



The Quarterly

World Parkinson's Day

Preparations for World Parkinson's Day on Monday 11th April, 2011 are now well underway. The Pharmacy Guild of Australia have agreed to run a competition state-wide by having a Parkinson's Awareness and Information Presentation in some of their pharmacies throughout Queensland with prizes awarded for the most outstanding "Awareness" presentations. Several support groups are also planning to run World Parkinson's Day morning teas.

Annual World Parkinson's Day is an important opportunity to boost awareness about Parkinson's disease and to show support for those affected. People throughout the world rally together for this significant event, and Parkinson's Queensland Inc. encourage YOU to participate in 2011. Here are some of the ways in which you can help support World Parkinson's Day in 2011:

- Host a "Party for Parkinson's" with your friends and family - free party kits are available by phoning 1800 644 189.
- Purchase and wear a tulip badge and ask your friends and family to do so also.
- Encourage a friend or family member to join Parkinson's Queensland Inc.
- Write a letter to your local newspaper to share your experiences with PD and boost awareness of the disorder.
- Contact your local member of parliament and urge them to support local PD initiatives.
- Sign the online global Parkinson's pledge (www.parkinsonspledge.org).
- Make a donation to Parkinson's Queensland Inc. for research and support services (see form on back page).

For more information on some of the ways you can help, please phone 1800 644 189.

Parkinson's Queensland Inc. was greatly saddened by the sudden death of *the Quarterly* editor Kevin Robins on the 30th December, 2010. Kevin was an absolute stalwart of the organisation with his tireless efforts on the Management Committee and his continual hard work behind the scenes.



Kevin was Co-ordinator of the Broadbeach and Young Onset Support Groups as well as running an Anxiety/Depression Support Group for many years, his interest in Parkinson's research and education was a prominent element where Kevin openly made himself available to share his knowledge, experiences and insight to people with Parkinson's (PwP) and carers alike. Kevin was held in very high esteem by his fellow Management Committee members and a broad range of people with PwP, carers, allied health professionals, GPs and neurologists, he will be sorely missed and our heartfelt thoughts and condolences go out to his wife Julia at this sad time.

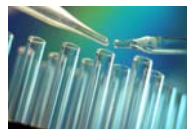
A farewell gathering for Kevin was held on Monday 31st January with over 80 people in attendance - the reflections and tributes made by many at this farewell epitomised the many positive characteristics that Kevin portrayed as a loved carer, a passionate volunteer and a person who succeeded in making a real difference in the lives of those people with Parkinson's.

Patrick Bulman, Chief Executive Officer

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"Committed to caring"

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A special thanks to the volunteers who
are so essential in keeping
Parkinson's Queensland Inc. going.

DISCLAIMER

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home and community care

A JOINT COMMONWEALTH AND STATE/TERRITORY PROGRAM
PROVIDING FUNDING AND ASSISTANCE FOR AUSTRALIANS IN NEED

- Deadline -

All submissions for articles or
advertising in the Winter issue
of the Quarterly magazine must
be received no later than
29th April 2011.

Support Groups of Parkinson's Qld Inc.

