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## Parkinson's Victoria Unity Walk A great day out – a great chance to win!



Participants from the 2009 Parkinson's Unity Walk leaving Federation Square to complete the 4km walk along Melbourne's scenic Yarra River.

Thanks to the generous support of our event Sponsors we have some incredible prizes up for grabs for participants and fundraisers for this year's Unity Walk.

### Major prize: Fundraise \$250

Everyone who fundraises over \$250 for Parkinson's Unity Walk will go into the draw to win a once in a lifetime holiday for 2 to beautiful Hawaii (includes return economy class airfares as well as a 5-day/4-night accommodation package at the magnificent Outrigger Luana Waikiki).

**This amazing holiday, valued at over \$5000, is generously donated by Hawaiian Airlines, Hawaii Tourism and the Outrigger Luana Waikiki. \*Conditions apply. Vic permit No: 10/2248**

### Major prize: Top fundraiser

Our highest individual fundraiser will win a magnificent trip for 2 on the Indian Pacific. You will travel in Gold Service from either Sydney-Perth or Perth-Sydney. **This wonderful prize is valued at over \$4000 and is courtesy of Great Southern Rail. Economy class**

**airfares will be provided to take you to Sydney to begin your journey and then return from Perth to Melbourne. \*Conditions apply**

### Early Bird prize

Register by our Early Bird deadline (Sunday 22 August) and be in the running to win **A Wish Upon a Star** accommodation package for two, valued at \$350, courtesy of The Langham, Melbourne.

**Register for Parkinson's Unity Walk and start fundraising today:**  
[www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au)

**A promotional poster is included with this newsletter to display in your local neighbourhood or workplace. Contact our office for more.**

**For every dollar raised through Parkinson's Unity Walk, 50 percent is directed towards funding research into Parkinson's and the remaining 50 percent will help fund our support and information services.**

# News & Highlights

*Here you'll find updates on some of the latest and most important news and announcements affecting the Parkinson's community.*

## Update on support project

The Western Health Parkinson's Project aims to provide community support for people living with Parkinson's in Melbourne's Western metropolitan region from a Parkinson's disease Clinical Consultant (PDCC) located in the area.

### *Who can access the service?*

Any person...

- With a confirmed diagnosis of Parkinson's
- Who consents to being seen by the PDCC, either at home or at Sunshine Hospital.

Home visits can be arranged for those living within the five municipalities of Brimbank, Maribyrnong, Melton, Hobson's Bay and Wyndham (those living outside these areas can still access the service but must travel to Sunshine Hospital for their consultation). The service is based out of the Sunshine Hospital Continence Clinic, at 176 Furlong Road, St Albans.

Unfortunately, at this stage the service cannot provide support to people living in High Level Residential Care or people in hospital, although staff from the Project can follow up once the individual is discharged home.

### *What is a PDCC?*

A **PDCC** is an experienced health care professional (in this case, a Registered Nurse) who has a special interest in Parkinson's. The **PDCC** aims to provide information, education and support to people living with Parkinson's in order to improve understanding of the condition, knowledge about existing available resources and also act as a point of contact in the community.

### *What can I expect from the PDCC?*

- Personal support to assist you with understanding your diagnosis.
- Useful and credible information that relates specifically to Parkinson's.
- Assistance with and guidance for making appointments at the Movement Disorder Clinic.
- Information about - and on your behalf co-ordination of - available services.
- Support with medication management.
- Assistance in making appropriate referrals to other health professionals.

### *Who can refer to the service?*

Anyone can: Your GP, your neurologist, a member of an allied health profession (such as a physiotherapist or occupational therapist), Parkinson's Victoria,

another hospital – or you can make a self-referral.

**For further information about the Project and accessing its services, contact Kylie Griffiths, Parkinson's disease Clinical Consultant: (03) 8345 1283; Email: [Kylie.Griffiths@wh.org.au](mailto:Kylie.Griffiths@wh.org.au)**

## Organ Donation & Parkinson's

A recent question on our information line has been "Can people living with Parkinson's donate organs, such as their kidneys or liver?"

**Donate life**, the national Organ Donation Coordination service has advised that organs are accepted from any person regardless of age, health or lifestyle and living with Parkinson's does not prevent you from donating organs.

**The most important thing about considering organ donation is to discuss it with your family and make them aware of your wishes. For more information contact the Health Team at Parkinson's Victoria. For further information about "Planning for the Future" refer to our article on page 13 of this newsletter.**

## A new treatment option

**Sifrol ER** - a new 24-hour sustained release tablet form of Sifrol\* - is now available under the Pharmaceutical Benefits Scheme (PBS), as of 1 August. (The PBS is a government scheme which subsidises the cost of some medications).

The new tablet delivers more constant medication over a 24-hour period and in clinical trials in Europe the data showed that more constant levels of plasma concentration were achieved than with the alternative three-times-a-day immediate release tablet.

The positive benefits of this for the patient are the potential reduction of severe motor fluctuations, and - for some people - improvement in sleep and assistance with night time difficulties.

A once a day formulation also has the benefit of reducing the number of tablets that are needed in a day.

Unfortunately, Sifrol ER can have all the same side effects as the alternative form of Sifrol, including nausea, constipation, hallucinations, confusion, dizziness and swelling of the feet. Sifrol ER also has the potential to cause some behavioural changes such as compulsive gambling, increased sex drive, compulsive shopping or eating.

**For more information about Sifrol ER and other treatment options for Parkinson's please contact the Health team at Parkinson's Victoria.**

**\*Sifrol is a dopamine agonist. Dopamine agonists activate dopamine receptors in the brain (in the absence of dopamine - the chemical messenger that is depleted in people with Parkinson's).**

Supporting Parkinson's can be

# A WALK IN THE PARK



Join Parkinson's Victoria for this fun family fundraising event on **Sunday 29 August 2010**. Whether you walk, stroll or roll, you can help.



Every day  
**25 AUSTRALIANS**  
are diagnosed with Parkinson's Disease.



The Parkinson's Unity Walk is a great family day out, suitable for children and adults of all ages and ability. Meet at Federation Square and join in the fun of a 4km, non-competitive stroll along the banks of the Yarra. Bring the pram, the kids, the grandparents, the dog, friends and family – and come together to raise funds in a community atmosphere.

**Parkinson's Unity Walk is more than just a day out – it's a chance to make a real difference.**

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**Parkinson's Victoria**  
supporting people with Parkinson's

Register & fundraise now: [www.unitywalk.com.au](http://www.unitywalk.com.au)

# Tulip Tributes

## Fundraising flicks

Our charity movie night screening of **Sex and the City 2** raised a phenomenal \$1900 (net)!

More than 150 guests enjoyed Cosmopolitans and nibbles before the film and a few lucky guests went home with one of our fabulous prizes. A great night was had by all!

Many thanks to our generous corporate sponsors: Endota Day Spa (Brighton Beach) who generously donated 2 treatment vouchers, Yuka Accessories who kindly donated a gorgeous leather metallic rose pink handbag; and Finch Publishing for their donation of two copies of the recently published self-help book **Getting Past your Breakup** by Susan Elliott.

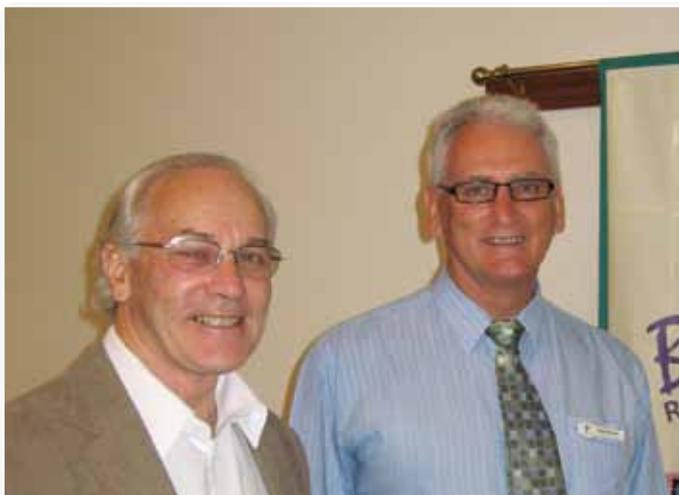
Thanks also to Dendy Brighton for their support and our wonderful volunteers, especially **Bronwyn** for helping to make the night so much fun and successful. Extra special thanks to dynamo sales girl **Ebony** who sold approximately 50 tickets to friends!

