



Ease the Burden and Find a Cure

Stand By Me

Where there's a will there's a way

by extreme sports enthusiast Eddie Canales



My name is Eddie Canales. I am 41 years old, married and a father to three boys aged seven, five and five months. I'm also a director of my own print management company.

After being diagnosed with Parkinson's disease at the age of 36, I was determined to continue to live my life as normally as possible.

I've always been an avid sportsman and have represented New South Wales and Australia in Judo. This gave me more determination to stay sports-minded and accomplish more than what would be expected.

Sky-diving was a challenge I wanted to fulfill by the time I turned 40.

I did my jump in December last year and would do it again at the drop of a hat. The adrenalin rush of jumping out

at 14,000 feet, free falling for 60 seconds at speeds of in excess of 220 kms/hour, breath-taking views of the coastline and landing softly on your behind as if you were sitting on your lounge.

Sky-diving, bungee jumping, whitewater rafting all done ... what's next on the list – any suggestions?

By the way I still ride a motorcross bike and provide the comic relief when we go riding due to my mishaps (much to the concern of my wife).

FEATURES

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Reprint from Annual Report – if you would like to receive a full copy of the financials please contact the office on 02 8875 8900.

President's Report

The 2006 year began with clear aims and objectives that united the Council, our CEO, staff and our volunteers into a co-operative unit. The results of this synergy are apparent

in all aspects of our work; support group interaction, fundraising and Stand By Me, to name a few.

Our commitment to support for members of Parkinson's NSW has continued to grow during 2006 in all areas – counselling, Info Line, and support groups. Council members have sought to be more accessible and responsive to members by visiting as many support groups as possible and hope to continue this initiative throughout 2007.

In January this year, we moved offices to allow for further growth and to have an environment that provides for private counselling and information services, administration, volunteers and meeting space.

Thanks to the amazing efforts of our members we were able to present a petition containing 18,000 signatures to the Legislative Assembly and the Legislative Council. We have spoken with politicians on all sides of the political spectrum and in most instances received a positive hearing. But despite all of our combined efforts, there has been no concrete aid as yet.

At our latest meeting with the Parliamentary Secretary for Health there was still no help forthcoming, however we have progressed to being "the First Reserve" for the next lot of funding, whatever that means!

Awareness continues to grow: the speaker's group was re-vitalized by David King in 2006 and he continues to do a wonderful job.

Vice President Allen Cropp initiated a program, with the co-operation of the Pharmacy Guild of NSW, which allowed for pharmacists to provide an information pamphlet about Parkinson's NSW and our support services. We have welcomed just over 100 new members as a result of our membership drive and pharmacy pamphlets.

The Parkinson's Awareness Week 'Get It On Time' campaign, which saw information packs distributed to hospitals and nursing homes, also gave vital information regarding medication for Parkinson's.

Research, which is universally important, has been given a new direction this past year. Council has developed a protocol to ensure that we place our research dollars in the project areas where they will be most effective. We have chosen our three seed grant recipients for 2006 and will closely follow their progress.

We applaud Councillor Kay Double's research which will result in a definitive test for Parkinson's.

PNSW is a member of CAMRA—Coalition for the Advancement of Medical Research Australia. As such we concurred with their positive stance regarding therapeutic cloning. Council felt strongly that we assume a leadership stance in this regard and our view was put via our website.

To achieve our goals we have had to focus firmly on fundraising. A fund raising summit was held early in the year and our needs as an organization were clearly mapped. We have worked to a plan and have been

successful in several areas. PNSW member Don Willcox's generous donation has helped us to purchase software to aid in this area. Our bequest program, with the establishment of The James Parkinson Society, is now fully in place.

We have benefited from the generosity of various foundations and service organizations as well as individuals. Each and every member, friend, acquaintance, or member of the public who has donated to PNSW is deserving of our great appreciation. With growing responsibilities, fundraising will continue to remain a priority in 2007.

My thanks go to the Council of 2006, CEO Miriam Dixon, the office staff and volunteers who together achieved a high proportion of the goals set at the start of the year.

It was my privilege to serve as your President in 2006 and I look forward to the challenges of 2007.