Beaudesert
Carol Price Ph: 5540 1400

Bribie Island
Ann Mitchell Ph: 3408 2120

Broadbeach
Call PQI for details Ph: 3209 1588

Bundaberg
Elaine Williams Ph: 4159 8118

Caboolture
Joy Boyle Ph: 5498 7333

Cairns
John Harris Ph: 4053 4556

Carers
Neil Page Ph: 3278 5152

Dalby
Call PQI for details Ph: 3209 1588

DBS Group
Sue Page Ph: 3278 5152

Gladstone
Call PQI for details Ph: 3209 1588

Indooroopilly
Call PQI for details Ph: 3209 1588

Ipswich
Di Bergman Ph: 3817 2361

Kedron
Call PQI for details Ph: 3209 1588

Logan
Margaret Vickers Ph: 3808 6356

Mackay
Call PQI for details Ph: 3209 1588

Mareeba
Slim Pearsall Ph: 4092 1374

Maryborough
Gail Wixon Ph: 4123 3407

Mitchelton
David Martin Ph: 3410 8054

Mt Gravatt (YOPD)
Call PQI for details Ph: 3209 1588

Mt Gravatt
Mavis Edwards Ph: 3341 5227

Nambour & District
Jean Scanes Ph: 5444 2312

Port Douglas
James Watson Ph: 4098 5335

Redlands/Bayside
Phyllis Trost Ph: 3207 4664

Rockhampton
Call PQI for details Ph: 3209 1588

Roma
Peter Thomas Ph: 4622 2512

Tewantin/Noosa
Joan Murray Ph: 5442 4110

Toowoomba
Delia Sharp Ph: 4696 8734

Townsville
Julie Fink Ph: 4799 9500

Warwick
Patsy Slatyer Ph: 4661 4566

Western Suburbs
Jocelyn Wilson Ph: 3378 1474

Yeppoon
Hugh Evans Ph: 4939 4686

CEO's Report



Welcome to this edition of *the Quarterly* reporting on the period during which Queensland was hit by the devastation of floods in regional and metropolitan areas of the State. The level of destruction is hard to personally comprehend unless you have physically experienced an event of this magnitude and foremost in our minds has been the physical and emotional impact of people with Parkinson's and their carers who have been affected directly

by the Queensland floods. PQI has maintained sustained and vigilant support to all members of the Parkinson's family through our support groups and individuals who have made contact directly through our office. If we can be of further assistance please do not hesitate to contact the state office on freecall 1800 644 189.

The CEO and the Client Services Officer, Lynda Foulis, have again been active with 13 visits to support groups in the last quarter - the regional road trips have continued to be fruitful with new support groups established in both Roma and Gladstone after local community consultation meetings had taken place. Additionally, a meeting with the Rockhampton Support Group resulted in the rejuvenation of this group - a new venue has been identified and PQI will continue to run this support group until the new coordinator takes over.

Parkinson's Queensland Inc. has commenced a significant campaign to source funding for Parkinson's Community Nurses to work state-wide, lobbying has commenced with Federal and State members with solid support already gained for this model of care. The primary role and function of the Parkinson's Community Nurses are to provide nursing assessment, education and ongoing support to PwP and their family carers in the community. The Parkinson's Community Nursing Service would contribute towards better management of treatment and through information and referrals, reduce the impact of symptoms and hospital and aged care admissions. The community model is successful in the UK where it is based on the recommendations of the National Institute of Health and Clinical Excellence (NICE) Guidelines for best practice management of Parkinson's disease published by the Royal College of Physicians in 2006.

Parkinson's nurses are central to the clinical management of Parkinson's disease providing clinical monitoring, a reliable source of clinical information and links to health care providers. It is anticipated that the service will be free to clients who can self refer or be referred by a health professional.

Family carers of PwP play a crucial role in maintaining the long term independence of PwP in their own home however these carers also need specific support and education to understand the needs of PwP and maintain their own health needs in the short and longer term. The Community Service would also provide education to allied health professionals, carers, government and private agencies, on the care and management of PwP.

I would also like to take this opportunity to wish Rebecca Hardwidge-Suddards (Information Officer) our very best wishes as she and husband Peter approach the birth of their first child. PQI recognises the commitment and quality work undertaken by Rebecca during her time with our organisation and we wish her well in all future endeavours. Similarly, I would like to extend a warm welcome to Vanessa Balcomb who has taken on the new role of Support Services Officer with tenacity, a positive mindset and excellent commitment, all good qualities to ensure she will be successful in this key role.

Patrick Bulman, Chief Executive Officer

President's Report



The recent sudden death of Kevin Robins, Secretary of PQI, has been a great shock to us all. In his role as Secretary of PQI and many other roles he was a major force in the organisation. He will be greatly missed by all on the Management Committee and on behalf of all of PQI I express our condolences to his wife Julia.

