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## Join the Walk & make a difference

*"If you were at the 2009 Parkinson's Unity Walk - you need to bring a friend in 2010. If you weren't - you need to bring yourself!" Shane Jacobson, in an interview following last year's walk.*



Shane Jacobson with Unity Walk participants (and fans) last year

**Put your best foot forward and join us for the 2010 Parkinson's Victoria Unity Walk on Sunday, 29 August, a message from CEO Glenn Mahoney:**

**"A real highlight of this event is the coming together of more than a thousand people in the centre of Melbourne for a common cause: to raise funds for Parkinson's research and services, and to raise community awareness of Parkinson's.**

There was such a diversity of people taking part last year: young and old, generations of families, and people walking in remembrance of a loved one. Our youngest participant was eight months old enjoying the view from her pram. Our oldest participant was 97, and proudly raised his arms to the applause of those gathered at the finish line to acknowledge his achievement.

The success of last year's Walk was very much due to the wonderful support we received from the Parkinson's community and in particular you - our members.

**We need your support again so that our Unity Walk can grow every year to become a major charity event in Victoria's calendar.**

We received so many favourable

comments from participants about how proud they were to be there with their families and friends, supporting a common cause. We have reviewed last year's event with the assistance of the many participants who completed feedback forms to make this year's event even better.

### Support Groups

**A special challenge to our 45 Support Groups across Victoria:** Please promote the walk to your members and let's aim to have representatives participating from every Parkinson's Support Group in Victoria.

We will have placards with the names of all individual Support Groups available to be carried by your representatives on the day: to see all 45 placards bobbing around the course will be a sight to behold.

**There is further information on the Walk in this edition of Signpost, so, as Shane Jacobson said, "If you were at the 2009 Parkinson's Unity Walk you need to bring a friend in 2010. If you weren't there- you need to bring yourself!"**

**We look forward to welcoming you to this wonderful and uplifting community event!"**

**Glenn Mahoney  
Chief Executive Officer**



Parkinson's Unity Walk: A great day out with the family! Wilbur Wilde (far right) joins in the fun.

# News & Highlights

Looking for the latest news, updates and special announcements from Parkinson's Victoria and beyond? You'll read about them here!

## Spreading colour with Youtube

Our **Painting with Parkinson's** support group, the brain child of artist and Parkinson's Victoria librarian, Anne Atkin, has long been enthusiastically supported by the City of Casey, Anne's local council.

Last year the Council organised professional filming of one of Anne's workshops and the finished product was shown along with 9 other films as part of Volunteer Week, 2009.

Featuring a voice over by Anne and footage of her art students, the **Painting with Parkinson's** film explains what the group is all about and the positive impact art 'therapy' can have for all people living with Parkinson's.

Log onto [youtube.com](http://youtube.com), then type **Painting with Parkinson's City of Casey** into the search option.

In April, **Painting with Parkinson's** hosted a follow up exhibition to its 2009 show, **Expressions of Colour**, aptly titled **More Expressions of Color**, at The Old Cheese Factory in Berwick.



Anne presents the Hon. Anthony Byrne, MP with the **Order of the Golden Paintbrushes**.

The exhibition celebrated the achievements of group members, not only in their paintings but in having experienced improved quality of life as a result of participating in the art workshops; as well as regaining some control, greater confidence and realising that Parkinson's does not take away your creativity.

The exhibition was opened by The Hon. Anthony Byrne MP, Federal Member for Holt. Mr Byrne has been a long time supporter and advocate for Anne and her Support Group, and this was formally recognised by Anne during the exhibition when she bestowed a rare honour on the MP: **The Order of the Golden Paintbrushes**, thus making Mr Byrne the first (and probably only) **Patron of Painting with Parkinson's**. It was noted that Anthony seemed genuinely emotional when receiving his award and Anne pointed out that it was a genuine Parkinson's award because if you looked closely, you could see that the plaque was on a slight angle!

To find out more about Anne's **Painting with Parkinson's** art group, contact Parkinson's Victoria.

## New faces

We are pleased to welcome Michelle Wootton as the newest addition to our Health Team. Michelle comes from a background of Health Promotion, with experience in a variety of non-profit settings.

Most recently she was involved in a project at the **Starlight Children's Foundation** called 'Livewire' – an online community for young people aged 10-21 who are living with a serious illness, chronic condition or disability.

Michelle's role as the organisation's **Outreach Officer VIC/TAS** involved building awareness of the online community and its benefits amongst health professionals, other non-profits, young people and their families.

Prior to her role at Starlight, Michelle was the **Patient Programs Officer** at **Ovarian Cancer Australia**, providing support to newly diagnosed women and their families via the toll-free referral line, and coordinating support groups Australia-wide. She was also involved in raising awareness of the disease through events and education sessions, and contributing to the development of new information resources.

Michelle will undertake a similar role within the Parkinson's Victoria Health Team and she is looking forward to engaging with the Parkinson's community, particularly as one of the friendly voices you hear on the end of our 1800 Help Line. Michelle has already been out to visit some of our support groups, and recently participated in a **Painting with Parkinson's** session with Anne Atkin. Michelle has also put her social networking experience to great use by creating the first ever Facebook page for Parkinson's Victoria (check it out at: <http://www.facebook.com/parkinsonsvic>).

**"I hope to significantly increase awareness of Parkinson's in the community, and help raise the profile of Parkinson's Victoria as part of the Health Team." Michelle.**

**We also welcome Ian Hosking as our new Finance Officer. Ian, who is a CPA and Chartered Accountant, comes to us with more than 30 years experience in public practice. Ian's father had Parkinson's, so the cause is one especially close to his heart.**

## Calling all artists

Could your original artwork feature in our 2010 selection of Christmas cards?

In 2009, our most popular Christmas card featured original artwork by botanical artist Jean Smith, who generously donated her exclusive design, The Holly and the Gum. Jean was diagnosed with Parkinson's in 2001.

In 2010, we are inviting people with Parkinson's who are professional or amateur artists to submit an original work from which Parkinson's Victoria will make a selection to feature on our 2010 card/s.

**The card will feature acknowledgement of the artist. For further information or to send your submission please email: [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au) (Please ensure you include your name and a brief explanation of your artwork and contact details)**

#### Editor's note:

- Artwork must be original and copyright must be owned by the artist or the individual making the submission.
- The final decision regarding selection of card design/s for use as Parkinson's Victoria's 2010 Christmas card artwork rests with the organisation.
- The owner of copyright must be able to provide an image of the artwork as a high resolution digital file (please do not send the actual artwork) and be prepared to provide use of the artwork to Parkinson's Victoria as a **donation** (no fee or royalties will apply).
- Once a selection is made, Parkinson's Victoria will work with the artist to finalise artwork for the Christmas card and artist acknowledgment text.

#### Fond farewell

It is with considerable sadness that we acknowledge the sudden passing in April of Mr Arthur 'Noel' Thomas, leader of our Bendigo Support Group, as a result of a short illness.

Noel had been in the role of Support Group leader for almost 18 months, and had assumed leadership when Rhonda Kennedy retired. Under Noel's guidance, the group has continued to develop.

Noel's involvement with Parkinson's and Parkinson's Victoria began when his wife Audrey was diagnosed, and his support for both Audrey and the support group was touching and remarkable.

Noel will be sadly missed by the Bendigo community, in particular by members of the Bendigo Parkinson's Support group, and Parkinson's Victoria staff.

**The Board volunteers and staff of Parkinson's Victoria extend their deepest sympathies to Audrey and the Thomas family.**

#### Ground-breaking report presented in Canberra

The launch of the recently completed report **Living with Young Onset Parkinson's** was held at Parliament House Canberra in March. The function was hosted

by Senator Carol Brown (Tas), with seven MP's and an advisor to Minister for Health Nicola Roxon in attendance. Representatives of the Pharmacy Guild, state Parkinson's Associations, the Rural Health Alliance and people with Parkinson's were also present.

Presentations from Nerissa Mapes, Rochelle Fowler and Paula Argy on the impact of Parkinson's in their lives were a highlight of the launch.

The report was received by Mark Butler, Parliamentary Secretary for Health, who commended Parkinson's Victoria on the initiative.

This ground-breaking Australian report is the culmination of 12 months of hard work and community consultation, and we gratefully acknowledge the generous and invaluable participation of the steering committee, several of our members and members of the wider community.

