



# *The Quarterly*

## World Parkinson's Day How We Celebrated

In celebration of World Parkinson's Day on the 11th of April, Parkinson's Queensland Inc held a morning tea in the state office. The morning tea was just one of many events held across the state.



Members and Staff sharing World Parkinson's Day Morning Tea



Several Support Groups in Kedron, Bribie Island, Nambour, Mareeba, Dalby and Port Douglas held morning teas taking advantage of the Party for Parkinson's packs that were available through the office. Pharmacy Guild held a competition for the best Parkinson's Awareness display in Queensland Chemist Shops, other events included a display at Greenslopes Private Hospital (pictured right) and a photographic exhibition by Young Onset Ambassador Mary-Louise Lloyd. Quest Newspapers also supported the day by including events in local newspapers.



## Unity Walk 2011....

**Date Claimer - 28th August 2011**

The Parkinson's Queensland Unity Walk for 2011 will be held on Sunday the 28th of August at New Farm Park, Brisbane. Registrations will be available for individuals, families and teams. Details including registration will be available on our website shortly. The annual event will coincide with the commencement of Parkinson's Awareness Week.

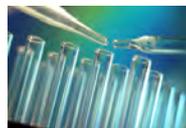
If you would like to volunteer on the day please contact the office on 1800 644 189



## What's Inside...



**Reports  
Page 3**



**Research  
Page 4**



**News  
Page 6**



**Back Page  
Page 8**

# Parkinson's Queensland Inc.

"Committed to caring"

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**Young Onset Ambassador:** Mary-Louise Lloyd

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

## DISCLAIMER

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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### Biloela

Call PQI for details Ph: 3209 1588

### Bribie Island

Ann Mitchell Ph: 3408 2120

### Broadbeach

Dawn Leigh Ph: 5599 5380

Margaret Bell Ph: 5598 5154

### Bundaberg

Elaine Williams Ph: 4159 8118

### Caboolture

Joy Boyle Ph: 5498 7333

### Carers

Neil Page Ph: 3278 5152

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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

Pauline Newman Ph: 4978 0646

### Hervey Bay

Jamie de Salis & Barry Vincent Ph: 4128 6046

### Indooroopilly

Call PQI for details Ph: 3209 1588

### Ipswich

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Call PQI for details Ph: 3209 1588

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Slim Pearsall Ph: 4092 1374

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### Mitchelton

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### Mt Gravatt

Mavis Edwards Ph: 3341 5227

### Nambour & District

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### Port Douglas

James Watson Ph: 4098 5335

### Redlands/Bayside

Phyllis Trost Ph: 3207 4664

### Rockhampton

Marlene Schultz Ph: 4933 4148

Thelma Neumann Ph: 4928 7690

### Roma

Peter Thomas Ph: 4622 2512

### Strathpine/Lawnton

David and Angela Martin Ph: 3410 8054

### 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

## Inside This Issue

- 1. World Parkinson's Day Events**
  - Unity Walk
- 2. Contact Information**
- 3. Office News**
  - CEO's report
  - President's report
  - New Information Officer
- 4. Research News**
  - Parkinson's and Malnutrition

## 5. Health & Wellbeing

- Carer Support Group
- What is a Support Group
- Helping Children to cope
- Young Carers Support

## 6 - 7. News & Events

- National Conference
- Young Onset Ambassador
- Pedal for Parkinson's
- Greenslopes Hospital New Program
- Duodopa

## 8. The Back Page

- Deadline -

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



## CEO's Report



World Parkinson's Day was held on the 11th April with a wide variety of activities profiling and raising the awareness of Parkinson's taking place across Queensland. Amongst the events included nine Support Groups holding a "Party for Parkinson's" day, Mary-Louise Lloyd through the kind assistance of Sony organised a very successful Photography Exhibition, Greenslopes Private Hospital created an Awareness display in their foyer and a World Parkinson's Day Morning Tea was held at the

Springwood office with a Media Release by Senator Claire Moore made available. Quest newspapers ran local stories on Parkinson's and we are awaiting the outcome of the Pharmacy Guild competition for the best Parkinson's Awareness display in a Chemist shop in Queensland.

