

# SIGNPOST

Summer 2013 • Volume 12 Issue 4 A Magazine for people living with Parkinson's

## Inside this ISSUE

President's message ..... 1

News & Highlights ..... 2

The lure of miracle cures .. 4

CEO's message ..... 5

Update from  
the Congress ..... 6

Thank you to our  
Walk sponsors ..... 7

Question time ..... 8

A Walk in the Park ..... 10

Advocacy update ..... 11

Peer support ..... 12

Tulip tributes ..... 14

Symptom Management . 15

Planning for the future ... 16

Personal dopa-meanings . 17

Clinical nurse update ..... 18

Participate for research 19

Research update ..... 20

## Forward... to the Future!



The film trilogy **Back to the Future** is a favourite of most people, especially those with Parkinson's, who admire the dynamic example set by lead actor, Michael J Fox.

Many of us have seen these movies over and over and can't help but be inspired by the way this young, vibrant, good-looking and cheeky movie-star used these personal traits and skills, decades later, to become a Parkinson's star and international advocate. However, I'm sure if Michael J Fox were starring in such rollicking adventures today, he would insist the films be called **Forward to the Future!**

Indeed, "forward to the future" is the path Parkinson's Victoria has chosen to take. In recent months, your Board, together with Parkinson's Victoria's CEO and staff, and assisted where necessary by professional facilitators, have been developing strategies to take us well into the future – well, at least the next five years or so.

We are focusing on major themes such as: **Research strategies, projects and clinical trials; governance and leadership; community and direct service delivery; financial planning and investment strategies; strategic relationships with other NFPs; and staff development.**

We will be sharing more about these strategic plans at our upcoming Annual General Meeting, and we certainly hope you will join us as we stride into the future.

Regrettably, we will not be joined on our journey by Vice President, Fred Van Ross and Board Member, Professor Meg Morris, at least not in an official capacity.

Having served 3 terms of 3 years and reaching his constitutional tenure of 9 years, Fred must stand down at the AGM on November 22, 2013.

Fred joined the Board in 2004 when it faced many challenges, and much hard work was essential if Parkinson's Victoria was to deliver on its mission to provide an improved quality of life and to facilitate and fund the search for a cure.

Fred has been a vocal advocate for people with Parkinson's and always made sure that the Board held their interests uppermost. He has chaired our Research Committee and served on a variety of other Committees, including our office relocation from Kingston to Cheltenham, and matters to do with our Rules and Incorporation.

Whilst on the Board, Fred has also chaired the Essendon Support Group, leading it to become a strong advocate for the cause in which he believes so strongly, and a loyal and active supporter of Parkinson's Victoria. As a valued Community Ambassador (our public speaking program), Fred has spoken all over Melbourne, presenting to a variety of community groups and in a major fundraising effort in 2009 and Fred cycled through Vietnam with his wife Christine and other supporters, including two who also have Parkinson's. Fred rose to meet every challenge and will surely continue to do so.

As President, I have found Fred to be a wonderfully loyal and hardworking deputy, either helping to take on some of my workload or offering frank and sage advice.

Most recently, he vigorously represented Parkinson's Victoria on the Parkinson's Australia Alliance in the lead up to the Federal election, as the Alliance strove to influence and persuade both sides of politics to be more generous in their support of Parkinson's.

# News & Highlights

Thank you Fred for just on a decade of service to the Board: we are certainly indebted to you. I am sure you will find ways to continue your contribution as we move "forward to the future".

Professor Meg Morris joined our Board 2 years ago having spent several years conducting various Parkinson's-related research projects, not to mention sitting on numerous national and international committees, publishing articles and books and advocating strongly on our behalf. Meg was a Member of our Research Committee and brought to the Board a depth of knowledge and breadth of experience which was essential to good governance. Meg has made the difficult decision to resign from the Board, due to increasing commitments as Head of Allied Health at La Trobe University. We will miss her wise counsel and wish her all the best.

I am confident that we shall continue to benefit from Fred and Meg's support, encouragement and knowledge. They may no longer be Members of the Board but they will certainly be helping take us "forward to the future".

At this time of year, I would especially like to thank CEO Emma Collin, the staff of Parkinson's Victoria, members of the Board and our multitude of volunteers for their dedication and commitment to our cause. They do wonderful things for people with Parkinson's, so often well beyond the call of duty.

Finally, on behalf of the Board, may I wish all our members and readers a peaceful and healthy Festive Season. May you and your family enjoy your holiday time together and return enthused, invigorated and inspired to seek "help for today and hope for tomorrow".

A holiday is indeed well deserved - congratulations and thank-you.

**Peter Raymond, President**

## **Thank's a Bunch!**

*This year, A Walk in the Park was generously supported by a number of companies who donated 'in-kind' towards the event's success.*

*We gratefully acknowledge the following for joining us for A Walk in the Park, and donating goods, services, volunteers, and support in various other forms:*

- Ernie Kemplay, donated his time and musical talents to entertain us on the day
- The team at Time Out Café (Federation Square) supported our charity BBQ
- Geoff Pearson shared his story on stage
- Rockys Fruit and Veggies donated 2000 pieces of delicious fruit
- Jill Goss and students from Avonde Calisthenics College, took us through a terrific warm up
- Glenferrie Rotary and Rotarians, for their amazing support running our BBQ, as well as a generous \$1000 donation from the Club and individuals donations from members
- Martin and Pleasance and Melbourne's Child, for donating give-away items
- Cargo Apparel, for their assistance in creating a fantastic range of Walk Merchandise
- Ric and Jen, who supplied "Posies for

Parkinson's" – a colourful addition to the day, which also resulted in a generous donation to Parkinson's Victoria.

- And of course, our team of AMAZING volunteers, including students from Swinburne University.

**Events like A Walk in the Park simply don't happen without lots of hard work and contributions from a range of people and companies who believe in the cause.**

**We can't thank them enough for their generosity and enthusiasm in supporting this year's Walk.**

## **Annual General Meeting**

A reminder to all members that the Parkinson's Victoria Annual General Meeting (AGM) will be held on Friday 22 November 2013 at **Herbert Smith Freehills, 42nd Floor, 101 Collins Street Melbourne.**

The AGM event will include a presentation by the Premier Dr Denis Napthine, nominations to the Board and presentation of special awards, including the prestigious annual **Sir Zelman Cowen Award for Outstanding Voluntary Service to the Parkinson's Community.**

All members are encouraged to attend and members of the public are welcome (RSVP essential). If you have not yet received your member AGM kit, please contact our office.

## Event details:

### Parkinson's Victoria AGM

12:15pm Registrations Open

12:30pm Luncheon

1:30pm AGM, followed by Guest Speaker and afternoon tea

4:15pm Close

To RSVP (including nomination of proxies), please complete and return the form sent to you in your AGM Member pack or contact Parkinson's Victoria: (03) 9581 8700 or [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au). RSVP's must be received by **Friday 15 November 2013**.

### Annual Christmas Appeal

Hopefully you have received our **2013 End of Year Appeal** in the post recently. Each year, we rely on the support of people like you, your friends and family to help fund crucial support services, including our free help line, community seminars, support groups and a range of resources and information kits.

Your membership is valued, but your donations help us continue to provide many of our support services for free. Please consider making a donation of whatever you can afford.

**We also look forward to receiving your 'Tribute' for our annual Tribute Tree (this was included with our End of Year Appeal mailout). If you did not receive our Appeal or Tribute card, please contact our office.**

**You are welcome to visit our office to view the Tree and read the tributes from now until January 31, 2014.**

**Parkinson's Victoria is located at 8b Park Road Cheltenham, opposite the Caltex service station and near the Cheltenham rail crossing (Nepean Highway).**

### Parkinson's & rhythm

*The four-week Argentinian tango for Parkinson's research project, run by researchers from La Trobe University, was a great success.*

Six individuals with Parkinson's committed their time and energy to participate in the twice-weekly dance program that was led by experienced dance instructor Rina Koseti.

The dance classes were thoroughly enjoyed by all participants and provided useful feasibility data that will guide the planning and development of future projects on a larger scale.

From the findings, researchers were able to demonstrate that the Argentinian tango appears to be beneficial for some people living with Parkinson's.

**The research team from La Trobe would like to thank the participants for their dedication and commitment to the project, and also Parkinson's Victoria who assisted in recruitment. Watch this space for future research exploring dance therapy for Parkinson's!**

## Correction

The Spring edition of **Signpost** (Volume 12, Issue 3) featured an article titled "Continuous Therapies and motor fluctuations".

