



the Quarterly

Parkinson's Queensland Unity Walk

There are less than 2 weeks remaining until the 2010 Parkinson's Queensland Unity Walk on Sunday 12th September so please throw your weight behind the event by encouraging your family and friends to join us on the day.

The 4km non-competitive community walk along the Wynnum Esplanade Foreshore is the largest annual fundraising and awareness event in Queensland for Parkinson's disease and is suitable for all ages. Check-in from 8:30am at Bayside Sea Scouts Hall (358 Upper Esplanade, Manly). The festivities this year will include live entertainment, refreshments, special guests and prizes for the highest fundraising efforts. Deputy Premier Paul Lucas will be officially opening the walk at 10:00am.

We understand that many people who wish to participate in the walk may be physically unable to do so. If you can't join us on the day, why not become a virtual walker? You can still be a part of this special event without even leaving home by registering online or making a donation to another participant for their efforts in the walk.

The walk is the keynote event concluding National Parkinson's Awareness Week from 29th August—4th September 2010. Entry is only \$25 for adults or \$15 for children under 16 and includes a free t-shirt! Register online now at www.parkinsonsqldunitywalk.org.au, or call 1800 644 189 for further information.

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Medical Cooling and Heating Electricity Concession Scheme

After several months of PQI and MS Australia lobbying the Queensland Government has introduced a new electricity concession to provide financial assistance to low-income Queenslanders who have a medical need to operate an air conditioner to keep cool (such as people with Parkinson's disease).

The concession commenced on 1st July 2010 and provides an annual rebate of \$216 to those eligible to assist with the increased electricity costs incurred by frequent operation of cooling or heating systems in order to regulate body temperature

For more information please contact Concession Services – Smart Service Queensland on 1800 460 849.



LEFT: CEO Patrick Bulman and MP Karen Struthers at a morning tea to celebrate the launch of the Medical Cooling & Heating Electricity Concession Scheme.

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

Parkinson's Queensland Inc. (PQI) has endeavoured to ensure that the information in this magazine is accurate, however, we accept no responsibility for any errors, omissions or inaccuracies in respect of the information contained in the material provided by PQI. Nor is the provision of material by PQI to be construed as any representation that there is no other material or information available in relation to the information provided. Further, PQI accepts no responsibility for persons who may rely upon this information for whatever purposes.

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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 Summer issue of the Quarterly magazine must be received no later than 29th October 2010.

Support Groups of Parkinson's Qld Inc.

Broadbeach

Kevin Robins Ph: 3807 0228

Mt Gravatt

Mavis Edwards Ph: 3341 5227

Young Onset PD

Kevin Robins Ph: 3807 0228

Logan

Margaret Vickers Ph: 3808 6356

Carers

Phone PQI Ph: 3209 1588

Redlands/Bayside

Phyllis Trost Ph: 3207 4664

Mitchelton

David Martin Ph: 3410 8054

Kedron

Pam Furner Ph: 5499 3890

DBS Group

Call PQI Ph: 3209 1588

Indooroopilly

Ann White Ph: 3878 9433

Western Suburbs

Jocelyn Wilson Ph: 3378 1474

Ipswich

Di Bergman Ph: 3817 2589

Beaudesert

Ann/Carol Ph: 5540 1400

Toowoomba

Delia Sharp Ph: 4696 8734

Warwick

Patsy Slatyer Ph: 4661 4566

Caboolture

Joy Boyle Ph: 5498 7333

Bribie Island

Ann Mitchell Ph: 3408 2120

Nambour & Districts

Jennifer Douglas Ph: 5476 1193

Tewantin/Noosa

Joan Murray Ph: 5442 4110

Maryborough

Gail Wixon Ph: 4123 3407

Bundaberg

Elaine Williams Ph: 4159 8118

Rockhampton

Jan Nolan Ph: 4928 5863

Mackay

Diane Phelan Ph: 4942 8884

Townsville

Julie Fink Ph: 4799 9500

Mareeba

Slim Pearsall Ph: 4092 1374

Cairns

Eddie Skitt Ph: 4058 0171

For DBS phone support please call Judy Rawlins on (07) 3886 1592.