## Music to our ears

Earlier this year we were grateful to receive a donation of \$670 from the **Church of Christ, Southern Community**. The donation came about through the musical talents of Mr Ernie Kemplay, an accomplished pianist, and parishioners from his local Church.

Ernie created a CD of piano music which was then sold, with proceeds going to the Southern Community Church and Parkinson's Victoria.

We are pleased to share an excerpt from a letter to us from Senior Minister David Brooker: **"As a community we are delighted with the response to the CD and are very happy to support Ernie's initiative... we are also pleased to partner with Parkinson's Victoria"**.



*Ernie Kemplay and Senior Minister of the Church of Christ, Southern Community, David Brooker.*

## Community Group helps you keep moving

Recently we were contacted by the **National Seniors Association, Mentone**, who were keen to make a grant application on our behalf to the **National Seniors Foundation Trust**. The grant specifically would fund the purchase of equipment aids to assist individuals visiting our office to maintain independence and to provide comfort and support while sitting or moving through the office, including a wheelchair, cane and pressure relief seat cushion.

We are pleased to advise that a portion of the application was accepted **and** that the Mentone branch has most generously followed up with a personal donation of \$451 to fund the purchase of the additional items not covered by the Foundation Trust grant.

**One of the wheelchairs purchased has since been 'loaned' to the nearby Kingston Centre, and features acknowledgement of the grant.**

## Fond Farwell

It is with great sadness that we bid farewell to a team member who has made a significant contribution over the past two and a half years.

Jackie Jenkins joined us to drive our **Bridging the Gaps** project; researching, developing and then launching our multi-lingual Parkinson's information. Jackie also developed the Progressive Supranuclear Palsy (PSP) information kits and our new Ambassador Information Kits.

**We wish Jackie all the best for the future and know she will be a wonderful asset to any future team and organization she works with.**

## Sizzling success

On July 4, Bunnings Moorabbin was again the site of a successful charity sausage sizzle - and we would especially like to thank the store for generously providing us with this opportunity to fundraise while using their facilities.

Bunnings Moorabbin also donated a beautiful Chiminea for us to raffle, which added some extra dollars to our fundraising results. We thank their staff who personally supported our efforts and were so helpful, and the following sponsors for their generosity: Bakers Delight (Glen Waverley), South City Meats (Hampton), Scicluna's (Mentone), Coles (Mentone) and Heinz.

And of course, we thank our amazing volunteers who gave up their Sunday to help out and created such a fun and friendly atmosphere: Thank you to Peter, Dean, David, Linda, Sze-Eh, Denise and Carl.

# Tulip Tributes



The smiles didn't stop all day: Some of our BBQ volunteers taking a well earned break (from left) Peter, Linda, Dean and Sze-Eh.

## Being neighbourly

Special thanks to Shepparton Support Group member Darnley Montgomery for his efforts in fundraising \$2,448 for Parkinson's Victoria within the Talagaroopna community.

## Moving to make a difference

**Congratulations to all those who participated in Run Melbourne on Sunday 18 July in support of Parkinson's and Parkinson's Victoria. What a fantastic day and fundraising result!**



Suzanne Rangan, running in our new Team Parkinson's gear, gets comfortable as she begins the 21km Half Marathon. Photo: [www.mosaicphotography.com.au](http://www.mosaicphotography.com.au)

We were delighted to have 80 energetic people competing in this event, which featured a 5km, 10km and half marathon (21km) race. More than 18,000 people participated and our team raised a whopping \$13,109!

It was terrific to meet many of the participants personally – as well as their supporters – when they visited our tent at Federation Square's River Terrace.

Run Melbourne was also the event that launched our exciting new Team Parkinson's sports gear which several participants wore during the race.

**Read more about our Team Parkinson's sports gear on page 10**

## Fond farewell

Parkinson's Victoria would like to pay tribute to Gloria Forbes, who is standing down as Leader of our Rosebud Support Group.

Having held this position for more than 12 years, Gloria is one of our longest serving support group leaders and her hard work and welcoming presence has ensured that the group has grown and developed over the years. Gloria was diagnosed with Parkinson's when she was 39 and was one of the 'stars' of our first Community Service Announcement (CSA) which aired on television.

During her time as support group leader, the Group has hosted a number of awareness raising activities as well as VIP guest speakers, including Steve Bracks and Don Chipp, the latter of whom insisted on a kiss before he would sign a copy of his biography, **Keeping the Bastards Honest**, for the support group.

**Thank you Gloria for your valuable contribution to the Rosebud community and to our work. We wish you all the best for the future.**

## A day on the green



From left: Mayor Steve Staikos, Charity Day Committee Leader Terri Farrel, Parkinson's Victoria Board Member Peter Raymond and Spring Valley Golf Club President, John Philp.

Spring Valley Golf Club's annual Charity Golf Day (28th May), with proceeds shared between Parkinson's Victoria and Kingston Charitable Trust was another fantastic success.

The full capacity field enjoyed a great game on the green, lunch and an afternoon of raffles and auctions. More than \$23,000 was raised, with 50 percent donated to support our work and services.

**We gratefully acknowledged the fantastic ongoing support we have had from Spring Valley Golf Club, its Charity Day Committee and Club Members. We also acknowledge the following sponsors who generously provided goods; Alias Wines, Lifestyle Portraits, Bunnings Moorabbin and Wasabi Hair.**

# Access, Advocacy and Assistance

## Driving Assessments and Parkinson's

*Driving and Parkinson's is a complicated issue, and the system used for driving assessments can be difficult to navigate. MICHELLE WOOTTON, our Client Services Officer, shares some of the common questions about driving and Parkinson's which we receive through our free information Help phone line – and the answers.*

### Why would someone with Parkinson's have to sit a driving assessment?

When you are first diagnosed with Parkinson's, it is a legal requirement to disclose your condition to VicRoads.

After you or someone else notifies VicRoads of your medical condition, they will conduct a medical review, which will take into account:

- The medical report from your doctor
- Assessing **Fitness to Drive** Guidelines
- Advice from VicRoads medical advisors
- Eyesight and specialist reports
- Your treatment plan and ability to manage the condition
- Reports from police and other third parties

If the above is not sufficient for VicRoads to make a decision about your ability to drive safely, they may request that you sit a driving test. This may be conducted by a VicRoads driving assessor or an occupational therapist.

### Why are assessments conducted by an occupational therapist, and not VicRoads?

The VicRoads standard driving test is designed for inexperienced drivers. It does not assess how a medical condition or the deterioration of driving skills affects the ability to drive safely.

Victorian law allows qualified occupational therapists to conduct driver assessments. Occupational therapists (OT), like doctors or optometrists, are independent specialists working in the field of health care. **They do not work for, and are not paid by VicRoads.**

Occupational therapists are health professionals who assist people with physical or intellectual disabilities to resume normal daily activities. The role of the OT driving assessor is to help the client to continue driving, so they will develop strategies or provide advice about aids or modifications to the vehicle to overcome any barriers. The OT may suggest particular conditions be placed on the licence for the client's safety, such as only driving in daylight hours, during non-peak times and/or within a certain radius of their home.

If a test is conducted by a VicRoads driving assessor,

they will be as strict as if the client were sitting their licence for the first time, and will not take into account the person's health condition or be able to provide advice about aids or vehicle modifications.

