MAGAZINE OF PARKINSON'S QUEENSLAND INC.

the Quarterly

www.parkinsons-qld.org.au Autumn 2010

Congratulations William Curnow

The Australia Day 2010 Honours List awarded Member of the General Division of the Order of Australia (AM) to one of our members, William (Bill) Curnow.

ABOVE: Bill Curnow at the 2008 AGM.

Bill's award is for service to the construction industry, particularly as an architect of correctional, educational and bio-security facilities, through the promotion and support of collaborative research projects and as an educator.

"*It is nice to receive praise in this way - but it must be remembered that I was always part of, or leader of a successful team and that the honour must be shared around. That said, I am very proud of the fact that I, and my teams have made significant improvements and innovations to a number of important but fundamentally different industries - bio-security/bio-containment, corrective services, hospital services, education, etc. This suggests that the model of "business re-engineering" which I and my colleagues developed is fundamentally correct and universal in its application. Collaborative research and development underpins the process," Mr Curnow says.*

"Business re-engineering" is a theme still uppermost in Bill's thinking. He sees big opportunities for improvement in education (among other things), by applying this principle – an aspect he is pursuing in his role on the board of St Peter's College and an area which PQI may also benefit from Bill's expertise in.

"Don't count the days, make the days count."
- Muhammad Ali

There are several different ways in which we can achieve improvement through self-help. One method is through psychological self-help. Psychological self-help deals with the enforcement of self-control on us by controlling our conscious. Some of the psychological self-help techniques deal with recognising our own weaknesses, dealing with them to improve circumstances and improve the end result.

Psychological self-help deals with changing us to bring about a change in our individual concept. Even a slight positive change in our self-concept can make a huge amount of difference to our own esteem. It motivates and inspires us towards personality improvement.

The human mind is constantly trying to find feasible solutions to problems that might approach even in the future. In fact, every time we plan a modus operandi, we are relying on the concept of self-help. However, it is not merely dealing with the problems we face, but emerging as a better person at the end of it all. It should also teach us to avoid problems in the future and dealing with life in a more positive fashion.

Our beliefs, faiths, and attitudes also help us improve our concept. Our families and friends provide the much needed emotional support and a sense of belonging that ultimately guides us towards improving ourselves on our own.

Just by believing that a task can be achieved, we help ourselves to achieve the task. There are several other such simple techniques that can be used as your techniques to improve the end result. When we are told to think positively, we fail to understand that the only thing that person is doing, is inducing us to help our self.

There are several books available that we may refer, to improve our performance. Most of these books deal with the basic principle: "God helps those who help themselves."

Kevin Robins, Editor

Parkinson's Queensland Inc.

"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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- Deadline -

All submissions for articles or advertising in the Winter issue of *the Quarterly* magazine must be received no later than 30th April 2010

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MANAGEMENT COMMITTEE NEWS

President's Report

Welcome to a new year and a new decade at PQI. I hope you all enjoyed the summer festive season. Already we have been busy at PQI. We have been through a selection process for a new CEO and we look forward to making an announcement soon – check our website for the most recent developments. Further details will be available in our next Quarterly magazine. We have also just submitted our report to HACC for the September – December quarter and it was great to see the snapshot of the achievements of our hard working staff, volunteers and Management Committee.

Two important goals for 2010 include:

(a) increased fundraising

(b) strengthening our Support Group network.

I've written previously about the importance of fundraising for Parkinson's research and PQI's operations and services. It is very pleasing to report that we have just dispersed nearly $160,000 to the successful applicants for PQI research grants from the 2009 round. Details of the funded projects are given in this issue. Planning is now underway to raise further funds. We need your help with this – one of our difficulties is in identifying companies to approach for sponsorship. From recent experience we have most success with those that have some connection with PD, either personally or through their business. **If you can suggest likely candidates please contact the office so that we can follow-up.**

It is always heartening to see PQI benefit from unexpected acts of generosity. A recent example is from David O'Loughlin. David's father and grandfather live with PD and he is raising funds for Parkinson's. Please give David your support – details are on our website or from the PQI office.

Our Support Groups make an important contribution to the delivery of information, education and other PQI services. This importance is now reflected in our new Constitution. We are in the process of revising our policy documents, in consultation with Support Group (SG) coordinators, to strengthen even further the holistic nature of our operations, and clarify the benefits and responsibilities for our Support Groups arising from PQI's insurances and status as a Deductible Gift Recipient (DGR) and registered charity. Planning is underway for a workshop later this year to bring the SG coordinators together to share experiences, learn more about PD and PQI with the goal of collectively working to improve the lives of those affected by PD. Sue and I have enjoyed visiting a number of Support Group meetings over the last year and this has been another important avenue for dialogue and feedback.