President's Report

Sue and I took a break in May, enjoying a river cruise in Europe. But we couldn't help ourselves – by pure coincidence meeting new people on our tours who are also living with PD.

We arrived home to find that things at PQI had moved at a cracking pace, with Lynda Foulis having joined our team as the new Client Services Coordinator with the very important task of looking after the support groups, among other things. Lynda has quickly settled in and is going about her tasks with good humour and efficiency.

This quarter has been very productive for PQI. With others we were successful in getting the Queensland Government to introduce the *Medical Cooling and Heating Electricity Concession Scheme* for those who qualify (see front page) and were successful in being awarded grants to help us run workshops for our support group coordinators. As reported elsewhere in this issue, the first of these was held very successfully in Brisbane on 31st July. During the detailed planning for this event it became clear that many potential participants living remote from Brisbane were unable to make the journey to Brisbane. For these we are developing a series of *Road Trips* where we take the message to them in a series of workshops and information sessions, and take the opportunity to increase public awareness along the way. Sue and I kicked off the first in early August visiting Toowoomba, Dalby, Roma, St George, Goondiwindi and Warwick. Other such trips are planned later this year and into 2011 to be guided by our experiences with the first.

Our AGM this year has been set for Saturday 16th October. At that I will be reporting on the real progress we have made in recent times in re-building PQI, with a growing list of members and support groups and improved services to members. Several of us, myself and Sue included, have decided not to stand for re-election this year, so there are vacancies on the Management Committee to be filled. Please consider serving PQI in this way. Although hard work at times, it is incredibly rewarding working for this worthy cause. Nomination forms will be distributed with the formal notice of meeting.

Since this is my last message to you as President I would like to thank you all for your support and understanding during my tenure. We have been on an exciting ride these last 2 years. Together we have made great progress and formed many lasting friendships. Although not serving on the Management Committee next year, Sue and I will look forward to continuing to serve PQI as volunteers for as long as we are needed.

Neil Page, President

CEO's Report

Welcome to another edition of *the Quarterly* and a new financial year. One of the important tasks that PQI have moved forward on in June 2010 is the sign off on the new strategic and business plans by the Management Committee which will assist in securing our financial future and grow our services to PQI members.

In planning for and achieving our financial objectives we have reviewed and identified the main drivers to improve our income generation. This includes elements such as fundraising activities, membership and Support Groups, advertising revenue and selective grants. We have also been able to successfully confirm that our HACC (Home & Community Care) funding will continue with a new two year agreement for the provision of Training, Information and Education Services throughout Queensland. This is one of our major income streams and reinforces PQI's ongoing commitment in meeting HACC's reporting compliance requirements.

A brief update on our major fundraiser the Parkinson's Qld Unity Walk – press releases and publicity campaigns rolled out this month and despite the "tightening of belts" by organisations our sponsorships and levels of interest from corporate and smaller organisations has surpassed our expectations so we are extremely appreciative of their Unity Walk support. A very special mention to our two major sponsors Heritage Building Society and The Pharmacy Guild of Australia for their commitment, drive and financial support which directly makes PQI's capacity to host this key event so much easier to undertake.

Thank you to all those individuals and support groups who have connections with Parkinson's disease and who continue to give of their voluntary time in various capacities. At PQI we recognise and appreciate the hard work that occurs behind the scenes that we don't always hear about or see, our message to each and everyone is "let's continue to work together to achieve the aims and objectives for people with Parkinson's and their carers".

Patrick Bulman, Chief Executive Officer

Notice of PQI Annual General Meeting

The 2010 AGM will be held on Saturday 16th October at Carina Leagues Club. Financial members are invited to attend and exercise their voting rights for the selection of the 2010/11 Management Committee. Further details are enclosed.

RESEARCH NEWS

Tests May Help Prevent Falls in People with Parkinson's

Tests may help predict who with Parkinson's disease may be more likely to fall, an Australian researcher says.