Diary Dates

APRIL

- 2 Bathurst Support Group Meeting
- 3 Living Alone With Parkinson's Seminar – Concord
- 5 InfoLine Volunteer Training
- 11 International Parkinson's Day
- 12 Goulburn Support Group Meeting
- 13 Carers Nepean and Blue Mountains – St Marys
- 14 Gila Bronner Sexuality & Parkinson's – Theatre Concord
- 17 Managing worry & stress – free four-week program commences
- 19 InfoLine Volunteer Training
- 20 Carers Nepean & Blue Mountains – Springwood
- 24 InfoLine Volunteer Training
- 26 Living Alone With Parkinson's Seminar – Newcastle

MAY

- 8 Bequest Lunch – Epping RSL Club
- 9-10 Carex Seniors Expo – Rosehill
- 17, 24, 31 Living Alone With Parkinson's Seminar – Gosford

JUNE

- 5 Living Alone With Parkinson's Seminar – (Dapto) Wollongong
- 6 PNSW Coffee Morning
- 7, 14 Living Alone With Parkinson's Seminar Gosford – 5 Sessions
- 14-29 Living Alone With Parkinson's Seminar Parramatta – 5 Sessions

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



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CEO's Report

As John Silk has said in his President's Report, 2006 was a year in which a united team of members of council, staff and volunteers have worked towards achieving benefits for

the NSW Parkinson's community.

I would like to take this opportunity to provide details of some of these efforts over the year.

Support groups

Under the guidance of our full-time support group coordinator, five new support groups were established in 2006 – Fairfield/Liverpool, Bankstown, Goulburn, Gunnedah and Nambucca Valley.

Workshops were organised for Support Group Leaders to introduce the new support group manual which was developed by Vice-President, Allen Cropp.

Counselling service

Our counselling service provides face-to-face, telephone and group counselling based on sound psychological intervention.

The counselling service has started a home visiting service for clients in metropolitan Sydney.

Our service provided 429 phone counselling sessions and 245 face-to-face counselling sessions in 2006.

Information and education services

The InfoLine responded to over 1000 calls and emails throughout 2006. In August we were able to expand our service with the employment of a fulltime Information and Resource Officer who speaks fluent Cantonese and Mandarin as well as English.

Awareness and advocacy

We met with Minister John Della Bosca (Minister for Ageing and Disability), Paul McLeay (Parliamentary Secretary for Health) and with Minister John Hatzistergos (Health Minister) Policy Advisor, as well as other Members of Parliament to put the case for Parkinson's funding.

We received over 18,000 signatures on our petitions which were presented to Parliament. The lobbying campaign will continue.

Our Speakers Group is the platform for building awareness at the local community level. In 2006 speakers gave talks to service clubs including Lions, Probus and Inner Wheel, nursing homes, retirement villages, and to culturally and linguistically diverse community groups e.g. Merrylands-Philippino support group. Presentations were also given to Allied Health students.

Volunteers needed

We are looking for more volunteers, especially those who speak other languages in addition to English, to answer the InfoLine at our North Ryde office.

If you can spare four hours per fortnight and would like to be on the front line to help, please ring Nancy on 1800 644 189.

TRAINING IS PROVIDED – THREE SESSIONS IN BASIC COUNSELLING AND HALF DAY ON PARKINSON'S DISEASE. COMMENCING MARCH 29.

Resourcing

Our most valuable resource has been the efforts of volunteers in running our support groups, providing local awareness activities, assisting with fundraising, and supporting our office activities.

We have been greatly assisted by our sponsors and providers of pro-bono assistance.

We have obtained grants to assist with support services from:

- Sidney Myer Foundation
- Cecilia Kilkeary Foundation
- AXA
- James N Kirby Foundation
- Australian Chinese Charity Foundation
- Perpetual Trustees

The Chinese community held a fundraising dinner that was attended by 300 guests. It was the first time we had held a joint event with an ethnic community to raise funds and awareness.

We continued to fundraise by merchandise and card sales, but our largest source of financial support comes from bequests and in-memoriams.

The Parkinson's bequest program was established in 2006 with the launch of the James Parkinson Society, which recognises those who make the generous commitment of including a bequest to Parkinson's NSW Inc in their will.