It is a pleasure to report that members of the Parkinson's family were recognised in the Australia Day Honours List. One of PQI's members, Bill Curnow has been made an AM (see front page for details) and John Silk, President of Parkinson's NSW and a major contributor to Parkinson's Australia operations, has been made an OAM. Our congratulations go to both for the important contributions they have made and the recognition that this has now received.

Neil Page, President

Operations Sub-Committee

Happy New Year! Once again your Operations Sub-Committee has been very busy:

- We have several new Supports Groups starting up this year with Beaudesert and Bribie Island having their 1st meetings in February. We are still very interested in starting up new Young People with Parkinson's Support Groups. If you are interested please ring the PQI Office.
- We are currently reviewing the Policies and Procedures Manual for Support Groups, with valuable contributions from Support Group coordinators. We expect to finalise this section shortly.
- We are also busy organising the "Parkinson's Queensland Unity Walk" planned for 12th September 2010. This will be a common title with the other states substituting their state names.
- The educational presentation to allied health workers is now in draft form and being worked on. We are negotiating with Queensland Health to utilise their teleconferencing facilities for education and information sharing across all of Qld.
- Power discounts for Parkinson's sufferers: Victoria has been receiving this for some time, NSW has just been granted this discount in December and we're waiting to hear a Qld decision.

Joy Boyle, Chair OSC

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Parkinson's Disease

Have you been diagnosed with Parkinson's Disease?
If so you could help advance knowledge of how we can best improve walking in people with Parkinson's Disease.

Our current research uses innovative technology to measure walking and provides specialised walking training from expert physiotherapists.

We need volunteers who:

- **Are aged over 21 years**
- **Have been diagnosed with Parkinson's Disease**
- **Have noticed changes in their walking**

The study involves coming to assessment sessions at the Princess Alexandra Hospital and 3-4 weeks of 1-on-1 specialized physiotherapy walking training usually at St Andrews Hospital. Participants will be provided taxi transportation or reimbursed for travel costs.

If you would like to participate in this ground breaking research please contact Glynnis Shenfield on (07) 3346 9870 or g.shenfield@uq.edu.au

THE UNIVERSITY OF QUEENSLAND
AUSTRALIA

RESEARCH NEWS

PhD Research Grant & Research Seeding Grant Recipients

Parkinson's Qld Inc. recently awarded funding for innovative research projects related to Parkinson's disease. In total, four grants have been awarded; 1 PhD Research Grant and 3 Research Seeding Grants.

The grant applicants were required to provide extensive information about the aim of the project, background, research plan and the significance/outcome. Each project applicant was assessed by an international review panel consisting of highly regarded professionals in the field.

The PQI PhD Research Grant Scheme and the PQI Research Seeding Grant Scheme are funded by the generosity of research donations made to PQI. Innovative research projects such as those listed below are vital to the advancement of Parkinson's disease knowledge and improved patient treatments.

Effects of Enhanced Somatosensory Information on Postural Stability in People with Parkinson's Disease

QUT PhD student, Mr Feng Qiu, will be researching how changes in somatosensory information (sensory signals from all tissues of the body including skin, muscles and joints), affects postural stability in people with Parkinson's disease.

The project will also investigate whether textured insoles, used to enhance somatosensory information from the feet, can be an important intervention to prevent falls in PD patients – thus providing a low-cost means of improving postural stability.

Dynamical Postural Stability and Falls Prediction in Parkinson's Disease

QUT Associate Professor, Dr Graham Kerr, will be initiating a study to enable the development of a prospectively validated falls risk test for people with PD. It will combine demographic, clinical tests and measures of dynamic postural stability to derive independent risk factors for falls. The falls risk tool will have wide application across medical and allied health areas for risk assessment and prescription of primary therapy.

How Does Genetic Background Interact With Environmental Exposures to Modify Parkinson's Risk?

Griffith University Associate Professor, Dr George Mellick, will undertake experiments to identify gene-gene and gene-environment interactions that substantially modify risk for PD.

In particular, pesticide exposure, cigarette smoking and genetic variability across a biological pathway that influences a body's ability to detoxify such exposures will be examined.

Activation of the Antioxidant Pathway Restores Metabolic Functions in Parkinson's Disease Patient-Derived Cell Lines

Dr Stephen Wood's (Griffith University) research project will compare cells from patients with typical Parkinson's disease with those from healthy controls. The cells will be used to identify molecular differences between the groups.