The impact of the report has already been felt Australia-wide, with national media outlets picking up the announcement and highlighting the significance of the report.

The report will assist advocacy and resource initiatives of Parkinson's organisations in Australia. In the coming months it will prove an invaluable supporting document to a funding submission by Parkinson's Australia to the Federal Government, which incorporates a funding request to establish a national Young Onset Parkinson's resource centre.

In addition, the *Living with Young Onset Parkinson's* report will continue to influence the decisions and directions of service providers who deliver support and resources to the Parkinson's community. And, importantly, the report and ongoing media coverage will help highlight the specific issues and concerns facing those living with Young Onset Parkinson's.

**For a copy of the full report, visit the publications section of our website.**



Contributors to the Young Onset Parkinson's research project (from left): Brendan Lourey, Amanda Spillare, Peter Raymond, Chris Fyffe, Glenn Mahoney and Catherine Watson.

# Parkinson's Victoria Unity Walk 2010

Last year's inaugural Parkinson's Unity Walk, hosted by Parkinson's Victoria, drew participants from all over the state. In 2010, we're hoping to beat last year's number of 1026 Walkers and raise even more funds for research and support.

We've already been getting enquiries about this year's event, so to assist you in getting involved below is a snapshot of *Frequently Asked Questions* in relation to Parkinson's Unity Walk.

## THE EVENT

### What is Parkinson's Unity Walk?

The Walk is the largest fundraising and awareness raising Event of its kind in Victoria: It's more than just a day out – it's a chance to make a real difference.

The Walk is a 4km, non-competitive stroll along the banks of the Yarra. Parents can push prams or strollers, grandchildren can walk with grandparents, and friends and family can come together to enjoy the community atmosphere and spectacular views of Melbourne's skyline all in aid of a great cause!

### Why was the event started?

The Walk was started as a highly effective way to highlight Parkinson's in the wider community and to raise significant funds to support the work of Parkinson's Victoria.

Importantly, it provides all members of the community with the opportunity to come together in a public display of solidarity and support in the fight against Parkinson's.

### When is the Walk?

Sunday, 29 August, 2010

### Where will Unity Walk take place?

The Parkinson's Victoria Unity Walk will again take place at Federation Square, Melbourne City (Corner Swanston and Flinders Street, opposite Flinders Street Station).

### What time will the Event start?

8.30-10.45am Registration (On-the-day registration/ collect your Event T-shirt)

11.00am Official start of Walk

1.00pm Event concludes

### How long will it take to complete the Walk?

The return route is 4km and should take approximately 1 hour to complete at a leisurely pace.

### Is the venue and course "disability" friendly?

Yes. Federation Square has lots of ramps and lifts, and a car park on-site.

The course along the Yarra River is flat and does not cross any roads. It is entirely wheelchair and pram/stroller friendly. There is also a shorter course option of 2km.

### What does my registration fee include?

Most importantly, a great day out with family and friends and the opportunity to help people with Parkinson's by fundraising in addition to participating in the event.

On the day you will also enjoy a fantastic, family atmosphere with face painting, entertainment and music.

Your registration fee also includes:

- Event T-Shirt
- Goodie bag
- Entry to the event
- Certificate of Appreciation and Participation
- Chance to win some fantastic prizes
- Fun warm up exercises
- Clearly marked and safe course and a professionally run event
- Photos posted online after the Event and available for purchase

### Are there prizes for participating in the event?

This is a participation event only, so there are no prizes for "winning" the Walk. However, there will be a number of random prizes awarded in various categories, including Team, Corporate, early bird registration and fundraising.

**MAJOR PRIZE! Courtesy of Hawaiian Airlines and Hawaii Tourism those who fundraise \$250 and over will have the chance to win a fantastic trip for 2 to Hawaii (includes airfares and accommodation).**

**More information about prizes will be available on the event website.**

## REGISTRATION and REGISTERING TO FUNDRAISE

### How do I register to walk?

You will be able to register online or by completing an entry form. Registrations open in June or email [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au) to register your interest today.

### What are the entry fees to participate in Parkinson's Unity Walk?

All Walkers must register to Walk. All prices are GST inclusive

#### Early bird (Until Midnight 22 August)

Adults: \$25

Health Care card holders/pensioners: \$20

Children (5-15 years): \$15

Children (0-5 years): FREE

Group/Family tickets will also be available

# Parkinson's Victoria Unity Walk 2010

## **Register after Midnight 22 August or on-the-day registrations:**

Adult: \$30

Health Care card holders/pensioners: \$25

Children (5-15 years) \$20

## **Why is there a registration fee for this event?**

Entry fees help cover the cost of staging this Event. You can help us to reduce Event administration costs by registering and fundraising online.

## **Can I get some friends and/or workmates together to enter as a team or corporate team?**

YES! There are great prizes up for grabs for TEAM entries. On the Event website, you will be able to nominate a team name and team captain at the time of registering but remember: each team member must be registered individually. Teams can also fundraise as a group.

## **Can we register to walk as a family?**

Yes. This is a great family day out and the walk is easy enough for people of all ages to get involved. We are also offering discounted entry fees for families.

## **Can I walk in honour of someone special?**

Yes! Dedicate your participation in the Parkinson's Unity Walk to the memory of a loved one or someone close to you who is living with Parkinson's. Create and wear on the day a Parkinson's Unity Walk 'Tribute Card' with your loved one's name and/or photo. You can also indicate on your entry form if you are walking in honour of someone.

## **I am unable to walk on the day – can someone walk for me?**

There are many people who would like to get involved with the Walk but are unable to do so, perhaps they are unwell, or simply cannot travel to the Event location. If you are unable to attend or participate in the Walk personally, why not ask someone to Walk on your behalf?

You or your friend or family member (proxy) can register and then wear a Tribute Card with your name.

If you don't know someone with Parkinson's but would like to walk on someone's behalf, let us know and we can partner you with a person living with Parkinson's who is keen to get involved.

## **SEEKING SPONSORSHIP/DONATIONS**

## **I realise that fundraising is a vital part of Parkinson's Unity Walk – in addition to my participation in the Walk itself. How can I fundraise?**

YES! An important part of Parkinson's Unity Walk is raising vital funds so Parkinson's Victoria can continue to help people living with Parkinson's through support programs, services, advocacy and research. 50

percent of funds go to research and 50 percent to services.

If everyone from last year's Unity Walk raised just \$100 it would mean an extra \$102,600 for people living with Parkinson's. These extra funds would enable Parkinson's Victoria to answer more phone calls, send out more information kits, provide more education, create greater awareness and deliver and enhance our support and service programs to help people with Parkinson's.

When you register to Walk you can elect whether you'd like to fundraise online or offline. We'll then help you reach your own fundraising goal by setting up an online Fundraising Page (which you can personalize) or by sending you a fundraising kit.

## **How can I get sponsored?**

Tell your friends, family, workmates, neighbours and social network that you're supporting people with Parkinson's by participating in the Walk.

Let them know that every dollar counts in the fight against Parkinson's and invite them to support you. Encourage them to join with you to complete the Walk and/or invite them to support your efforts with a sponsorship donation. All donations of \$2.00 and over are tax deductible.

## **Where will the money raised from the Walk go?**

For every dollar raised, 50 percent is directed towards funding research into Parkinson's. The remaining 50 percent will help fund the support and information services of Parkinson's Victoria.

## **How much has been raised from Parkinson's Unity Walk?**

In 2009, in our first year hosting Parkinson's Unity Walk, we raised an amazing \$60,000. This year our fundraising goal is \$100,000.

## **How will my fundraising be acknowledged?**

Top fundraisers will be featured and updated on the Parkinson's Unity Walk website in the lead up to the event.

## **Can my company sponsor the Walk?**

Absolutely. Corporate sponsorship is essential to the success of Parkinson's Unity Walk. Please contact our Marketing and Fundraising Coordinator for more information: (03) 9551 1122 or email [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)

## **Where can I find more information?**

Stay tuned for the Parkinson's Victoria Unity Walk website, coming soon.

In the meantime you can contact Parkinson's Victoria by email: [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au) or phone (03) 9551 1122 or tollfree 1800 644 189. You can also become a member of the Parkinson's Unity Walk Facebook group.