The way forward

I would like to thank the President, Executive, Council, other volunteers and our staff for their dedication in working together for the Parkinson's community.

As we continue to push forward looking for advances in government funding, services and research, the fundraising efforts and other support from our members, friends and benefactors will be as important as ever.

Council Members for 2007



Left to Right - Dick Babb, Peter McWilliam, Allen Cropp, Dr Sarah Mott, Chris Davis, Patricia Barkley, Dr Kay Double, Rebecca Silk, Bruce King OAM, John Silk, Samuel Chu and Greg Pynt.

Alternative Therapies

Parkinson's NSW cannot support any complementary treatments/medications. If you choose to use complementary treatments please ensure that you check with your doctor before doing so.

Research

EXPERIMENTAL RESEARCH ON SURGERY FOR PARKINSON'S DISEASE

by Dr Jasmine Henderson, Parkinson's Research Group, Dept. Pharmacology, Bosch Institute & School of Medical Sciences, University of Sydney

Many people with Parkinson's disease (PD) find that over time there is an overall reduction in the effect of their medication and/or that they develop unwanted side effects such as dyskinesias (abnormal twisting movements).

While levodopa is still the best drug treatment for the majority of people,¹ some are referred by their neurologist to a neurosurgeon to have brain surgery. Neurosurgery can certainly be of assistance but does carry with it a greater risk than taking levodopa. Complications such as infection, haemorrhage or inaccurate targeting of brain regions may occur, affecting between one and four per cent of patients operated on.¹ Nevertheless, great advances have been made in the field over the past decade. As a result the variety of surgical options have increased for patients and deep brain stimulation has shown great promise.

Such refinements have also been possible as a result of working these procedures up in animal models. Our lab has been comparing drug and surgical therapies for PD in rats. We have performed several studies examining the effects of surgical lesions damaging abnormal areas of the brain in an attempt to 'normalise' how these brain areas talk to other parts of the brain. The goal is to improve PD symptoms including movement. Rats, however, do not naturally develop PD so we initially induce it surgically. The animals slow down and develop abnormal posture, and have trouble moving, similar to humans with PD. Unlike humans, rats don't develop tremor (shaking). After the rats have recovered from the first surgery they receive a second surgery to lesion one of the areas known to be overactive in PD. The areas we have investigated include the subthalamic nucleus, globus pallidus and thalamus.^{2,4} These are all areas currently targeted in PD patients.¹

In rats, lesions of the motor or movement related part of the thalamus (called thalamotomy) improved the response time of the animals to sensory stimulation.² In other words they reacted faster to tickling their whiskers whilst they were distracted by eating chocolate! This may sound strange but it is established that people with PD have more trouble doing two things at once (dual task performance) and there are problems processing sensory information which this simple, timed test mimics to some extent. Thalamotomy also reduced abnormal drug-induced turning movements in the rats. In fact pallidotomy, (lesioning the globus pallidus) also produces this type of improvement,³ supporting clinical data that both kinds of surgery can be helpful for treating dyskinesias. Subthalamotomy (lesioning the subthalamic nucleus) in monkeys improved slowness in initiating movements (akinesia) and reduced abnormal turning to some extent.⁴ However, lesioning only one side of the brain can result in

the side effect of abnormal head position,⁴ which has also been seen after this procedure in patients. While lesioning is still commonly used in patients and provides benefits, one of its major disadvantages is that lesions are irreversible. If the wrong brain area is targeted, then the results are permanent.¹ The place targeted also has bearing on what is improved.¹ For example in PD patients tremor and to some extent rigidity (muscle stiffness) is assisted by thalamotomy, whereas pallidotomy is used to improve levodopa-induced dyskinesias and subthalamotomy can reduce rigidity, tremor and akinesia.

Deep brain stimulation may be performed on the same brain regions but does not usually cause irreversible damage.¹ Another benefit is that the stimulation can be gradually adjusted to suit the individual and minimise side effects whilst maximising improvement in symptoms. This technique involves placing electrodes into the brain and stimulating at very high frequency (approximately 130-180Hz), which alters the abnormal activity in the brain area targeted and improves symptoms. The patient has leads tunnelled under the skin in the neck which connect from the electrodes to a control unit in the chest which can be turned on and off by passing a magnet over it. This procedure is more expensive to perform than lesioning, but is generally preferred due to its reversibility.¹

Overall there have been some promising developments in surgery for PD. Preclinical studies have contributed to our understanding of how some surgical approaches work and in testing new methods or refining existing ones.