Unfortunately, due to an editorial error, the following corrections must be advised:

1. **Second column, paragraph three should read:** "... medication is administered **subcutaneously, intestinally** or topically..." [not **intravenously** as the original article stated].
2. **Second column, paragraph seven should read:** "This medication provides continuous infusion of a levodopa (dopamine) gel directly into the... small intestine..." [not subcutaneously].

NB: in addition, the pump used is considered a large pump, rather than small, particularly for those of a small physical frame.

## Parkinson's Victoria Holiday hours

The Board and staff of Parkinson's Victoria wish you and your loved ones a safe and happy Festive Season and our very best for the coming year.

Please be advised that the office of Parkinson's Victoria (8b Park Road, Cheltenham, VIC 3192) will be closed from 3.00pm on Tuesday 24 December (Christmas Eve) and will reopen and resume regular office hours from 9.00am on Thursday 2 January. Our office hours are 9-5pm Monday to Friday.

**If you require assistance during our office closure, please contact your treating doctor or the Emergency Department of your nearest hospital.**

# The lure of miracle cures

*Stories of medical breakthroughs are in the news almost every day. Research promising miracle treatments and cures are promoted, but how do we know if these stories and studies are credible? MAITHA ALKHASAW\*, who is completing a double degree in Health Science at Monash University, recently spent time at Parkinson's Victoria as part of her Health Promotion practicum unit. In this article, Maitha explores the issue of medical treatment 'reporting' and highlights some important things to remember when considering new or unusual treatments and therapies.*

## *Treatments, how to determine the good from the bad*

Firstly, decide what the story is **actually** promising the treatment will do and be on the lookout for legal disclaimers regarding the benefits. Some might even state there is little or no evidence to substantiate the benefits. Secondly, discern if the claims are backed by scientific evidence and not just personal testimonials; it is not uncommon for people to be given incentives for positive feedback.

Be cautious of treatments only available online.

## *How to spot good reporting*

A good medical reporter will always publish the name of the scientific journal in which the research has been published.

Published studies in scientific journals have been *peer-reviewed*, meaning they have been critiqued by independent reviewers, who assess the quality and originality of the research undertaken.

Be cautious of websites that claim effectiveness of a

treatment based on news reports and do not have published peer-reviewed research to back up their scientific claims.

## *What have I got to lose?*

### *Financial costs*

Just because a treatment is expensive, does not mean it is the most effective.

Some people opt to travel abroad to try new therapies, such as stem cell treatments. Carefully weigh up all costs of any treatment against the proposed benefits, and investigate thoroughly the information backing up any claims, particularly how reliable that information is.

### *Health risks*

Some alternative treatments can be harmful and have negative health effects, or they may interact with other medications. It is important to always discuss new treatment ideas that you would like to explore with your doctor before trying them. Any treatment that requires you to cease your conventional treatments can be risky, always consult your health professional first.

Be mindful that just because something claims to be 'natural' or 'herbal', does not make it safe or even beneficial. Many products using these claims are not compliant with relevant standards.

Be suspicious of advertisements or companies which ask you not to consult your doctor about treatments, and remember; if you aren't convinced by your doctor's opinion, you can always get a second one.

Advertisement

**TabTimer™ supplies a range of reminder devices to help keep medicines on time.**

Medication Reminders | Pill Box Reminders | Vibrating Reminder Watches & Clocks | + Pet Medication Reminders



**Contact TabTimer™ and help keep your medicines on time.**

**www.TabTimer.com.au 1300 TAB TIMER (1300 822 846)**

For terms and conditions of sale see www.TabTimer.com.au . TabTimer™, 'helps keep medications on time'™ and the TabTimer™ logo are trademarks of TabTimer Pty Ltd © 2011 ABN: 99 137 415 948

# CEO's Message

## Emotional costs

A large potential cost of undertaking an alternative or 'new' therapy or treatment is the potential disappointment you might face if the outcomes do not meet your expectations. When considering a new therapy or treatment, don't be afraid to ask critical questions about it; be sure to ask about the nature of the treatment offered, the amount and type of evidence and research that has been undertaken to prove its effectiveness, and the potential side effects and risks.

If in doubt, discuss it with your doctor or neurologist, or contact Parkinson's Victoria. A doctor would openly discuss potential risks and side-effects of a prescribed treatment, as well as the benefits, so you should have the same expectation of anyone trying to sell you an alternative treatment.

Finally, use your common sense, if a claim sounds too good to be true, it probably is!

**"I've got nothing to lose by trying it" is a guide to weighing up claims about cures and treatments from Sense about Science, a UK not-for-profit organisation ([www.senseaboutscience.org](http://www.senseaboutscience.org)). You can download the publication from the website (click on the Publications and Resources section).**

\*Maitha is required to complete a placement of 100 hours as part of her practicum, and will finish up With Parkinson's Victoria late November. During her time with us she has been learning all aspects of our Health Team's support services and is developing an understanding of how we respond to the needs of people living with Parkinson's as well as raising awareness in the community. Maitha was involved in the planning of our recent Young Onset Conference, including assisting in the compilation of a report based on an attendee survey. One of Maitha's career aims is to work in the area of health promotion and social sciences.



Welcome to the Summer edition of our member newsletter, **Signpost**, our last for 2013. I am excited to share that the focus of this edition is **research and innovation**.

Parkinson's Victoria's mission clearly articulates its commitment to 'facilitate and fund research projects which seek to improve quality of life outcomes for people living with the condition and the search for a cure'.

This edition of **Signpost** highlights some of our supported and funded research projects, including the **ESSENCE project** with Monash Health (pg 20); our **demonstration research project** with Goulburn Valley Health (pg 19); and our **Dancing with Parkinson's Project** with La Trobe University (pg 3), as well as providing an overview of other national and international research updates and reviews.

Each year, the Parkinson's Victoria Board receives a number of applications to support research. Applications are assessed and evaluated against a set criteria, reviewing their clarity, innovation and soundness of rationale and methodology; the contribution to the existing body of knowledge; the feasibility and probability of success; the credentials of the applicant(s); contributions of in-kind or financial support from other sources; the potential of outcomes to open new doors; and of course, sound ethics.

In coming months, the Board will consider a number of applications for research funding or in-kind support or a combination of both.

A number of the applications will have a focus on Parkinson's-specific models of best practice care, while a further application will be to support recurrent funding for the *Victorian Brain Bank Network* (VBBN).

The VBBN serves as a link between clinicians, neuro-pathologists and research scientists who are working towards understanding the cause of Parkinson's, what therapies, knowledge and actions will lead to better care, and ultimately a cure for the condition.

Over the past 12 months, the VBBN has been able to support seven new or continuing Australian and international research projects with Parkinson's and related condition's tissue samples at *The Florey Institute of Neuroscience and Mental Health, Monash University, Prince Henry's Institute of Medical Research, Murdoch's Children's Research Institute, Bio 21 (The University of Melbourne and Chungbuk National University, South Korea)*.

Several years ago, Parkinson's Victoria provided seed funding for the Florey Institute's Parkinson's Research Registry. Today, our financial contribution is no longer required, and instead, we provide ongoing in-kind support for this critical program which is dramatically contributing to the body of knowledge that will support improved Parkinson's diagnosis and the search for a cure.

Research is fundamental to delivering on our vision of '**A world without Parkinson's**' and with continued support from you - through donations and bequests - we can plan and implement in the coming years an increased commitment and contribution to research. We will initiate more seed funding for projects and continue to partner with leading research and clinical trial leaders to meet this end.

I hope you enjoy what I think is an excellent read!

**Emma Collin, CEO**  
[emma@parkinsons-vic.org.au](mailto:emma@parkinsons-vic.org.au)

# Update from the Parkinson's Congress

Earlier this year, VICTOR MCCONVEY from our Health Team attended the Movement Disorder Society's 17th International Congress of Parkinson's Disease and Movement Disorders, held in Sydney. The spring edition of Signpost featured an update on the Congress, and here, Victor offers an additional overview of some key insights from the event.



## Thinking changes in Parkinson's

Over the years there have been many studies into changes in the thought processes of people diagnosed with Parkinson's.

In 1999, **The Sydney multicentre study of Parkinson's disease** published a paper indicating the prognosis of Parkinson's was 12 years and that 100 per cent of those diagnosed would develop dementia.