As a temporary measure David O'Brien, our Treasurer, will take on all the statutory duties of Secretary.

I am pleased to be able to welcome two new members to the Management Committee. Margaret Vickers, a long time volunteer in the PQI office, and carer for husband Bob, will be joining the committee. Margaret has a detailed knowledge of the operations of PQI and will bring that experience to the committee. Deb Johnson, an experienced health administrator, who is also a carer, will also be joining the Management Committee. Deb has experience working in community groups and we look forward to the value she will add to our committee.

The Unity Walk will continue to be a major fundraiser in 2011. We have set up a committee to manage the project and are looking for a better venue to allow us to expand this for 2011 and beyond.

Queensland has been asked by Parkinson's Australia to host the next National Conference. The Management Committee has agreed to accept the task and planning is already underway. The National Conference is run every 3 years and is planned for July 2012.

Parkinson's Australia several years ago introduced an education based program for GP's to raise awareness of the problems Parkinson's patient's face. This was provided with the financial assistance of a drug company however continuation and updates are funded by Parkinson's Australia. Although initial take up by the GP's was slow, there is now encouraging signs of more GP's availing themselves of the course.

John Bird, President

UQ Speech Research Update

The Telerehabilitation Research Unit in the School of Health and Rehabilitation Sciences at the University of Queensland has been actively involved in developing telerehabilitation applications for the management of the speech disorders in people with Parkinson's disease. This research has been funded by two National Health and Medical Research Council (NHMRC) project grants (301029; 631514). The following is a brief summary of studies recently completed, and those currently underway.

Dr. Gabriella Constantinescu has recently completed her doctoral project "A telehealth application for the assessment and treatment of disordered speech in Parkinson's disease". The aim of this project was to validate the assessment and treatment of the speech disturbance associated with PD over the Internet within a laboratory setting. The treatment used in this study was the Lee Silverman Voice Treatment (LSVT[®]) program. The online assessment and treatment was compared to traditional face-to-face delivery.

In the assessment study, 61 participants with mild to severe speech disorders were assessed simultaneously online (across the Internet) and face-to-face by two speech clinicians. Results showed that overall, the speech and voice difficulties associated with PD could be accurately assessed over the Internet and that these results were comparable to assessments conducted face-to-face. The treatment study involved 34 participants with mild to moderate speech difficulties. The participants were randomly assigned to receive the LSVT[®] either online or face-to-face. The results showed that participants in the online treatment group achieved significant improvements in their speech following treatment. These improvements were found to be comparable to those gains made by participants in the face-to-face treatment group.

Following on from the research outlined above, Professor Deborah Theodoros was awarded a further NHMRC project grant in 2010 to take the next step of delivering the LSVT[®] program to people with PD in their own homes. This research project is titled "Home-based speech treatment for Parkinson's disease via telerehabilitation: Clinical and economic outcomes". This study is using a mobile, multi-media videoconferencing system called eHAB[™]. This system combines real time videoconferencing with customised speech and voice measurement tools to allow the speech pathologist to deliver LSVT[®] over the Internet. Participants will be randomly allocated to one of three groups: (1) Online metropolitan treatment group; (2) Online rural treatment group, and (3) Face-to-face treatment group. Participants in the face-to-face group will be treated at the University of Queensland. Free transport will be provided for participants to attend these sessions. Participants in the online treatment groups will have an eHAB[™] installed in their home for the duration of the LSVT[®] program. People who have been diagnosed with PD by a neurologist, have difficulty with their

speech, and have not had the LSVT[®] program before, may be eligible to participate in this study. For further information on this research project please contact **Dr Anne Hill** on (07) 3365 8876 or email a.hill@uq.edu.au or **Professor Deborah Theodoros** on (07) 3365 2806 or email d.theodoros@uq.edu.au in the School of Health and Rehabilitation Sciences at the University of Queensland.

We would like to take this opportunity to thank all of the people with PD who have participated in our research. Your participation and enthusiasm is not only inspiring, but also greatly appreciated.