One of the highlights of World Parkinson's Day was the announcement of Mary-Louise Lloyd as the Young Onset Ambassador for Queensland – the role encompasses working with the young onset Parkinson's disease clientele who do not necessarily want to belong to a Support Group but who wish to have a social support structure in place that best fulfills their needs – this is a journey which Mary herself is both familiar with and continues on.

Support Group activity has been prolific since the last reporting period with Community Consultation sessions occurring all over the State. As a consequence PQI now has new Support Groups in place in Biloela, Browns Plains, Strathpine/Lawnton, Hervey Bay, Laidley, Deep Brain Stimulation (DBS) Group and the Carer's Group. This activity has resulted in a total of 38 operational Support Groups with 90% growth in Support Groups over the previous 12 months. Community Consultation sessions are also planned next month in Gympie and Gatton.

It is interesting to note that the increase in Support Groups has had a positive impact on membership with latest membership figures indicating an increase of over 10% in this financial year, further planning suggests that growth in Support Groups could reach 45-50 by the end of the 2011/12 financial year as awareness spreads and the profile of the organisation is raised.

The submission for the Parkinson's Community Nurses has been completed and meetings arranged with both major state political parties for April 21<sup>st</sup> and May 4<sup>th</sup>. Within the submission the role of the Parkinson's Community Nurses has been clearly articulated with a key function being the main conduit between the Person living with Parkinson's (PLwP), the Carers, GP's Neurologists and Allied Health – the implementation of this model in other States confirms that cost effective care within the home can be provided with a corresponding reduction in hospital and nursing home admissions.

**Patrick Bulman, Chief Executive Officer**

## President's Report

Over the last few months staff have coordinated numerous meetings of Support Groups and formed new groups throughout the State.

There has been a conscious effort to reinforce the link with Support Groups and members.

I have visited several support groups and look forward to continuing that activity throughout the year as opportunities arise.

I encourage all those participating in Support Groups to become members of PQI.

A major fundraising and awareness event for PQI is the Unity Walk. This is to be held on 28<sup>th</sup> August at New Farm Park. The new venue

will allow greater participation in the event and hopefully be an opportunity to expand the event.

I encourage all of you to join the Walk and to seek donations to ensure this major event on our calendar is a success.

PQI annually grants funds for research and in February the funds for the 2011 grants were disbursed to the successful applicants.



This is an important part of our function as an organisation and is dependant on donations and bequests for its funding.

The CEO and I recently presented a detailed submission to the State Government for funding of four Parkinson's Community Nurses and the Opposition will be briefed in the near future. This will be an ongoing direct lobbying process that has had success in some other states. We are aiming to see some results of this activity in the 2012 State Budget.

**John Bird, President**

## New Information Officer



My name is Tanya Turner-Jones and I started at PQI on the 14th of February as the Information Officer. Previously I worked in a government funded information and referral service under the auspices of a charity. During my time there my responsibilities included attending community events and expos, speaking engagements, responding to telephone enquiries and various administrative duties.

My role as the Information Officer encompasses many aspects of the services provided by PQI. As part of my role I will be responding to enquiries over the phone and maintaining the information resources as well as presenting Education and Awareness Sessions.

## Malnutrition in the Parkinson's Community: Study seeks volunteers

People with Parkinson's disease are pre-disposed to malnutrition, yet very little is known about the prevalence of this problem or the best way to overcome it. A PhD student at Queensland University of Technology (QUT) is looking for participants for a study which aims to shed some light on the issue.

"Parkinson's disease is a progressive neurological disorder. The characteristic symptoms most people know of are motor symptoms, including tremor," said Jamie Sheard, who is undertaking her PhD research at QUT's Institute for Health and Biomedical Innovation (IHBI).