Study leader Graham Kerr of Queensland University of Technology cautions falls are a major problem for people with Parkinson's disease and can lead to injuries and reduced mobility, which can result in increasing weakness, loss of independence and increased use of nursing homes.

The study, published in *Neurology*, finds the best predictors of whether a person was likely to fall included a test of overall Parkinson's symptoms, a questionnaire on how often people tended to "freeze" while walking and a test of balance. When these tests were combined, the results produced a sensitivity of 78 percent and a specificity of 84 percent for predicting falls.

"These tests are easy to implement and take only a short time to

complete," Kerr said in a statement. "Once we can identify those at risk of falling, we can take steps to try to prevent these falls."

Kerr and colleagues tested 101 people with Parkinson's disease who were able to walk without any aids to evaluate their Parkinson's symptoms, balance and mobility. The participants then reported any falls that occurred over a six-month period.

Research participants are currently being sought for a study that aims to identify risk factors for falling in people with PD, and determine whether a new textured insole can improve postural stability and prevent falls. The research will be conducted during three visits to the Institute of Health and Biomedical Innovation at the Queensland University of Technology, Kelvin Grove Campus. For more information or if you would like to participate in the study please contact Miss Jodi Rippey (07) 3138 6304 or Miss Cara Graepel (07) 3138 6429.

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Modified Equipment: Making Your Life Easier

Every person living with Parkinson's disease is affected differently and multiple facets of a person's life can be altered. Medication is not the only way to manage the symptoms you experience and there are many assistive technology products available to improve your safety, independence and quality of life. Some of the most commonly affected areas of daily life include: mobility, eating and drinking, communication, handwriting and continence.

Mobility

People with Parkinson's disease can experience tremor and loss of balance which causes them to feel unsteady when walking. They may also experience episodes of "freezing" where initiating movement (or getting going) can be difficult. There are several aides available that can be used to provide support and stability when walking. Some aides are in common use by many people, whilst others are designed specifically with Parkinson's in mind. Examples of these include:

- The U-Step Walker (completely surrounds the user and has a laser guided prompt)

- The Laser Cane Walking Stick (also has a laser guided prompt)

People whose mobility has been affected may find a walking stick, walking frame, or seat walker useful as they provide stability and support of varying degrees. If getting in and out of bed or up and down from a chair is difficult, raising the height of the bed or chair using raisers can assist. An armchair with solid supportive arms can also help when transferring. People with Parkinson's can occasionally find promoting by auditory or visual aides helpful when initiating movement and getting up from a bed or chair.

Eating and Drinking

Standard cutlery can be made easier to use by enlarging the handle with slip-on foam tubing. Cutlery is also available with ready made built-up handles. Weighted cutlery is considered a good option for people with Parkinson's as the weight can help to dampen down tremors and make eating a smoother less shaky task. Angled cutlery with bendable shafts can assist people with limited movement to manipulate food into their mouth. A clip-on plate guard or plate with a high lip can be useful for preventing food spillage off the plate when people have reduced control or movement. Two handled mugs and cups are particularly useful for people with Parkinson's as they provide a way to stabilise the cup in your hands and carefully bring it to your mouth.

Communication

As the muscles that control speech become affected by the progression of Parkinson's, people can experience loss of volume, a change in the rate of speech, uncontrolled repetitions of words or sounds and difficulty initiating speech. There are a huge range of

options for people looking for alternative communication methods to assist them. Examples of devices that can be used include: Amplification devices (makes your natural speech louder)

- Telephone relay systems

- Low Tech devices - communication books, letter boards

- High Tech devices - computer software programs, speech generating devices

Handwriting

For those people who experience difficulty with handwriting due to tremor or decreased coordination weighted pens are often found to be useful. In some instances people wear weighted cuffs on the wrists when writing to produce smoother writing. Ruled paper with thick black lines, signature and envelope guides can all help to increase the size of peoples writing or decrease the "spidery" nature of writing that some people with Parkinson's experience.

