disease develop as a result of the relatively selective death of dopamine-producing cells in an area of the brain called the substantia nigra. (Figure A). In the human brain the substantia nigra is more complex in structure than in other species in that it is made up of four different groups of dopamine-producing cells. These four cell groups are called the dorsal, ventral, lateral and medial tiers (Figure B). In PD the ventral and lateral tiers of cells suffer extensive cell loss in the early stages of the disease, while the dorsal and medial tiers are relatively preserved. Currently it is unknown why specific dopamine cells within the substantia nigra appear to be more vulnerable to the disease process, but we believe that this may be related to the way these cells make dopamine.

Tyrosine hydroxylase (TH) is an enzyme involved in the production of dopamine. Humans have 4 different types of TH: TH1, TH2, TH3 and TH 4. Each type of TH regulates the production of dopamine via different biochemical events, but the consequences of this for the cell are unknown. We are investigating the hypothesis that specific biochemical events will result in increased production of dopamine, and therefore increased production of dopamine metabolites and other substances associated with cell damage in Parkinson's Disease.

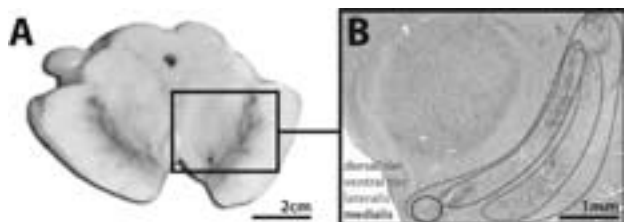


Figure legend:

- A Section through the human midbrain. The dark coloured substantia nigra is outlined in black.
- B An enlarged image of the substantia nigra indicating the four tiers of cells.

### Young Men's Parkinson's Network

Are you under 60? Living with Pd?

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

Your partners are welcome to come and enjoy a coffee  
with other partners while the Men's Network meets

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

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

#### Our research:

In this research project, we are mapping the distribution of the different types of TH in each of the four tiers of the substantia nigra to investigate whether particular forms of TH are associated with cell death in Parkinson's Disease. We are using biochemistry techniques to determine the different amounts of the four types of TH present, and will also study the way in which each of the TH subtypes are controlled, and the consequences of this on the amount of dopamine produced.

We hope this research will shed light on why particular dopamine-producing cells are more vulnerable in Parkinson's Disease, and may lead to the development of new treatments or preventative approaches based on this knowledge. This project is partially supported by the National Health and Medical Research Council (NHMRC) of Australia, and we are grateful for this Research Grant from Parkinson's NSW to support Ms Stefanie Reyes, a key researcher on this project, as Ms Reyes' position was not funded by the NHMRC.



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

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

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

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

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

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

So if you require any mobility or rehabilitation equipment please call Koala T Care for a no obligation free quote.

**"EVERYDAY LIVING MADE EASIER"**

#### Contact details for Koala T Care

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

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

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

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

Web: www.koalat.com.au

## Results of MitoQ Trial for Parkinson's Disease

By Dr Victor Fung, Westmead Hospital

The results of the PROTECT trial, which studied whether MitoQ (mitoquinone) slows the progression of motor disability in Parkinson's Disease, were recently reported in April 2008 at the American Academy of Neurology Meeting in Chicago by the Principal Investigator A/Prof. Barry Snow, from Auckland, New Zealand. Unfortunately, the study *failed* to show that MitoQ slows the progression of Parkinson's Disease.

PROTECT involved 120 people with Parkinson's Disease, a third of whom were given placebo, a third 40mg daily of MitoQ, and a third 80mg daily of MitoQ. The participants were then followed every 3 months for a year, with clinical assessments of their Parkinson's Disease each visit. At the end of a year's treatment, there was no difference in the change in symptoms between placebo and either dose of MitoQ.

The cause(s) of Parkinson's Disease remains unknown. There are many scientific observations that give clues about what damages brain cells in Parkinson's Disease. One observation is that brain cells in Parkinson's Disease are subject to a process called oxidative stress. Due to oxidative stress from the breakdown of toxins or waste products, cells produce free oxygen (instead of oxygen attached to other molecules, which is what happens during breathing), which then damages those cells. This has led many people to believe that drugs that protect cells from oxidative stress (antioxidants) might slow the progression of Parkinson's Disease. One commonly available over-the-counter antioxidant is co-enzyme Q10. A preliminary United States study of co-enzyme Q10 in 2002 suggested that treatment might slow the progression of Parkinson's Disease, but for many reasons the results were inconclusive.