"However Parkinson's disease affects a lot of non-motor symptoms



as well. People may have difficulty swallowing, lack senses of smell and taste, lack appetite and a condition whereby they feel full fairly quickly. In addition, depression and anxiety are quite

common.

"It's been reported that there is a higher risk of malnutrition for people suffering from Parkinson's disease than for the rest of the community. However, no one is entirely sure what leads to this occurring - whether it is caused by the motor symptoms or other symptoms."

Ms Sheard said that it was important to get to the bottom of this issue, as malnutrition could greatly decrease a person's functional

ability, immunity and quality of life. Yet despite there being an estimated 55,000 people with the disease in Australia, she said to date there were no dietetic guidelines available for practitioners treating Parkinson's patients.

"In my research I hope to talk to 150 people over the age of 18 with Parkinson's disease. Based on my findings, I will be able to form an estimate of the rate of nutritional problems among those who have this condition," she said.

"I also want to identify the factors which put someone at a higher risk of getting malnourished if they have Parkinson's disease. The research will help in the formation of dietetic guidelines which hopefully will reduce the number of people with Parkinson's who suffer from nutritional deficiencies."

Ms Sheard would like to hear from people with good nutritional status as well as those with a poorer nutritional status. She said it was integral to her study to compare these two groups and identify the differences between them.

"For study participants, we will have a two-hour consultation either in the person's home or at QUT's Kelvin Grove campus. It involves a nutritional assessment, cognitive assessment, and some non-motor assessments looking at issues such as appetite and sense of taste," she said.

"For those in the study who are identified as being potentially at risk of malnutrition, there is the option to take part in a 12-week intervention which would seek to improve their nutritional status." If you are interested in taking part in Ms Sheard's research, she can be contacted on (07) 3138 6183 or [jamie.sheard@qut.edu.au](mailto:jamie.sheard@qut.edu.au).

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## Supporting Carers

## Supporting Young Queensland Carers

Young carers are people under the age of 26 who provide care in a family affected by illness, disability, mental health and/or drug or alcohol issues of one or more family members or friends.

In Australia there are approximately 380,000 young carers under the age of 26 and of these it is estimated that 170,600 are under the age of 18.

Young carers provide a wide range of practical and emotional assistance to those for whom they care including:

- accompanying the person cared for to medical appointments
- assisting the person they care for with dressing, bathing, toileting and mobility
- administering or reminders about medication
- providing social support to the care recipient
- providing support during periods of increased emotional or physical stress
- buying groceries, cooking, cleaning, handling household finances
- advocacy and negotiation with service providers

If you are a young carer looking for support or information, contact Carers Qld Young Carers Program on 1800 242 636.

## Explaining Parkinson's to Children

For many people, the diagnosis and appearance of symptoms of Parkinson's brings with it questions from their children, grandchildren and other young people in their lives.

According to the Parkinson's Disease Foundation ([www.pdf.org](http://www.pdf.org)) being open with children and explaining your diagnosis in simple terms as well as encouraging children to ask questions can help children better understand. If children are struggling to understand or are not coping it is best to speak to your GP or a Counsellor and work through this as a family.

Parkinson's Queensland also has a book "I'll Hold Your Hand so You Don't Fall by Rasheda Ali (daughter of Muhammad Ali).

## Carer Support Group

The first meeting of the reconvened Carer's Support Group was held at the PQI office on 15<sup>th</sup> April. We considered a number of important strategic questions grouped around "What do we want a carer's group to do?". We didn't want to duplicate what others do, such as Carer's Queensland, but saw value in at least (a) providing a forum to discuss PD specific issues for carers, (b) facilitating the development of networks of people with shared hobbies and interests and (c) identifying and discussing published information on self care for carers.

A challenge for us is to reach carers who can't make the meetings of the Carer's Group. We agreed to try to do this by either (a) offering to include them in meetings by telephone or Skype or (b) having a support *hotline* for one-on-one support outside meeting times.