# Access, Advocacy & Assistance

*Your vote can change lives*

**State Election 2010 (27 November):** Help us secure government funding for Parkinson's nurses across Victoria.

In the lead up to Tasmania's state election several weeks ago, both Liberal and Labor parties committed to funding Parkinson's nurse positions in Tasmania - should they be elected.

This result was very pleasing and followed much lobbying of local candidates by Parkinson's Tasmania, Support Groups and Members.

Similarly, in South Australia, the Liberal Party made a written commitment to fund Parkinson's South Australia to enable the appointment of Parkinson's nurses. While this commitment was not matched by the Labor Party, it is reassuring that Australian political parties are finally responding to the call for improved Parkinson's support.

**The Victorian election will be held on 27 November, 2010.**

In the lead up to the election Parkinson's Victoria will be asking all candidates to commit to recurrent funding of eight Parkinson's nurses who will be located across metropolitan and regional Victoria.

**Parkinson's nurses help people to 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 specialist Parkinson's nurses 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 and improving medication management and independence.

We are asking for your help with this campaign to influence future decision makers.

Materials for our **Parkinson's Nurse Campaign** are currently being finalised and will be available from our website shortly. We can also email and post materials to you.

The recent campaigns in Tasmania and South Australia were successful only as a result of members and supporters becoming actively involved; contacting their candidates and calling on family and friends to assist with lobbying.

**Please take the time to read our election materials, then contact your candidates and call on them to commit to funding in return for your vote.**

**Remember that while up to 20,000 Victorians are diagnosed with Parkinson's, if you count the families, friends and work colleagues the condition also impact on, this number is closer to more than 100,000. This translates into a significant number of votes.**

## Where to turn for support and information

Our Health Team can provide information and support on a broad range of topics related to Parkinson's. **You do not have to wait until you are at a crisis point or only ring to discuss medication questions.**

Our Health Team can assist with answers and information regarding:

- Medication
- Symptoms and symptom management strategies
- Tips and advice for increasing your mobility and independence
- Updates on research
- Information about research trials and participating
- Advice on referrals to allied health staff and other health professionals, including Movement Disorder Clinics
- Tips on getting the most out of your GP and neurologist appointments
- Information about your rights at work
- Travel and health insurance
- Information and guidance on eligibility for government subsidies and assistance schemes
- Tips and information for you to help a loved one cope with their diagnosis and move forward
- Information about support networks
- Information on Parkinson's and...sexuality, continence, depression, exercise, diet, driving, etc
- Information on mobility aids to enhance independence and personal safety

And much, much more!

**Our free information and help phone line is open to ALL members of the community.**

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**Better health, brighter life**

<sup>1</sup>CAAS refers to the Australian Government Continence Aids Assistance Scheme, ending 30th June 2010.

<sup>2</sup>CAPS refers to the Australian Government Continence Aids Payment Scheme, starting 1st July 2010.

\* Terms and Conditions apply: visit [www.brightsky.com.au](http://www.brightsky.com.au) or call 1 300 88 66 01

BrightSky Australia is the healthcare product division of a leading Australian disability NGO, ParaQuad NSW.

## Making faces: Parkinson's Victoria joins Facebook!

We are excited to announce the launch of our very first Facebook page:

<http://www.facebook.com/parkinsonsvic>

### Become a "fan" of our page and join the Cause!

It's a great way to stay up to date on our news, engage with other supporters and find out what we've been up to with events, fundraising activities and media.

### What is a Facebook Page?

Facebook pages are an online (Internet) vehicle for organisations, businesses, celebrities and bands to broadcast information to "fans" in an official, public manner. (Individuals also use Facebook to share personal information and news with friends.)

Through our Facebook page, Parkinson's Victoria can now communicate to you and other interested members of the public, both here in Victorian and around the world, the latest news and research, upcoming events, seminars and fundraising activities, and services offered. We can also let you know about media stories to watch out for so it's worthwhile logging on throughout the day to make sure you get the latest updates!

The page will also include photos, media releases and links to useful sites, such as our very own YouTube channel, and we'll be constantly updating and changing content.

### What is a Cause page?

Over 150 million people log into Facebook on a daily basis world-wide! Just imagine if they all knew about Parkinson's and registered their desire to become a "fan" – a supporter of the Cause by following our page!

In addition to the sheer reach of this network being invaluable, the **Cause** section of Facebook provides charities such as Parkinson's Victoria, with specialised tools for spreading awareness, building community, fundraising and promoting other important activities.

**Our Cause page will help Parkinson's Victoria work harder for you** by reaching out to a new supporter demographic; expanding our network of financial donors (so we have more funds to undertake more services); engaging with existing supporters; and importantly, it will help us to spread the word about how we help those living with Parkinson's **and** how others can help by getting involved and supporting our activities.

### Not a member of Facebook yet?

Joining Facebook is easy and free, and it's a great way of keeping in touch with family, friends, and the Parkinson's community.

Aside from staying in touch with us by becoming a 'fan', you can set up your own personal profile and use Facebook to search for old work colleagues, school or university friends and other people you have lost touch with over time. You can also share your personal news and photos via your own personal Facebook profile page.

All you have to do is visit [www.facebook.com](http://www.facebook.com), enter your details on the 'sign-up' section of the homepage, then follow the prompts.

Your Facebook profile allows you to share what's going on in your life and keep in touch with your contacts, upload photos, share links and videos.

**Editor's note: For a great article on 'cyber safety' see page 9.**

**Why not tell your kids, grandkids and other family members about our Facebook page? They might like to sign up and stay in touch too! It's free to join!**

## Problems keeping medications on time?

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## Cyber Safety

*Being able to 'go online' and use the internet or World Wide Web (www) has changed the world we live in and in many cases, the way we live. MICHELLE WOOTTON from our Health Team shares some useful tips for having a positive online experience.*

A relatively 'new' capability of the web has been what's referred to as 'social media'.

Essentially, social media are vehicles that utilize the Internet to allow people - from anywhere in the world or next door to each other - to engage in 'dialogue' with others.

Importantly, social media is designed to transform people from being content consumers to content producers, hence 'blogs', chat rooms, forums, Facebook, Twitter and so on enable people to share thoughts, questions, comments and commentary on topics of their choosing and interest, and to seek and provide responses to those comments.

### Tips to stay safe online when using Facebook:

- **Buy or download reputable anti-virus and anti-spyware software for your computer** and turn on any spam filters available from your email account provider or anti-virus program. This will prevent the majority of spam/junk emails from entering your inbox.
  - **Be careful who you add or accept on Facebook as a friend and who you chat to online.** As a general rule, it is a good idea to only add/accept friends you know in real life, however, the internet can be a great place to meet new people and make some new connections.
  - **People can lie.** Don't agree to meet up with someone alone if you have only chatted to them online, and don't give out personal information such as your address or phone number. People can easily use a fake name, age and photo to deceive you. If you do decide to meet an online friend in person, take someone else with you and only meet in a public place.
  - **Think before you hit 'send' or 'post'.** While one of the great things about text messaging via your mobile phone or sending a message or photo via Facebook is how quick and easy they are to use, you never know where it may end up, or the impact it may have in the short or long term. The person you send the message to may forward it onto others or you may simply regret sending it, so make sure you are happy for it to go public.
  - **Only shop online at secure websites.** A secure website can be identified by the letters "https" at the start of the web address; an unsecured website address begins with "http". An image of a padlock in the browser is also used to identify a secure website. Reputable companies typically also provide details of their physical location and a phone number (landline) on which to contact them. Check the delivery charges and return policy carefully.
  - **If you are browsing the internet for information related to Parkinson's, stick to the websites of reputable organisations** such as Parkinson's Victoria or Parkinson's UK.  
There are many websites that will promote a cure or an alternative treatment for Parkinson's. Be wary – these sites are often created by people who are simply looking to make some money, and/or have not done adequate research to back-up the results they promise.  
**Never change/stop your medication or try an alternative therapy without first consulting your GP or Neurologist.**
  - **Don't be afraid of the internet!** Just like in the real world, there are always dangers to be careful of. Keep in mind that fraud and scams have been around for a lot longer than computers. If you are aware of the risks and know what to look out for, you can stay safe online and enjoy all the benefits the internet has to offer.
- **Make sure your personal Facebook profile is set to 'private' in the privacy settings.** This means that only the friends you have added (or those whose friendship you have 'accepted') can view your information and photos. If you don't have it set to private anyone who types in your name and finds your profile can see all of your details, including photos and contact information. Also, make sure that your profile picture is something that you would be happy for anyone to see, as this is still visible if someone searches for your profile but they are not a 'friend'.
  - **Use a strong password and keep it secret.** A strong password contains a mixture of upper and lower case letters, numbers and keyboard symbols. **Do not share your password with anyone;** it is yours and yours alone. If you forget your password, it can usually be re-set by Facebook or your email provider.
  - **Never open or respond to emails or messages if you don't know who they are from,** they are almost always 'spam/junk emails' that contain 'scams' or 'viruses'. Scams may ask for your bank details, pin number or personal information to either steal your money or your identity. Viruses can attack and damage data on your computer and can even spread to your friends via your email address without you knowing.  
If you are sent an offer that looks "too good to be true", it probably is! Check your credit card and bank account statements regularly and report any suspicious transactions to your bank or financial institution.