One of the potential problems with co-enzyme Q10 is that very little of the drug enters into the mitochondria within cells. Mitochondria are energy producing structures within cells which also deal with oxidative stress. MitoQ is a synthetic form of co-enzyme Q10 that reaches much higher concentrations within mitochondria. Therefore it was hoped that MitoQ would show a much greater benefit in slowing disease progression, as it would be more effective at reducing the effects of oxidative stress.

Why then did this study fail? The most likely explanation for the failure for the PROTECT study is that antioxidants are not effective in slowing the progression of Parkinson's Disease, at least not when they are started at a stage when symptoms have already developed. There was good evidence from pre-clinical studies that MitoQ is an effective antioxidant, and that it gets to where it is needed, within the mitochondria. To the credit of the 120 people with Parkinson's Disease who participated and the researchers, the PROTECT study was carried out with the highest level of rigour and efficiency. We are confident that sufficient doses of MitoQ were used, because dose-limiting nausea, a side effect of both MitoQ and co-enzyme Q10, occurred in a significant proportion of participants treated with the higher dose (nausea, vomiting and diarrhoea were the only significant side effects in the study).

So far, three antioxidants have been studied as treatment for Parkinson's Disease: vitamin E, co-enzyme Q10 and MitoQ. Studies with vitamin E have also been negative (although some have argued that too low doses have

been used). Based on the results of the preliminary co-enzyme Q10 study, a much larger study is currently under way in the USA but the results will not be available for at least 2-3 years.

In the meantime, what can we learn from the PROTECT study?

First, patients should not assume that evidence from laboratory experiments means that a drug will work in the clinical setting. All therapies need to be proven in large, well-conducted clinical trials before being adopted as routine therapy, as what works in controlled conditions in a test tube or experimental animal models may not work in real life. As another example, the antibiotic minocycline extended survival in a mouse model of motor neuron disease, but was recently shown to speed progression and increased mortality in human patients with motor neuron disease. The extension of this argument is that theory-based treatments cannot always be assumed to be safe without evidence from clinical trials.

Second, although the negative result from the PROTECT study was a great disappointment to both participants with Parkinson's Disease and researchers, this study highlights the importance of clinical trials in improving treatment in Parkinson's Disease. Without people with Parkinson's Disease being willing to participate in such studies, there will be no progress as new therapies will not be able to be proven to work, and ineffective therapies might continue to be recommended, potentially to the detriment of patients. Based on the results of the PROTECT study, the balance of evidence would suggest that people with Parkinson's Disease do not need to take co-enzyme Q10 'just in case', and can safely await the results of the ongoing studies in the USA before deciding whether to adopt this therapy.

Third, this study was carried out entirely by patients and researchers in New Zealand and Australia. It is an admirable achievement and shows that this successful partnership can continue to serve as a model for ongoing, urgent efforts to find more effective therapy for Parkinson's Disease. On behalf of Barry Snow and all the researchers involved in this study, we wish to thank all the patients and families who participated.

### PD and familial cancers

We have been asked the question: Has there been any association found between PD and familial cancers? Please see our website [www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au) or call our InfoLine 1800 644 189 for further information.

### Tai-Chi Exercise Class

BY JOAN PERKINS

I am the Physiotherapist in the PD Clinic at Concord Hospital and am also a qualified Tai-Chi Instructor.

I would like to commence a 12 week Tai-Chi Class for people with PD.

Tai-Chi improves muscle strength, balance, flexibility and posture.