1. Horstink M et al. Review of the therapeutic management of Parkinson's disease. *Eur J Neurol* 2006;13(11): 1186-202.
2. Oehr C, Allbutt HN, Henderson JM. Effect of ventrolateral thalamic lesions in an animal model of PD (manuscript submitted).
3. Henderson JM, Doherty K, Allbutt HN, Billing R. Effects of pallidotomy in an animal model of PD. *Behav Brain Res* 2006;169:29-38.
4. Henderson JM, Annett LE, Torres EM, Dunnett SB. Behavioural effects of subthalamic lesions in hemiparkinsonian marmosets. *Eur J Neurosci* 1998;10:689-98.

Centrelink?

Have you had any problems receiving centrelink payments in particular carer's benefits or Disability Support Pension if so could you please contact the office on 1800 644 189

Medical Review

If you take a number of different medicines, it's worth asking your pharmacist or GP about a Home Medicines Review.

A Home Medicines Review is a way for your pharmacist and GP to help you manage your medicines at home. Your GP gives you a referral to the community pharmacy of your choice. The pharmacist then talks with you, preferably in your home, and provides a written report to the GP, who discusses the recommendations with you.

For more information please contact the Parkinson's NSW InfoLine on 1800 644 189.

Research

FATIGUE STUDIES

Want to help with the latest medical research? Here's a chance to get involved with two studies into fatigue.

STUDY 1

The Centre for Postgraduate Nursing at the Christchurch School of Medicine in New Zealand is conducting a study looking at the experience of fatigue in adults with any chronic illness.

To date there has been scant research exploring the similarities and differences in fatigue experienced by people across a range of chronic conditions. A website has been created where people can submit a personal story or complete an online survey.

The aim of the study is to add to the body of knowledge about fatigue and its management, and thereby improve the quality of life of people with a chronic condition. The site is anonymous and confidential; stories will not be made viewable and email addresses will not be disclosed – even to the researchers.

If you are interested, please visit www.fatiguestudy.org. Study results will be made available on the site later this year.

STUDY 2

Setareh Ghahari, a PhD student in the School of Occupational Therapy, Curtin University of Technology, is looking for volunteers to study an online fatigue self-management group intervention program.

The topic of the study is evaluation of an online fatigue self-management group intervention for adults with chronic neurological conditions.

The study involves using an online self-management program designed to help people with fatigue secondary to chronic disease manage their disease, the emotional and daily life consequences. Users will be asked to evaluate the program's effectiveness and compare it with the face-to-face version, an online support group and a control group in a sample of adults with chronic neurological conditions.

If you are interested in participating, call Nancy on 1800 644 189 for a brochure or contact:

Setareh Ghahari
School of Occupational Therapy
Curtin University of Technology
GPO Box U1987 Perth
Western Australia 6845
Telephone: 08 9266 1790
Email: ghahari.setareh@postgrad.curtin.edu.au

Sexuality & Parkinson's Presentation

The presentation will be given by Gila Bronner, Director of the Sex Therapy Service, Sexual Medicine Service at the Sheba Medical Centre, Israel.

Introduced by Dr Sarah Mott from the Royal Rehabilitation Centre.

When: April 14, 10.30 am

Where: Lecture Theatre, Clinical Sciences Building
Concord Hospital

To make a booking or find out more, call 02 8875 8900 or 1800 644 189.

RSVP: Wednesday April 11, 2007.

Men's Parkinson's Network

by Gary Cearns

First of all I would like to thank you for putting together this group. I was apprehensive about attending support groups, but it was good to talk to others who are in a similar situation to myself, that being:

- Diagnosed at what I consider to be a young age.
- A male who finds it difficult to talk about Pd (after many years of hiding it so I could continue working)
- Worried about what the future holds and not necessarily wanting to see what I may become.
- Being set an expectation by the medical profession that after eight years of Pd I would be 'stuffed' (the doctor's words, not mine!)