# Question Time

## Exercise and Parkinson's

*Exercise should play a part in every person's lifestyle. However, for people with Parkinson's it can offer additional benefits. Our Parkinson's Physiotherapist, SHELLEY POLLAK has put together some Frequently Asked Questions about exercise and Parkinson's in the hope that it may inspire people to start exercising and incentivise others to get back into it.*

It is well known that regular cardiovascular and strength training exercises provide significant benefits to the general community with regards to heart health, blood pressure, cholesterol, osteoporosis, mood and our overall immune system. However, it may not be as well recognised that regular exercise can have significant benefits to people with Parkinson's.

Considering Parkinson's can increase a person's rigidity (stiffness) and make them move more slowly, it is not surprising that as a consequence, they become less active. Unfortunately, this can very easily turn into a vicious cycle.

Apathy can also play a big role in people finding it difficult to exercise as internal motivation is affected in many people with Parkinson's. Once this joins the cycle of *inactivity*, it can be quite hard to break.

### How does exercise benefit people with Parkinson's?

Considerable evidence has been published to suggest that strength and endurance training, balance exercises and stretching all help to improve people's with Parkinson's independence and fitness, as well as quality of life and mood. Also significant is that they help reduce falls. Unfortunately, there is no consensus as to which specific exercises - or how much - should be done to achieve optimal results.

Despite this, there are still some general principles that should be followed:

- Strength training should be *progressive* and *resistive*. In other words use weights that are always challenging: As soon as you find one level of weights easy, increase the weight.
- Strengthen muscles in the context of movements you do throughout the day, such as walking, squats and climbing stairs. Being able to complete 50 bicep curls won't necessarily translate into improving your walking!
- Don't exercise through pain. If it hurts, don't do it (but keep in mind there is a difference between pain from injury and simply feeling your muscles working or tiring).
- If you suffer from fatigue, choose a time of day when you feel most energised. Alternatively, instead of trying to do one long session (such as 30 minutes), break up your exercises into multiple shorter sessions throughout the day. Research

has shown that 'cumulative' exercise throughout the day can be just as beneficial as one longer session per day.

### What areas should I focus on?

Every person will have different areas of their body and fitness that they want or need to focus on. For example, for some people it might be a priority to address their balance, while for others it may be their posture.

The most important thing is to use your time effectively and remember to focus on the muscle groups that are the most vulnerable in Parkinson's. Specifically, these are the *anti-gravity muscles*; the ones that help keep us standing up straight. These include:

- Neck muscles: a good range of movement in this area will help prevent falls and assist with maintaining good posture.
- Upper back and between your shoulder blades: will keep you standing up straight.
- Pectoral muscles (the chest area): stretch them when you can to help prevent rounded shoulders.
- Buttock and thigh muscles: assist with walking, moving in bed, getting up from a chair/couch.
- Calf muscles: help with walking. Stretch and strengthen them to have good balance.

### How frequently should I exercise?

It is recommended for people in the general community to exercise 3-5 days a week for at least 30 minutes at a time. If you have not exercised for some time, keep the frequency the same, but reduce the *length* of time you exercise. You may find you can only tolerate 10 minutes of exercise each day, but if you do that consistently for 3-5 days per week you will soon find that your tolerance will improve and you can lengthen each session.

Remember, a "session" of exercise can simply mean going out for a walk or doing some stretches at home. It doesn't have to mean a session at the gym!

### Where should I go?

The best place to start is with a physiotherapist who is experienced in treating people with Parkinson's. They will be able to do a thorough assessment and then prescribe an exercise program that will suit your individual needs.

You may then be able to follow that program independently at home or at your local gym. Or, it may be more appropriate to do each session together with the physiotherapist at the clinic.

**Contact your local Movement Disorder Clinic, Community Health Centre or private physiotherapist to get started. (To locate your local clinic visit [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) and click through to the "Parkinson's Help Finder".)**

**Of course you can always call our Health Team and we can point you in the right direction.**

*Ensuring the community and health professionals have access to credible, current and comprehensive information about Parkinson's is one of our top priorities.*

## Bridging the Gaps Evaluation

An evaluation report documenting the outcomes and processes of our **Bridging the Gaps** Project is now available from Parkinson's Victoria.

The report outlines the process, challenges and success of the project which aimed to develop appropriate information resources for - and raise awareness of Parkinson's among - people from culturally and linguistically diverse (CALD) communities.

A snapshot of project highlights include:

**AIM:** *Develop and distribute bilingual information resources, in print, audio and electronic formats.*

### RESULT:

- Since the launch of the materials in May 2009, a total of 26,300 printed bilingual information resources have been distributed to the community and health professionals.
- A languages URL (website link) has been included on the Parkinson's Victoria website and has received 2144 hits to date. It is consistently among the top 10 entry pages to the Parkinson's Victoria website.
- Our audio reads of **Bilingual Help Sheets** have received a higher numbers of hits than the print versions (when first released) and continue to be very popular.

**AIM:** *Strengthen linkages between Parkinson's Victoria and CALD communities, and improve awareness among staff, volunteers and management of the issues facing people from CALD backgrounds who are living with Parkinson's.*

### RESULT:

- Parkinson's Victoria has actively participated in key networks for CALD service providers and represented the organisation at multicultural expos, festivals and workshops.
- We have pro-actively identified individuals from CALD backgrounds with a personal or professional interest in Parkinson's.
- The project has resulted in a significant increase of CALD clients and service providers.

**AIM:** *Develop a community education campaign - targeting key CALD community groups - and deliver Parkinson's information sessions and "launches" of CALD materials.*

### RESULT:

- A major launch was conducted by Parkinson's Victoria and officiated by Lord Mayor John So at Melbourne Town Hall in 2009, attended by 50 representatives of ethnic and health

organisations and people living with Parkinson's.

- More than 600 CALD community members have attended a Parkinson's information session in a language other than English in the period October 2008 to December 2009.

**AIM:** *Develop a media campaign targeting members of CALD communities generally, focussing on ethnic media as a means of raising awareness of Parkinson's and the bilingual resources.*

### RESULT:

- Community Service Announcements and a number of interviews and Parkinson's presentations have been broadcast on ethnic radio.
- Articles and advertisements have featured in ethnic publications, including Menorah Independent Jewish Magazine, Golden Years Newsletter on Ethnic Aged Care issues and El-Telegraph Arabic Newspaper.

### Summary

The success of the Bridging the Gaps project is attributed to factors such as planning, networking, the establishment of an advisory group and a thorough community checking process.

Challenges for the future include improved access and distribution nationally of these resources and improved data collection in relation to our work with CALD clients so we may better improve resources, develop new initiatives and respond to the specific needs of these communities.

Unfortunately, funding for this project ceases in June 2010, however our organisation continues to seek funds which will support the initiative.

**The evaluation report will inform the development of Parkinson's Victoria's work with CALD communities into the future, as well as providing a valuable resource for other organisations who wish to undertake similar projects. For a copy of the report contact us or visit our website.**

## Enhancing the skills of allied health

Parkinson's Victoria will be conducting a Physiotherapy Seminar in August at Monash University, Caulfield Campus.

Its purpose is professional development for physiotherapists who already have experience treating people with Parkinson's but are looking to enhance this experience.