Please contact Parkinson's NSW to register your interest and details Ph: 1800 644 189

# The Alexander Technique

## RANDOMISED CONTROLLED TRIAL FOR IDIOPATHIC PARKINSON'S DISEASE

In 2002, a report on the effectiveness of the Alexander Technique for people with idiopathic Parkinson's Disease was published in the Clinical Rehabilitation Journal. The report concluded "There is evidence that lessons in the Alexander Technique are likely to lead to sustained benefit for people with Parkinson's Disease."<sup>1</sup>

The study was carried out at the University of Westminster, Central London in the UK, and involved a small number of people (ninety three) with idiopathic Parkinson's Disease. It was a "randomised controlled trial with three groups, one receiving lessons in the Alexander Technique, another receiving massage and one with no additional intervention". Participants reported their experiences via the "Self-Assessment Parkinson's Disease Disability Scale (SPDDS)" with additional self-reporting via other questionnaires. The SPDDS involved answering a questionnaire which included questions about 25 separate actions such as walking, getting dressed and turning over in bed, with participants identifying via a simple scale (1-5) how easy or difficult these were at their best time and their worst time. There was no physical measurement in this study; the results are based exclusively on participants' responses to the questions, which were asked before the Alexander lessons, after the lessons and again six months later.

The Alexander Technique is usually taught in private lessons of 30 minutes to an hour in duration. During this study, participants attended two 40-minute lessons a week over twelve weeks with accredited Alexander Teachers<sup>2</sup>. It is not unusual for people to attend many more lessons than this in learning to use the Technique.

Participants in the study maintained their drug therapy throughout the trial. The results showed a small, but statistically significant, improvement for participants using the Alexander Technique compared to the other two groups. The author of the study summarised as follows:

- A relatively small number of lessons in the Alexander Technique leads to sustained benefits in patients with idiopathic Parkinson's Disease.
- The sustained benefits are mainly due to acquiring the ability to apply Alexander Technique skills in daily life.
- Touch and attention alone do not lead to sustained benefits.

Improvements in self-confidence, along with reduced panic and stress were also noted in the study, which was attributed to the personal benefits of successfully "acquiring new coping skills".

### About the Alexander Technique

The Alexander Technique was developed by an Australian, F.M. Alexander, early last century in response to his own difficulties in using his voice. The success of his work took him to the UK, where he began a professional training process to train Alexander Technique teachers. The Alexander Technique is now used worldwide in rehabilitation from injury and the training of performing artists. It is still best known in the UK, though there are a growing number of teachers around the world, including Australia.

The Alexander Technique leads to improved self-awareness and control of action. The student learns a series of principles and processes refined from Alexander's original discoveries about coordination. The Technique is taught with gentle hands-on guidance from the teacher, with instruction and coaching in self-application. There are three main areas of information:

**Coordination** – Alexander observed that the movements and balance of head, neck and back have a central coordinating role in our activities in a manner that can be stated simply as *the head leads and the body follows*. The Alexander teacher assists the student to re-direct the balance of their head, neck and back in order to take best advantage of this central coordination pattern. Alexander teachers call this 'moving up' and it generally results in reduced perception of tension, with a greater feeling of ease and flow in movement.

**Body Perception and Mapping** – amazingly, the sense of how we move, or what is actually happening during a movement is often inaccurate. The amount of force required to do an action, the actual movements occurring during an action, and even sometimes such basic things as the direction part of the body is moving in, can all be inaccurate. In particular, it is not unusual for people to have an inaccurate sense of their own body structure, such as the location of their hip joints, or the depth of their spine in their body. The Alexander teacher helps to correct mis-conceptions about how the person functions, and in doing so assists the person to move more in accordance with their actual structure.

**Action Planning** – The final aspect of the work involves being clear about what you are actually doing during an activity. It is surprising how much improvement in coordination can be gained from simply understanding better what the action involves. An example of this may be the dominance of the sense of moving backwards as well as downwards while sitting into a chair. While the chair is indeed behind the person, attention to allowing the body to move forward from the hip joints, in order to bring the weight of the body more over the feet, will generally result in an easier sitting action.

Overall, we could say the Alexander Technique involves a practical recognition and re-organisation of the manner with which we coordinate.

Success with the Alexander Technique involves a willingness to work on the principles in daily life and activities. The study indicates that a relatively small number of lessons can make a difference, however coordination difficulties can take time to readjust. With persistence, the Technique can lead to ongoing improvements in self-management and control.