At the time this was important research, but further research and improved treatments have had a significant and positive impact on health outcomes.

Norway's "**PARKWEST**" study and the UK's 2012 study "**CAMPAIGN**" looked specifically at cognitive change in Parkinson's, identifying both range and frequency of changes. These studies have gone a long way to identifying and understanding the thinking changes occurring in Parkinson's, and perhaps most importantly, dispelling the myth that dementia is an intrinsic part of the neurological condition.

The updated research indicates that approximately only 5 per cent of people will develop cognitive changes as part of Parkinson's, with occurrence happening as early as 5 years after diagnosis. Risk factors for developing changes include age, severity of motor complications and cognitive changes detectable on diagnosis.

The research also identified the following as the most common cognitive changes:

- Bradyphrenia or slowed thinking
- Mild cognitive impairment
- Dementia

Within this range of cognitive changes, particular areas of "thinking" which are affected include attention, executive function, language and word-finding, memory, and visual/spatial problems which commonly lead to freezing.

An additional phase of the research identified some effective treatment strategies, including use of *acetyl cholinesterase inhibitors* (e.g. Aricept, Exelon), regular reviews of medications and removal of medications that can contribute to confusion.

## Exercise and cognitive changes

Importantly, the **CAMPAIGN** and **PARKWEST** research identified exercise as being a valuable method of reducing the progression of cognitive changes, which complements similar findings from several other projects.

**PARK FIT** and other research projects that investigated the benefits of resistance training in Parkinson's are starting to reveal some important potential gains. A notable improvement following exercise included improved thinking and memory, in addition to reduced cough and aspiration and improved continence (as a result of specific pelvic floor isometric exercises).

Other benefits of an exercise regime incorporating power or resistance training were improved muscle tone and a positive motor benefit with reduced "off time".

However, increased physical activity will also increase the body's uptake of dopamine and medication should be reviewed in light of this; when exercising a medication is likely to be used up more quickly, meaning Parkinson's symptoms can reappear earlier than expected between doses.

## Deep Brain Stimulation (DBS)

Research improving **Deep Brain Stimulation (DBS)** surgery is regularly discussed at the International Movement Disorder Congress, and in Sydney results of the **EARLYSTIM** research were discussed.

**EARLYSTIM** is an international multi-site project looking at the benefits (if any) of early DBS (within 10 years of diagnosis) versus surgery done much later.

Emerging results, which indicate that earlier surgery often results in improved surgical outcomes and symptom control, are causing a shift in medical opinion where DBS has traditionally been viewed as

# Update from the Parkinson's Congress

a treatment offered for **advanced Parkinson's**, when medication management is becoming difficult.

There was also discussion about new or alternative sites for the placement of DBS electrodes in the brain.

Where traditionally the electrodes have been placed in the **subthalamic nucleus (STN)**, an alternative deep brain location now being trialled is the **pedunculopontine nucleus (PPN)**. The new location has seen significant improvements for those experiencing difficulties with walking and freezing.

Other benefits of the alternative site include improved balance, and some trial participants appear to have improved cognition.

Trials for alternative sites have thus far been conducted on a very small scale. Research is ongoing and likely to include a trial site in Australia in the near future.

## *The challenge of neuro-protection*

Medication that has the potential to be **neuro-protective**, in other words - the ability to slow the progression of Parkinson's - is an important and ongoing area of research. The result may be an immunisation which halts the accumulation and aggregation of the protein **alphasynuclein**. Accumulation of this protein has been implicated in the death of dopamine-producing cells, however the initial cause of this aggregation is unknown.

Understanding the pathology of Parkinson's (why it occurs and how) and why the protein **alphasynuclein** accumulates will help researchers in finding ways to slow symptoms and possibly even prevent Parkinson's altogether.

One of the key challenges for developing an effective **neuro-protective** medication is that no two cases of Parkinson's are the same; in other words, an effective neuro-protective medication for one person may not be effective for another.

To overcome this, researchers are concentrating their efforts on those with **familial or inherited** Parkinson's, as a result of a mutated gene; Familial Parkinson's accounts for around 10 per cent of the Parkinson's population. In familial Parkinson's, the symptoms follow a more predictable pattern, making age of onset, symptoms and disease progression more predictable.

It is worth noting that research into neuro-protective medication has progressed to the animal model phase.

**While researchers continue to strive for a cure, it is important to acknowledge the value of research focussed on improving symptoms, through advances in medication, and quality of life.**

## WALK IN THE PARK SPONSOR THANK YOU

**THANK YOU TO OUR AMAZING AND GENEROUS SPONSORS OF THIS YEAR'S A WALK IN THE PARK, WHICH TOOK PLACE ON SUNDAY 25 AUGUST AT FEDERATION SQUARE.**

**WE COULDN'T DO IT WITHOUT YOU!**

**IT WAS ALSO GREAT TO SEE SO MANY OF OUR VALUED CORPORATE SPONSORS PARTICIPATE IN THE EVENT ON THE DAY! WHAT A WONDERFUL WAY FOR THEM TO EXPERIENCE FIRST HAND WHAT THE WALK IS ALL ABOUT AND MEET MEMBERS OF OUR INCREDIBLE COMMUNITY!**

**SEGUE**  
your financial direction



**all health  
training**



# Question time

Every day, our help line receives calls from members of the community, family of those diagnosed, health and allied health professionals, and even employers and other service providers.

Our Health Team have heard it all when it comes to questions about Parkinson's and here we share some recent (but common) questions and answers.

**Please note: Our Help Line does not provide medical advice, but aims to provide information and support to assist people to understand and live well with Parkinson's, including making informed decisions and playing an active part in their healthcare.**

**Q) I was recently in hospital and getting my medications 'on time' was difficult. Is there anything I could do to make sure this doesn't happen again?**

A) Getting medication on time while in hospital has been identified by people living with Parkinson's worldwide as their number one challenge.

One of the best ways to avoid medication being administered too early or late is to pre-plan your stay in hospital as much as possible.

A good place to start is during your pre-admission clinic or you can try phoning the admissions nurse to discuss your medication needs and drug regimen. Make sure to ask if it's possible to self-administer your medication (during your stay, staff will still check that you have taken them at the correct times).

If this option isn't available, once in hospital, ask for your medications about 5 minutes before you need them. You can also try taking a medication timer with you so you are reminded to **ask** at the right time!

**Parkinson's Victoria has a free Hospital Kit with a range of additional information, tips and tools to assist people with Parkinson's while in hospital. Contact our help line to find out more.**

**Q) I've heard that exercise is good if you have Parkinson's, but how do I find ways of exercising?**

A) Yes, exercise is beneficial if you are living with Parkinson's (and of course, if you're not!), however it can be difficult to know what type of exercise is the best or most suitable for your needs and where to start.

If motivation is a problem and/or if you need guidance on how to exercise, seeing a physiotherapist or exercise physiologist who has a special interest in Parkinson's is an excellent idea.

Alternatively, if you are comfortable exercising in public and feel capable of more independent exercise, visit your local gym and speak with one of the personal trainers (all gyms will have personal trainers who can offer tailored programs and fitness assessments – but make sure to ask if there are additional costs). Health or fitness professionals should be able to design an exercise program which takes your Parkinson's into consideration. If they are not familiar with Parkinson's or would like additional information, encourage them to phone our Help Line and speak with a member of our Health Team.

If the gym or the idea of a traditional workout is not your style, there are plenty of alternatives. Community programs and organisations offer gentle group exercise classes, such as **Tai Chi** for arthritis; Council on the Ageing (COTA) runs **"Living longer, living stronger"** through community health centres and there are also walking groups.

**If you are considering taking up any form of exercise consult your GP first.**

**Parkinson's Victoria has developed an exercise DVD with a series of simple exercises, including modified Tai Chi moves, which are suitable for people living with Parkinson's. For a copy (\$10 including postage), please phone our Help Line.**

**Q) I have Parkinson's and am planning a trip overseas. I am worried about getting travel insurance. What should I do?**

A) Travel insurance is always a good idea, but as with any policy you need to read the fine print, especially those regarding to pre-existing conditions.

For example, if you break a tooth at home and this is filled but something happens while you are overseas, the insurance company may treat this as a 'pre-existing condition', and therefore not cover it with your travel insurance. There has been concern that some insurers consider Parkinson's a 'pre-existing' condition so health issues that occur while travelling which may be the result of, or related to Parkinson's, might not be covered.

