



the Quarterly

Prime Minister Kevin Rudd Shows His Support for World Parkinson's Day

Letter extract from The Honourable Kevin Rudd MP, Prime Minister of Australia

Parkinson's Disease is a condition that affects people in very different ways. That's why World Parkinson's Day, alongside Parkinson's Awareness Week, is crucial to increase knowledge of this challenging illness. Understanding the difficulties faced by people with Parkinson's Disease will lift awareness and help reduce the stigma associated with the condition.



Research is essential in providing a greater understanding of Parkinson's Disease and its causes. It is the key to better treatments and management of the condition and ultimately improving the quality of life for people living with Parkinson's Disease. The Australian Government understands this and has committed over \$51 million since 2008 including \$22 million through the National Health and Medical Research Council for specific Parkinson's Disease research," said Prime Minister Rudd.

Organisations such as Parkinson's Australia, Parkinson's Queensland Inc. and other state affiliates play a critical role providing support for research, awareness and education. The dedication and goodwill of these organisations' members in assisting people with Parkinson's Disease and their families should be commended.

The Honourable Kevin Rudd MP
Prime Minister of Australia

Many times in life we are faced with challenging situations that take away our ability to be the best we can. It could be for a moment, a day, or months, but the bottom line is that the situation makes us forget who we are or a positive thing we have promised to do. Yet life being so kind brings us to the spot where we are reminded of who we are and given the chance to express the divinity in us. Through these reminders, we are given the chance to remedy such challenging situations. Sometimes these reminders are shrouded in the little things we encounter or in the characters we casually meet. At other times, they are laid bare before us through persons very close or commonly around us.

Many times we take for granted these people and situations that serve as instruments for these reminders. Consequently, we fail to note these reminders. We dwell on the frivolities; we refuse to budge from our positions of pride and we refuse to compromise even when such a little concession would make all the difference in the world. Doing so, we unconsciously extend the difficult situation not knowing that our momentary ego-triumph is only a postponement of that which we think we are running from.

Yet life knows better. It kindly comes around again in another form and in another situation to present us with yet another chance. I am still learning.

Kevin Robins, Editor

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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.

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- Deadline -

All submissions for articles or
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of *the Quarterly* magazine must
be received no later than
31st July 2010

Support Groups of Parkinson's Qld Inc.

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Mt Gravatt
Mavis Edwards Ph: 3341 5227
Young Onset PD
Kevin Robins Ph: 3807 0228
Logan
Margaret Vickers Ph: 3808 6356
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Phone PQI Ph: 3209 1588
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Eddie Skitt Ph: 4058 0171
**For DBS phone support please call
Judy Rawlins on (07) 3886 1592.**

MANAGEMENT COMMITTEE NEWS

President's Report

We are well into another hectic year working hard to improve our services to members. With our new CEO, Patrick Bulman, on board this is so much easier. Patrick has brought great skills to this role from which we are benefitting already. Unfortunately we have lost one of our small team – Paula finishing up as Care Co-ordinator on 6th May. All at PQI have really appreciated the care and commitment Paula brought to the position and wish her well for the future. We are now working through the process of recruiting a new person for this crucial role.

Since my last report to you I have had the pleasure of visiting the Mt Gravatt and Beaudesert Support Groups. I really enjoy this direct contact with members and hearing at first hand about their concerns and sharing knowledge about what is going on in the Parkinson's world. As Patrick has written elsewhere in this issue, we are committed to improving this interaction.

As always, PQI is struggling to find the resources to deliver the services we know you need and deserve. With this issue you will find details of membership renewals, due by the end of June. The Management Committee regrets that we have been forced to make a modest increase in our membership fees for the 2010/11 year - the first increase for a number of years. At the new rates our membership fees still compare very favourably with those of other states. Even with the new rates our budget is likely to be in substantial deficit both this year and next, a situation that can only be accepted for a short time as we build the organisation to a more sustainable level. Patrick has mentioned our plans for fundraising – please help with this (and donations) so that we can continue to service those across Queensland affected by PD.