In Australia, Alexander teachers are found mainly in the major cities, with a limited number in regional areas, or travelling to teach regionally. Private lessons in the Technique range from 20 minutes to an hour, and teachers set their own fee (generally in the range \$40-\$80 depending on the teacher's experience and the length of sessions). In some areas there are group classes available and some (limited) health fund cover is available for Alexander lessons. There are a range of



## The Alexander Technique

### RANDOMISED CONTROLLED TRIAL FOR IDIOPATHIC PARKINSON'S DISEASE *continued*

books and websites, some of more practical value than others. Lessons with a teacher provide a foundation for an ongoing use of the principles over time, and at least a few lessons are recommended in order to make best use of the reading material available. More information on the Technique, and a recommendation for reading can be found at [www.alexandertechnique.com.au](http://www.alexandertechnique.com.au) or by calling teacher Greg Holdaway on 02 4757 3999 or 0408 257 174.

#### About the Author

Greg Holdaway became an Alexander Technique teacher from a background in professional dance and dance teaching. He has been teaching the Alexander Technique for 15 years, and is now furthering his knowledge of movement science and coordination at the University of Sydney. He was accredited by the Australian Society of Teachers of the Alexander Technique, and is a member of Alexander Technique International<sup>2</sup>.

1. All quotations in this article are from the transcript of the study: Randomized controlled trial of the Alexander Technique for idiopathic Parkinson's disease. **C Stallibrass** School of Integrated Medicine, University of Westminster; **P Sissons** Peta Sissons Consultancy; and **C Chalmers** Department of Statistics, LSE, London, UK. Published in *Clinical Rehabilitation* 2002; **16**: 695-708. An abstract of the study is available at: <http://cre.sagepub.com/cgi/content/abstract/16/7/695>
2. In Australia, Alexander teachers are accredited by the Australian Society of Teachers of the Alexander Technique (Austat Inc.) or by Alexander Technique International (ATI Inc.). An accredited teacher will generally have had over 1600 hours of intensive training over at least three years. See [www.austat.org.au](http://www.austat.org.au) or [www.ati-net.com](http://www.ati-net.com) for more information.



---

### Trusted Non-Medical Home Care and Companionship Services

Home Instead CAREGivers provide one to one support to help older people retain an independent lifestyle in their own home for as long as possible. From a few hours a day, up to 24 hours - seven days a week, including weekends and holidays - Home Instead CAREGivers can assist with some or all of the following services:

- Personal Care
- Companionship
- Light Housekeeping
- Meal Preparation
- Medication Reminders
- Transport
- Respite & Convalescence Care
- Early Stages Dementia and Alzheimer's Care




[homeinstead.com.au](http://homeinstead.com.au)

Sydney North West: (02) 9836 1599  
 Sydney Northern Suburbs: (02) 9144 2322  
 Sydney Eastern Suburbs: (02) 9387 4800



## Parkinson's NSW Golf Day

### 'PUTTING IN FOR PARKINSON'S'

Proudly supported by Sydney Markets  
 Money raised will go to the Parkinson's NSW Counselling Service

Following on from the great success of last year's inaugural golf day, it is with great pleasure and excitement that Parkinson's NSW cordially invites you to our annual golf day and to **'Putt in for Parkinson's'**.

We had a significant number of Parkinson's players last year and we would like to see that number grow. Many who attended last year's inaugural event voiced their approval, commenting that it was one of the best golf days they had attended. We intend to keep up that standard, in fact exceed it. The proceeds will once again go to the Parkinson's Counselling Service; a vital service that helps take away much of the initial anxiety and uncertainty that confronts people with the disease, their carers and families.

All players this year will have carts, courtesy of Yamaha, and in Monash Country Club you have one of the best courses you'll ever play on, so our goal is to ensure the day is a memorable one, lots of fun and that everyone walks away with something, including a broad smile on their face. As was the case last year, we will have a stack of prizes, fine food and hospitality provided by one of Sydney's finest golf clubs. Here are the details:

EVENT DETAILS	
When:	Thursday 13 November 2008
Where:	Monash Country Club, Powderworks Road, Ingleside
Cost:	Individual - \$200 Team of 4 - \$700 Sponsorship - \$1,200 & \$2,500

EVENT TIMES	
11am	Registration, BBQ brunch
12noon	Ambrose Shotgun Start
6pm	Drinks, Dinner, Prizes, Auctions