To date, a significant dysregulation of pathways involved in the body's response to chemicals and oxidative stress has been identified and functional differences in these pathways in PD cells have been restored. Subsequently, the purpose of the project is to determine whether the disrupted pathways are symptomatic or causative of typical Parkinson's disease.

These grants have been made possible through the generous support of donors and from bequests where those gifting funds indicate they want them to go to research.

We also welcome gifts to support our services.

Freezing? But It's Summer!

Freezing of gait (walking) or movement is described as a sudden break in motor activity that interrupts a movement or a switch from one movement to another.

Most people complain their feet seem "glued to the floor" - they are unable to turn or move forward and in some situations this can result in a fall. Other people have trouble taking the first step – this is known as gait-ignition failure.

The result of such disability of movement can result in decreased independence, anxiety and social isolation.
People suffering from freezing of gait will avoid situations that trigger the problem. Situations that involve crowds, doorways, elevators, rushed situations can all cause freezing.

Treatments can include:

- Slight medication alterations
- Taking your PD medication first thing in the morning (before getting up)
- The frequency of doses may require altering
- Ensuring medication is given on time as scheduled

These are helpful tips if the freezing of movement is related to "off" time of medication. However some people suffer from freezing at anytime during their medication cycle. If this is the case it is unlikely medications or surgery can prevent this phenomenon.

Some people with PD have shared ingenious yet simple tips to overcome freezing. If certain stimuli can trigger freezing other stimuli seem to assist in overcoming it.

- Use of mobility aids such as a walking-stick placed in front of you can act as a cue to step towards. Some sticks are available for purchase that has a spring loaded stick that flicks down to act as a guide to step over. Other sticks have a laser pointer attached – the beam of light acts as the step guide.
- Look to an obvious crack or line in your line of sight. This can be your guide to step forward.
- Throw a tissue or handkerchief to the ground and step over it (check your local littering laws if you don't have someone with you to pick it up!).
- When attempting rising from a chair or to interrupt a frozen moment – keep a small ball handy in your pocket! A few bounces of the ball can often interrupt the freezing and the movement can be attempted again successfully. You will also be surprised at how readily you can catch the ball – give it a go!!
- Internal talking or "mantras" can help for movements requiring several sequences: an example such as getting out of a chair – (1) move to the edge of the chair (2) puts hands on arm of chair (3) feet flat on the floor underneath me (4) nose over toes leaning forward (5) head up (6) push up (7) stand tall!
- In small confined spaces such as kitchens or bathrooms try having rhythmic music or sound cues. The sound can stimulate small rhythmical steps to get around the space.

Physiotherapy has an integral role in helping with freezing of gait and movement. Physiotherapists can analyse freezing triggers and work on cognitive and sensory cues to assist in overcoming the problem.

It is important to remember in Parkinson's disease the neuronal pathways controlling automatic movement are affected. Therefore there is a need to retrain and "seal in" the automatic movement to become voluntary controlled movement. Researchers know this voluntary neuronal pathway remains intact in PD.

If fear, anxiety and panic triggers freezing of movement, treatment that focuses on behaviour or thought processes may offer help. Positive thought processing may help overcome the physical freezing.

Finally:

- Don't be pressured – ensure that your carers, family, friends are aware you can't safely move as fast as them.
- Don't be afraid to ask for help – most people (even strangers) are happy to offer a hand if required.
- Keep positive and your mind active.
- If you have any of your own tips on overcoming freezing let the staff at PQI know. All of the tips offered in this article have come from people with PD. Often the best help and ideas come from those living with the problem.

Ref: http://www.nwpf.org/public/ewsletters/53NovemberDecember2009.pdf
EPDAPlus Spring 2009 Issue 10 (www.EPDA.EU.com)

Karen O'Maley (RN)
Nurse Consultant - Movement Disorders/Parkinson's

The long haul of chronic illness can be back breaking work, for both partners. It certainly takes a physical toll.

Couples know too well the exhaustion of dealing with symptoms and daily responsibilities, which don't wait for flare ups to quiet down. Illness certainly takes a psychological toll as roles shift and communication channels get clogged with emotional static.

Sometimes it doesn't take a big thing to break the tension and reduce the stress. Sometimes a very little thing can create a momentary oasis whose restfulness and beauty can then trickle back and lighten the ordinary for a while.

For me, it's making sure we always say good night to each other, out loud and with intention. It's also laughing together, about anything, especially something silly or raunchy.

Kevin Robins

Parkinson's Quilt Project

The object of the quilt project is to focus the world's attention on people with PD. It will raise awareness about the impact PD has on people living with the disease, their friends and family and caregivers as well as others who are affected.