Professor Deborah Theodoros
Division of Speech Pathology
School of Health and Rehabilitation Sciences
The University of Queensland

Research Participants Needed

An individualised dietetic approach to improving motor symptoms, non-motor symptoms, quality of life and nutritional status in Parkinson's disease

Nutrition and nutritional status is an important consideration in Parkinson's disease especially as they relate to PD symptoms, including motor (tremor, slowness of movement) and non-motor (difficulties swallowing, gastrointestinal discomfort) symptoms. Volunteers are being sought to participate in a study that aims to provide information about important dietary factors related to PD to improve services provided by nutrition professionals. The study requires 80 people with Parkinson's disease whose symptoms are currently managed using levodopa-based therapy and who have not undergone surgical treatment for management of Parkinson's disease symptoms.

The research will be conducted during four visits to the Institute of Health and Biomedical Innovation at the Queensland University of Technology, Kelvin Grove Campus over a 13 week period. Parking can be arranged free of charge for these visits. In addition, you will be asked to complete questionnaires at home. For more information or if you would like to participate in the study please contact **Ms Jamie Sheard** on (07) 3138 6138 or jamie.sheard@qut.edu.au

Who Cares For Carers?



PQI does, but we would like to be better at it. We need your help to do this.

Carers play a pivotal role in supporting PwP over the long haul of this illness, helping them to maintain the best quality of life possible in the circumstances, and living at home as long as possible. This is not an easy task and PQI is looking at its support group activities to find ways of providing better support to the carers.

Of course help is available from other sources, but PD has unique features as an illness, and PQI is best placed at providing PD specific support. We are currently reviewing our Carer's Support Group as currently structured, as well as carers information provided to all support groups. We are very conscious that the need extends right across the state and we are looking at innovative ways of supporting carers (as well as those with PD) in the more remote parts of QLD.

If you are a carer, or anyone else with an interest in carers, please talk to us about what you think the carers need most. Is it someone to talk to who is in the same position in life, is it the need for information about the likely progression of the illness, or something else? If a face-to-face meeting isn't always possible, do you think that a telephone hook-up would be of value, or an internet based conference? Do you need some arrangements to be made for your loved one while you are at a meeting, face-to-face or otherwise?

If you are able to help us with any of these questions, please phone **Neil Page** on **(07) 3278 5152** or email **npa2@telstra.com** to discuss any options and explore any ideas you may have.

We hope to conclude this review by the end of March 2011 so that during this year we can develop better solutions to helping our treasured carers.

Practical Tips For Safe Mobility

- Maintain good posture by conscious attention and daily stretches.
- Maintain an enjoyable exercise routine.
- Wear appropriate footwear (closed with flat or low heels).
- Rise from lying or sitting position slowly and remain by the bed or chair for a short period of time.
- Report dizziness upon standing to your GP as this may be caused by a drop in blood pressure.
- Remove unnecessary mats.
- Maintain an uncluttered environment.
- Be cautious when stepping backwards.
- Arrange a referral to a physiotherapist with expertise in PD for assessment and introduction of an exercise program.
- Concentrate on large steps and a heel/toe walking pattern.
- Avoid dual tasking.
- Turn in a wide arc rather than a sharp change of direction.
- Strategies or cues to overcome freezing of gait include counting 'one, two, three' or clapping to maintain a rhythm or initiate movement. Swaying from side to side may overcome freezing of gait. A physiotherapist may apply tape to the floor in problem areas. This acts as a visual cue to overcome freezing.
- If freezing of gait occurs do not try to automatically continue with mobility. Use a strategy discussed in dot point above or accept the freeze and wait for mobility to return.
- Be aware of visual changes and report any difficulty with descending stairs to the treating specialist.
- Report falls to GP and treating specialist.