## Donations

### \$50 and over received between 1 March 2008 and 31 May 2008

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

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

#### IN MEMORIAM

Albert Cork  
Alex Slibar  
Alexander Kelly  
Allen Cropp  
Anthony Healey  
Archibald Shepherd  
Arthur Lane  
Austin Dunn  
Barry Moody  
Bernard Acton  
Bessie Scott  
Bob Lees  
Brian Campbell  
Brian Mulcahy  
Bunny Bradley  
Charles Briers  
Charles Coroneos  
Clive Gledhill  
Dante Maniscalco  
Daphne Duncan  
Darrell O'Regan  
David Jenkins  
Dimitrios Kyprianos  
Douglas Knight  
E A (Mick) James  
Edward Brown  
Elizabeth Gready  
Eric Hookham  
Eric Youl  
Ern Spencer  
Essie Gordon  
Eunice Tonks  
Fortunato Romano  
Frederick Cowen  
Frederick Kirkham  
Geoff Foot  
George Meade  
George Spath  
Giovanni Natoli  
Giuseppe Libro  
Guiseppe Pulvirenti  
Gladys Chuck  
Gladys Davis  
Gladys Robinson  
Gladys Webb  
Gordon McKillop  
Graham Paton  
Gwendoline Bailes  
Harold (Bill) Coulter  
Harold Oliver  
Hazel Hallam  
Hazel Parish

Helene Mackenzie  
Hilda Thornton  
HJ Edgley  
Irene Summers  
James Noakes  
Janette Mary Fawkes  
Jean Riddell  
Jean Hatt  
Jeeves Jeevaratnam  
Jessie Eaton  
Jim Blackstock  
Jim Gorman  
Joan Macky  
Joan Maloney  
Joe Edgley  
John Carlon  
John Chapple  
John Cotton  
John Gillespie  
John McNally  
John Meynink  
John Thorpe  
Joy Nicoll  
Keith Lloyd  
Keith Marsden  
Keith Simpson  
Ken Todd  
Kiriari Kilazoglou  
Lionel Besgrove  
Lydia Hirshman  
Margaret Graham  
Margaret Harwin  
Margaret Ivanyi  
Marge Woolley  
Maria Furnsby  
Maria Grazia Rossi  
Maria Macri  
Marian Iannuzzi  
Martin Blake  
Matthew Morrissey  
Max Priddis  
May Doris Neil  
Merle Jones  
Michael Grimmett  
Milton Petridis  
Mr Fawcett  
Myfanwy Vaughan  
Nancy Mamo  
Narciso Granzotto  
Norma Colby  
Norman Bunch  
Olive Gilmour  
Robert Bosustow

Robert Holmes  
Sepala Gunasekara  
William McPherson  
  
**GENERAL**  
A Adler  
Donald Andrews  
Alfred Argo  
Martin Ash  
Warren Ashley  
Betty Babister  
Peter Barton  
Howard Bate  
Harry Bell  
George Benson  
Roy Benson  
Kathleen Blofeld  
Johanna Boland  
Richard Boon  
Kenneth Boore  
R & B Bosustow  
Anthony Boyle  
Joseph Brennan  
A J Brindley  
Mike Brookes  
Norman Brown  
Ray Browning  
Mary Bryant  
Caroline Bunney  
Annie Cage  
Casino RSM  
Bowling Club  
Kathryn Castelletto  
D Christensen  
Christine Clark  
Steve & Susan Cohen  
John Debaye  
Brigitte David  
Joan Davidson  
R Dawes  
Trish Dean  
Stephen Dennett  
J D Donoghue  
Ronald Dorrian  
Allan Downes  
A E Earl  
Elwyn Elphick  
Robert Erdos  
Eventide Homes  
Eileen Flanigan  
Elizabeth Gascoigne  
Felix Ghyes  
Nathan & Hanna  
Glattstein  
Diana Glazer

Naomi Godden  
Hans Gotthard  
Helen Grebert  
Maurice Green  
Margaret Guinane  
Nancy Guldbrandsen  
Mary Guth  
Jean Hale  
William Hannaford  
Michelle Hannon  
Henning Hansen  
Pamela Harrison  
G Hatsatouris  
Max Heather  
Bill Henderson  
Frances Hennessy  
Jennifer Hershon  
Noel Hetherington  
Bill Hill  
S Ho  
Catherine Hoare  
Rose Hodges  
Susanne Hogan  
Jane Holland  
Alan Hughes  
Anthony & Tanya Igra  
Illawarra Combined  
Seniors' Dance Groups  
Greg Ireland  
Irene Jackson  
Mervyn Kedzlie  
Patricia Kennedy  
Lucelle King  
Elaine King  
Janice King  
Jack & Maxine Klarinet  
Christopher Kloster  
Bronwyn Kosman  
Eve Laron  
Geoff Leech  
Lioness Club of Oak  
Flats  
N Littlefield  
Marion Magill  
Peter Marshall  
C Marshall  
J McInnes  
Ellen McNamara  
John Mleczko  
Kay Morgan  
Janice Mossfield  
Ross Motbey  
S Forbes & R Farrar  
Marcia Mullins