Neil Page, President

CEO's Report

Welcome one and all to another edition of the Quarterly. It is great to be part of an organisation that is driving hard on a number of fronts to improve the lives of people with Parkinson's, their carers and family members. I would like to take this opportunity to provide a snapshot of activities the PQI team is working on - this includes a Queensland Support Group Co-ordinators' Workshop planned for July 30th and 31st July in Brisbane. We plan to have two representatives from each of our Support Groups attending on what will be a tremendous opportunity to network, share knowledge and ideas and have access to well credentialed external speakers.

We are committed to visiting every support group throughout Queensland this next year including geographic areas the PQI team have identified where there are currently a core number of PQI members (and potential members) and where a new support group could feasibly be established. Details of the road trip will be announced in future editions of the Quarterly and through our regular Support Group Newsletters.

The planning for our Unity Walk on the 12th September 2010 is

well underway with sponsors coming on board and a project team being developed to ensure the event receives the exposure it deserves during Parkinson's Awareness Week. The Unity Walk is one of many fundraising activities planned for the next 15 months - a golf day, a special Mother's Day raffle and a Qld schools gold coin donation initiative are just some of the examples of activities under development. These activities link directly with our business and strategic plans which are being revamped to ensure our financial sustainability into the future.

We look forward to your continued involvement in the future success of Parkinson's Queensland Inc.

Patrick Bulman, CEO

Operations Sub-Committee Report

Our Sub-Committee has been able to reduce our workload due to having Patrick, the new CEO, come on board. He is a welcome member of the team.

We are currently waiting to hear if we have been successful in gaining a grant to run the Support Group Co-ordinator Workshop. If successful we plan on helping with air-fares and expenses, if unsuccessful we will still have the workshop but at a reduced scale i.e. billeting out of town members etc. We have just finished updating all the SG Co-ordinator Papers so these will be available to be reviewed and discussed at the workshop.

To help with our fundraising a merchandising order form has been produced and is being sent out with all mail-outs from the office.

Planning for this years Parkinson's Qld Unity Walk is well established and we are hoping for more team entries this year. Last year the bus load of students from Toowoomba was wonderful so we are hoping that this will encourage others to do the same this year. We would like to see more group entries for the Support Group Challenge this year.

We are also planning a morning tea for life members on Friday 9th July. Invitations have been mailed out.

We would like to congratulate Rebecca (our Information Officer) on her recent wedding to Peter on 24th April. You made a lovely bride and we wish you all the best for the future.



LEFT: Rebecca Saunders (Information Officer) and her husband Peter on their recent wedding day.

(Image courtesy of Life in Images Photography)

Joy Boyle, OSC Chair

RESEARCH NEWS

Young Australian Scientists Trained in Latest Stem Cell Discoveries

The Australian Stem Cell Centre (ASCC) will be training young researchers for the first time in the techniques of growing and using human induced pluripotent stem (iPS) cells in research.

The training will be conducted through StemCore, the ASCC's national facility for the provision of stem cells and advice.

Japanese scientists first discovered iPS cells in 2006 when they reprogrammed ordinary skin cells into versatile stem cells. This discovery was significant as it offers the long-term prospect of personalised and disease specific cell lines being available for treating disease, testing medicines and for research purposes. iPS cells also represent a new and innovative way for scientists to study and understand disease and development.

The ASCC is delivering training programs, referred to as the StemCore iPS Cell Workshop, for the first time in Australia. It is an intensive hands-on laboratory based training course, which allows participants to gain direct experience in growing and analysing human pluripotent stem cells. Demand for the course has been high and this week's inaugural course is fully booked.

From Monday, participants will spend the week receiving hands-

on training and lectures at the Australian Institute for Bioengineering and Nanotechnology located within the University of Queensland. The participants will take back to their home institutions the knowledge and skills required to make, grow and expand iPS cells for use in research. They will also learn how the stem cells created can be directed to turn into the different cell types of the body, such as heart cells or neural cells.

The course will be led by Associate Professor Ernst Wolvetang, an expert in embryonic stem cells, iPS cells, cell reprogramming and genetic stability. According to Associate Professor Wolvetang "more and more researchers are looking to use iPS cells as these reprogrammed cells can be generated from patients with genetic disorders to create and study disease models in the laboratory which may provide a future platform for drug screening" he added that "for example the StemCore iPS laboratory is helping Professor's Carolyn Sue and Alan MacKay-Sim to make iPS cell lines from patients with Parkinson's disease and Schizophrenia, respectively".