Continence

As muscles become weaker or harder to control, urinary incontinence can be experienced. Several products are available to assist with managing urinary incontinence which can be mild to severe in nature. Products included pads, pull-up pants, chair and bed waterproof sheets and protector pads. Pads and pants can be sourced in either re-usable or disposable options depending on particular preferences.

Government funding is available to assist with the purchase of continence aids.

About LifeTec

LifeTec Queensland is a leading provider of professional information, consultation, and education on assistive technology that can help individuals improve their quality of life and remain independent. In partnership with a range of complementary organisations, LifeTec Queensland provides free professional advice on the range of available solutions regardless of a person's age or level of ability. Our health professionals assist people to maximise their independence and their ability to manage everyday tasks whether in the home, workplace, or out in the community.

Need to know more?

Telephone, fax or e-mail your enquiry to obtain further information from one of the therapists about products. Alternatively, you can make an appointment to trial the equipment at our display centres or through our outreach service. Please phone LifeTec Queensland for further details 1300 885 886.

- Gaenor Walker, Occupational Therapist



Support Group Co-ordinators' Workshop

On 31st July PQI held a Support Group Co-ordinators' Workshop at the Yurana Activity Hall in Springwood with eleven Support Groups represented from across the South-East corner. The feedback from the meeting has been overwhelmingly positive and attendees were able to debate a broad range of issues enhanced by team presentations and a stimulating session from Associate Professor George Mellick from Griffith University which was warmly appreciated. The task now is to collate the information gained from the Support Group Workshop attendees and convert this into an action plan with clear objectives and time frames.

Planning is now underway for our second road trip which will take in the geographic areas of Rockhampton, Gladstone, Biloela and Yeppoon in late September and early October. The Yeppoon Support Group has recently come under the umbrella of PQI and we are delighted at the prospect of a new Gladstone Support Group commencing in the near future. Similarly it has been pleasing to note the levels of interest from individuals indicating a desire to form or run a new Support Group in locations such as Hervey Bay, Dalby and Roma. Equally important however is that

PQI will continue to demonstrate our commitment and willingness to sustain and strengthen existing Support Groups by collaboration, effective communication, listening to our members and active support.



ABOVE: Julie Pring from Caboolture Support Group discussing recommendations for future improvement of support group development.

Introducing PQI's Newest Staff Member

My name is Lynda Foulis and I started at PQI on 8th June as the Client Services Coordinator.



Previously I worked at a charity for children with autism for four years. During my time there I worked within the Fund-raising Department and ran the Parent Helpline. I was involved in parent training, workshops as well as working with the children, families and allied health professionals.

Since I started at PQI I have made contact with all the Support Group Coordinators and am looking forward to meeting you all over the following months. I have visited several support groups which are all as individual as the people who attend and run them. Each support group has been a wealth of information and knowledge and I hope that through the support group newsletter you can each share your information with each other and network, there is no better way to spice up a support group than through joint and shared knowledge.

Over the coming months we will be visiting all the support groups throughout Qld and holding workshops throughout rural and remote Queensland to raise awareness of PD and identify where the greatest need in the community for support groups is and then assisting in the creation of the support group. I am very excited to be part of the team here at PQI and look forward to meeting you all.

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PBS Approves Sifrol ER

Sifrol ER, a new 24 hour sustained release form of Sifrol became available on the 1st August under the Pharmaceutical Benefits Scheme. Data from clinical trials demonstrated more constant levels of plasma concentration were achieved with a once-a-day tablet than with the three-times-a-day immediate release tablet.

The 24 hour release tablet will allow a more constant medication level throughout the 24 hour period, potentially reducing the severity of motor fluctuations, and for some people improving sleep and assisting with night time difficulties. Sifrol ER still has the same potential side effects as Sifrol (nausea, constipation, hallucinations, confusion, dizziness and swelling of feet) so please consult your Neurologist or GP to discuss any change to your medication regime.