Austin Mumme  
National Seniors  
Northern Beaches  
Jeffrey Newman  
Teresa & Simon Orski  
Jan Osborn  
Dorothy Osborne  
Patricia Paine  
Alice Paton  
John Peachey  
Peats Ridge District CWA  
Y Perczuk  
Chris Pickering  
John Pierscher  
Allan Poole  
W & J Pope  
Lillian Powell  
Matthew Prowse  
Gwen Radki  
Donald Raffell  
Helen Ransom  
John Read  
Bonnie Reily  
Mary Rennie  
Ritchies Stores  
Joan Robinson  
Rotary Club of Burwood  
Inc  
Elinor Russell  
David Samer  
Gisella Scheinberg  
Robert Schibeci  
Peter Shea  
John Silversmith  
D Stern  
Owen Streatfeild  
A Stricker  
A Tallon  
Richard Thompson  
Bino Todd  
Samuel Tong  
William Townsend  
June Underwood  
Saraswathy  
Varnakulasingam  
Keeva & Liz Vozoff  
George Walker  
H F Ward  
Michael Waters  
Keith Webster  
Gwen Whatson  
Shirley Wilson  
Judy Winning

Allan Woolford  
Stephanie Wright

#### RESEARCH

Ken Beenie  
Harry Bell  
Graeme & Gwenda  
Chapman  
John Coughlan  
N Elliott  
M and De Foundas  
Ken & Mandy Fischer  
Saumya Gunasekara  
Catherine Hoare  
Jan Holmes  
Irene Jackson  
Jaycar Electronics  
Joan Kavallaris  
Stephanie Kavallaris  
Androulla Kavallaris  
Mario Kavallaris  
John Kavallaris  
Lucy Kavallaris  
George Kavallaris  
Steve & Joanna  
Koupparis  
Andras Markus  
Murray Gardens  
Retirement Estate  
Mr & Mrs B Nicholson  
Ruth Ponniah  
Judy Pownall  
J Sanderson  
Margaret Stubbs  
Patricia Swanbrough  
Tony Tesoriero  
Keeva & Liz Vozoff

#### SUPPORT GROUPS

Cowra Parkinson's  
Support Group  
Parkes Parkinson's  
Support Group  
William Townsend  
St George/Sutherland  
Parkinson's Support  
Group  
Tamworth Parkinson's  
Support Group

#### DONATIONS WERE RECEIVED IN CELEBRATION OF:

The birthday of  
Walter Orski  
The birthday of  
Stephanie Kavallaris

## Hunter Hall's 2007 Charitable Donations Scheme

Hunter Hall has made donations to Parkinson's Australia. You might like to consider Hunter Hall if you are looking for somewhere to invest funds.

Hunter Hall International, one of Australia's leading international fund managers, has continued its philanthropic endeavours in 2007, after donating over \$1.2m in charitable donations as part of its Shareholder Nominated Charitable Donations Scheme in 2007.

Hunter Hall International Limited (HHL) is an ethical fund manager which donates 5% of its pre-tax profits to charities or charitable purposes that support social, environmental or humanitarian causes.

This is done through the Hunter Hall Shareholder Nominated Charitable Donations Scheme, which allows shareholders, on a basis proportional to the number of shares they own, to nominate Australian registered charities for the receipt of donations.

Hunter Hall's philanthropic vision is the first of its kind, as it empowers and involves shareholders by allowing

them to choose from a list of charities. Parkinson's Australia is included on this list, originally chosen in consultation with the corporate giving organisation Givewell, is reviewed annually by the Hunter Hall Charitable Donations Scheme Committee. Shareholders with larger holdings also have the opportunity to select any Australian registered charity.