While you may be able to negotiate a higher excess for claims relating to pre-existing conditions, keep in mind that an insurer is likely to link any claim to this condition so they can avoid paying you. If your incident was unrelated to your Parkinson's, you will have to prove it, and this may end up in a dispute involving the insurance ombudsman, a hassle you don't want if you have had an injury.

For example, 'Maria' who has Parkinson's fell while in New York and required surgery to fix a broken bone. Her insurer refused to pay, sighting Parkinson's as the cause of the fall, when in reality it had been caused by an uneven, cracked sidewalk. Fortunately, her travel companion had taken photos on his phone and several by-standers had immediately offered their details as witnesses. In addition, the local shop owner was happy to provide a statement verifying the pavement had been broken for 3 days and had not been marked as a hazard. However, it was only after all this information had been presented that the insurance company honoured the policy.

Some simple advice includes:

- Informing your insurer of your Parkinson's diagnosis to ensure you are covered (or in the case that you are not, you can find an alternative insurer).
- Consider the services of an insurance broker to source the best insurance policy/provider on your behalf. They will not only shop around for the best deal but they'll understand all the legal jargon and be able to assess policies against your specific needs and concerns. A broker will also know if you are likely to be refused insurance, and would not proceed with an application in this instance. This is important to know because if you are refused insurance you will have to declare this in future applications (a bit like a bad credit rating).
- If you choose to investigate options yourself, make sure you shop around and compare products and costs, but keep in mind that a cheaper policy with lots of exclusions or large excess payments may end up costing a lot more if you have to claim.
- If you have private health insurance check if they also offer travel insurance.
- In the event you need to make a claim gather as much information about the incident as possible (including photos and contact details of any witnesses), police and medical reports. If you've tripped over, take a photo of the area (uneven, broken or wet surfaces) and; consider taking photos of the location/street names to help you remember later.

**For personal advice on a range of legal issues or concerns, you might like to contact Maurice Blackburn Lawyers [www.mauriceblackburn.com.au](http://www.mauriceblackburn.com.au)**

**They are familiar with issues relating to Parkinson's and have worked with Parkinson's Victoria, providing advice, information and presentations at seminars.**

## Christmas Cards on sale now!

*Once again, Parkinson's Victoria has a great selection of Christmas cards on offer, including designs by artists living with Parkinson's.*

*Card sales help fund our support programs and the cards themselves help raise awareness as each one carries a message!*

*You can purchase Parkinson's Victoria cards by completing and returning the order form included with this edition of Signpost or ordering online at [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) (click on the Christmas card button). You can also phone our office or visit us at 8b Park Road, Cheltenham during office hours.*

*The following community organisations also stock Parkinson's Victoria cards. Please contact the individual shop for opening hours.*

*Thank you to the wonderful shop volunteers who help to sell our cards each year.*

- **NIDDRIE:** Lentara Uniting Care Combined Charities Christmas Card Shop, 6/44 Carrington Road
- **BENDIGO:** St Paul's Combined Charities Christmas Card Shop, Myers Street
- **MORNINGTON:** Community Information and Support Centre, 320 Main Street
- **GEELONG:** Combined Charities Card Shop, 100 Yarra Street
- **CAMBERWELL:** Camcare Combined Charities Card & Gift Shop, 51 St Johns Avenue
- **BALLARAT:** Combined Charities Card Shop, 27 Magpie Street
- **HEIDELBERG:** Banyule Support & Information, 101 Burgundy Street
- **SHEPPARTON:** Combined Charities Christmas Card Shop, Scots' Church Hall, Corner Fryers and Corio Streets, (enter by Fryers Street)



# A WALK IN THE PARK 2013

What an amazing day this year's Walk in the Park was!

Thank you to everyone who joined us on Sunday, 25 August at Melbourne's Federation Square and who supported the event.

Support came in lots of different ways; you may have participated on the day, supported a Walker through sponsorship, or been actively involved in fundraising, perhaps even hosting your own fundraising event. Many people helped us out with media stories and interviews, and lots of people supported by simply 'spreading the word'. Some amazing people did ALL of the above! Thank you!

Your feedback says you **"loved this year's walk and thought it was excellent!"**

We are very excited to announce that we exceeded this year's Walk fundraising goal of \$150,000...!

Thanks to the amazing efforts of Walkers and supporters, a total of just over \$170,000 was raised through donations and sponsorship. This is an increase of around 200% on last year! What an incredible result!

This money will be used to help offset the costs associated with delivering our support programs throughout the year, the development of new initiatives, and of course, will help fund important research.

Thank you to everyone who also gave feedback about the event, especially those who took the time to complete our online survey\*. Congratulations to K. Simnet of Knoxfield who won the \$50 Gold Class Voucher that was up for grabs\*\*.

## THIS YEAR'S WALK CELEBRATED A NUMBER OF KEY MILESTONES...

- ☞ The 2013 Victorian Walk was the largest in the event's 5-year history, and the largest Walk nationally, with a total of 2241 people participating (an increase of 27% from last year). 52% participated in the Walk for the first time!
  - ☞ More than 88% of Walk participants did not have Parkinson's (on par with previous years), and a resounding 60% of participants walked **'to show their support for a loved one'**.
  - ☞ The event rated 'excellent' overall as a community event, a way to raise awareness and as a fundraising event for Parkinson's Victoria. The majority of people actively supported the fundraising aspect of the event, either making a donation, or sponsoring themselves or another Walker (68% used our online fundraising tools). However, 25% of walkers did not participate in fundraising or make a donation.
  - ☞ 70% felt the \$25 minimum fundraising goal was reasonable (to qualify for a fundraising t-shirt) while 13% felt it should have been a higher amount. This 'incentive to fundraise' worked very well, increasing not only the **number of people fundraising** (up by 141%) but also the **average amount raised** (up 33%). It also increased the **number** of donors (an increase of 228%). (Interestingly, 11% felt a t-shirt should have been available to everyone for free)
  - ☞ Walkers of all ages participated, with the majority aged between 55-64 (27%), followed by 35-44 year olds (21.4%).
  - ☞ Almost 100% of participants let other people know that they were taking part in the Walk. This is really important as it helps to raise awareness of the event and the cause. It also means you're proud to be a part of this major event. Unfortunately, some walkers didn't tell others that they were walking because they didn't think they would be interested.
  - ☞ Hundreds of people found out about Parkinson's Victoria for the first time as a result of the Walk (34% previously had no contact with us!)
  - ☞ 52% of walkers thought the online registration process was "extremely easy" (37.5% thought it was "quite easy").
- We look forward to seeing you and your friends at next year's Walk. Mark it in your diary and start telling your friends that on Sunday 31 August you'll be at Melbourne's Federation Square taking **A Walk in the Park** in the fight against Parkinson's.
- \*Responses drawn from survey results.**
- \*\*The Gold Class pass was drawn randomly from a list of emails submitted by those who wished to enter the draw, having completed the survey.**

**LOST ITEMS ON THE DAY OF THE WALK:** Please contact Melissa at Parkinson's Victoria (03) 9581 8700.  
**UNCOLLECTED MERCHANDISE:** If you did not receive pre-ordered merchandise before or on the day, please email Judith Mooney: [judith@parkinsons-vic.org](mailto:judith@parkinsons-vic.org).

You can view all the photos from this year's A Walk in the Park on our Facebook page (even if you do not have a Facebook account): [https://www.facebook.com/parkinsonsvic/photos\\_stream](https://www.facebook.com/parkinsonsvic/photos_stream)

# Advocacy update

## Update on National Campaign

In April this year, in pursuit of tangible commitments in support of the Parkinson's cause from both political parties, Parkinson's Associations from across Australia engaged a professional lobby group to position work for people living with Parkinson's, and more broadly to open up dialogue with the Government, the Opposition and other key stakeholders.

Under the banner of the newly formed **Parkinson's Alliance**, the Associations developed a Federal Election Manifesto, titled "A better deal for people living with Parkinson's and their carers". (This was distributed to members with the last edition of **Signpost**).

The manifesto focused specifically on funding for urban, rural and remote neurological nurses, an expansion of the dementia program commitment made by the Coalition to include other neurodegenerative diseases, and a call by the Government to match the Coalition's commitment.

In recent months, Parkinson's Victoria has organised meetings with Josh Frydenberg, the Member for Kooyong and the new Parliamentary Secretary for Prime Minister and Cabinet; Senator Mitch Fifield, the new Assistant Minister for Social Services; Len Hatch, advisor to Senator Jacinta Collins, the former Deputy Leader of the Government in the Senate and 9 other members of Parliament or their advisors across the country.