Source: Australian Stem Cell Centre, <http://www.stemcellcentre.edu.au/NewsEvents/News/TrainingAustralianScientistsinLatestStemCellDiscoveries1.aspx>

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Have you been involved with the completion of an Enduring Power of Attorney or an Advance Health Directive?

The School of Social Work and Human Services at the University of Queensland is looking for participants for a project that aims to explore any issues associated with Queensland's enduring powers of attorney (EPA) and advance health directive (AHD) forms and suggest improvements concerning their usability and effectiveness for the people who use them.

Who are we looking for?

We are looking for people who have completed an EPA or an AHD in the last two years or have been appointed an attorney under an EPA in the last two years to participate in focus groups. We would like to hear about your experiences with the forms and give you the opportunity to tell us what you think of the forms, and suggest any improvements.

If you are interested, or require further details, please contact **Carlie Rocco on 3346 7314 or email: c.rocco@uq.edu.au**



Negotiating Your Work Hours

This article has been prepared by Maurice Blackburn Lawyers (MBL), and PQI gratefully acknowledges their contribution on this important topic, one of concern to many members. The views expressed are those of Maurice Blackburn Lawyers.

Readers wishing further information on this topic are encouraged to contact MBL Disability Helpline (1800 196 050) or seek alternative advice from appropriately experienced legal practitioners.

One of the biggest legal issues for people with Parkinson's who are in the workforce is whether they have the right to reduce their hours of work. More than any other symptom, fatigue affects people with Parkinson's in the workplace. Many have great difficulty maintaining full-time work and would benefit by a reduction in working hours whether by working alternate days or reduced hours per day. The transition from full-time to part-time work may be relatively smooth with the co-operation of treating doctors and a supportive employer. However, this is not always the case.

Some employers are unable or unwilling to accommodate people with Parkinson's with requests to reduce their work hours, sometimes with the result that workers have to leave their job. The question that is often asked is whether an employer can be forced to agree to a worker reducing their hours to part-time because of Parkinson's. Until recently the answer was probably 'no'. However, several Court decisions in 2004, and some recent legislative changes might mean that workers with disabilities are able to reduce their work hours in some circumstances.

Generally speaking, under anti-discrimination laws, it is unlawful for employers to discriminate against workers because of a disability. It is also unlawful for employers to indirectly discriminate against people with disabilities by having in place a policy or practice that affects people with disabilities more than other people. However employers will usually be excused if their conduct was reasonable.

Over the years the Courts have interpreted the anti-discrimination laws and have limited them to discrimination against workers in the jobs they were employed to do. This meant that an employer could not be forced to offer a disabled

employee different work or reduced hours because that would, in effect, be requiring the employee to provide a different contract of employment.

Whilst your employer might have to modify your workplace to accommodate your Parkinson's (e.g. provide you with a fan or wheelchair access), they did not have to offer you part-time work.

However, recent decisions made by the Federal Magistrates' Court might change this. The Court decided that it was unlawful indirect discrimination against women to refuse to allow them to return part-time from maternity leave. The women in the Court cases were awarded compensation against their employers under the Sex Discrimination Act because their employers had no reasonable excuse not to offer part-time work.

For the same reasons, the Disability Discrimination Act (Cth) and the Anti-Discrimination Act (QLD) might protect people with Parkinson's being discriminated against by their employers refusing reasonable requests to work part-time.

Many employers think that anti-discrimination laws are more powerful than they actually are, which can help you in negotiating a reduction in your work hours. However, keep in mind that anti-discrimination cases do not usually result in your work being changed. Most cases are settled for compensation, sometimes with the worker resigning from their employment. It is also very important to consider whether going part-time will have any effect on your superannuation and insurance rights.

Most workers are covered for disability benefits in their employment superannuation and many also have income protection insurance. Sometimes those benefits can be reduced or even lost if you reduce your work below a minimum number of hours per week.

Before you decide to go part-time – or stop work altogether – get advice about your rights. The information provided is general advice. If you are having difficulty with your employer it is important that you obtain advice regarding your specific circumstances. It is important that you get professional advice before making any decisions about reducing your work hours or stopping work.

NEWS & EVENTS

Entertainment Books Available Now - Only \$65!