We have secured a number of excellent speakers to participate in this first-of-its-kind event, including Parkinson's Specialist Neurologist Professor Iansek and Professor Meg Morris Head of Melbourne University School of Health.

**Health team note: The seminar is for physiotherapists only.**

# Fundraising & Events

## *Eat, drink and fundraise!*

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 informal and take-away outlets. All outlets featured in the Book carry "25-50 percent off" or "2-for-1" offers. Best of all, every book purchased means a donation to Parkinson's Victoria!

**Books cost \$65 each, with \$13 going directly to Parkinson's Victoria.**

**To purchase your 2010/11 book contact:  
Parkinson's Victoria: (03) 95511 122 or  
judith@parkinsons-vic.org.au**

## *Putting for Parkinson's*

For the third year in a row, Parkinson's Victoria is proud to announce that Spring Valley Golf Club has elected our organization as the beneficiary of funds raised through its annual Charity Golf Day. So far, this annual event has raised just over \$17,000 for Parkinson's Victoria!

**Event details: Spring Valley Mixed Charity Golf Day  
Date/Time: Friday 28 May, Registration 7.30am,  
shotgun start at 8.30am.**

**Location: Spring Valley Golf Club, Heatherton Road,  
Clayton South.**

**Entry Fee: \$60 per person (includes game, entry into  
the main 4BBB Stableford competition, and a light  
lunch).**

**To register as an individual or team, download a  
form from [www.springvalleygolf.com.au](http://www.springvalleygolf.com.au) or [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au)**

**Registrations close Monday 17 May or when field  
capacity is reached.**

**Enquiries: Spring Valley Golf Club (03) 9562 3811.**

## *Charity Movie Night*

Carrie and the girls are back! You're invited to join Parkinson's Victoria for a special Charity Screening of Sex & the City 2. At the same time you'll be supporting a great cause!

**When: Wednesday 9 JUNE, 2010**

**Time: 8.15pm (movie screens at 9.00 pm)**

**Tickets: \$30 includes movie ticket, a Cosmopolitan  
and nibbles (pre-movie)**

**Where: Palace "Dendy" Brighton, 26 Church Street,  
Brighton**

**How to book: Reserve your seat today!**

**Email your contact details and quantity of tickets  
required to [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)**

**or call (03) 9551 1122 or call Judith 0447 376 374**

## *Supporting the community*

Ritchies Supermarket and Liquor stores have developed a simple and effective way to raise funds for Parkinson's Victoria: Register for one of their Community Benefits cards by completing an in-store form and nominating Parkinson's Victoria as your

preferred charity. You'll then receive two plastic cards – one for yourself and one to give to a friend or family member - which is then swiped every time you make a purchase. Not only does 1 percent of the total get donated to Parkinson's Victoria but all card holders are entitled to exclusive weekly specials on a range of items!

**So far, \$20,000 has been raised for Parkinson's Victoria through the Ritchies Benefits Card scheme. Visit [www.ritchies.com.au](http://www.ritchies.com.au) to find out more or to locate your nearest store.**

## *Return of the Gala Ball*

**The Tulip Ball is back for 2010 and it's shaping up to be bigger and better than the first!**

Everyone is invited to attend this gala black tie event on Saturday 13 November at the exclusive "Members Only" RACV Club, 501 Bourke Street, Melbourne.

The event will include a sumptuous dinner, entertainment, amazing auction items and raffles! Your support will help raise awareness of Parkinson's and funds, with all proceeds to Parkinson's Victoria. Tulip events hosted in 2008 and 2009 have already raised \$40,500!

**If you would like to attend, donate or sponsor this event, please contact event organizers**

**Julie Sewell: [sewelljd@bigpond.com](mailto:sewelljd@bigpond.com)**

**or Jo Hill: [johill@interchem.com.au](mailto:johill@interchem.com.au)**

## *The artist reinvented*

In April, Kingston Arts Centre (Moorabbin) was pleased to present Phoenix Rising – an exhibition by Harley Gale.



clockwise from left: The artist at work; from one of Harley's earlier exhibitions (circa 1972), **TSunami** (Gale 2009)

# Fundraising & Events

This exhibition follows on from Harley's 1972 exhibitions **A Sail in Time and Space** and **The Garden of Earthly Delights**.

Harley uses colourfield, action painting and the happy accident to illustrate the Chinese belief that the universe is in my heart and the heart is in my universe.

Although Harley commenced tertiary studies in medicine and later went on to practice as an acupuncturist for many years, his love of art, particularly Eastern influences, have continued to influence and inspire him. Most recently the development of Parkinson's has led Harley back to his old love of painting and he is now firmly focused on storytelling through his artwork.

The Phoenix Rising theme of this most recent exhibition could be said to reflect Harley's desire to reinvent himself as an established artist who happens to have Parkinson's – rather than someone with Parkinson's who paints. Harley is based in Goonengerry, Northern NSW.

**Harley Gale's exhibition, officially opened on Thursday, 8 April by Phillip Jack, a former journalist with the Financial Review, was attended by more than 70 guests. If you would like to know more about Gale's work or enquire about purchasing one of his artworks, please contact Judith at Parkinson's Victoria: [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au) or call (03) 9551 1122.**

## *Estate Planning Seminars*

*What do Kerry Packer, Richard Pratt, Peter Brock, David Hookes and Anna Nicole Smith have in common?*

At some point their final will and testament has been challenged or questioned. But, "What does this have to do with us regular folk?", you might ask.

Inheritance law can be potentially complex to interpret and apply. High profile estate disputes serve as a reminder to ensure your own estate is in order. The key element is having an up-to-date will.

Spheres of Influence International, in association with the Law Institute of Victoria and endorsed by Bowls Australia and supported by Bowls Victoria, is hosting a special event to assist you in navigating this important activity.

## **How Does Estate Planning Law Influence You?**

**Forums on Elder Law** is an insight into the law that affects Australians writing a will; managing superannuation; faced with being a Trustee of a deceased estate or Power of Attorney; financial planning or facing discrimination.

### **Event details**

**How does Estate Planning Law Influence You? A Forum on Elder Law**

**Choose from the following dates and locations:  
Thursday 20 May at Glen Waverley Bowls Club**

**Thursday 10 June at Strathmore Bowling Club**

**Thursday 9 September at City of Frankston Bowls Club**

**Thursday 7 October at Belmont Bowling Club**

**All sessions 1:00pm to 4.30pm**

**Cost: Adult \$49.50 inc GST, Pensioner \$24.75 inc GST (includes light refreshments and complimentary beverage, coaching and social game of lawn bowls).**

**For further information or to book visit:**

**[www.spheresofinfluence.com.au](http://www.spheresofinfluence.com.au)**

**or call (03) 9705 0666 (let them know you read about it in the Parkinson's Victoria newsletter, Signpost).**

## *More upcoming Parkinson's Victoria Fundraising Events*

- Sunday 4 July Bunnings Charity Sausage Sizzle (all day at Bunnings Moorabbin; Corner Warrigal Road and Fairchild Street). Call Judith (03) 9551 1122 if you can assist with a donation of BBQ sausages (we need approximately 65-70 kilos in total!)
- Sunday 18 July: Run Melbourne (5km Walk/Run; 10km run or 21km/Half Marathon). Enter Run Melbourne and then create a fundraising page at [www.everydayhero.com](http://www.everydayhero.com) and **nominate Parkinson's Victoria** as your preferred charity. Others have already signed up and are aiming high with their fundraising goal: THANK YOU to Kyle, Nathan, Andrew and Russell. **If you have signed up – let us know!**
- Wednesday 1 September: Fundraising Dinner at Parliament House (Victoria), with 3-course meal, raffles, special guest speaker and tour of the House while Parliament is sitting. Limited number of tickets available: \$220 each. Book your ticket today by calling (03) 9551 1122 or email [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)

## **Please donate today**

*Inside this edition of Signpost you will find a red reply paid donation envelope. Please use the envelope to make a tax deductible donation to support our work today.*

*Government funding delivers only 22 percent of the funds that we require to undertake our day-to-day work in the community providing information, support and education. We raise the remaining 78 percent through donations, events, trusts and bequests.*

Please: you can help us continue our work with a donation **today**. If you prefer to make your donation over the phone, please contact our office: (03) 9551 1122 or 1800 644 189.