What I got out of this first meeting was that there are probably many more good years ahead of me. Sure, life is going to change, but I can still function with a quality of life. That there are men out there that feel the same way I did when I was working. They are hiding their condition because of the fear of losing their job once colleagues or their employers find out. That I'm not alone in the Pd struggle – there are others in the same boat.

If others gained, like I did, just one thing from such a get-together, I believe it was worth every bit of effort PNSW put into getting this group off the ground.



If you or someone you care for is in the early stages of Parkinson's disease, you or the person you care for, may want to consider helping research into the disease by taking part in a clinical study. We're conducting a major worldwide study on an experimental medication to assess its effectiveness and safety in Parkinson's disease – and we need volunteers like you to help our research move forward.

You or a person you care for, may qualify if:

- you are at least 30 years old;
- you have been diagnosed with Parkinson's disease;
- you have not been treated for your condition with L-dopa or dopamine agonists, OR if you have been treated with L-dopa or dopamine agonists, the total treatment is 90 days or less.

YOU CAN FIND OUT MORE ABOUT JOINING THE VERMEER STUDY ON PARKINSON'S DISEASE BY CALLING **02 9767 6416** OR **02 9767 5184**.

On the Groupvine

by Trish Morgan

2007 started with a new support group – the Ulladulla Shakers. This is the offspring of Shoalhaven Shakers, which has members who live close to Ulladulla. Twenty-three people attended, including the Patron /Local Member for the South Coast, Shelley Hancock. Seven new members were welcomed into the group and appreciated the information and support offered. This group will thrive under the capable hands of Barry Mitchell and Margaret Graham.

2006 saw five new support groups start – Bankstown, Fairfield/Liverpool, Goulburn, Gunnedah and Nambucca Valley, which started with the help of Coffs Harbour support group members, Vera Heil and Margaret and Bruce Butcher.

Bankstown is the youngest and will meet on the fourth Monday of the month.

Goulburn, under the leadership of Mick and Gill O'Connor, has a strong membership and will be visited in April by the Vice-President of PNSW, Allen Cropp, who will present a workshop on Awareness.

Gunnedah was initiated by local pharmacist, Lisa Hagley. Fairfield/Liverpool celebrated its first birthday on March 12. Neurologist Dr Sue Hodgkinson talked about drugs and their side-effects. Warwick Brown, his wife Liz, Joe Minter and John Mleczo will steer this group which already has a loyal membership.

Other support group news

Casino support group goes from strength to strength with twice-yearly meetings on a Saturday when Dr Geoffrey Boyce, a neurologist, keeps them up to date. On February 24, 70 people came from Ballina, Casino and Lismore for a session which focused on those newly-diagnosed.

The Tamworth Seminar on March 5 was a triumph for Tamworth support group, with over 100 people coming from Willow Tree to Walcha and Gynea. Those attending were grateful to hear up-to date information and to meet others living with Parkinson's disease. The venue, the speakers, the support from the Mayor and local State and Federal Members made it a special event.



Gunnedah Support Group – Tamworth Seminar.



Nambucca Valley Support Group.

Eurobodalla was fortunate to celebrate its fifteenth birthday on March 16, with Dr Kay Double and Laraine McAnally as guest speakers. Miriam Dixon presented service awards to former leaders Herb Pettit and Jeanette Urbanik; a certificate of appreciation to Batemans Bay Bowling Club for their support for the past four years; and a certificate of congratulations to Eurobodalla support group on achieving 15 years.

Bathurst support group will host a meeting of members from the Blue Mountains to Parkes, Dubbo and Young, on Monday April 2. John Silk, President, Allen Cropp, Vice-President, and Trish Morgan, Support Group Coordinator, are travelling west to talk to members about plans for 2007, fundraising, awareness activities with a light-hearted approach, and support for carers.



Anne Grey – life with Parkinson's

Anne is a member of Parkinson's NSW and an avid bike rider.

Anne took to the road with her husband Carl in 2005 to participate in the Harley Owners National Rally. This trip took them to the Devils Marbles in the Northern Territory – they travelled a total of 7500 kilometres.