The campaign timeframe was particularly short.

This, coupled with a deteriorating Federal budget position and crowded medical advocacy space (dominated by other not-for-profit service providers who are well established with a high profile), meant that both the Government and Opposition were not able to commit or provide an indication of support for new (Parkinson's-related) health spending in the lead up to the election.

Although the federal campaign was challenging, there was a sense of increased awareness of the needs of the Parkinson's community across the political sphere. We know we need to maintain our profile and later this year, Josh Frydenberg has committed to meeting with us again, along with a local support group to discuss our local and national challenges.

## Raising Awareness

This year, to support our work to raise awareness of the needs of people living Parkinson's and their carers in the community, we asked several politicians to join us for **A Walk in the Park**, our major annual fundraising and awareness raising event. We were thrilled with the support we received from the Premier, Dr Denis Napthine, who was not only first over the starting line, but shared with us, and the media on the day, his own family's journey with Parkinson's. The Premier spoke openly about the need for greater community awareness and support, relaying details of his father and aunt's diagnosis and experiences.

Other MP's from both the Federal Government and Opposition also joined us, including Josh Frydenberg and Anna Burke, the Member for Chisholm.

## State Advocacy

During **A Walk in the Park**, we took the opportunity to ask the Premier for a meeting regarding a specialist nurse for the Warrnambool region.

Andrew Sugget, local support group Coordinator and Parkinson's Victoria Board member, set up the meeting with the Premier in his local office. The meeting was also attended by local sub-acute care provider Lyndock and members of the Parkinson's Victoria team. We were able to provide an overview of Parkinson's nurse models across the state and country and discuss international research supporting such an intervention, which research has shown leads to reduced hospitalisation and increased quality of life outcomes for people with Parkinson's. The Premier has sought a submission from Parkinson's Victoria prior to next year's state election, proposing a movement disorder nurse model for both a local and statewide service. We will look to undertake this piece of work in the coming months.

Warrnambool is not the only area keen to advocate locally for improved health services. Our Geelong Young @ Park group is also active in this area of advocacy, and they are seeking a Movement Disorder Nurse in the Barwon Region. Lisa Neville, the local state MP will be their first port of call to voice their concerns about local health services and the need for specialist nurse support.

**We hope to have your support locally as we meet with many more politicians in the lead up to the 2014 State Election.**

# Peer Support

*Signpost will now feature a dedicated section tailored specifically to Parkinson's Peer Support Groups. From the desk of Support Group Coordinator, BREANNA WOTHERSPOON on our Health Team, this is where you will find information and updates on recent and upcoming support group activities, new ideas for meetings, and helpful advice on managing a peer support group.*

## **Idea X-Change**

*It should be no surprise that some of the best ideas for running support groups come from the support groups themselves!*

Looking for guest speaker ideas for your next meeting or activities for your group? Be inspired by updates from Support Groups across the state:

- In August the **South Gippsland Parkinson's Support Group** hosted Federal Member for McMillan, Russell Broadbent. Russell responded to questions relating to the availability of respite care, the need for financial assistance for medications specifically for people living with Parkinson's, and the current situation regarding those arriving in Australia seeking refugee status and illegal immigrants.
- The **Ballarat Parkinson's Support Group** was fortunate to have leading neurologist Professor Malcolm Horne attend their September meeting. Professor Horne offered a comprehensive presentation on "Advances in Parkinson's Research".
- In October **Dianne Rayner** from our Health Team visited the **Rosebud Support Group** and provided an update on developments in Parkinson's treatment options, including the latest (Parkinson's) addition to the Pharmaceutical Benefits Scheme; the **Neupro** patch.

## **FUN-raising**

*For those who want to help raise funds to support the work of Parkinson's Victoria, or to help cover Support Group costs - and to have some fun while doing it - why not follow in the footsteps of these Support Groups?*

- In August, the **Warragul Parkinson's Support Group** with assistance from the Drouin Men's Shed, hosted a BBQ at their local Bunnings store. A total of \$782 was raised and will be donated to the Parkinson's Victoria Research Fund.
- The **Koroit Parkinson's Support Group** is holding a garage sale soon and members are donating and collecting pre-loved items to sell, with funds helping to offset Support Group costs.

## **Congratulations!**

In September, the **Essendon Parkinson's Support Group** hosted an insightful seminar on **Pain and Parkinson's**, attended by around 100 people.

Dr Simon Sung, Movement Disorder Fellow at Melbourne Health, presented a keynote on his collaborative and ground breaking work on the subject, dispelling the belief that Parkinson's is a painless condition, while explaining the commonly identified patterns and type of pain experienced.

Professor Robert Iansek OAM, discussed a study he is currently undertaking comparing health outcomes for those who have received specialised Parkinson's-focused care and those who have received standard care. And, Parkinson's Nurse Consultant Victor McConvey from our Health Team presented a "Summary of the Key Research Areas" that were discussed at the **International Movement Disorder Congress**, held in Sydney in June.

The seminar, which included a generous afternoon tea, also gave attendees the chance to mingle, speak with the presenters and to meet other members of the community.

**The event's success reflects the need for specialised information that is accessible to all. Congratulations to support group leader Fred Van Ross and members of the Essendon Parkinson's Support Group for putting together a highly informative and valuable seminar.**

## **In the spotlight**

*This edition...highlighting **Young Onset Peer Support***

If you are living with Young Onset Parkinson's and want to meet others who are in a similar situation, consider joining one of our Young @ Park Support Groups.

Based in Melbourne and Geelong, the focus is on friendship, fun and peer support.

Groups are tailored specifically for people with Parkinson's who are under the age of 65, and partners, family and friends are also welcome to attend.

**To find out more please contact staff at Parkinson's Victoria. Or if you would like to go on the e-news mailing list for the Melbourne Y@P group, send an email to [youngonset@parkinsons-vic.org.au](mailto:youngonset@parkinsons-vic.org.au)**

## **Support Group & Ambassador Training Day**

Each year, Parkinson's Victoria hosts a **Support Group Leader Training Day**. This year, Parkinson's Victoria Ambassadors were invited to join the session, with the program expanded to provide useful information relevant to both groups of volunteers.

# Peer Support

On Saturday, 24 August, 33 valued volunteers, representing 18 Support Groups and 8 Ambassadors, came together to learn, listen, and share ideas and feedback about their personal experiences.

Emma Collin, CEO, commended both groups on their achievements over the past 12 months, through the Support Group and Ambassador programs. This included increasing the number and diversity of Support Groups (up 14 per cent) and the reach of the Ambassador program, with 25 Ambassadors delivering presentations to over 1000 people!

Victor McConvey provided an update on Parkinson's research, garnered from attending the Movement Disorder Society's 17th International Congress [you can read more about the Congress on page 6]. He also delivered an excerpt from 'The Role of the Movement Disorders Nurse: A global perspective' a presentation he delivered at the congress.

*(For those Support Groups who did not have a representative at the Training Day, a copy of Victor's presentation notes will be sent out.)*

Attendees, including staff from Parkinson's Victoria, then giggled and chuckled their way through a session of **Laughter Yoga Therapy** before sharing a delicious lunch.

In the afternoon the group was joined by representatives from Progressive PR, a company specialising in media which has worked with Parkinson's Victoria for the past 3 years to secure editorials, radio and TV interviews, equating to almost \$800,000 in free media.

Jodie and Darren, who have also talked with many of our Support Group leaders, members and Ambassadors over the years, talked about the process for promoting the Parkinson's cause through the media, and the value of having individuals from the Parkinson's community who are willing and able to share their personal stories.

To wrap up the day, separate sessions were run for Support Groups and Ambassadors on topics relevant to their specific roles.

The Support Group Leaders discussed different models of leadership and they were encouraged to think about the leadership model currently used by their group, the various tasks that Leaders take on in their role, how the responsibilities are (or aren't) shared, and how they could be more evenly shared in future.

Leaders do an incredible job supporting their local community and supporting the broader work of Parkinson's Victoria, so it's important that they don't feel they have to "do it alone".