# Health & Symptom Management

## Complementary therapies: Myth or Magic?

*Do you believe acupuncture or vitamins can provide relief from and/or assist in managing symptoms of Parkinson's? If someone said that eating a kilo of broccoli every day would cure Parkinson's symptoms – or even the condition itself – would you give it a go? While several complementary therapies have merit, many others have no foundation of evidence to support claims, and several are simply scams to take your money. If you are considering complementary therapies to assist in managing Parkinson's there is some important information you should know, writes Parkinson's Specialist Nurse Consultant VICTOR MCCONVEY.*

Many people diagnosed with Parkinson's wonder if there are more treatments available than those prescribed by their Neurologist. Often people look towards **complementary** therapies, such as acupuncture or naturopathy, and that's where things start to get confusing!

Doctors can sometimes give the impression that there is little value in complementary therapies. As a result, many are not keen to engage in discussions about the pros and cons of alternative or additional treatments that may in fact have some value in helping manage the symptoms of Parkinson's.

This view is typically influenced by the fact that modern day medicine focuses on **evidence-based practice**.

This means that all of the treatments doctors offer and might prescribe - which in the case of Parkinson's is mainly medication or surgery - have been proven under scientific conditions to be effective.

The way this evidence is collected is through a series of *clinical* trials, which are often:

- 1) Placebo controlled (i.e. some participants will be administered a substitute drug, referred to as a placebo as its ingredients are harmless and do not contain the drug being tested)
- 2) Randomised (in other words, who gets the real drug is not known and is selected by a computer) and
- 3) "Blind" tested (meaning participants do not know if they are taking the real or placebo drug) or double blind (which means neither the participant nor the professionals conducting the trial know who is receiving the drug or placebo).

When a trial is conducted it often has many participants. Importantly, the trial is peer reviewed

to ensure its validity, and it has approval of an ethics committee.

Once the trial is completed it provides not only a scientific basis to the treatment but most importantly the process helps ensure that the treatments are safe and effective.

On the other hand, many complementary therapies are not supported by scientific evidence. These therapies are often *holistic*, looking at the whole person rather than a few symptoms. They typically have origins in tradition and emphasise the role and importance of the energy system of the body and the necessity of balance and harmony.

Many people living with Parkinson's have felt significant benefit from pursuing a complementary therapy, including the feeling that it provides some balance to the very scientific therapies their doctor is prescribing.

### Are you considering a complementary therapy?

When considering a complementary therapy it is important to see it as a therapy that sits alongside the treatments your neurologist has prescribed. Complementary therapies should be just that: a **COMPLEMENT** to other treatments, not an **alternative**. Any person who advocates that a treatment is an alternative to your current doctor-prescribed treatment and who encourages you to halt the latter in favour of the former - should be regarded with caution.

If you are considering a complementary therapy we stress the importance of undertaking your own research.

When you are investigating potential complementary therapies the wide range of information and options can make things very confusing, especially if you have been doing your research on the Internet. Beware: the Internet is an unregulated environment and not all claims will be true. (*Refer to page 8 for some tips on having a positive internet experience*).

Some practical advice provided by Ezard Ernst, a Professor of Complementary therapies at Exeter Universities Medical School goes like this: "...*If a treatment sounds too good to be true- it probably is...*" This is a good rule of thumb in assessing the potential value of a complementary therapy (and as you can see, even those in the field of complementary medicine practice some healthy scepticism).

### A few other considerations to make before embarking on a complementary therapy are:

- Is there any evidence to support the treatment's value in relation to treating the symptoms of Parkinson's\*?

# Health & Symptom Management

- If it works for one person, does it mean it will work for everyone?
- What are the qualifications of the practitioner and what is their experience with Parkinson's?
- How long will it be before any benefits from the treatment are felt?
- Are there any risks or side effects associated with the treatment?
- How much will it cost?
- Are the claims too good to be true?
- **Never alter the treatment plan your Neurologist has developed with you without consultation.**

There are a number of complementary therapies commonly used in helping individuals to manage their symptoms of Parkinson's and which Parkinson's Victoria advocates. These include:

- **Regular exercise and strategy training:** The benefits of regular exercise on Parkinson's symptoms seem obvious, but research is still being carried out. The early results are very positive and there is an emerging evidence base to support the value of exercise in Parkinson's in maintaining mobility, reducing falls and restoring posture. *(For more information about exercise and Parkinson's, see our article on page 10)*
- **Co-Enzyme Q10:** This antioxidant is thought to potentially be able to slow the progression of Parkinson's through slowing the oxidative processes that relate to the death of dopamine-producing cells. (This cell death is what causes Parkinson's, although we do not yet understand why it happens.)  
  
The potential benefits of taking CoQ10 are so great that many neurologists encourage their patients to take it. However, there is currently no evidence base to support the hypothesis and clinical trials to date have been either too small or invalid.  
  
Trials currently underway continue to assess the value of Co Q10 and to establish the effective dose range.\*
- **Relaxation therapy:** Learning relaxation techniques and participating in relaxation therapy classes appears to have a beneficial effect on anxiety and panic associated with Parkinson's. In addition, a small research study conducted at a Melbourne Hospital has also highlighted its positive benefits in managing dyskinesias (abnormal movement of voluntary muscles).
- **Hypnotherapy:** Hypnosis occurs when you are relaxed and your critical faculties are suspended

leaving you open to suggestion. Research indicates that hypnosis can reduce anxiety, relieve chronic pain and can assist with panic and insomnia; however it should be avoided if the individual is affected by depression.

- **Tai Chi:** A healing martial art that features a series of slow meditative physical exercises designed for relaxation, balance and health. Initial studies have shown Tai Chi can improve balance, walking and sleep, and reduce falls and anxiety.
- **Massage:** There are a variety of massages that may provide relief from some Parkinson's symptoms. These include relaxation and aroma therapy massage, and deep tissue and remedial massage.

There is little doubt about the value of massage and a small pilot study indicates that massage therapy can loosen muscles thus improving the ability to carry out activities of daily living for some people with Parkinson's.

## Summary

There are many and varied complementary therapies available that can be of assistance in managing Parkinson's, but to find an effective treatment for you it is important to do some investigation first and to continually evaluate the effectiveness of the therapy and the benefits it is providing. It is also essential to remember that these therapies should complement (not replace) any treatments prescribed by your treating doctors.

**For more information about the variety of treatments and complementary therapies that may assist in managing symptoms of Parkinson's, and the latest research, contact our health team.**

Log onto <http://www.youngparkinsons.org> to see an excellent video on **Complementary Therapies, presented by neurologist Dr Melanie Brandabur, Clinical Director of the Parkinson's Institute and Clinical Centre, Sunnyvale California. (Click on the webcast archive of the "Young Onset Conference" held in Sacramento 13 March 2010. The presentation is entitled "Complementary Therapies: Expanding your Symptom Management Options")**

**\*Health Team note: As yet there is no known cure for Parkinson's. Treatments of any kind can only seek to treat the symptoms of the condition and not the condition itself, including the progress of the condition.**

**\*The Current dose of Co Q10 is thought to be between 800mg and 1200mg twice daily and high dose strengths are not currently available in Australia.**

# Personal Reflections

## More than I Gambled on

*The following true story is a cautionary tale, warning of the possible side-effects of some medications prescribed to treat the symptoms of Parkinson's.*

*The author, who wishes to remain anonymous, advises all people diagnosed with Parkinson's to discuss any side-effects of medication – or unusual behaviour – with their neurologist and warns people to be alert to significant changes in behaviour and mental well-being.*

### **Spin ... spin ... spin. Yes. Jackpot again!**

I was a star. The crowd gathered around. I had won again. I could hear the adulation. "Did you see that? He bet maximum every line until he won. Wow. What a player! What a way to go!"

It was nearly midnight and I was the centre of attention – again. I had been playing the pokies since 8-00 a.m. After 4 hours restless sleep I had dressed for work but – once again – had never quite got there. My senior management role enabled me to pretty well do as I liked so I decided to pop in for a few minutes on my way. A few minutes had become a few hours and before I could blink it was midnight and I was looking at another magic payout of thousands of dollars.