### What can I expect from an OT driver assessment?

#### 1. A medical assessment

You will be asked to provide a medical report from your own doctor or specialist which shows that you are medically fit. If you have eyesight problems, you may also have to provide an eyesight report. Being medically fit does not exempt you from undergoing a driver assessment, as your doctor cannot assess your driving skills.

#### 2. An off-road assessment

The occupational therapist will ask you about your driving history, test your understanding of road law, and assess your physical, visual, sensory and thinking abilities. This may take up to two hours.

This assessment evaluates your understanding of safe driving, any necessary vehicle modifications or licence conditions and determines the requirements for your on-road assessment, for example:

- The type of vehicle (e.g. automatic or manual)
- Any vehicle modifications
- Where the assessment should be conducted.

#### 3. An on-road assessment

The assessment will occur in a dual controlled car. A driving instructor will be present during your assessment to maintain the safety of the vehicle and give route instructions. The occupational therapist and the driving instructor are the only people permitted in the vehicle. It will take about an hour and a half (of which about one hour will involve you driving).

The main areas observed will be:

- Physical limitations
- Judgement and ability to adjust to traffic situations
- Reacting appropriately to traffic
- Abiding by road laws.

If vehicle modifications are required (eg. steering aid, left foot accelerator), the equipment is fitted and trialed to ensure you can safely use it.

After the assessment, the OT will send through the report to VicRoads, who will advise over the phone if you can retain a full licence or whether it will be made conditional or cancelled. If your licence is made conditional or cancelled, you have the right to appeal and re-sit the test.

### What costs are involved with an Occupational Therapy driving assessment?

There are no current subsidy schemes or Medicare rebates available, but some OT's may provide a

# Access, Advocacy and Assistance

discount to health care card holders/pensioners at their own discretion. It is often cheaper to get the test done through a public rehabilitation centre or movement disorder clinic with a specialist OT driving rehabilitation program.

The OT must conduct the assessment in a dual control car. A driving instructor will be present during your assessment to maintain the safety of the vehicle and give route instructions.

The fees charged include an off and on-road assessment, plus the costs involved for a driving instructor and the use of their dual control car. After the assessment, the OT submits a report to VicRoads with the results of the test. VicRoads do not charge any additional fees for the medical review.

Some OT's will charge a set fee, while others will break it down into separate costs for the off and on-road assessments, plus charge extra for the driving instructor.

You can expect to pay anywhere between \$160 and \$608 (all-inclusive) for your initial driving assessment. You should not incur any fees directly from VicRoads in addition to this.

Parkinson's Victoria encourages clients to contact a few OT's in their area to find their cheapest option. Unfortunately clients in regional areas may have limited or no choice.

An up-to-date list of OT driving assessors can be found on the Parkinson's Victoria 'Help Finder' website under the 'Driving & Transport' section.

## How can clients make a complaint about the fees associated with an OT driving assessment?

Unfortunately, the peak bodies associated with OT driving assessments, VicRoads and OT Australia Victoria, do not exert much influence or responsibility in this area, and both have official disclaimers:

"VicRoads is not responsible for the regulation of occupational therapists. If any complaint alleges that conduct was inappropriate or unprofessional, the matter will be referred to OT AUSTRALIA Victoria,

which will endeavour to resolve the matter by investigation, mediation, or referral to the Health Services Commissioner."

That being said, the disclaimer from OT Australia (Victoria) states: "Fees charged by OTs are a commercial matter between the member and their clients and are outside OT AUSTRALIA Victoria's jurisdiction. OT AUSTRALIA Victoria is not in a position to investigate or handle complaints made against occupational therapists who are not members of the Association. Complaints against these occupational therapists need to be referred directly to the Health Services Commissioner."

## Why are some clients required to have an annual review of their driving ability?

According to the '**Assessing Fitness to Drive**' criteria, if a person has a neuromuscular condition (Multiple Sclerosis, Parkinson's, Peripheral Neuropathy, etc) that has progressed so as to impair driving, the criteria for an unconditional licence are not met.

A **conditional licence** may be granted by VicRoads, taking into account the opinion of the treating doctor/GP, and the nature of the driving task. A conditional licence will also be subject to "**at least annual review\***", taking into account:

- Response to treatments
- Report of a driver assessor and
- Modifications to the vehicle.

A conditional licence may specify that the client is only able to drive under particular driving conditions (eg. only during daylight hours or non-peak times of day) or within a certain radius (eg. within 5kms from home).

**\* The mandatory 'at least annual review' of driving skills is a significant financial burden to people with Parkinson's and other progressive, neurological conditions. Parkinson's Victoria will be conducting further investigation into this matter. If you would like to be part of a consumer advisory committee, please contact Michelle Wootton: (03) 9551 1122 or [michelle@parkinsons-vic.org.au](mailto:michelle@parkinsons-vic.org.au)**

Parkinson's Victoria Unity Walk proudly supported by...



## Hawaiian Airlines and Hawaii Tourism

This year Hawaiian airlines celebrates the 80th anniversary of its first flight between the islands of Hawaii.

Hawaiian Airlines operates three weekly, nonstop flights from Sydney to Honolulu, with onward connections to the islands of Hawaii and 10 US mainland cities. Hawaiian Airlines fares from Australia include complimentary meals, snacks, drinks, main screen entertainment and a generous baggage allowance of 2 x 32kg items per passenger – no hidden extras! [www.hawaiianair.com.au/](http://www.hawaiianair.com.au/) [www.gohawaii.com/au](http://www.gohawaii.com/au)

# Personal reflections

## Some thoughts to share

A broken vacuum cleaner is how I can best describe myself. I don't mean that I, the real inner me is broken; that is hopefully whole. It's just the best way to explain the frustration of this chronic disease to those who (thank G-d) have no experience with Parkinson's.

Did you ever try to clean your dusty carpets with a vacuum cleaner that has a wire coming loose? It may be a safety hazard, but nevertheless, the carpet is so dirty and the machine runs well *sometimes*...so you plug it in and switch it on.

After a false start or two, the motor gives a promising hum, and you begin. It's encouraging to see the carpet coming clean, and you enthusiastically rush around the room, hoping to finish quickly.

Suddenly, you give a little tug on the wand and sputter, sputter, power is gone. You twist the wand back to where it was before, and the motor gasps

and comes back on, but at half the power. You try going over the same bit of carpet ten times. It's getting a little cleaner, but taking forever for an imperfect job. After 20 minutes, the vacuum suddenly comes back to full power, as if nothing was wrong with it at all. This lasts about half an hour.

You've finished cleaning everywhere except the hallway, when suddenly you feel the energy surge fading away. The motor gives a feeble attempt to turn over, but it's just too hard. It spits out the last dust ball it had swallowed, too tired to even retract its cord...

**About the author: M Gordon, now 52, was diagnosed around 9 years ago. At the time she was still breastfeeding her youngest child. It took a long time to get the right diagnosis: "The GP said it couldn't be Parkinson's because only one hand shook! When I'm feeling well, I can't understand what I was complaining about, I'm fine! Then, boom, I'm suddenly like a wind up doll that's almost all wound down."**

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**mecu offers a range of personal banking, financial planning and insurance solutions. If you would like to know more about responsible banking please call 132 888; visit [mecu.com.au](http://mecu.com.au); or a local service centre.**

## STOP PRESS COMMUNITY SEMINAR

If you live in the South-Eastern suburbs and are keen to learn more about Parkinson's, then you should attend this informative community seminar.

Attendees will benefit from a presentation by Professor Bob Iansek and our Parkinson's Clinical Nurse Consultant, Victor McConvey.