Twelve months later they hit the road on another rally to Airlie Beach, Townsville, Charters Towers and Roma. That trip was 4500 kilometres long.

Anne is a pillion passenger on these trips and she says that "life does go on with Parkinson's".

What an inspiration.

Detailed Statement of Financial Position as at 31st December 2006

	2006 \$	2005 \$
Current Assets		
Cash Assets	843,638	687,673
Receivables	19,365	17,572
Inventories	23,904	9,494
GST refund	4,179	1,289
Total Current Assets	891,087	716,028
Non-Current Assets		
Property, Plant and Equipment	25,945	17,737
Total Assets	917,031	733,765
Current Liabilities		
Payables	105,783	42,500
Grants received held in trust	74,861	
Provision for relocation expenses	100,000	
Total Current Liabilities	280,644	42,500
Total Liabilities	280,644	42,500
Net Assets	636,387	691,265
Members' Fund		
Accumulated surplus (deficit)	636,387	691,265
Total Members' Funds	636,387	691,265

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Coffee Morning



Come and meet staff and volunteers at Parkinson's NSW

Talk to people living with Parkinson's

10.30am - 11.45am, 6 June
25 Khartoum Rd, North Ryde
RSVP – 4 June

See you there!

Book Reviews

Parkinson's Disease – 300 Tips for Making Life Easier by S.P. Schwarz

REVIEWED BY DON WILLCOX

This smallish US book is written by a well known writer and health educator, who has lived with Parkinson's since 1979. It is packed with useful, handy, practical hints on how to cope with all aspects of the Parkinsonian lifestyle.

Sections include: 'making homes safe and accessible', 'looking good, feeling better', 'communicating', 'managing mealtimes', 'empowering yourself', 'handling medical issues', 'driving and travel'.

Other useful features include:

- Large clear type, with key points in bold type
- Contents pages, resources lists and index
- Simple, direct, easily understandable language
- A friendly, encouraging, sympathetic and positive tone.

Technical and medical aspects of PD are not covered. However, this is an excellent small book on coping with the condition in everyday life, from one who has 'been there and done that'.

CLASS/CATEGORY A1

Elsevier, 2002. ISBN 1-888799-65-X. 136 pages.

RRP \$50.60

The Parkinson's disease treatment book: partnering with your doctor to get the most out of your medication

by J. Eric Ahlskog

REVIEWED BY MAUREEN MORRISON

From the pen of the Chairman Emeritus of the National Parkinson Foundation, Nathan Slewett, comes the following: "Eric Ahlskog of the Mayo Clinic is one of the country's leading experts on Parkinson's disease, and his book is most comprehensive and informative ..."

And from Associate Professor of Neurology at Harvard Medical School, Daniel Tarsy: "While all motor aspects of this disease are well covered, special attention is given to the many non-motor problems, that are often neglected in treatment, such as sexuality issues, blood pressure regulation, and depression to name just a few, while at the same time dispelling some of the myths surrounding this disease."

From Part 1 through to Part 12, each section of this book is organised in such a way that it is almost a cover-to-cover read, with a pertinent 'Questions and Answers' section included at the end of each chapter.

Highlighted headings in layperson's language translate every technical detail into an understandable read, while an excellent glossary covers all those neurological words you may have heard about, but have no idea what they mean. Did you know, for instance, that the word diplopia means double vision?

New York, OUP, 2005. ISBN 0-19-517193-4. 530 pages.

This title may be available at your local library.

POETRY BOOK FOR SALE \$10

ALL PROCEEDS TO PARKINSON'S SUPPORT & RESEARCH (Plus Postage \$4.70 – posted in cardboard Toughpak)

Out Of My Mind Poems by Dennis Smith

The following poems are about Parkinson's Disease:

PD And Me pg 14	Marg From Bombala . . . pg 32
Some Parkinson's Moments . pg 15	Random PD Thoughts . . . pg 39
Me And Bobby McD pg 22	Westmead Visit pg 43
Oops Wrong Medicine pg 28	Deep Brain Stimulation . . pg 43

To purchase phone Dennis Smith on (02) 6247 8003

OR email dandsmith@netspace.net.au

OR send \$14.70 and address details to

Dennis Smith – PO Box 224 Campbell ACT 2612

Avoiding Falls

by Allen Cropp and Joan Perkins, Concord Hospital Physiotherapist

How often is the main topic of discussion at a support group meeting the awareness of the possibility of having a fall? Knowledge of how falls occur helps to reduce the risk of falls.