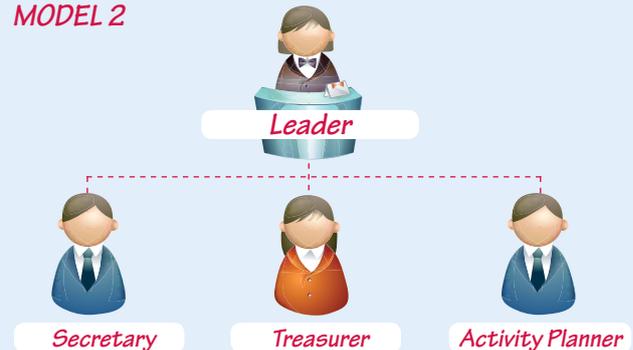
Leadership models that some groups currently use are:

## MODEL 1



Having two 'co-leaders' who share the load between them, each taking on different aspects of managing the group.

## MODEL 2



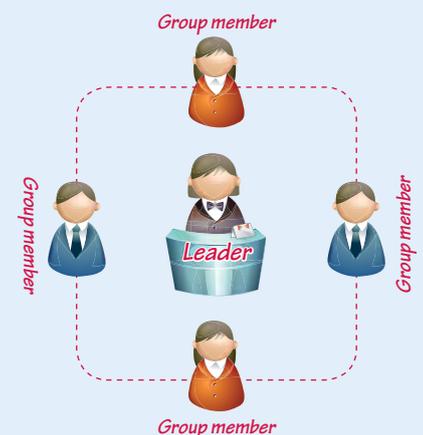
A leader facilitates the group and coordinates a committee, which shares responsibilities.

For example, the Secretary prepares a group newsletter and reminds members when the next meeting is coming up, the Treasurer takes care of the group's finances, including applying for grants and keeping financial records, while an Activity Planner organises guest speakers and special meeting activities.

## MODEL 3

A leader coordinates the group, but various responsibilities rotate around group members.

For example, group members may take turns organising a guest or activity; or group members may take it in turns preparing food for everyone to share at the meeting.



All Support Group members are encouraged to think about how the responsibilities of running a Support Group can be shared.

**If you have any suggestions on what content you would like to see included in the Peer Support section of *Signpost*, or you would like to share with others some of the things your group has been up to, contact Breanna at Parkinson's Victoria.**

# Tulip Tributes

*Every year, Parkinson's Victoria is incredibly fortunate to have members of the community – people with Parkinson's, friends, family and workmates – get 'Moving to Make a Difference'.*

*These creative, inspiring, dedicated, and selfless people host fundraising events to help fund our support programs, ensuring we can provide as much as possible to the community for free.*

*We are proud to highlight some of our recent fundraisers and hope you will join with us as we take this opportunity to say 'Thank you!'*

- Alan Barber: On his way to running the famed **New York Marathon for Parkinson's Victoria** this month, Alan and an amazing team of supporters from Ocean Grove and beyond have so far raised almost \$15,000 from donations and fundraising events. All proceeds to Parkinson's Victoria. In addition, Alan has spoken with local media and galvanised the local community to get behind this worthy cause.
  - Karen Wallace organised a morning tea earlier in the year and raised \$235.
  - Ginetta Bianchin and Lynette De Bona hosted a Postie Fashion Party.
  - Ashlee Chambers held a fundraiser at the **Rose GPO Hotel** (with great support from owners Sam & Breanne Austin), raising \$3621 towards her Walk fundraising goal.
  - Earlier this year, Tim Diamond hosted the second **"Tessies Golf Day"**, in honour of his mum, with the support of the 13th Beach Golf Club, and a total of \$10000 was raised!
  - Melanie Franks and Fabienne Parr hosted **Intimo Lingerie Parties** and donated proceeds of \$525, and just over \$2000 (respectively)
  - Gideon Goldberg celebrated his bar mitzvah and asked friends and family to donate to Parkinson's Victoria in lieu of gifts. A total of \$7207 was donated. In 2009, sister Ella celebrated her bat mitzvah and also asked friends and family to donate in lieu of gifts, resulting in a donation of \$4205.
  - Lauren Keys held a Birthday Brunch and made a 'birthday donation'. Jeff Nickson also celebrated a birthday, his 75th, and asked for donations in lieu of gifts. A total of \$1000 was donated as part of Jeff and wife Margaret's Walk in the Park 2013 fundraising tally.
  - From Sydney, Belinda Nussbaum is running **Punch4Parkinsons** kick boxing classes. Participants donate to Parkinson's Victoria, instead of paying Belinda for the weekly class. Donations continue to come in, with around \$300 already donated.
  - Linda Walsh has asked her local newsagency, SupaNews, to host a Parkinson's Victoria collection tin and over the past 12+ months, several tins have been returned with close to \$500 collected in loose change.
  - We also again had a very fit bunch of people participating in various fun runs, including Run Melbourne, the Melbourne Marathon, and City to Sea and over \$11,000 has already been raised.
- Throughout 2013, we've also had tremendous support from the corporate sector, thanks to a 'champion' in the office who proposed a fundraising event in support of Parkinson's Victoria. The result has been donations of several hundred dollars. We are proud to acknowledge the support of:
- The team at Boulderstone, who hosted a morning tea.
  - The Country Womens' Association (Toongabbie) which donated proceeds from their annual fundraiser.
  - Students from Essendon Keilor College, who organised a sausage Sizzler for their school Athletics Carnival.
  - Students of Kilbreda College, Mentone.
  - The Spring Valley Golf Club, which once again donated proceeds from their annual charity golf day. This year, a donation of \$8033 was received.
  - Latown Sequence Dance Group sold DVD's of their dance classes.
  - Maryvale Private Hospital P/L Social Club held a trivia night \$300
  - The Mildura Parkinson's Support Group co-hosted Beyond the Mask 2, with Vanessa and Alan Humphrey and Ursula Smee, and donated almost \$1000
  - Staff from the NAB (Credit Risk Department) organised a staff 'bake off', and the team at the NAB (Credit Risk Appetite) organised a casual dress day and morning tea
  - Officeworks South Yarra celebrated the opening of their 150th store and Parkinson's Victoria was able to host an information stand in-store
  - Members of Painting for Parkinson's Group made Gift Tags and sold them, with proceeds donated to Parkinson's Victoria
  - Artist Tony Roche, who is also living with Parkinson's, held a solo exhibition, with the generous support of The Vines Café. Tony sold 7 paintings and donated a percentage of the proceeds, a total of \$210!
  - The Victorian Firearms Registry Social Club conducted a fundraiser and the Victoria Police-T2L4 Social Club hosted a charity day at work.

# Symptom Management

## Keep moving & thinking

More and more research is validating the importance of exercise for people living with Parkinson's, with both physical and mental benefits. ALISHA CHAND from our Health Team highlights some practical exercises for mind and body.

**Physical** exercise is vital in maintaining balance, mobility and day-to-day activities. It can also enhance cognitive function. Exercising the **mind** is also of great importance; brain exercises can help maintain or even improve cognitive function including memory, concentration and problem solving skills.

### Posture & Parkinson's

A bowed head and drooped shoulders illustrate one of the hallmark features of Parkinson's: "the stooped posture". The cause is associated with increased muscle rigidity or stiffness and involves a bowed head, drooped shoulders, over curvature of the upper back and bended knees.

### How can poor posture affect you?

- Difficulty speaking clearly and loudly
- Increased postural instability, which can impede balance and lead to falls
- Difficulty swallowing
- Decreased strength of postural muscles
- Altered spatial awareness
- Difficulty in moving your neck and upper extremities

The following is a simple exercise to help improve posture (adapted from Parkinson's Victoria's new DVD **'Keep Moving! An exercise guide for people living with Parkinson's**. For a copy contact Parkinson's Victoria).

### The Chin Tuck

**Step 1:** Stand tall against a wall with your feet shoulder width apart. Your heels should be touching the wall as well as your back.

**Step 2:** Move your chin backwards so that the back of your head is touching the wall- this may not be possible at the start but it is the aim. Hold this posture for 5 seconds then relax. Repeat this 5 times.

TIP: Be sure not to tilt your chin up or down, rather move it backwards so that you're giving yourself a double chin. As you get better, hold this posture for longer, up to 10 seconds each time.

### Keep thinking

Challenging your mind with different memory games is a great way to exercise it and improve memory function.

Research has shown that learning a new language can improve both episodic memory (memory of

autobiographical events) and semantic language skills (the meaning and relationship of words and concepts) at all age levels, while bilingualism (speaking two languages) can strengthen problem-solving skills.