### Event details

**Date/Time: Friday, 10 September, 2-4.00pm**

**Venue: to be confirmed**

**RSVP: This is a free event, however registrations are essential. For more information and to book your seat today, please contact our office.**

## A Fair Go for Parkinson's

*Why is it that governments fund regional breast care nurses, diabetes nurses, MS regional advisors and cancer nurses, but if you don't live in Melbourne you don't have access to a Parkinson's specialist nurse? Did you know that there are only three government-funded Parkinson's Specialist Nurses employed in the entire state of Victoria? And that they are trying to provide support to an estimated 20,000 people living with Parkinson's? It is simply not good enough.*

The Victorian election is scheduled for 27 November 2010. We will be asking all candidates to commit to the recurrent funding of **ten** Parkinson's nurses to be located across metropolitan and regional Victoria.

Parkinson's nurses help people manage their medication, offer advice and information about living with Parkinson's, and ensure that local hospitals, aged care facilities and health service providers have a good understanding of how to care for people with Parkinson's.

Not only do Parkinson's nurses help improve quality of life for people living with Parkinson's, they actually decrease health care costs by reducing avoidable hospital admissions, enabling people to remain in their own homes, improving medication management and independence.

We are asking for your help with this campaign. The only reason the recent campaign in Tasmania was successful was through members and supporters' active involvement, contacting their candidates and asking family and friends to assist with lobbying.

**Please read the materials we have made available online (under the **Advocacy** section) contact your candidates and seek their commitment in return for your vote. Remember that while up to 20,000 Victorians have Parkinson's, this represents more than 100,000 votes if we include families, friends and work colleagues. It is time governments provided a fair go for Parkinson's. For more information, contact Glenn Mahoney, CEO, or visit our website.**

*Parkinson's Victoria Unity Walk proudly supported by...*

### The Langham, Melbourne

Experience the incomparable hospitality of the Langham Melbourne hotel. Voted for the second consecutive year, winner of the Travel + Leisure Magazine USA **World's Best Awards Readers' Survey** as the top city hotel in Australia, New Zealand and the South Pacific.

Within The Langham Hotel Melbourne you will discover a world of modern yet timeless elegance.



## Hope for Tomorrow

### A Bequest brings hope for the future, a message from our CEO

Parkinson's Victoria incorporates the theme **Help for Today, Hope for Tomorrow** into our logo and service philosophy. It really sums up, in just a few words, what Parkinson's Victoria is all about: providing practical help and support to the 20,000 Victorians currently living with the condition, and hope for the future - not only for those already diagnosed, but for the 2,000 and more Victorians who will be diagnosed every year until a cure is discovered.

Today, I ask you to consider helping Parkinson's Victoria in a very practical and personal way: by remembering Parkinson's Victoria in your will in the form of a bequest.

Our work is only possible because of donations and bequests. One of our most significant sources of funding is through the bequests we receive when people remember Parkinson's Victoria in their will. Every gift - large or small - makes a difference to our work and the people we help. Even a modest donation in a will can help others beyond our own lifetime. Often people are able to leave a gift in their will that they are unable to give during their lifetime.

A will is a legal document that determines how your assets will be distributed. Sadly, the Law Institute of Victoria estimates that up to 50 percent of Australians pass away without having a current will. In these cases, the government may decide on the distribution of an individual's assets, which can lead to further distress among families.

A will is the only way to be confident your affairs will be settled as you wish. A will can be a way of expressing your love and concern for family, friends and close associates, and organisations with whom you have a strong affinity or commitment to.

We recommend you seek professional advice to ensure that your wishes are expressed correctly in your will.

**If you have, or are thinking of leaving a bequest to Parkinson's Victoria in your will, it would really assist us to know your intentions, as it will help us plan for the future. It will also enable us to say thank you.**

**If you would like further information about remembering Parkinson's Victoria in your will, or would like to discuss this with me personally, please contact me on (03) 9551 1122 or toll free on 1800 644 189.**

**Making a bequest is a way to give beyond our life time, a way to make a lasting contribution towards the fight against Parkinson's: A way to provide Help for Today and give Hope for Tomorrow.**

Glenn Mahoney  
Chief Executive Officer

# Fundraising/Events

## *Pearls of Wisdom at Parliament*

Parkinson's Victoria will be celebrating 30 years of service to the community by hosting **Pearls of Wisdom**, an exclusive fundraising event at Parliament House, Melbourne, during National Parkinson's Awareness Week (30 August – 5 September).

The evening has been made possible by Nationals Leader in the Legislative Council, Mr Peter Hall MLC, and we gratefully acknowledge this wonderful support.

Limited tickets are available and include a 3-course menu and drinks, raffles, personal tours of the House by Members of Parliament, and a special keynote presentation by Graeme Joy, first Australian to ski to the North Pole.

### **Events details:**

**Date: Wednesday 1 September**

**Venue: Parliament House, Melbourne**

**Cost: \$220**

**To purchase tickets, please contact Parkinson's Victoria.**

## *Coming up next*

**Parkinson's Passion** is still blooming thanks to Treloar Roses and Parkinson's Support Groups.

Treloar Roses, the Australian distributor of **Parkinson's Passion** - a bright orange floribunda rose named by our community to raise awareness - is generously donating 10 percent of the proceeds of sales to Parkinson's Australia.

Aside from private gardens, the rose is slowly appearing in public gardens around the state!

You can now see **Parkinson's Passion** at the Morwell Centenary Rose Garden and Pevensy Gardens in Geelong. Local support groups from Warrnambool and Portland are also planning events for later this year.

## *Exhibition celebrates life*

**Beyond the Mask II**, an exhibition of artwork by Victorians living with Parkinson's, will be formally opened by Professor David de Kretser, AC, Governor of Victoria accompanied by his wife, Mrs de Kretser, on Thursday 26 August at the Kingston Arts Centre, Moorabbin.

This invitation-only event will be followed by an open-to-the-public exhibition, until 14 September, 2010.

The exhibition celebrates the creative and imaginative spirit of artists – both amateur and professional - who live with Parkinson's.

### **Event Details:**

**Beyond the Mask II**

**Public opening times: Friday 27 August to Tuesday 14 September (Mon-Fri 9.00am-5.30pm; Sat 12.30-5.30pm)**

**Where: Kingston Art Centre Gallery, 979 Nepean Highway, Moorabbin.**

## *Get fit & fundraise*

We were excited to see our new Team Parkinson's gear – sports singlets and caps – make their first public appearance during the recent Run Melbourne event on Sunday 18 July.

A new logo was created exclusively for supporters who are keen to 'get fit (or undertake a fitness challenge) and fundraise'. The singlet features the phrase "I'm moving to make a difference for people with Parkinson's". The gear is designed to acknowledge and reward the efforts of fundraisers, raise awareness and create a community spirit. We also hope they inspire those who wear them!

**Team Parkinson's sports singlets (\$25) and caps (\$15) are available from Parkinson's Victoria (plus postage). Register for Parkinson's Unity Walk and fundraise \$100 and you'll receive a free Team Parkinson's cap!**



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# Fundraising/Events

## Strike, rattle and donate

Our bi-annual "tin rattle" will be happening again from 8-10.00am on Thursday 2 September at city loop train stations.

Each year, our volunteers generously give their time, energy and smiles to collect donations from city commuters.

Our tin rattles raise up to \$13,000 annually to support our work in the community. They also give us the chance to raise the profile of Parkinson's with the public, something we know is important to you. This event is made possible thanks to the generous support of Metro trains and our terrific volunteers!

**If you would like to volunteer for our next tin rattle, please contact our office to find out how you can make a difference.**

## 2010 Christmas cards

Show your support for people living with Parkinson's and help spread a message of awareness and understanding this festive season by purchasing our Christmas cards. Our new range includes 2 cards exclusively designed for Parkinson's Victoria by artists Jean Smith and Anne Atkin – **thank you Jean and Anne for your beautiful designs.**

All our cards feature the Parkinson's Victoria logo and a message about how we support the community.