People with Parkinson's disease mostly fall as a result of balance disturbance, freezing of the legs, dizziness resulting from low blood pressure, or dizziness related to medication or environmental hazards. Falls mostly occur while standing up, walking, turning around, squatting, bending, performing two tasks at once or negotiating obstacles on the ground.

In Parkinson's disease the main problem is a failure to quickly activate the muscles in the correct order in response to a knock, pull or push or when the support surface moves (e.g. standing in a moving bus).

Normally when one's balance is unexpectedly challenged, the body quickly reacts by taking a step, reaching out with arms, or by bending forward. In Parkinson's disease these responses do not always occur unless you deliberately ready yourself for the challenge to your balance.

Allen Cropp

In the past two years I have had at least four falls that could be classified as Parkinson's falls.

How can I make such a statement? Each of the falls seems to come out of nowhere. It was not as a result of a trip, nor did I have any recollection of two of these falls.

Following on from these two falls I have had both hips replaced and subsequently two dislocations of the same hip which was the second hip replacement. The second replacement resulted from an accident shortly after the first replacement and involved what I would call a Parkinson's fall.

As a result of these two incidents I am conscious of the possibility of a fall. I am also very wary about getting in and out of public transport, especially the high step on a public bus.

Other potential problem areas include going down a flight of steps such as those on a railway station. A handrail is most important for such a situation. Doing two things at once, e.g. negotiating stairs and carrying parcels, can also increase the risk of a fall.

Carers information session

A group program will be conducted by counsellors from Parkinson's NSW on issues associated with caring for someone living with Parkinson's disease.

Learn about:

- the impact of Parkinson's on the person and their carer
- the importance of communication
 - the caring role
 - caring for yourself
 - support services.

The program will be held on Tuesday March 27 at Parkinson's NSW, 25 Khartoum Road North Ryde.

To book or find out more, call either Janine Rod or Deborah England on 02 8875 8900 or 1800 644 189. No fee required.

When I am not at home I take a walking stick with me most times. This gives me an added feeling of security and stability.

One of my areas of great concern is when I am seated in a theatre or sporting venue. To get out I could finish up falling into someone's lap!

Walking too fast could also be a problem as it would be easy to trip over an unseen object.

Joan Perkins' suggestions to minimise the risk of falling:

- Deliberately think of getting your balance.
- When standing, stand with a wide base of support.
- Use a handrail whenever possible.
- Ready yourself by thinking of taking a step.
- Try to avoid doing two things at once, e.g. talking while riding an escalator or walking and carrying shopping bags.
- Identify any potential hazards in the environment.
- Plan out the safest route in busy shopping centres and cluttered rooms.
- Think about maintaining your balance.
- Don't rush.
- Turn slowly.
- Stand tall when walking.

If you are experiencing falls it is recommended that you see a physiotherapist for assessment.

For more information or to make an appointment with Joan Perkins, call the Parkinson's disease clinic at Concord Hospital on 9767 6183.

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On Sleep

by Deborah England, Parkinson's NSW Specialist Counsellor

Sleep, like many other things, tends to be something we all take for granted until we lose it or have difficulty with it. There are many things, however, that we can do to maximise the opportunity to sleep.

The following list is by no means exhaustive and you may find other strategies that will work for you. Some of the things mentioned here are easier to achieve than others.

- Go to bed only when you are sleepy.
- Wherever possible, try to develop a sleep pattern – this can be achieved by having a regular bed time and waking time.
- Prior to bedtime try to do something enjoyable and/or relaxing.
- Make your bedroom as quiet and comfortable as possible – a place associated with rest not stress.
- Reserve the bed for sleep and intimacy with your partner. Avoid using the bed or bedroom, if possible, for watching TV, studying and so forth.
- Avoid exercising before sleep as this can lead to higher levels of arousal.
- Also avoid, if you can, taking the troubles or worries of the day with you as these, in reality, can be dealt with tomorrow.
- Simple strategies such as having a snack or drinking some warm milk can help. Hunger can interfere with sleep.
- Aim to avoid caffeinated drinks and alcohol. Both can have some stimulating effects which may affect sleep.