Established in a spirit of hope, the Trust will invest in activities Hunter Hall perceives will have a positive outcome for the wellbeing of people, animals and the environment. A portion of the Trusts management and performance fees, 0.5% and 20% respectively, will also be donated to charitable organisations.

Hunter Hall sees its Shareholder Nominated Charitable Donations Scheme, Ethical Investment Policy and Global Deep Green Trust as positive steps towards making the world a better place and will continue to develop their philanthropic endeavours.

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

by Margaret Byron, Bequest Officer

It is said that it takes a minute to find a special person, an hour to appreciate them, a day to love them, but an entire lifetime to forget them. When I first read this saying it made me think of many of the people whose lives have touched mine. I cast my mind back decades ago: school friends, colleagues, people from churches and clubs to which I belonged. We don't forget special people who have been linked to us, however briefly. The "special person" may be a spouse or a friend. If the special person has Parkinson's Disease, you can give something that, in turn, can touch the lives of that special person and other people with PD. Those people may not know you, may not have the chance to love you but will have the rest of their lives to appreciate you. I am talking about making a bequest to Parkinson's NSW. A percentage of your estate will make you into a very special person, touching the lives of people who have Parkinson's Disease in a very practical way.

If you have already made a bequest to Parkinson's NSW, we would like to know so that we can show our appreciation for your very special gift. If you have any questions about making a bequest, or if you need the specific wording for your solicitor, please contact Margaret on (02) 9876 5351 any time between 8am and 8pm.

## Counselling Corner *by Janine Rod*

### Stress and PD

Stress is an unavoidable part of life. Stress is good in that it is often what motivates us to get something accomplished. Stress can be physical, emotional or psychological and can be due to 'good' (happy) events or 'bad' (sad, frightening) events. When stress or stresses become too much they become what we typically think of as 'stress' but what might more appropriately be thought of as 'distress'. In any case, whether stress is 'good' or 'bad', it causes a very complex set of temporary chemical changes in the body and brain.

In persons living with PD, the net effect is usually to make their PD symptoms worse while they are under that stress. This is often to the point where the person living with Parkinson's or those around them can notice it. This applies to all of the PD symptoms but is usually most obvious with respect to tremor. This does not mean PD has deteriorated. It is temporary and will go back to the baseline when you are no longer under the increased stress.

People who are easily adversely affected by stress (anxious or depressed much or all of the time) may have a much harder time controlling their PD symptoms adequately with PD medications. They require higher doses for the same amount of benefit. It is often advantageous to address problems like undue stress, anxiety or depression directly and treat them independently and vigorously. This may involve stress management techniques, counselling or medication.

Ultimately, people living with Parkinson's who take advantage of these treatments certainly enjoy life more (despite continued unavoidable stresses), and may have an easier time regulating their PD symptoms with PD medications.

## Support group contact details

GROUP	CONTACT	PHONE
Albury/Wodonga	Valerie Leyden	02 6040 6153
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown	Trish Morgan	02 8875 8903
Bathurst	Jennifer Mannell	02 6332 8963
Bingara	Joan Bush	02 6724 1976
Blue Mountains	Hazel Tolhurst	02 4757 4214
Broken Hill	Colleen O'Brien	08 8087 2175
Casino	Dawn Dennis	02 6662 6141
Castle Hill	Gayle Parker	02 9634 0578
Central Coast	Les Norris	0418 607 684
Chinatown Bi-lingual		0421 224 712
Coalfields	Betty Rumbel	02 4931 5210
Coffs Harbour	Vera Heil	02 6652 9959
Cowra	Ray Heilman	02 6341 3692
Deniliquin/Finley	Glenis Gordon	03 5881 3295
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta		02 9876 4284
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla	Ian Parr	02 4472 2037
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	02 4822 6732
Grafton	Cathy Eggins	02 6642 2156
Griffith	Joyce Giacomelli	02 6966 9900
Gunnedah	Lisa Hagley	02 6742 0018
Hawkesbury	Jill Sykes	02 4730 4302
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South		02 4232 2807
Lower North Shore		02 9412 2740
Macarthur	Maree Sinclair	02 4626 4959
Manly/Mosman	Bill Lindsay	02 9949 3991
Manning/Great Lakes	Bruce King	02 6555 9409
Maroubra	Trish/Lyn	02 8875 8900
Nambucca Valley	Margaret Butcher	02 6564 8231
Narrabri	Janice Holmes	02 6792 1468
Nepean	Joe Golding	02 9670 5093
Newcastle	Verlie Sullivan	02 4954 0338
Parkes	Con Diamond	02 6862 1925
Pittwater/Warringah	Margaret Smith	02 9913 7745
Port Macquarie	Patricia Stephenson	02 6584 0212
Shoalhaven/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	Patricia May	02 4981 0641
Tweed Heads		07 5524 9417
Wagga Wagga	John Allen	02 6925 2713
Yass	Peter Wells	02 6226 2233
Young Onset	Sarah Lines	02 4627 5632