Next meeting is 10am Friday 20<sup>th</sup> May at the PQI office. Please let Lynda or Neil know by phoning 1800 644 189 if you would like to attend in person, by phone or Skype so that we can plan accordingly. Separate activities are available at the PQI office for carers if you would like to bring them too.

## What is a Support Group?

Support Groups are an integral part of the services provided by PQI and for people with PD. Support Groups are run by volunteer coordinators throughout Queensland and provide friendship, emotional and practical support with people facing similar challenges allowing everyone to share feelings, resources and experiences.

A support group is an informal gathering of people who share similar experiences, situations or problems. What is a Parkinson's Support Group? Parkinson's Support Groups offer members a chance to meet and talk with other people who are going through similar experiences while offering each other emotional and practical support.

**Remember, support groups can change lives!!!**

(See Page 3 for a Support Group near you!)

# NEWS & EVENTS

## National Parkinson's Australia Conference 2012

Planning is underway for the National Parkinson's Australia Conference 2012 to be hosted by Parkinson's Queensland Inc. The conference will be held on the 13th and 14th of July at the Brisbane Convention and Exhibition Centre. Our target audience is broadly based — people with Parkinson's, their carers, allied health practitioners and researchers, drawn from around Australia and New Zealand. We are planning for both invited and contributed presentations covering topics that include: *Advances in Surgical Treatments, Advances in Drug Treatments, Young Onset, Parkinson's Nurse Specialists, Exercise Treatments, Depression and Anxiety, People with Parkinson's in Aged Care, Balance and Falls, Nutrition, Caring for the Carers and My Life with Parkinson's.*

## Parkinson's Queensland Welcomes Young Onset Ambassador

When approximately 1 in 5 people who are diagnosed with Parkinson's disease are of working age, Parkinson's can no longer be regarded as an 'old' persons disease or merely part of the natural course of ageing. With Young Onset Parkinson's comes a different range of issues including financial and employment issues, caring for children and ageing parents as well as the normal challenges that come with managing PD. People with Young Onset Parkinson's often feel disconnected from services and can feel isolated.

As part of Parkinson's Queensland's commitment to representing people with Young Onset Parkinson's, we are pleased to announce the appointment of Mary-Louise Lloyd as the Parkinson's Queensland Young Ambassador. Mary-Louise continues to travel extensively and pursue her love of photography and has kindly made herself available for others with Young Onset PD to contact her. To contact Mary-Louise please call the PQI Office on 1800 644 189 for relevant details.

## Pedal for Parkinson's

On Tuesday 3rd May 2011 our CEO Patrick Bulman launched "Pedal for Parkinson's". Patrick will be riding the equivalent distance from Brisbane to Cairns (1,700kms) on a stationary bike to raise awareness and funds for Parkinson's Disease. To donate, please visit [www.everydayhero.com.au/pedalforparkinsons\\_](http://www.everydayhero.com.au/pedalforparkinsons_).



## Duodopa now available on PBS

For Australians currently enduring the severe and immobilising effects of advanced Parkinson's disease a treatment option is now subsidised that could help them and their families control this chronic disease.

The treatment Duodopa® (levodopa/carbidopa) will be funded by the Federal Government's Pharmaceutical Benefits Scheme (PBS) starting from 1 May 2011 for the management of advanced Parkinson's disease in adults with severe disabling motor fluctuations (involuntary movements) not adequately controlled by oral therapy.

Duodopa treatment involves delivering the medicine directly to the small intestine where it is absorbed. The aim of treatment is to achieve consistent supply of medication to maintain good motor control.

In the first instance, please contact your GP and/or Neurologist for further information.

## Driving: Should you or Shouldn't you?

At a recent Question and Answer forum with Neurologist Professor Peter Silburn, the question of driving with advancing Parkinson's was raised. With this in mind the following information was taken from the Queensland Transport fact sheet on recently introduced legislation.

Driving a motor vehicle is a complex task involving perception, appropriate judgement, adequate response time and reasonable physical capability. A range of medical conditions as well as certain treatments may impair any of these factors.