**The sale of all cards helps fund our information, education and support services and will raise awareness about Parkinson's.**

Cards can be purchased securely online [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) or contact our office.

Alternatively, you can purchase our cards from the following outlets:

- St Paul's Combined Charities Christmas Card Shop (Myers Street, **Bendigo**)
- Mornington Community Information and Support Centre (320 Main Street)
- Camcare Combined Charities Card & Gift Shop (19 Fairholm Grove, **Camberwell**)
- **Ballarat** Combined Charities Card Shop (27 Magpie Street).
- **Banyule** Support & Information Centre (101 Burgundy Street, Heidelberg)

## Best value in town

The Entertainment Book is your guide to the best restaurants, hotel accommodation, attractions, sports and leisure activities, as well as casual and family dining and take away. All outlets featured in the book carry "25-50% off" or "2-for-1" discount offers. And, best of all – every book sold through Parkinson's Victoria means a donation to support our work!

**Limited books are still available. To purchase your copy (\$65 (\$13 to Parkinson's Victoria) plus \$8 postage) contact our office or email: [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)**

## Thank your clients, show you care

In partnership with **Charity Greeting Cards**, we are pleased to offer supporters the opportunity to purchase Christmas cards and a range of stunning gift hampers for clients, suppliers, family and friends – and to support Parkinson's Victoria at the same time!

### Corporate Cards

Choose your preferred design from the range on offer (also featuring Parkinson's Victoria logo and information), and add your own personal message and/or logo.

Log onto: [christmascards4charity.com.au/parkins](http://christmascards4charity.com.au/parkins) (online orders receive a 5 percent discount) or phone our office to request an order form. Orders are dispatched professionally and quickly and 40 cents from every card sold is donated to Parkinson's Victoria.

### Corporate Hampers

Log onto [charityhampers.com.au/parkins](http://charityhampers.com.au/parkins) and choose from the selection of gourmet hampers on offer, all featuring delicious goodies such as biscuits, condiments and nibbles, and priced from \$50-\$150. You can also contact Parkinson's Victoria to request an order form.

Hampers feature a Parkinson's Victoria logo sticker to show your support and 10 percent of the retail price is donated back to Parkinson's Victoria.

**There are no costs to Parkinson's Victoria for either of these initiatives, which helps us to keep administration costs down and makes it a fantastic fundraising idea for the organisation! Remember to let your work, children, extended family, social and sporting clubs know about this wonderful opportunity to support Parkinson's while building relationship with clients.**

## Return of the Tulip Ball

Book your tickets now to the 2010 Tulip Ball: Dinner, entertainment, amazing auction items and raffles! Why not get a group together?

The biennial Tulip Ball® is Melbourne's premier gala event promoting the experiences of those living with Parkinson's and raising funds for Parkinson's Victoria.

Named after the worldwide symbol of Parkinson's disease - the tulip - the Tulip Ball® was founded by Julie Sewell and Joanna Hill in 2008.

Inspired by Julie's husband and Joanna's father, John Sewell, the first Tulip Ball® took place at the Royal South Yarra Tennis Club and was a celebrated success raising tens of thousands of dollars for Parkinson's Victoria and the quest for a cure.

Galvanized by a desire to emulate John's courage and resolve in fighting Parkinson's, Julie and her children Joanna and David are determined to raise the profile of a condition that affects over 80,000 Australians, with more than 2000 new diagnoses every year in Victoria alone and 25 a day across the country.

### Event details

**When: Saturday 13 November, 2010**

**Where: The prestigious 'Members Only' RACV City Club, 501 Bourke Street Melbourne**

**Purchase tickets today: [www.tulipball.org](http://www.tulipball.org) (\$140 pp)**

# Access, Advocacy & Assistance

## Facebook Cause Page - 'A Fair Go for Parkinson's'

Facebook 'Causes' are online campaigns to inform and inspire others to make a difference.

A Cause can spread awareness to a new demographic, teach followers how to make changes in their daily lives, or encourage people to share personal stories and find support. They are typically started by non-profit organisations or individuals who are passionate about a particular issue.

Members of a Cause can show their support by taking a 'pledge' to invite their friends to join the Cause, read articles, watch media or sign a petition.

Parkinson's Victoria has posted a link on our Cause page directing members to donate securely via our website if they wish to contribute to the Cause financially.

Parkinson's Victoria's Cause page, aptly titled '**A Fair Go for Parkinson's**' was created to improve awareness, funding and services for all people living with Parkinson's.

As membership of our Cause page grows, we will have a greater voice for lobbying government, driving social change and educating the community.

**You can support the Cause by signing up and inviting all of your Facebook friends to sign up too. There is a link to the Cause from the Parkinson's Victoria Facebook fan page – [www.facebook.com/parkinsonsvic](http://www.facebook.com/parkinsonsvic)**

## National Disability Insurance Scheme

Parkinson's Victoria is part of a coalition of organisational supporters for a proposed **National Disability Insurance Scheme (NDIS)**, initiated by Yooralla, The Spastic Centre and Disability Services Australia.

Australia's current approach to disability services is crisis-driven and welfare-based. Those who acquire a disability through a workplace or a motor vehicle accident generally receive financial support. However, there is no automatic support in place to meet the needs of: those who acquire permanent disabilities in other accidents; who are born with a permanent disability; acquire a permanent disability

through a medical condition; or have a permanent mental illness.

A National Disability Insurance Scheme (NDIS) would change this. The Scheme would provide funding for essential care, support, therapy, aids, equipment, home modifications and access to the community, education and training.

People with Parkinson's would significantly benefit from this proposed scheme, and reforms to respite services, support and care options will reduce the pressure on families and caregivers.

**You can [take action](#) now by emailing your MP, visiting your MP or signing the online petition (under the [Take Action/Spread the Word](#) section of the [NDIS site](#)), but most importantly, by spreading the word to family, friends and colleagues.**

Visit [www.ndis.gov.au](http://www.ndis.gov.au) or click on the link from the [Parkinson's Victoria home page](#) to find out more.

## Carers Card

Carers contribute \$7.8 billion worth of unpaid work to the Victorian community each year. As a result, they are typically unable to work for a salary, and often struggle to afford simple, day-to-day living expenses. Looking after carers is long overdue but the State Government is seeking to redress this by introducing the **Victorian Carer Card Program**, officially launched in July this year by the Hon Lisa Neville MP.

The program, which has been formed through a collaboration of government, community and private business, provides recognition, understanding and support for carers throughout Victoria, through a discounts and benefits scheme that boasts more than 700 participating business and government venues.

Discounts range from travel and leisure, education and home maintenance to health and wellness, automotive and retail. Additional benefits of the card include free public transport on Sundays along with two return off-peak travel vouchers for travel anywhere within Victoria. Carers will also be able to enjoy discounted entries to government venues such as zoos, museums and various tourist attractions.

**Carer Card Program information and carer application forms are now available. For more information visit <http://carercard.vic.gov.au/>**

# Planning for the future

*We all prefer to make our own decisions about our personal lives, health and finances. But what happens if we become unable to make those decisions for ourselves? Illness or injury can significantly impact on the individual's ability to make or action decisions but there are a number of legal avenues you can pursue in order to ensure your wishes are carried out.*

*Our Parkinson's Specialist Nurse Consultant VICTOR MCCONVEY explains.*

"Thinking ahead" or discussing your wishes regarding medical treatment is an important consideration for everyone, regardless of your current state of health. However, living with a progressive illness such as Parkinson's can make this planning a little more complicated: For example, it is often harder to make decisions regarding withdrawing or reducing medical treatment when taking medication has been a part of one's life for many years.

It is also likely that, while many people are able to engage in these types of discussions, they do not know how or where to start.

Having acknowledged this situation, the health care system is currently engaged in serious debate about advance care planning, and increasingly patients are being asked to give some thought to the future. Currently if there is any doubt over your medical treatment wishes, health professionals will actively treat and prolong life unless - in their assessment - it is considered futile.