- If you do choose to have a snack, avoid chocolate as chocolate is a rich source of caffeine.
- Avoid daytime naps as these often prove to be at the expense of your night's sleep.
- If you find that you are still tossing and turning after 30 minutes or so, you may choose to get out of bed and watch TV, read, or listen to music until you start to feel sleepy again. The premise here is to associate bed with sleep, not wakefulness.
- Use sleeping medication with caution. Sleep patterns, like most things, can take a while to become established.
- Many people say that they find satin sheets an advantage as they make movement in bed easier, they also say that a doona, rather than quilts and blankets is lighter to move under and easier to handle.

Hopefully some of these things will be of benefit to you. Persevere, as it takes time to develop good sleep habits. Like the shampoo, it won't happen overnight but it will happen.

The James Parkinson Society bringing hope for the future

by Margaret Byron, Bequest Officer

In November last year, an interesting article appeared in the Sydney Morning Herald. It contained a list of the top suburbs and towns for bequests in Australia, naming the residents of suburbs 'most willing to shape the future of Australia' by including a gift to charity in their wills.

The top ten included Castle Hill, Port Macquarie and Mosman in NSW; the other seven were in Victoria. Martin Paul, a spokesman for the organisation which compiled the list, said, '... if everyone included a charity in their will imagine how much more each charity could achieve.'

I am sure that you are aware of how much Parkinson's NSW is doing to support all people with Parkinson's disease in the state; from the newly-diagnosed to carers of people who have struggled with the disease for decades. We are never short of plans for further support and research!

The James Parkinson Society's first sponsored Bequest Lunch for 2007 will take place on Tuesday May 8 at Epping RSL Club. Because it is sponsored, there will be no charge to you nor will there be any cost to Parkinson's NSW. We will be inviting our more senior members in the Sydney metropolitan area. If you don't get an invitation, please let us know by ringing the Parkinson's NSW office on 8875 8900. It just means that we haven't got a record of your date of birth. If you will be visiting Sydney then you and a partner would be most welcome.

We are also looking forward to our second Bequest Lunch this year – to be held on July 5 in Newcastle. Look out for more details in the next Stand by Me.

If you would like more information or would like to discuss any aspect of making a bequest to Parkinson's NSW please call Margaret on 02 9876 5351 any time between 8am and 8pm.

Managing Worry and Stress

A group program will be conducted by Parkinson's NSW counsellors Janine Rod and Deborah England on managing the worry and stress associated with having Parkinson's disease or caring for someone living with Parkinson's.

Learn about:

- the source of your concerns
- breathing and relaxation techniques to keep your anxiety under control
- managing anxious thoughts
- problem solving strategies to reduce anxiety
- communicating your feelings effectively.

The program will be held each Wednesday for four weeks starting on April 17 between 10am and 12pm at Parkinson's NSW.

If you would like to be in the program or to find out more, please call Janine or Deb on 02 8875 8900 or 1800 644 189. No fee required.

Donations

\$50 and over received between 16 November 06 and 9 March 07

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

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In recognition of their tireless support to people living with Parkinson's disease, their carers, family and friends through your valuable volunteering.

Kay Messiter

In recognition of your tireless support to people living with Parkinson's disease, their carers, family and friends as Information Officer for Parkinson's NSW

Certificate of appreciation



Joanna Knott

In recognition of her tireless work as convenor for Coalition for the Advancement of Medical Research Australia and the successful campaign to allow all forms of stem cell research to be carried out in Australia.

Lions Club and Research



Mr Ralph Joseph (right) represented Bondi Lions. The Lions club made generous donations to allow **Dr John Burne** (left) to undertake his research.

Seed Grant recipients



Left to Right - **Dr Carolyn Sue**, Research stem cell models for Parkinson's disease; **Dr Colleen Canning**, Research falls in Parkinson's disease; **Dr John Burne**, Research into speech and swallowing dysfunction in Parkinson's disease.

Support group contact details

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