**PARKINSON'S NSW INC.**

PO Box 71  
NORTH RYDE BC NSW 1670  
Toll Free No: 1800 644 189  
Phone: 02 8875 8900  
Fax: 02 8875 8999  
Email: [pnswn@parkinsonsnsw.org.au](mailto:pnswn@parkinsonsnsw.org.au)  
Web: [www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au)

**COUNCIL**

John Silk *President*  
Chris Davis *Vice President*  
Greg Pynt *Treasurer*  
Chris Davis *Secretary*

**Council Members**

Patricia Barkley  
Samuel Chu  
Dr Kay Double  
Bruce King OAM  
Phillip Maundrell  
Dr Sarah Mott  
Allan Poole  
Rebecca Silk  
Peter McWilliam

**ADVISORY COMMITTEE**

Jacqueline Baker  
Philip Board  
Dr Colleen Canning  
Prof. Lynn Chenoweth  
Dr Alistair Corbett  
Dr Kay Double  
Jan Forbes  
Dr Victor Fung  
Prof. Glenda Halliday  
Dr Michael Hayes  
Dr Jasmine Henderson  
Dr Frini Karayanidis  
Laraine McAnally  
Sue Mercer  
Prof. John Morris  
Dr Sarah Mott  
Dr Dominic Rowe  
Dr Raymond Schwartz

**STAFF**

Miriam Dixon  
*CEO*  
Trish Morgan  
*Support Group Coordinator*  
Beulah Barker  
*Office Manager*  
Janine Rod  
*Parkinson's Specialist Counsellor*  
Deborah England  
*Parkinson's Specialist Counsellor*  
Chris Searles  
*Administration*  
Marianna Sain  
*Administration*  
Margaret Byron  
*Bequest Officer*  
Claerwen Armstrong  
*Information & Resource Officer*

**Administration Volunteers**

Teddy Bradley  
Susan Tait  
Judy Marshall  
Joy McGrane  
Sue Rance  
Raimund Stienen

**InfoLine Volunteers**

Lyn Smith

**Stand By Me Editor**

Gabrielle Chariton  
Sam Urry

**Ambassador**

Glenn Wheeler

**PATRONS**

Her Excellency  
Prof. Marie Bashir AC CVO  
Governor of NSW

Sir Nicholas Shehadie AC

**HON. ADVISOR**

Lady Angela Carrick

## 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.

### Speeding Vibrations

YOUNG ON-SET NETWORK

Diagnosed under 60?

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

**ALL WELCOME!**

Contact:  
Sarah Lines 02 4627 5632  
[jsl022@bigpond.com](mailto:jsl022@bigpond.com)

### Coffee Information Morning

Come and meet  
staff and volunteers at  
Parkinson's NSW

Talk to people living  
with Parkinson's

10.30am start  
2 September 2008

25 Khartoum Road, North Ryde

RSVP – 29 August 2008

**Ph 1800 644 189**



## The icecream boy

Peter Dawkins, who had a stellar career in music production, and was appointed the first CEO of Parkinson's NSW in 1994 - a position he held for six years, has suffered from Parkinson's disease now for some 20 years and he has been through the mill. He fought hard to keep working in the face of increasingly severe symptoms, but had to stop. Peter was one of the first patients in Australia to undergo deep brain stimulation, but it had limited success for him and, after a couple of years, he had the surgery re-done, this time successfully.

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

## To become a member, visit our website:

[www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au)

or

Call InfoLine: 1800 644 189

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

- Individual Membership: \$35
- Professional Membership: \$75
- Organisations: \$100
- Life Membership: \$350

Parkinson's NSW Inc. ABN 93 023 603 545

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.

Designed by New Age Graphics Pty Ltd – 0412 334 665