It is especially important to consider the impact a particular illness has on the individual (and the burden of treatment on quality of life), when the illness is not "life-ending" - remembering that one's understanding of quality of life will change over time.

It is also impossible to predict the future or the progression of Parkinson's in any individual, and it is because of this unpredictability that you should speak with your family about treatments, even identifying some situations where you would - or would not - want treatment to continue.

In long term illnesses, such as Parkinson's, it is sometimes useful to identify sentinel events where you would consider altering treatment. These events may include developing pneumonia; cognitive changes related to dementia; or a severe reduction in - or difficulty with - swallowing that means tube feeding is being considered.

It is important to remember that even when these "sentinel" events occur, healthcare staff will continue to discuss treatment options and likely outcomes with your next of kin who will be able to consider all the information and make a decision regarding treatment.

Completing paperwork prescribing Power of Attorney (Financial, Medical and Guardianship) should follow an in-depth discussion with the appropriate individuals involved, making them aware of any wishes concerning treatment.

## *Some steps to help plan ahead*

**Appoint an agent:** This will involve legally appointing an Enduring Power of Attorney (Financial and Medical) or Guardianship by completing, signing relevant paperwork and having it witnessed by a third party. An agent should be someone you feel comfortable with and who is able to act on your behalf. You should trust them with confidential and private information about your affairs, and feel confident they will honour your wishes or instructions. Your choice of agent does not have to be a family member, but should be someone willing to take on the responsibility that comes with the role.

Legal advice is available from a/your family solicitor. There are also some "Do-it-Yourself Guides" available from the **Office of the Public Advocate** or available for purchase from your local newsagent.

## *The various types of Power of Attorney are:*

**General Power of Attorney**

**Enduring Power of Attorney (financial)**

**Enduring Power of Attorney (medical treatment)**

**Enduring Power of Guardianship**

**NB: It is often a good idea to appoint an Enduring Power of Attorney for financial, medical treatment and Guardianship at the same time.**

The person that you appoint is not able to make any decisions on your behalf until you are no longer able to make those decisions yourself, and guidance surrounding when this occurs will come from your treating doctors.

**Communicate:** Once you have considered who could act as your agent, you need to have a discussion with them about what your wishes are. It should include; examples of situations you would find unacceptable in regards to your health and any specific treatments you wish to refuse.

**Put in on Paper:** Document what your wishes are. This can be a letter or statement outlining your wishes and choices. You should give a copy to any people involved in your care and may include your GP, Neurologist and your Power of Attorney. You should also take a copy with you to hospital.

## *Conclusion*

**Starting discussions about your future treatment can also be difficult, but they are important and worth having. It is important to understand that such discussions are ongoing and will possibly change over time, and can be influenced by new and improved treatments that enhance your quality of life or changes in your circumstances.**

**Additional Information is available from the Health Team at Parkinson's Victoria and copies of **Take Control**, a kit for making powers of attorney and guardianship is available from the Office of the Public Advocate: 1300 309 337 [www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au)**

# Symptom Management

## Swaying to the Rhythm

*SHELLEY POLLAK, our Parkinson's Physiotherapist, shares some encouraging research about the benefits of "following the beat" to combat stability-related Parkinson's symptoms.*

Exercise has a bad name. Very few of us want to do it, though most of us would agree that we should. The way you really know something is unpopular is by the number of disparaging jokes or sayings there are about it. When looking up "exercise" on the internet, here are a few sayings I came across:

*"Whenever I feel like exercise, I lie down until the feeling passes."*

*"Aerobics: a series of strenuous exercises which help convert fats, sugars, and starches into aches, pains, and cramps."*

*"Exercise is a dirty word. Every time I hear it, I wash my mouth out with chocolate."*

And that's just the tip of the iceberg!

We have become a nation that prefers to watch another re-run on TV, but can't find a spare half hour to do some exercise.

With Parkinson's, the reason will often have to do with apathy and depression in relation to the condition. When you superimpose those emotions onto "boring" exercises, the resultant lack of desire to exercise becomes very predictable.

With this in mind, I thought I would share some research outcomes published on the effects of **Tango** dancing and **Tai Chi** on Parkinson's symptoms, with the hope that it may rekindle your interest in exercise. (Keep in mind that exercise does not have to mean a session at the gym or a 5km run!)

Tai Chi is a martial art that involves slow, controlled movement and maintenance of various postures guided by mental imagery. It has been applied to treat many musculoskeletal conditions, such as arthritis and osteoporosis.

Although it is based on traditional Chinese philosophy, the exercises in Tai Chi can be adapted easily to physiotherapy principles.

Studies looking at the effect of Tai Chi on Parkinson's often show excellent results, but the quality of studies to date have been poor. Often this means the studies were small or the comparison group was either absent or not founded on evidence-based "best practice", such as strategy training or resistive exercise, making drawing solid conclusions difficult.

That being said, there is still good reason to give Tai Chi a try, as there are many ways that it can affect Parkinson's symptoms in a positive way. This includes improvement in balance, which is particularly interesting as balance is a symptom that is not

very responsive to medication. It is also important because between 50-70 percent of people with Parkinson's will experience one or more falls over a year.

Improvement in balance from Tai Chi may be attributed to improvement in trunk flexibility and overall strength, as well as motor imagery as a means of internal cueing (in other words the mental imagery which forms part of Tai Chi practice can assist individuals to manage or overcome stability issues). Furthermore, Tai Chi may help promote attention-span through its meditative effects.

An alternative to Tai Chi - and one that is certainly livelier - is Tango dancing.

The steps of the Tango specifically, as opposed to other types of dance, involve frequent movement initiation and cessation, spontaneous direction changes and a wide range of movement speeds. Although there is much less research done on this form of exercise in relation to benefits/impact on Parkinson's symptoms, the theory behind potential benefits is very interesting.

Several studies have looked at the benefit of Tango on Parkinson's symptoms and several mechanisms have been suggested to account for the improvements made in an individual's mobility/stability. The most convincing refers to the involvement of external cues.

Individuals with Parkinson's often move slowly, but can achieve normal speed and size through focused attention, especially with the aid of external cues. Focused attention (either with or without the use of cues) bypasses the dysfunctional basal ganglia and accesses a different part of the brain (the frontal cortex) in order to achieve normal movement.

Tango dancing provides two different external cues. Music acts as a cue for the speed of movement, while the co-ordinated steps with your partner may help facilitate smoother movement. The partner may also enhance balance by virtue of the physical contact you share. The holding of hands, the facilitation of weight shifting, and walking together towards a target all help to improve movement.

Overall, both Tango dancing and Tai Chi cannot be considered as evidence based "best practice" for the treatment of Parkinson's symptoms and improvement of mobility. However, in the earlier stages of Parkinson's, any form of activity may be useful in maintaining the gains achieved with specific, targeted supervised exercise.

**So please, let this article be an example of how to think outside the box and find a type of exercise that suits your balance and personal interests and start enjoying exercise again!**

For further information or to discuss your mobility concerns, contact our Health Team.

## Participate for Parkinson's

### Home based Rehab

Keen to keep active at home? Researchers at The University of Melbourne are currently undertaking a study: **Home based rehabilitation to reduce Falls and Disability in Parkinson Disease** to explore the effectiveness of different therapies in preventing falls, and improving mobility and quality of life.

#### I'm interested in participating, what do I have to do?

You will receive therapy, in your home, once a week for six weeks. The type of therapy will be allocated randomly. For some people, therapy will involve exercises (strength training and movement strategies). For others, it will involve "life-skills" education for people with PD.