NEWS & EVENTS

Parliamentary Parkinson's Update



Hi, it is a real pleasure to be included in the Parkinson's Queensland Inc. quarterly publication. I have worked with Parkinson's Australia and Parkinson's Queensland Inc. for many years, and I know the commitment and struggles of so many people living with Parkinson's. We are fortunate to have an across-party Parliamentary Friends Group in the National Parliament, supported by Parkinson's Australia, which maintains information about

the condition, its impact on individuals and families, and what needs to be done in Australia to raise awareness, research and assistance.

Over the years, we have met with people who are prepared to share their experiences, as well as many international respected clinicians and researchers who are dedicated to the fight against this condition. Recently, we listened to a report on the Shoalhaven project, the exciting NSW project engaging community Parkinson's nurses. The report was enhanced by discussion with one of the nurses who reflected on her work, the response from people with Parkinson's, their families and carers, as well as local medical professionals. This is a wonderful initiative, providing real hope for all of us who know the need.

We will continue to work with government to advocate for resources for Parkinson's research and support. We all know people in our families and our community who need this support, so we must work together.. Please contact me anytime, my office is in Fortitude Valley.

Senator Claire Moore
Labor Senator for Queensland
Phone: (07) 3252 7101 Fax: (07) 3252 8957
Email: senator.moore@aph.gov.au
www.clairemoore.net

New Support Services Officer



My name is Vanessa Balcomb and I started at PQI on the 8th November as the Support Services Officer. Previously, I worked for a not-for-profit organisation for 2 years. During my time there I worked within the Administration & Fundraising Department and also was the Workplace Health & Safety Officer. I was involved in working with allied health professionals, as well as working with clients and their families.

My role as the Support Services Officer encompasses many aspects of the services provided by PQI. As part of my role I will be the first point of contact on the freecall 1800 644 189 number and

supporting the Chief Executive Officer, Client Services Co-ordinator and Information Officer as well as maintaining the PQI website.

National Young Onset Conference

The inaugural National Young Onset Parkinson's Conference was held in Melbourne over two days in November. Over 100 attendees participated in a variety of informative workshops, networking activities and presentations by highly esteemed international and national guest speakers on a range of PD topics.

Conference convener, Catherine Watson, says that in addition to the valuable information presented over the two days, the conference offered a wonderful opportunity for attendees to meet other people living with Young Onset Parkinson's and their partners—with many people agreeing to maintain contact with each other post-event. If you'd like to be on the National Young Onset Conference mailing list, please email **Catherine Watson** catherine@parkinsons-vic.org.au.

FREE COMMUNITY EVENT

Parkinson's Queensland Inc.
invite you to a 'Question & Answer'
open forum with
PROFESSOR PETER SILBURN

6 - 8pm

Wednesday, 30th March 2011

Auditorium - Building B71

UQ Centre for Clinical Research
Royal Brisbane and Women's Hospital

Bookings essential, phone 1800 644 189.

PQI would like to kindly acknowledge the
generous contribution made by
Boehringer-Ingelheim
towards advertising of this seminar.

A DVD recording of this session will be made available for a small cost for those unable to attend the seminar.

New Round of PQI Grants Awarded

Parkinson's Queensland's Inc. research grants are funded through the generosity of individual and corporate donors and bequests. The primary aim of the Parkinson's Queensland Inc. Seeding Grant Scheme is to support individual researchers and research teams to conduct high quality research into Parkinson's disease. This includes both basic and applied science research. In the 2010/11 round PQI awarded a total of \$75,000 funding to qualified research students for innovative research projects related to Parkinson's disease. In total, four grants were awarded; 2 PhD Grants and 2 Research Seeding Grants.

Novel methods of detection of anxiety in Parkinson's disease

Dr Nadeeka Dissanayaka (University of Queensland) will be exploring and developing strategies to diagnose anxiety in PD at early stages of the disease. Clinical interviews, psycholinguistic methods (affective priming) and brain waves recording (electroencephalography) will be used. This will facilitate clear definitions of anxiety related to PD, providing a means by which novel assessment methods for anxiety in PD can be developed. Identifying early diagnostic methods for anxiety in PD will improve clinical practice and future clinical trials establishing better treatment strategies.