It was a great way to lose weight - who needs to eat when you can win thousands? Even going to the toilet was a chore. Many a last minute rush and fumble had averted a disaster – but I couldn't afford to lose my lucky machine.

Anyway, the staff were fantastic. I had come to know them really well; they had become my friends, almost family. They knew my name, my favourite machines, my taste in coffee and sandwiches. All supplied free of charge. I was also the proud bearer of a platinum frequent player card which entitled me to points and prizes.

My head was spinning. I was a winner.

My winning ways had all begun some months earlier when, for some reason, I had decided to venture into the warm and colourful gaming venue around the corner. I had a few spare minutes one evening, my wife was at a meeting and I couldn't resist the atmospheric lure of the music and lights.

I was more excited than I had been for years. I figured that the only way to win was to bet big; none of this small change stuff.

And bet big I did.

I had worked it out that if you bet every line to the maximum you had to win. You just needed to outlast the machine.

And outlast it I did.

Three hundred dollars later I landed the jackpot: **\$1700** dollars. And to cap it off, I won the venue jackpot: **\$2000**. A cheque was in my pocket for \$3700. What a feeling.

When I got home my wife was not quite so happy. "Where have you been? I was worried sick. It's 11.30pm. I've been home for hours. Where have you been?"

Her anxiety did not last long as I handed over the cheque. "Don't worry. I was at a loose end while you were out so decided to play the pokies. Sorry for being late. Time got away. But just as well it did, hey? Look at that cheque."

And that's how it started.

Of course I wasn't always so lucky. Some nights the machines just wouldn't pay up. At least, not for an hour or two. So I was forced to outlay perhaps a thousand dollars until it turned in my favour. Sometimes I lost my favourite machine when I had to rush off to the ATM to withdraw more money to play with. (Fortunately there was an ATM right outside the venue – two in fact.) But then the authorities decided to place a \$200 limit on how much you could withdraw from one ATM. I needed \$1000 per day so I had to spend 15 minutes going to another ATM so I could keep playing. Sometimes I ran out of money in my account so I worked out I could withdraw on my credit card over the counter at the bank. In fact, I could withdraw multiple amounts at different banks on the same day. Their systems did not operate in real time so by the time a computer somewhere had realised I had overstepped my limit I had the money in my hot little hands ready for another triumph.

I also opened up a few new credit cards with banks and institutions who had offered me unlimited credit. I withdrew credit against several mortgages.

And then there was my superannuation plus our broker allowed me to sell my wife's shares over the phone without her permission.

Throw in a few other accounts I was responsible for and getting money was no problem. In fact it was rather exciting running – literally - from one ATM to another - from one bank teller to another. Nothing was more thrilling than seeing a wad of bank notes sliding out from the ATM.

I even found some cash my wife had hidden for a rainy day. I borrowed that too. Loose change lying around the office; parking meter coins in the car's ashtray; a few dollars here and there borrowed from friends and family kept me going. At times I had to

# Personal Reflections

suffer the ignominy of playing one cent machines where I joined the forlorn ranks of the truly desperate. Of course I couldn't spend all day every day at the pokies. But I could go close. As I drove around for work I learned where all the venues were; in every suburb and street I learned exactly where to park what hours they opened and which ones were lucky. Near work I could duck out at lunchtime. I lived to play the pokies.

Every minute of every hour, every day.

Sometimes I would be the only person playing; at other times I would be the centre of attention sitting side by side with other desperate addicts.

When the venue offered large jackpots I would take on the syndicates who flooded in and occupied as many machines as possible. Despite a couple of wins, weight of numbers eventually told and the syndicates won every time. And I lost thousands.

At midnight when the family was sound asleep I would sneak out through the garage and run to the gaming venue. As I drew close I would gather myself together, draw breath and ready myself for another evening's entertainment. A smile of recognition would pass across the security guards lips as I strode confidently in to spin my way to pleasure and success. It was the most exciting adventure I had ever undertaken.

By 2-00am there were perhaps only 30 people still playing. By 3-00am perhaps a dozen. By 4.00am I was alone as I trudged home. In the early days I would walk home with hundreds, even thousands of dollars in my pocket. I would have been an obvious target to attack and rob.

Eventually, I walked home every night with no money in my pocket. In fact "winning" had become irrelevant. Sometimes I got as far as the exit with my winnings only to turn around and go straight back in and lose it all. But I didn't care. The adrenalin rush, the lights, the music, the fame – they were all more important than winning money.

Two voices were arguing in my head. One was telling me to stop before my life, my marriage, my family was ruined. The other was telling me I could keep going. I just needed to take some winnings instead of re-investing them.

One day the rational voice won and I called in to see a Gambling Counsellor; I was advised to come back the next day – the office closed at 5.00pm!

One morning, around 3.00am, I trudged home – once again with no money. I had exhausted all sources of funds; pay day was a month away and I had no money for petrol and personal expenses.

I was a disaster: a tragedy waiting to happen.

I sat on the edge of the bed and woke my wife up. I told her everything. I ruined her life; it would be years before she could trust me again.

Typically, my wife took swift and decisive action. The next day she took immediate control of all our finances leaving me with access to nothing but a few dollars pocket money. We went to see our family doctor who prescribed sedatives to help me sleep. We undertook counselling. And most important of all, we went to see my neurologist who immediately took me off the dopamine agonist he had initially prescribed for my recently diagnosed Parkinson's.

Yes - for me the medication had increased the uptake of dopamine, the brain chemical so essential for the initiation and control of movement and balance. But what I didn't know was that it also enhanced feelings of pleasure and well-being. And pathological gambling.

Changing medication produced almost instant improvement and within three months I had overcome my obsession with the seductive lights and enticing music of poker machines. For the next eighteen months or so I saw a psychiatrist every time I saw my neurologist, until such time we were all satisfied that the destructive urges were at last overcome.

Eight years later I count my blessings, not my winnings. Had I continued I would have surely lost my family, my home and probably my freedom.

Prison was only a spin away.

**Health Team note: Developing the urge to gamble or develop other behaviours, such as hypersexuality or hobbyism, are known as *Impulse Control Disorders* and are a documented possible side effect of *Dopamine Agonist Medications (Cabaser, Permax, Parlodel and Sifrol)* used to manage Parkinson's and *Restless Leg syndrome*.**

***This side effect is rare, affecting less than 3-7 percent of people on Dopamine Agonists.***

***When an individual develops Impulse Control Disorder they often become secretive and reluctant to divulge their situation or seek help.***

***These behaviours can be managed and often stopping or reducing the dose or changing to another Agonist is sufficient.***

***If you are affected by Impulse Control Disorder or other side effects of medication or if you have any concerns or questions about your medications, side effects, symptoms or Parkinson's in general, you should speak with your neurologist or the Health Team at Parkinson's Victoria.***

# Our Supporters

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## 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 25 January and 19 April 2010, and individuals in whose name in memoriam donations were received. In addition, listed are the various companies, organizations 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.*

*We thank those who supported our recent fundraising events, specifically those who attended our February Movie Night (11 February) and those who donated to our Annual City Train Station Tin Rattle (8 April). We also thank 34 supporters who have donated but wish to remain anonymous, and those who have supported our Ambassadors of Hope speakers program.*

## Donations \$200 and over (individual)

Diane Boyle  
Robert Buckle  
Peter and Lesley Dyer  
Susan Fallaw  
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Frank Materia  
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James Robinson  
Eliza Somerfield  
Fiona Windsor

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## Donations \$1000 and over

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Manjit (Dolly) Kaher (50th birthday)  
Margaret Beaver (70th birthday)

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St. Paul's Christmas Card Shop  
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## Parkinson's Support Groups

Essendon  
Mildura  
Moe

## Team Parkinson's Challengers

Ed Beesley  
Mathew Beesley  
Dean Edwards  
David Gibson

*Developing support for Australians living with Young Onset Parkinson's is a top priority of Parkinson's Victoria.*

*As such, we have spearheaded several initiatives, including the Young Onset Parkinson's Project - a collaboration with the Parkies with a Purpose support group - which explores and seeks to understand the unique needs and concerns of these individuals. Research Coordinators DR CHRIS FYFFE and JEFFREY MCCUBBERY recently released the findings of the project in a report titled **Living with Young Onset Parkinson's disease: The issues and impact of young onset Parkinson's disease in Australia**. Here we share the report's Executive Summary.*

People with Young Onset Parkinson's disease have different information, advocacy and community support needs from people diagnosed with Parkinson's in their older years. This has not been recognised in Australia, despite extensive service development for people with other progressive and disabling conditions that develop in young and middle adult years, and unlike the situation for people with Young Onset Parkinson's disease in USA and UK.