#### If you have:

- Parkinson's
- Do not have any medical conditions that limit your ability to exercise
- You are willing to receive therapy in the home
- Live in metropolitan Melbourne

Then you may be eligible to participate

**If you would like more information about being involved in this study, please contact Joy Tan on (03) 8344 9757 or email: [joyt@unimelb.edu.au](mailto:joyt@unimelb.edu.au); or Dr Jenny McGinley [mcginley@unimelb.edu.au](mailto:mcginley@unimelb.edu.au)**

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## Volunteering for Parkinson's

*We owe many thanks to our volunteers who assist us in creating successful events and changing the lives of those living with Parkinson's.*



### Volunteer Super Heroes

Some of the best superheroes are the ones who are never acknowledged. They are the individuals who feel an internal need to do right; making a difference for the community, without the desire to be externally commended for their work. Consider the good deeds of *Superman*, the *Batman & Robin* duo, and *The Bionic Man*. Individuals in a dog-eat-dog world; much like the one we reside in today. In each story line, it's the actions of **one** person who has the ability to have immense impact on others.

It takes a decent person to make a change and be recognized, but it takes a great one to make a difference and remain anonymous.

That's precisely what volunteers for Parkinson's Victoria do. Our volunteers are men and women, from all walks of life, sharing one similar quality; the desire to do good and make a difference.

Parkinson's Victoria Volunteers are a special calibre of people. They rise early to help us with event set up and stand in the cold to raise donations. They have boundless energy and a smile on their faces – ready to jump in and help with whatever needs to be done; to "meet and greet" and make others feel welcome.

And just like superheros they have their costumes; their yellow 'volunteers' vest. These vests give normal people the power to stand up and make a difference. They have no fear of judgement and they never question their actions. They see the greater good without the need for recognition from the community.

A lot of our Volunteer activities involve helping out 'behind the scenes'; assisting with various activities that help keep our organization going. For Parkinson's Victoria and the Parkinson's community, our volunteers are our superheros and they deserve to be commended for their tireless efforts to make a difference!

We encourage you to acknowledge their efforts the next time you see one of our "Superheros". A simple thank you will mean so much!

*"No matter how big and powerful government gets, and the many services it provides, it can never take the place of volunteers." --Ronald Reagan*

**If you have volunteered for Parkinson's Victoria, whether at an education event, fundraising event or in our office, **THANK YOU!** Your contribution helps us achieve so much more.**



# Education

## *First National Young Onset Conference*

We are pleased to announce that the inaugural **National Young Onset Parkinson's Conference** will be held in Melbourne from 12-13 November 2010.

This Australia-first event will bring together people from all around the country who are living with Young Onset Parkinson's, providing them with the opportunity to meet others, hear a variety of presentations from experts and participate in workshops. The conference will provide information relevant to people who may still be working, raising children, wanting to travel, and who generally want to know more about how they can live 'well' with Parkinson's.

The conference will commence with a social dinner on Friday 12 November and continue with the conference the following day, Saturday 13.

**To register your interest in attending this event, contact Catherine at Parkinson's Victoria, on [catherine@parkinsons-vic.org.au](mailto:catherine@parkinsons-vic.org.au) or (03)9551 1122.**

## *Annual Recently Diagnosed Seminar*

Have you been diagnosed with Parkinson's in the past 5 years? Our 2010 **Recently Diagnosed Seminar** will be held on Saturday, 23 October at the Treacy Centre in Parkville.

This event is an ideal forum for those diagnosed with Parkinson's within the last 5 years to learn more about the condition and living well with Parkinson's. Family members, partners and friends are also encouraged to attend.

### **Event details:**

**Time: 10:00am – 2:30pm**

**Cost: \$35 each for members and families (\$50 each for non-members and families). Registrations are essential and forms are available from [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) or by phoning our office.**

## *New Parkinson's therapy program in Melbourne's North*

**Uniting Aged Care Lumeah Day Therapy Centre** in Preston has recently implemented a weekly get together for people living with Parkinson's (those diagnosed and carers) and is looking for new participants.

The format of the group involves a one hour physiotherapy session for the person with Parkinson's, while carers have their own meeting facilitated by the centre's social worker. Following the physiotherapy session, the group reunites for a chance to talk, share and learn from each other.

**If you would like to know more please contact the centre directly: (03) 9416 8433.**

## *Parkinson's Television – reaching more people*

Since the launch of our very own Parkinson's Television (on YouTube) at the beginning of the year, Parkinson's Victoria staff members have become aspiring film directors, stars, and producers in our quest to deliver

education about myriad aspects of Parkinson's to the community and to ensure this information is easily accessible for as many people as possible.

A recent addition to our Parkinson's Television "library" is a presentation by our Parkinson's Specialist Nurse Consultant on **Bladder and Bowel Management in Parkinson's**.

**To watch this 6-minute video free from your own computer, visit: [www.youtube.com/parkinsonsvic](http://www.youtube.com/parkinsonsvic) or follow the YouTube link from our homepage.**

## *World Parkinson's Congress in Scotland*

The **2nd World Parkinson's Congress (WPC)** will take place in Glasgow, Scotland in late September, 2010.

This major international event brings together not only expert medical professionals and scientists who are leading the way in Parkinson's research, but also people working in all areas of Parkinson's treatment and support (such as allied health professionals).

Importantly, the World Parkinson's Congress provides a wonderful opportunity for people living with Parkinson's to get together and learn about the latest developments in Parkinson's research, treatment and support.

Victor McConvey and Catherine Watson from our Health Team will be representing Parkinson's Victoria at this year's Congress. We are also pleased to advise that an abstract by Victor has been accepted for the Scientific section, and he will be presenting his work in the area of specialist support for people with Parkinson's who require palliative care.

Catherine will be representing Anne Atkin and her abstract on **Painting with Parkinson's** (art as therapy). Anne established this unique art/support group in 2006, just one year after her own diagnosis, and it has gone from strength to strength.

Anne's research and work in the area of art as therapy for people living with Parkinson's will be presented as part of the **Living with Parkinson's** section. We commend Anne on the success of her initiative and congratulate her on this international recognition.

**One of our top priorities in serving the community is delivering credible, current and relevant information and support. Attending events such as the World Parkinson's Congress helps us to achieve that; ensuring our Health Team's advice, information, education and support initiatives reflect international standards so we can better support you.**

We also take this opportunity to wish Sharon Bensted and her daughters well for their entry in the **World Parkinson's Congress Video Competition**. People touched by Parkinson's were invited to submit a short video to the Congress committee, and a selection will be shown during the event. Sharon and her daughters' submission has been shortlisted from 50 entries from around the world. The video can be seen on our website.

## Pedal 4 Parkinson's

Bike rider extraordinaire, Sarah McDonald, will be undertaking her third annual **Pedal 4 Parkinson's** bike ride from Sydney to Melbourne on 7 December.

The ride aims to raise awareness and funds in support of those living with Parkinson's.

**Sarah explains her inspiration:** "A few years ago my father was diagnosed with Parkinson's. Over time I became frustrated and depressed at the fact that there was nothing I could do to help.

Dad was told that healthy eating and exercise would help him manage his symptoms, as a result my mother and father got into bike riding, and my own passion for cycling was inspired by theirs. I have never been one to sit back and just watch as things fall apart, especially when it involves someone as dear and important to me as my father, so I saw it as only fitting that I did a cycle to support the cause."

**During her 2010 ride, following a serious bike accident between Lakes Entrance and Bairnsdale, Sarah was forced to complete the last few kilometers into Melbourne city on foot.**

**While the accident resulted in an ambulance ride to – and overnight stay at – the local hospital, and some serious bruising and pain, nothing could dampen her commitment to complete the challenge.**



Sarah McDonald (centre in cap) - with fellow Pedal 4 Parkinson's riders and supporters - celebrating the team's arrival at Melbourne, Federation Square on 21 January, 2010.