Seminar DVDs Available

A DVD of the Pain & Non-Motor Dysfunction seminar held in mid July is now available for purchase for only \$10.00 + \$2.50 postage. Copies are also available of the three seminars previously held:

- Important aspects of Parkinson's disease for those newly diagnosed
- Hospitalisation
- Mood & Anxiety

Please call the office if you would like to purchase any of these DVDs. Please note that the DVDs are of amateur quality only. Each support group has now been sent an entire set of the seminar DVDs.

The next seminar hosted by Professor Peter Silburn will be held during the day on Friday 19th November. Topic, venue & time will be announced shortly—if you would like to be notified of these details once they have been organised please notify the office and provide your name and contact phone number.

Rotary Club of Biloela

PQI would like to thank the Rotary Club of Biloela for their generous donation of \$13,000 raised from a special fundraising ball held in the Biloela Butter Factory. The donation was gratefully accepted on behalf of PQI by Jan Nolan and Thelma Neumann from the Rockhampton Support Group.

The donation will be put to good use towards the improvement of PQI services to rural areas as identified throughout the upcoming road trips.

Research Open Day

A free Research Open Day will be hosted by PQI and Associate Professor George Mellick at the Eskitis Institute for Cell and Molecular Therapies, Griffith University on Wednesday 8th September from 10:30am. The open day will feature a laboratory tour, guest speakers and updates on current research projects in QLD. Please call 1800 644 189 to RSVP—bookings are limited to 70 people.

George Mellick leads the Clinical Neuroscience Group and specialises in investigating the causes, development and incidence of Parkinson's disease, and examines the influence of complex interactions between genetic and environmental factors on disease risk.

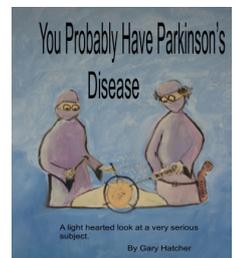
New PD Initiative Launched

The Royal College of Nursing Australia has announced the establishment of a new faculty to support nursing and community services that assist people with Parkinson's disease and other progressive neurological movement disorders to manage their complex conditions. It is hoped that The Movement Disorders and Parkinson's Nurses Faculty will help fill a care gap in Australia, by raising awareness of the issues around this health area that is often misunderstood and poorly resourced.

Parkinson's and movement disorder nurses is a growing field in Australia, and specialised nursing is essential to provide people who have these disorders with the support they need to retain independence in the community, and reduce hospital stays. Such nurses play an essential role in developing care and treatment strategies for individuals.

"You Probably Have Parkinson's Disease"

PQI member Gary Hatcher recently launched his book titled *You Probably Have Parkinson's Disease* to a receptive group of friends, family, neighbours, former colleagues and medical professionals at the Bracken Ridge Community Centre. Gary's book is a light hearted look at his own personal journey since being diagnosed with Parkinson's disease in 2002.



Gary's life motto is "I can do anything as long as I don't take it too seriously", so it's no surprise that his book is peppered with humour and spirit as he details the early stages of life with PD and subsequent recovery from Deep Brain Stimulation surgery in 2009. To purchase a copy of Gary's book please call (07) 3261 1769 or email ruthgary@ozemail.com.au.

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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 July 2010. Although we can't list all your names, your support is gratefully appreciated. Listed are those who kindly donated **\$50 or more**.

Donations:

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Donations in Memory:

Leslin Dettrick, Wilma Farley, Beatrice Flanders, Paddy Murray, Lelio Dalla Pozza, Brian Stirling, Lawrence Tweedale, Edith Wagstaff, Judy Walker, Anne Wyatt.

The staff and management committee of PQI would like to pass on their sincere condolences to Joan Murray following the death of her beloved husband Paddy. Paddy made an enormous contribution to the Noosa/Tewantin Support Group over the past 9 years and was well liked and respected within the community. Paddy will be sadly missed.

Volunteering Efforts Awarded



ABOVE: Bob & Margaret Vickers receiving an award from Kerry Rea in recognition of their tremendous volunteering efforts. Not only do they co-ordinate the Logan Support Group, but they also volunteer one day every week in the office. Congratulations Bob & Margaret!