Although the extent to which medical conditions contribute to road crashes is difficult to assess there is international recognition of and community expectation that medical standards for driving be established and applied. The medical standards for driving recognised by all driver licensing authorities in Australia are contained in the Assessing Fitness to Drive 2003 publication.

In November 2004 a driver who suffered an epileptic fit hit the car of 22 month old Jet Rowland's mother's. The impact killed Jet, severely injured his mother Anita Rowland and left his brother Bailey confined to a wheelchair. Medical Condition Reporting



Legislation introduced after the tragedy has been named "Jet's Law" in recognition of the little boy whose death inspired the laws. Driver licence holders have a mandatory requirement to report any long term or permanent medical condition that may affect their ability to drive safely to Queensland Transport. As soon as the condition develops or as soon as there is an adverse change to an existing condition, you need to take steps to inform Queensland Transport.

Queensland Transport recommends that you should talk to your health professional about your medical condition and any potential impact this may have on your ability to drive safely. Health professionals are qualified to check if you are medically fit to drive.

They may provide a medical certificate or official letter stating your fitness to drive.

*Fact Sheet: Jet's Law, Drivers licence holders and Medical Condition Reporting, Queensland Transport*

If you have decided to cease driving or want to plan ahead please contact Parkinson's Queensland for information on Community Transport services in your area.

## Greenslopes Private Hospital Introduces New Program for People with Parkinson's

The Greenslopes Private Hospital is delighted to announce the development and implementation of a Parkinson's Program. The Parkinson's Program will be available to both Veteran and private patients and will consist of individual and group therapy and education sessions. It will run on a Tuesday and Thursday, for 6 weeks along side the LSVT (Lee Silverman Voice Treatment) Program.

The LSVT Program is an intensive and scientifically proven voice program specifically designed for people with voice and speech difficulties arising from Parkinson's disease. This Program is beneficial for people who have a soft voice or for whom others might find it difficult to understand. The LSVT Program runs 4 days a week for 4 weeks.

The Parkinson's Program aims to provide relevant information to assist patients and carers to manage their condition, maximise independence and improve quality of life.

Features of the Program include:

- Speech Pathology can assist with eating and drinking difficulties and speech clarity and volume.
- Physiotherapy can assist with improving strength and endurance, balance and coordination of movement and improving the way you walk.
- Occupational Therapy can assist with improving your ability to do everyday activities such as hobbies, handwriting and memory.

The Program also includes education sessions from a Psychologist, Social Worker, Pharmacist, Dietitian and Nurse. Carers are most welcome to attend the education sessions.

A referral is required from your G.P. or specialist to the Greenslopes Private Hospital Geriatrician or Rehabilitation Specialist. For more information please contact the Rehabilitation Liaison Nurse on (07) 3394 7418.

## Make a donation to Parkinson's Queensland Inc.

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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 April 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:

J. Martin; L.Tencate; R. Joyce; B.Fuge; Mary O'Keeffe Trust; Redlands/Bayside Support Group; K & J Sinnamon; M. Boyd; D. Boyd; V. Shaw; Fr Wright; N & A Russell; Australian Catholic University; J & D Leigh; W & M Curnow; J. Baker; A. Banfield; S. Morero; A. Donovan; Glasshouse Mountains Advancement Network Inc; Centenary Memorial Gardens; P J. Donovan; J. Cox; H. Mcilmoyle.

### Donations in Memory:

Robert & Gwen Wood; Kevin Robins; Lynette Hooper; Ronald William Garrison; Jim Morero; Robert (Bob) Joseph Bauman; Ian Wilson; Gladys Lillian Ashe; Ralf Guzak

### Research Donations:

The Inner Wheel Club of Gayndah Inc; Burstows Funeral Care; H L Dobbie

## Congratulations to Port Douglas Support Group on a job well done!

The Port Douglas Support Group held a very successful fundraising event to celebrate World Parkinson's Day and raised \$1200 for Parkinson's.



**Pictured :** Port Douglas Support Group Coordinator James Watson presenting cheque to CEO Patrick Bulman