**Sarah will cross the NSW/VIC border on 13 December 2010 and on the way to Melbourne will take in the following towns/suburbs: Genoa, Alfred, Cann River, Lind NP, Cabbage Tree Creek, Newmerella Tostaree, Lakes Entrance, Bairnsdale, Providence Ponds, Sale, Rosedale, Traralgon, Moe, Warragul, Bunyip North, Beaconsfield, Frankston, Mordialloc and is scheduled to complete her ride at Federation Square on the morning of Saturday 18 December.**

**Anyone keen to help or say hello as she passes through are encouraged to contact Sarah directly: 0432 713 298 or email: [smcd6737@uni.sydney.edu.au](mailto:smcd6737@uni.sydney.edu.au)**

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# Volunteer Awards

## Volunteer Recognition Awards

Parkinson's Victoria values the outstanding contribution volunteers make in reducing the impact of Parkinson's. We have several ways to ensure that volunteers are appropriately recognized for their services:

*Certificate of Appreciation:* Recognises the contribution of an individual or an organization to an event or activity.

*Five and Ten Year Services Awards:* Recognises the continuous service of volunteers in an administrative, project or service capacity.

*Honorary Life Membership:* Recognises outstanding service, normally over a period of at least fifteen years.

Further to these awards, we introduced the **Sir Zelman Cowen Award** in 2006. This award, the highest honour available, is presented annually to an individual, recognising their outstanding service to Parkinson's Victoria or services to people living with Parkinson's. Our four awardees to date have collectively given over 90 years of service between them!

Sir Zelman Cowen generously gave his permission for the award to be in his name, which is most appropriate, recognizing his outstanding community service to all Australians, and his personal journey with Parkinson's.

Last year, we were delighted to present the **Sir Zelman Cowen Award** to Geoff Alexander for his service to the Shepparton and District Parkinson's Support Group and local community.

**Nominations for these awards can be forwarded in writing to Glenn Mahoney by Friday 17 September 2010 for consideration by the Board of Parkinson's Victoria.**



Parkinson's Victoria President Royce Pepin (left) presents the Sir Zelman Cowen Award to our 2009 winner, Geoff Alexander, Shepparton Support Group Leader.

# PETER HALL

MEMBER FOR EASTERN VICTORIA REGION  
NATIONALS LEADER IN THE LEGISLATIVE COUNCIL



Contact Peter for information or assistance with State Government matters.

**Contact Peter:**  
181 Franklin St, (PO Box 1506) TRARALGON VIC 3844  
Phone 03 5174 7066 Email peter.hall@parliament.vic.gov.au

Authorised by Peter Hall, 181 Franklin St, TRARALGON, VIC 3844



# GSR

## Great Southern Rail and the Indian Pacific

Travelling between the Indian and Pacific oceans for over 40 years, the Indian Pacific is truly one of the world's great train journeys.

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While submissions for inclusion in **Signpost** are welcomed, the final decision rests with the editor. All submissions are subject to the publisher's editorial guidelines and may be edited for space or clarity.

## Parkinson's Victoria Inc.:

Parkinson's Victoria is a not-for-profit organisation and is the peak state body which provides information, education, advocacy and support to the twenty thousand Victorians living with this chronic progressive condition, their family, friends and allied health professionals.

*We gratefully acknowledge the generous donations that have been made in recent months to support our work in the community.*

*Due to the large number of donations we receive, we are unfortunately unable to list all donors individually.*

*Listed below are the names of those who kindly donated \$200 or more between 20 April and 27 July 2010, and individuals in whose name in memoriam donations were received. In addition, listed are the companies, organisations and other individuals who have kindly supported our work during this period.*

*We extend our sympathies to the families who have lost loved ones, and our thanks go to the friends and family members who have donated to Parkinson's Victoria in their memory.*

*Thank you to everyone - members and non-members - who generously gave during our recent mid-year annual appeal. This year your financial support raised an incredible \$49,000. Thank you!*

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## Payroll Giving (staff from the following companies)

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## Unity Walk Supporters

The logistics and cost of staging an event such as Parkinson's Unity Walk are significant, but the positive benefits for the community are immense, and include: increased awareness, media, community support and donations.

The corporate sponsorship we have secured for this event will assist in covering the costs and will help create a fantastic and successful event. We are grateful for the generous support of our sponsors and supporters.

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# Ambassadors

## Speaking your language

*Ambassador Coordinator, PETER RAYMOND, shares a recent experience presenting his personal story of living with Parkinson's to a group from the Italian Senior Citizens Club Doncaster.*

**"Buongiorno e benvenuti. Sono Peter e sono una persona con il morbo di Parkinson."** <sup>1</sup>

A muffled ripple of laughter went around the auditorium. Peter wasn't sure whether the 150 Italian Senior Citizens gathered together for their weekly meeting were laughing in appreciation or embarrassment.

He looked across at the interpreter who nodded his approval. Peter's schoolboy Italian was quite acceptable. But it was at this point that Peter decided that wisdom was indeed the better part of valour.

Reverting to the English with which he felt most comfortable, Peter began his Ambassador Presentation on behalf of Parkinson's Victoria. Speaking more slowly than usual and in shorter sentences, he slipped into a comfortable routine with John, the interpreter whose services were funded by the Department of Human Services.

Although not familiar with Parkinson's himself, John's job was made easier by the brochure *Understanding Parkinson's*, printed in Italian, which was similar in content to Peter's presentation. The audience, too, had been given this brochure and could follow Peter by both listening to the interpreter and reading the brochure.

After his presentation Peter left behind copies of Help Sheets printed in Italian on one side and English the other.

Of course, it wasn't always this easy.

In fact, prior to the Bridging the Gaps Project, Peter and other Ambassadors rarely presented to non-English speaking communities. The language barrier made it all too difficult.

*"(Funded) by the Lord Mayor's Charitable Foundation, the Bridging the Gaps project successfully developed and published a range of quality information resources about Parkinson's for Culturally and Linguistically Diverse (CALD) communities across Australia. It has also engaged in a range of awareness-raising strategies targeting CALD community members in Victoria, including broad distribution of bi-lingual and multilingual Parkinson's publications, Parkinson's information sessions targeting CALD community members and key messages delivered via ethnic media.*

*The Project has indeed begun to 'bridge the gaps'. Access to Parkinson's information for people with low English proficiency has been significantly*

*increased and many CALD community members in Victoria now have greater understanding and awareness of the condition.*

*It has made and strengthened important links with CALD services and communities and generated improved understandings of the needs of CALD people living with Parkinson's. Parkinson's Victoria is now better able to meet those needs and people from CALD backgrounds now have greater access to our services.*

The successful implementation of **Bridging the Gaps** has meant that Peter and other Ambassadors can now confidently accept appointments to speak and present to a broad range of CALD communities including Turkish, Greek, Russian, Croatian, Arabic, Vietnamese, Chinese, Italian and Macedonian.

*"Ambassador presentations have been shown to be a very powerful way to break down myths and misunderstandings and educate CALD community members about Parkinson's. Ambassadors provide a real-life demonstration of our key message: that with support and information, people with Parkinson's can continue to live a long and productive life. Funding is currently being sought to further resource the Parkinson's Ambassador Program to maximise positive outcomes from CALD sessions."*



*Peter and interpreter during a presentation to Turkish Senior Citizens, Mordialloc.*

After 45 minutes, Peter looked around and saw that there were no more questions. John, the interpreter had done his job well and the bi-lingual brochures had indeed, "bridged any gap".

Peter hesitated.

Oh why not? It worked at the beginning. Smiling confidently Peter launched into his best Italian: "Grazie. Mi fa piacere di essere qui con voi oggi. Arrivederci" <sup>2</sup>, and once again a muffled ripple of laughter went around the auditorium.

Peter's Italian wasn't so bad after all!

<sup>1</sup> Hello and welcome. I'm Peter and I'm a person living with Parkinson's.

<sup>2</sup> Thank-you. I'm pleased to be here with you today. Goodbye