Parkinson's disease is a severely disabling condition for the significant sub-group of the population of people with Parkinson's disease who are diagnosed younger. Unlike many people diagnosed in later life, younger people typically live for decades with the condition and experience the full spectrum of the condition's debilitating physical, cognitive and emotional effects. These effects are occurring when people have very full lives and when people's identities and futures are being shaped by pursuing careers and accumulating assets; forming and maintaining close friendships and partnerships; establishing families and raising children; and engaging in active and social leisure pursuits. This is also the time for laying the foundations for retirement and older age.

For the first time in Australia, people with young onset Parkinson's disease and their family members were asked to identify the issues and impacts arising from living with this condition and to make comment about the availability and appropriateness of current services and supports. Respondents described how young onset Parkinson's disease introduced major disruptions and changes to their personal, family and work lives. People wanted ongoing research to find a cure for Parkinson's disease; accurate technical and peer information about Parkinson's disease from specialists and other people living daily with Parkinson's; and information and coordinated support to live as well as possible despite varied and changing emotional, physical and cognitive effects. Descriptions of anxiety, stress and uncertainty in daily life were frequent. People wanted expert medical response to the disease — diagnosis, symptom management and medication regimes — and nearly

all respondents were in contact with neurologists, GPs and Parkinson's associations. Respondents also wanted advice about how to live with Parkinson's. Surprisingly few people had tried other professional and community support services such as counselling, employment assistance or financial planning. There was frustration and distress when staff in these various community support or health services did not understand the issues for people living daily with young onset Parkinson's disease.

As the project was initiated by Parkinson's Victoria, the findings are directed in the first instance to the role of Parkinson's associations. There is a need to promote the profile and issues for people with young onset Parkinson's disease so that individuals and their families can easily find information; and professional, health and community support services can develop and respond to how people can live their preferred lifestyle as well as possible. Parkinson's associations are potentially well placed to be the conduit between, on the one hand, specialist medical and diagnostic processes and, on the other hand, access to coordinated support for community living. This includes individual and system-wide information about what is available; development work with community agencies to ensure their relevance to people with young onset Parkinson's; and assistance to people with young onset Parkinson's to network, support each other, lobby and advocate. There is also the opportunity for the associations to develop improved databases and foster new directions for research sensitive to the circumstances of people living with young onset Parkinson's.

**The Research Coordinators would like to thank the following for their invaluable contribution to the Young Onset Parkinson's Project:**

**Project Steering Committee members**

**Glenn Mahoney, CEO Parkinson's Victoria**

**Amanda Spillare, former Client Services Coordinator, Parkinson's Victoria**

**Catherine Watson, Community Development Worker, Parkinson's Victoria**

**Brendan Lourey, Living with young onset Parkinson's, Parkinson's Victoria Board member**

**Barbara Went, Group Manager, Ambulatory Clinics, Kingston Centre, Victoria**

**Chris Fyffe, Project Coordinator**

**We also thank Parkies with a Purpose (Victoria), for funding the project, and all survey respondents and workshop participants, including those who travelled long distances to contribute.**

**Editor's note: The project is just one phase of our approach to responding to the needs of those living with Young Onset Parkinson's and to developing appropriate support networks. For a copy of the complete report visit the publications section of our website.**

# Tulip Tributes

## Crossing the language barrier

Bilingual Parkinson's professionals are making an important contribution to our Bridging the Gaps project by sharing information and raising awareness of Parkinson's among people from culturally and linguistically diverse (CALD) communities.

Bilingual professionals, including Physiotherapists, Occupational Therapists, Nurses, Social Workers, a Neuropsychologist and a Neurologist, have volunteered their assistance with checking written materials, advising on content and presenting and recording information in many languages.

In November 2009, at an event hosted by Parkinson's Victoria, Neuropsychologist Dr Evrim March presented an information session in Turkish to a large group in Dallas. An interview with Dr March also featured on Turkish radio, as well as a recording of her presentation. In March 2009, Movement Disorders Occupational Therapist Margarita Makoutonina made a series of voice recordings in Russian, making our Help Sheets accessible to Russian speaking people with literacy or vision issues.

**Voluntary assistance from bilingual Parkinson's professionals is really helping to 'bridge the gaps' in Parkinson's information and awareness among people from CALD communities in Victoria. We extend a big thank you to all those involved for their generous support.**

## To our "Valentines"

Thank you to everyone who came along to our Movie Night at the Palace Dendy Brighton for the opening night of the movie Valentine's Day on Thursday 11 February.

More than \$1900 was raised on the night: What an amazing effort!

Proceeds from the night help fund our support and information services. You can RSVP today to our next event, Sex and the City 2 (also at Dendy Brighton, Wednesday 9 June).

**A special thank you to Endota Spa, Brighton Beach for providing the goodie bags, items for the door prize and first prize for the raffle.**

**We would also like to thank the following businesses for generously supporting the evening:**

- **Dendy Palace Brighton**
- **Cotton on Foundation**
- **Florentine Restaurant – Church St, Brighton**
- **Curves – Hampton and Brighton**
- **Deck Bar Restaurant – Bay St, Brighton**

## Taking up the Challenge

In March we had 4 fit and fired up Challengers head off to Vietnam to complete the second part of their Team Parkinson's Charity Challenge. Between them, Dean, Matt, Ed and David raised more than \$30,000 to support our work and then headed off for a grueling guided bike ride through Vietnam. We're pleased to report they did find some time to relax and all reports are they had a fantastic time.

**Thank you guys for a terrific effort raising funds and awareness.**

## Shake, rattle and... thank you

We'd like to give a BIG Tulip Tribute to the wonderful volunteers who generously gave their time to assist us during our annual World Parkinson's Day tin rattle.

In the wee hours of the morning on Thursday 8 April, almost 40 enthusiastic volunteers donned Parkinson's Victoria tops and 'shook a tin' to collect donations from commuters at Flinders Street, Parliament, Flagstaff and Melbourne Central train stations.

In just 2 hours (7-9am) we raised \$3,704 - A fantastic effort! It's amazing what impact a friendly smile and a great cause can have, and we also give a big THANK YOU to all those who donated so generously.

**This activity is certainly not for everyone and we appreciate those who selflessly challenged themselves to make the early morning start and to ask for donations from strangers in order to benefit others.**

**Our 2009 World Parkinson's Day Volunteers were:**

**Jill, Marion, Fiona, Timothy, Laurie, Roselind, Clare, Glenn, Deepak, Andrew, Sue, Judy, Melanie, Amanda, Jason, Craig, Sean, Luke, Kate, Susan, Sue, Felice, Angel, Lyn, Robyn, Erica, John, Lisa, Michael, Hayley, Paul and Marcia. And we thank Parkinson's Victoria staff: Denise, Shelley, Victor, Michelle, Lesley and Judith.**

## Family favourites

A special thanks from our Team goes out to our regular Volunteers, Pam and Bronwyn. Pam has been invaluable in the office for the past 12 or so months, making her practically part of our 'family'. Pam has made a significant contribution assisting with various administration duties; nothing is ever too much trouble and everything is done with a smile.

Bronwyn has been assisting in the Fundraising and Events department and was instrumental in the success of our February charity movie night. Bronwyn has great attention to detail and a wonderful creative flair which mean these events are well put together and a great experience for all.

**Thank you Pam and Bronwyn.**

## Shave for a cure

In April, Shane Murphy - a member of the Young at Park Support Group - underwent Deep Brain Stimulation (DBS) surgery to reduce some of the effects of his Parkinson's symptoms.

Shane's great sense of humour and commitment to help the Cause meant he made the most of his pre-surgery preparations by growing and then shaving his head (DBS surgery requires the head to be hair free). He also asked friends and family to sponsor his 'great shave' and raised \$145.95 in the process. While 'under the scissors, Shane also managed to help spread the message about Parkinson's to curious passersby.

**Well done Shane and we wish you all the best for a great outcome from your recent surgery!**