### To get you started learn how to say, "I have Parkinson's" in these 6 languages:

- Spanish: "Tengo Parkinson"
- Italian: "Ho il Parkinson"
- Greek: "echo ti noso tou Parkinson"
- Russian: "U menya yest' Parkinsona"
- Chinese (traditional): "Wo you pa jinsen shi zheng"
- Vietnamese: "toi co Parkinson"

### Tips for learning these phrases:

- Set some time aside each day (when your brain is most active (receptive) e.g. you're not tired) to practise these phrases.
- Recite and repeat them, write them down, and practise saying them out loud to someone else.
- Try focusing on a new phrase each couple of days until you can recite all 6 languages from memory.

### Word-find

More than just a way to pass the time when you are bored, **word finds** are another great way to keep your mind busy, and they can help build your concentration skills.

Try our simple research-themed word-find below. How long does it take you to find all the words? Remember: the words might be backwards, diagonal, horizontal or vertical.

### Word-find words:

NEW	STUDY	EXPERIMENTAL
PARKINSONS	TREATMENT	FUTURE
RESEARCH	BRAIN	INNOVATIVE
SCIENTIFIC	CONFERENCE	NEUROLOGICAL

S H C R A E S E R P G L  
C T S N O S N I K R A P  
I N C I Q N E W U C Y I  
E E H A M K D R I D Y J  
N M Q R G J W G U W Q M  
T I Y B S I O T B T V P  
I R E E T L S G B C U M  
F E S C O G J F H M K F  
I P A R T I C I P A T E  
C X U T R E A T M E N T  
A E C N E R E F N O C I  
N I N N O V A T I V E O

# Planning for the Future

*Living with Parkinson's can often bring mixed feelings about the future. DIANNE RAYNER provides some advice that will help with decision making regarding you or a loved one's future, that will also provide peace of mind today!*

Even though the condition progresses slowly, a diagnosis of Parkinson's is still, typically, going to cause stress and worry, thinking about what it all means and planning for what lies ahead.

At some point through this journey, you will need to review your financial situation, insurance cover, health planning, housing needs and myriad other practical issues along the way for long-term life planning.

Stop and take the time now to develop plans for the future, especially around legal and property planning, and you will significantly reduce stress and anxiety. Having a conversation with your family about any concerns can help get the ball rolling.

## Financial planning

- Financial advice: seek appropriate **professional advice** from a Financial Adviser to ensure you and your family are well protected in relation to work, income and expenses, assets, entitlements, superannuation financial obligation, insurance and estate.
- Trust/ee: you can legally appoint a trustee to distribute goods and properties to other beneficiaries on your behalf. If a large amount of property or assets are owned, monies and goods can be distributed while a person is still alive.
- Will: similar to a trust, a will is a document in which a person specifies the method to be applied in the management and distribution of their estate after their death.
- Durable Power of Attorney: this legal process allows an individual to name a person to serve as their representative in financial and/or personal matters, including specific instructions regarding an Estate.

## Power of Attorney

**Power of Attorney** and **Enduring Power of Attorney** are legal documents which give another person the authority to make financial and legal decisions on your behalf.

They can only be drawn up while you are able to sign your name and make decisions.

The difference between the two is that while an Enduring Power of Attorney remains valid if you become unable to make decisions, a Power of Attorney lapses at that point.

## Insurance Coverage

Policies may differ, depending on particular terms and conditions, so it's important to look at your insurance entitlements in detail as they may be

affected by your Parkinson's diagnosis.

Some travel insurance policies may limit your cover for Parkinson's-related health costs. Read more about travel insurance on page 8. Health insurance policies may cover some costs and not others.

## Health planning

Everyone can benefit from a well-balanced, healthy diet, but for people with Parkinson's it's even more important.

Your diet should include a variety of foods from all four food groups: grains, vegetables and fruit, dairy, and meats (alternatives if you are a vegetarian). If you are experiencing dietary problems, talk to your doctor, or consider asking for a referral to a registered dietician for further information.

## Housing Needs

Consider what your individual housing needs might be in the future: is your current home suitable and safe should you have mobility challenges? Do you need to think about downsizing? Modifications? Moving closer to family or support services?

You may be able to function very well at home at the moment, but in the future this may change.

An Occupational Therapist (OT) can advise you on safety in and around your home. This can help prevent falls or other injuries and help you to manage day-to-day activities. If balance becomes an issue, a Physiotherapist can help with ways to prevent and/or manage falls.

There may come a time when you need extra support to make it easier to live at home. Home-based services help with a variety of practical household duties, nursing and personal care as required. If you are eligible, these services can be accessed through subsidised government packages, otherwise there are private services available for a fee.

## Social & physical needs

Stay connected to family and friends so you don't become isolated. Keep in touch by phone, visits or e-mail. If you feel depressed or anxious, talk to your doctor. Continue doing the things you enjoy or find a new hobby. Join one of many Parkinson's Victoria support groups or think about volunteering with a local community group or even with Parkinson's Victoria.

A good exercise plan can literally help your body better manage your Parkinson's symptoms. Regular exercise helps maintain flexibility and good posture, keeps muscles strong and joints flexible, and improves blood circulation. It can also help you to manage day-to-day stress and give you a sense of achievement and control over your condition.

**For further information regarding future planning in general, please call the Parkinson's Victoria Help Line and speak with a member of our Health Team.**

# Personal Dopa-meanings

*This section gives people from our community the chance to share thoughts, reflections, and experiences through a creative piece of writing.*

## Life

For as long as I can remember, my passion has always been for writing. Poetic words used to fill my head. I would go for long, long walks and words would just flow through my mind leaving me feeling high and joyful.

Looking back at these joyful experiences I believed that they protected me from the negativity of the world. Once, when I was seventeen years old, my mother-in-law told me how she disliked people and I responded, 'Oh I can find something beautiful about everyone'. She looked at me like I was crazy and replied, "well I'm sure I can't!"

I used to love writing long letters and writing poetically each day in my journal; writing short stories and poetry. It was such a happy, fulfilling life and it lasted for many years. Then the sorrows of life kicked in and I took them to my journal. I opened my heart to it like I would a dear friend, and I felt so much relief.

In amongst the sadness of life there were happy times, but as I grew older the happy times became less and I faced one tragedy after another until my joy slowly diminished and my health fell apart. I felt I had lost everything. I could no longer go for long walks. I was too exhausted to do my journal and the loss of my joy left me feeling barren and empty. I tried to write but there was a big black hole. It felt like a huge stone wall - I couldn't seem to climb over it.

I started to withdraw from the world, just seeing a few good friends, and lost interest in most things.

But something happened yesterday. The weather was suddenly warmer. I felt lighter and the need to go for a walk. I made my way to the beach where there is a pathway close to the water. The gentle sun felt beautiful on my face, the breeze through my hair, the lapping sound of the sea. I felt a moment of peace and happiness - even joy. I did the same thing today and my walking was better, although I still limped home. I'm going back tomorrow and the next day. I need to soak up the scenery, to smell the sea and look at the tiny yellow wild flowers.

I need to sit for a while and look up to the sky and thank God for such a beautiful world.

**Joyce Aslangul, Kingston Support Group, September 2013**

PETER NASSAU joined our editorial team last year as a volunteer to help source and present personal contributions from the community for **Signpost**.

Submit articles for Personal Dopa-meanings, or contact Peter C/- Parkinson's Victoria: info@parkinsons-vic.org.au (please mark it "**Signpost**") or 8b Park Road, Cheltenham VIC 3192.

If you would like to share your story or reflections with **Signpost** readers, Peter can help, or you can simply submit your completed poem or creative piece. Stories may be edited for space or clarity. Unfortunately due to the large number of submissions we receive, we are unable to guarantee inclusion

Advertisement

# Agilitas

WALK WITH CONFIDENCE



Available now at [www.agilitas.com.au](http://www.agilitas.com.au)

Or Freecall: 1800 91 31 41

Agilitas is a world-first product that uses visual cueing to overcome the debilitating Parkinson's disease symptom, "freezing of gait".

FAST FACTS: **AGILITAS...**

- ... is compact, lightweight and easy to use.
- ... automatically switches the cueing light on when it detects a freeze of gait episode.
- ... may help the wearer negotiate corners, doorways and even stairs with confidence.