Each panel is 2 feet square, and 8 panels will make up a quilt. They will be exhibited at the World Congress initially and will be available to rent through 2011.

I would love to see some contribution from all our members. The web site which explains it all is http://support.pdf.org.quilt It will depend on how many people are interested, whether we make only one 2 foot square or something bigger.

We have until June 1st to get the quilts to America. We will send them from our Queensland office, onto Parkinson's Australia for despatch by FedEx to the USA.

The organisers send out an instruction package before you can begin. It costs US$25 to register for a panel and this goes to the cost of making up the quilts. There is more information on the web, so give it a go, and call the office who will put you in touch with me if you are having difficulties.

Sue Page

Setting Limits is the Key

Realising the added pressure of being a full-time caregiver is not the only challenge faced by many. In many cases, it is the stress of caring for a loved one, all while maintaining a job and supporting a family. It is at this moment where setting limits and making choices becomes most important. The key step is learning how to say "no," yet maintaining a strong bond with your care recipient. Taking a step back and seeing life as an equal distribution of give-and-take between family and care giving, often yields a myriad of benefits and positive change.

These benefits include:

- Setting limits can reward the caregiver and the care recipient. The loved one learns some independence, while the caregiver gets a break and stays away from "burnout."
- Taking a step back and saying "no" at times can be beneficial to your health. Caregivers tend to be at high risk for illness and realising that you cannot do everything allows you the opportunity to spend time with family and friends.
- By allowing other family members to step in at times to assist you, you gain the freedom and momentary break that can help in refocusing your attention to the care recipient.

Juggling a family, a job, and being a caregiver is difficult, and that is why it is vital for your health, well-being, and familial bonds that you set a standard to follow early.
Setting limits does not mean you are being selfish or avoiding responsibility, rather it allows you the opportunity to continue to provide the quality care you would hope to give.

http://www.caregiver.com

Dash to the InfoLine

- Quality of life in Parkinson's disease (PD) is dependent on the physical and non-physical symptoms of the condition.
- Symptoms like **D**epression, **A**nxiety, **S**leep disturbance and **H**allucinations (**DASH** symptoms), as well as cognitive decline (i.e. difficulty with memory and thinking functions) often have a greater impact on quality of life than the physical symptoms of Parkinson's disease.
- **DASH** symptoms are often under-recognised and are commonly associated with cognitive decline.
- **DASH** symptoms may respond to drug and non-drug treatments.

Treating **DASH** symptoms should help improve your quality of life and **MAY** help prevent cognitive decline. A booklet containing information that will help you better understand and recognise **DASH** symptoms, and contains a number of helpful tips aimed at further improving quality of life, is available if you **DASH to the InfoLine** (1800 644 189).

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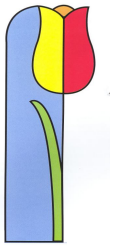

PROFESSOR PETER SILBURN

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Bookings essential

Please phone 1800 644 189 or (07) 3209 1588

At University of Qld Centre for Clinical Research
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An amateur quality DVD is available to members who were unable to attend the "Important Aspects of PD for those Newly Diagnosed" Seminar 2nd Sep 2009, by Prof P. Silburn and his team. Cost: $10 + Postage, please phone PQI.

Supplement Trialled

CHICAGO, US - Parkinson's disease is progressive in nature, and right now medications only ease the symptoms. But a new study is investigating a nutritional supplement, in hopes it can help slow the loss of brain cells.

The supplement is **Coenzyme Q10**.

An earlier study with Parkinson's patients found promising results at 1,200 milligrams of CoQ10. This time, they're pushing the boundaries further, with some patients receiving 2,400 milligrams.

Effects of Coenzyme Q10 (CoQ) in Parkinson Disease (QE3)

The purpose of this study is to evaluate the safety and effectiveness of high dosages of Coenzyme Q10 in slowing clinical decline in people who have early Parkinson disease.

Detailed Description: In a previous phase II clinical trial, investigators demonstrated that Coenzyme Q10 (CoQ) at dosages of 300, 600, and 1200 mg/day was safe and well-tolerated in individuals with early, untreated PD. The findings also suggested that CoQ may slow the progressive impairment of PD as measured by the Unified Parkinson Disease Rating Scale (UPDRS).

In this study, researchers will conduct a randomised, placebo-controlled, phase III trial of CoQ to confirm and extend the results of the earlier phase II study.

The primary objective of this trial is to compare the effect of two dosages of CoQ (1200 and 2400 mg/day) and placebo on the total UPDRS score in people with early PD. The study also will evaluate independent function, cognition, and quality of life. Plasma CoQ levels will be measured at months 1, 8 and 16 and correlated with changes in UPDRS scores.