Frontal cortex activation mapping during cognitive tests of executive function in Parkinson's disease patients receiving deep brain therapy

QUT Associate Professor, Dr Graham Kerr, will be utilising non-

invasive functional near-infrared topography to map frontal cortex (FC) activation during cognitive tests of executive function in the elderly, PD patients, and PD patients receiving sub thalamic nucleus deep brain stimulation (STN-DBS) therapy. Outcomes of this research will clarify the relationship between FC activation and cognitive dysfunction and provide a better understanding of the stimulation parameters that influence executive functioning in PD patients receiving STN-DBS therapy.

Brain structural change correlates of postural instability and cognition in Parkinson's disease

University of Queensland PhD student, Ms Dong Xu, will be using advanced MRI-based methods combined with quantitative gait and cognitive assessments to investigate the relationship between brain structure, cognitive decline and falls in PD. This research will contribute to the development of objective diagnostic imaging markers for determining postural instability and falls risk in people with PD.

Measuring and understanding community walking in people with Parkinson's disease

University of Queensland PhD student, Mrs Robyn Lamont, will be commencing a study to compare the accuracy and reliability of two methods of quantifying community walking in PD (an activPAL and pedometer). The study will also involve determining the relationship between community walking and symptoms of PD including gait and executive function.

Support Group Co-ordinator Honoured

The staff and management committee of PQI would like to extend their congratulations to James Watson, Port Douglas/Mossman Support Group Co-ordinator for recently winning the Cairns Regional Council's Volunteer of the Year at last month's Australia Day Awards.

James has been a very active advocate for Parkinson's disease in Port Douglas over the past year and will be holding a fundraising event at the Court House on Saturday 26th March, 2011. James is also starting up a Mossman Young Onset Parkinson's Disease Support Group. Well done James!

RIGHT: James receiving his award.



Make a donation to Parkinson's Queensland Inc.

Please accept my donation of

\$20

\$50

\$100

\$

Please find enclosed my cheque or money order made payable to Parkinson's Queensland Inc.

or

Please debit my credit card:

Mastercard

Visa

Card Number:

____/____/____/____

Cardholder's signature:

Expiry Date:

Name

Address

Phone

Email

A bequest to Parkinson's Queensland Inc. is a way to ensure future generations have ongoing PD support and services. For more information on making a donation to Parkinson's Queensland Inc. in your will, please phone us on 1800 644 189 or (07) 3209 1588.

Please post your donation and completed form to:

Parkinson's Queensland Inc.
PO Box 1684
Springwood QLD 4127

Donations

Thank you to those who have generously donated to Parkinson's Queensland Inc. in recent months to the end of January 2011. Although we can't list all of your names, your support is gratefully appreciated. Listed are those who kindly donated **\$50 or more**.

General Donations:

Alwyn Peffer & Co Pty Ltd, A. Deeprise, D & F Ellett, I. Fritz, Lions Club of Yeppoon Inc., Mt Gravatt Support Group, Oak Tree Villages, C. Petherick, S. Taylor, The Sandy Michell Legacy

2010 Christmas Appeal Donations:

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Donations in Memory:

Philip Askew, Margaret Brown, Elsie-May Carroll, Alan Colwill, Althea Cooper, Kevin Green, Mary Kenny, P. Kraak, Ian McPhee, Jim McVeigh, Jim Morero, Daniel Pegg, Trevor Read, Kevin Robins, Ivor Saffery, Ronald Schubert, Gordon Stokes, Robert & Gwen Wood

Bequests:

Estate of Gordon James Farleigh, Estate of Mary O'Keeffe

Research Donations:

Estate of Vera Maud Kendall, Kenmore School House Quilters, Western Suburbs Support Group



LEFT: The Nambour & Districts Support Group enjoying their Christmas get-together. The group would like to warmly thank Jennifer Douglas who has resigned as co-ordinator.