The brand new 2010/11 Entertainment Book features hundreds of discount vouchers for restaurants, hotel accommodation, and theme parks. Entertainment books make a great gift for birthdays, and they really pay for themselves with the value you will get from them!

The Entertainment Book is available for \$65 from PQI, and the organisation receives \$13 from the sale of each one. To purchase yours now, please phone **1800 644 189** or email info@parkinsons-qld.org.au.

Christmas Cards

The Schoolhouse Quilters of Kenmore have chosen to donate the proceeds of their annual charity quilt challenge to Parkinson's disease research. They have made A4 sized quilts with the theme of Christmas that are being photographed and made into Christmas cards. An order form will be in the next issue of the Quarterly.

FREE SEMINAR

Parkinson's Queensland Inc.

invite you to hear
PROFESSOR PETER SILBURN
and his team speaking about

Pain and other non-motor dysfunction
in Parkinson's Disease

6 - 8pm

Wednesday July 14th 2010

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 **Novartis & Boehringer-Ingelheim** towards advertising of past seminars.

New Issues to Consider in Managing Parkinson's Disease

This topic was addressed by Dr Matthew Stern, Professor of Neurology and Director of the Parkinson's Disease and Movement Disorders Centre at the University of Pennsylvania, at the educational evening organised by Novartis Pharmaceuticals in April. PQI was kindly invited to be represented at this session directed to PD specialists.

Dr Stern spoke about a wide range of current issues involved with managing PD. Included was a presentation about his research on detecting PD before the appearance of common neurological symptoms. The aim behind this research is to identify the disease in its very early stages and develop treatment regimes that delay or arrest its development. He mentioned that early "markers" often observed are loss of smell, altered sleep patterns, anxiety and depression and slowing bowel activity. Together with other evidence, careful analysis may identify patients at risk of developing PD guiding earlier intervention. Further details about this research can be found in *Movement Disorders* 25, S1, S89-S93 (2010).

Neil Page, President

David O'Loughlin raises over \$3500!

RIGHT: CEO Patrick Bulman presenting David O'Loughlin with an Ipod in appreciation of his phenomenal fundraising effort—cycling over 800kms from Bangkok to Phuket. Well done David!



Plans Underway for Parkinson's Queensland Unity Walk 2010

On 12th September we will again be holding our major fundraising event for the year, the Parkinson's Queensland Unity Walk. The 4km walk to raise money for Parkinson's disease research and support services will commence at 10am from the Bayside Sea Scouts Hall—Lower Esplanade, Manly. The event this year will even feature live entertainment by 5 piece band Lo Fi Way.

Online registrations will open shortly, so be sure to keep an eye on www.parkinsonsqldunitywalk.org.au for any updates! The Parkinson's Queensland Unity Walk is proudly sponsored by:



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THE BACK PAGE



ABOVE: CEO Patrick Bulman and President Neil Page meeting members of the Mt Gravatt Support Group.

Support Group News

The **DBS** group had their second tri-monthly meeting and were lucky to have Karen O'Maley as their guest speaker. Karen answered any questions that members had about care after the surgery, and also pre-surgery enquiries. The next meeting will feature Matt Eastburn (Medtronics) as a guest speaker.



LEFT: The office staff were fortunate enough recently to enjoy a visit from Warwick life members Graeme & Sheila Parkinson (pictured). Graeme was the Stanthorpe Support Group Co-ordinator for many years. They also donated several resources to the library, which were gratefully accepted.

Donations

Thank you to those who have generously donated to Parkinson's Queensland Inc. in recent months to the end of April 2010. Although we can't list all your names, your support is gratefully appreciated. Listed are those who kindly donated **\$50 or more**.

Donations:

R. Barnes, J. Barrett, Boehringer-Ingelheim, D. Boyd, W. Byrne, M. Clarke, S. Everingham, J. Ford, N. Groves, J. Hatch, Heller Foundation Pty Ltd, A. Hitchcock, V. Hood, R. Hopkins, P. Jacobs, M. Jones, L. Ko, P. Lamont, B. Lawson, G. McVeigh, S. Morero, Novartis Australia, M. Parry, M. Prentice, V. Renouf, M. Spry, R. Taylor, B. Thomas, M. Thompson, D. Timmins, G. Turner, B. Vincent, M. Whelan.

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