Information gained from this trial could lead to changes in management of people with early PD.

http://www.clinicaltrials.gov

World Parkinson Congress 2010

World Parkinson Congress aims to provide an international forum for the latest scientific discoveries, medical practices and caregiver initiatives related to Parkinson's disease. By bringing physicians, scientists, allied health professionals, caregivers and people with Parkinson's disease together, we hope to create a world-wide dialogue that will help expedite the discovery of a cure and best treatment practices for this devastating disease.

Sinemet CR Shortage

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Merck Sharp & Dohme (the Australian supplier of SINEMET CR tablets), regrets to inform that SINEMET CR tablets will be in very short supply from now until early 2011.

Please contact your doctor as soon as possible so that a suitable alternative treatment can be prescribed for you.

This worldwide shortage of SINEMET CR is not related to any product quality or safety issue. This shortage is related to a change in the source of supply.

Please note that the shortage of SINEMET CR does **not** affect the availability of SINEMET 100/25mg or SINEMET 250/25mg tablets.

Any questions about the availability of SINEMET CR should be directed to a doctor or pharmacist who will be provided with information about the situation.

Pedalling for Parkinson's

ABOVE: David O'Loughlin with his father.

In April 2010, David O'Loughlin will be cycling approximately 880 kilometres from Bangkok to Phuket in 40°C heat for 12 days to raise funds and awareness for Parkinson's disease.

David's father has Parkinson's disease and he is raising money to make a positive difference to the lives of those affected.

David hopes to raise $5000 for Parkinson's disease research and support services.

To support David's epic journey, please visit:
http://www.everdayhero.com.au/david_oloughlin_6

Remember, every dollar raised helps!

THE BACK PAGE

Support Group News

The **Mareeba Support Group of Parkinson's Qld Inc.** got off to an interesting start to its formation on the 27th of January with seven (7) attendees and five (5) apologies.

Unfortunately, the weather was not in favour for travel with roads flooded, so those from other towns were not able to attend. However, the gathering was full of enthusiasm, sharing, and asking questions of symptoms and medications.

Coordinator, Slim and wife Betty distributed magazines and brochures all relating to Parkinson's disease, printed medication warning sheets, and blue booklets on Parkinson's disease.

All were keen to continue in the activity.

Venue was the Mareeba Leagues Club who generously donated space for us, and we all had lunch together after the meeting.

The next meeting will be held late March or early April, and confirmation will be mailed to all later.

Slim Pearsall

The **Broadbeach Support Group of Parkinson's Qld Inc.** did not have a break over the recent Christmas/New Year period. Returning in January was an unusual affair this year but, we had plenty of encouragement from those in attendance for the start of another exciting year.

Coordinator, Kevin and his wife Julia, are ever so diligent in their approach to each meeting, as are Norm (treasurer), Gloria (refreshments), and Carol & Mike (library).

But the group is not just about these six people; it's about every single person who comes to each meeting. It's the special bond we have for each other, the compassion, the contact outside the group, whether visiting for coffee or a telephone chat.

As with most Parkinson's support groups, there is a waning of group numbers. Mobility becomes more difficult with disease progression and others move into nursing homes. Ultimately though, we continue in our support to those affected by Parkinson's disease.

Kevin Robins

The **Bribie Island Support Group of Parkinson's Qld Inc.** had their first meeting in early February 2010. The meeting was a great success. 14 people were in attendance and they agreed to continue with the group.

Library Donation

Kevin Robins has generously donated several books and DVDs to our library. Donated resources are greatly appreciated and are always put to good use. Kevin's ongoing involvement with PQI is highly valued and we would like to take this opportunity to thank Kevin for his tireless efforts.

Donations

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

Donations:

D. Caldwell, G. Clarke, V. Connors, Cornetts IGA, R. Craig, D & S Dally, P. Ellem, D & F Ellett, K. Goodchild, D. Groves, F. Hacon, G. Heath, Lions Club of Sunnybank, J & P Murray, Nambour & District Support Group of PQI, G. Newcombe, V & W Nicholson, Noosa Outlook Retirement Village, R. Persal, PMA Insurance, R. Polke, D. Richards, Ritchies IGA, Rotary Club of Noosa Heads, R. Russell, G.A. Schenk, R. Sonnenschein, R. Stirling, H. Swarbrick, Tabtimer, Toowoomba Support Group of PQI, Western Suburbs Support Group of PQI, R & G Wood, Ziff Brothers Investments.

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