Try Agilitas at:

- Neuro Rehab at Home  
03 9361 2234 – Melbourne

# Clinical Nurse update

*In an Australian-first, Parkinson's Victoria announced in May this year a partnership with Goulburn Valley Health and the Shepparton Parkinson's Support Group, to fund a Movement Disorder Nurse in the Goulburn Valley.*

The three organisations are now co-funding the new position for the first two years as a pilot program and will seek Government funding to continue the program after the initial term.

Parkinson's Victoria CEO Emma Collin said "This is welcome news for people who live with Parkinson's and other movement disorders in the Goulburn Valley. This role will ensure easier, better and more efficient access to specialist medical advice, which will improve the quality of life for people with Parkinson's and their carers and families," said Ms Collin.

GV Health Divisional Clinical Director of Medicine, Dr Arup Bhattacharya said that for a long time, patients with Parkinson's and other movement disorders have been frustrated about having to travel to Melbourne for review.

"With the establishment of a local movement disorder clinic, and now the addition of a dedicated Movement Disorder Nurse, we are able to offer a comprehensive and fulfilling service to those living with Parkinson's in the Goulburn Valley," said Dr Bhattacharya.

The Movement Disorder Nurse will bring many benefits to the community by:

- delivering care closer to people's homes (in most cases in their homes)
- being able to attend quickly to emergency situations
- educating patients and carers about Parkinson's and providing information and insight as to what to expect
- being able to provide links to valuable support services, such as speech therapy and physiotherapy
- providing education to hospital and care home staff about how to care for people with Parkinson's
- serving as a liaison between the local support group and patients
- assisting local GPs to care for people with Parkinson's
- reducing wait times for specialist review.

The Movement Disorder Nurse will not only support people with Parkinson's, but also other conditions commonly misdiagnosed as Parkinson's, such as Progressive Supranuclear Palsy (PSP) and Multiple System Atrophy (MSA).

***It is Parkinson's Victoria's intention to use the results of this research to support the pursuit of Movement Disorder Nurses statewide, with a key focus on the benefits for regional and rural centres. As indicated in our advocacy report (pg 11), we will continue to work with government and local communities to increase nurse services across the state.***

## And, an update from Shepparton...

*Specialist Neurological Nurse, SHEREE AMBROSINI was recruited to fill the position of Movement Disorder Nurse at Goulburn Valley Health. Originally from the Goulburn Valley, Sheree has vast experience working with neurological patients across several Melbourne hospitals. Here, she shares some of her experience in the role to date.*

In May this year, I was honoured to be appointed Movement Disorders Nurse in the Goulburn Valley.

Neuroscience has been a passion of mine since I began nursing more than 20 years ago, and much of my nursing experience has involved working with older persons and in aged care and various neurological care environments.

While working on a Neurosurgery and Neurological ward in Melbourne, I successfully completed a **Post Graduate Degree in Advanced Clinical Nursing – Neurosciences**.

Having a specialist movement disorder nurse in our rural area complements the services already available to our community and allied health practitioners in the greater Goulburn Valley area. One of the most valuable benefits of a locally-based specialist is increased ease of access to information and education, as well as improved support for carers, providing health checks and referrals to appropriate services or practitioners. All this will lead to an increase in the quality of life for people living with Parkinson's. Providing education to Residential Aged Care Facilities and acute services in the region will also be an integral part of this role.

I would like to see a network of specialist nurses throughout Australia that provide an advanced level of service to those living with Parkinson's in Australia to match programs in place in the United Kingdom. Currently I am studying **Masters of Nursing (Gerontology)** to enable me to better facilitate this process. In addition, in order to highlight to relevant government departments that this service is desperately required and offers significant benefits to both individuals and the wider community, we are collecting data and undertaking further research into how a Movement Disorder Nurse helps people in our community. This evaluation framework will enable the project to be used as a model or case study in the successful deployment to other regional areas.

***Feedback from the Shepparton community regarding the appointment of a Movement Disorder Nurse has been extremely positive. It has been rewarding to see the hard work of the local Shepparton Support Group and our work with Goulburn Valley Health have such a fantastic outcome for the local community and we look forward to seeing similar developments for other communities throughout Victoria and Australia.***

# Participate for research

## Publication details

**Signpost** - is an information service of Parkinson's Victoria Inc.

## Editor:

Judith Mooney, Marketing Coordinator, Parkinson's Victoria  
Judith@parkinsons-vic.org.au

## Publisher:

Parkinson's Victoria Inc.

## Website:

www.parkinsons-vic.org.au

## Office:

8b Park Road,  
Cheltenham, Victoria, 3192

Phone: (03) 9581 8700

FREECALL 1800 644 189

Email: info@parkinsons-vic.org.au

ABN: 68 038 728 034

Print Post Approved PP33962/00002

## Designed and printed by:

Doran Printing: (03) 9587 4333

www.doranprinting.com.au

## Frequency:

**Signpost** is published quarterly and distributed to members of Parkinson's Victoria. If you would like to become a member call (03) 9581 8700 or email info@parkinsons-vic.org.au.

## Advertising enquiries:

Judith Mooney  
judith@parkinsons-vic.org.au

## Disclaimer:

Information and articles contained in **Signpost** are intended to provide the reader with useful and accurate information of a general nature. While every effort is made to ensure information is accurate and up-to-date at the time of publication, Parkinson's Victoria Inc. does not guarantee correctness or completeness of information. Information is not intended to substitute for legal or medical advice, nor is Parkinson's Victoria Inc. recommending legal or medical advice. Readers are advised to seek their own medical or legal advice as appropriate.

## Advertising disclaimer:

Advertisements appearing in this publication are provided to assist consumers to locate and purchase suitable products and services. Parkinson's Victoria Inc. does not endorse any one product or service over another, nor does it receive commission on sale of items. Consumers are encouraged to seek advice from their health care or allied health professional and discuss the supplier's terms and conditions when purchasing a product or service, as Parkinson's Victoria Inc. is not liable in the event a product is not satisfactory.

## Editorial policy:

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 20,000 Victorians living with this chronic progressive condition, their family, friends and allied health professionals.

## Mood & wellbeing research

The **National Ageing Research Institute (NARI)** is currently investigating the effectiveness of an exercise program for improving mood and wellbeing of older adults who are providing care to someone at home.

Titled **Improving Mood through Physical Activity for Carers and Care recipients Trial (IMPACCT)**, the study is looking for volunteers in the Melbourne, Ballarat and Geelong region.

Volunteers aged 55 or over, who are living at home with somebody they care for aged 60 or over, might be eligible to participate.

Participation in the study is voluntary and free, and all assessments and interventions will take place in the home and over the telephone, so no travel is required.

IMPACCT is a randomised controlled trial, and participants will be randomly allocated to receive one of the following:

- A 6-month home-based exercise program individually tailored by a physiotherapist
- Social visits at home for friendly conversation
- Usual care

**If you would like more information about IMPACCT, please contact Edwina McCarthy at NARI: (03) 8387 2315 or email [e.mccarthy@nari.unimelb.edu.au](mailto:e.mccarthy@nari.unimelb.edu.au)**

**The project has been funded through the National Health and Medical Research Council: Project Grant APP1033828**

## Parkinson's Freezing 'App'

**Professor Meg Morris and the team at La Trobe University are excited to announce the development of the Parkinson's Freezing App, a resource for Parkinson's patients and carers in the management of freezing of gait episodes.**

By providing easy to use and accessible "cueing strategies" for re-initiating movement, the App seeks to combine fun and functional strategies with the latest research that allows people with Parkinson's to continue moving confidently in the activities they enjoy.

**Freezing** is a symptom of Parkinson's that involves the transient inability to move one's feet while walking. It is often likened to having your feet stuck on the floor and may occur more frequently when turning or walking through doors.

While Parkinson's involves difficulty with automatic movements such as walking, cueing strategies provide a means of utilising alternative pathways in the brain to re-initiate movement, in other words 'to get moving again'.

Cueing strategies may be visual, such as a strip on the floor, or auditory, such as a rhythm or music.

Each individual is different and it's important to trial what is most effective for you, just as it's important to share new ideas for cues too. The Parkinson's Freezing App seeks to do this by providing an initial go-to guide that will facilitate the discovery of novel ideas and approaches.

The App is currently anticipated for release on Google Play at the end of the year.

## Would you like to help?

As part of creating the App the team at La Trobe are seeking volunteer participants for the filming of freezing of gait episodes and the use of different cueing strategies to resolve them.

**If you would like to participate in the filming of these videos, or are interested in participating in future Parkinson's Apps please contact the team: Natalie Stepan: [n.stepan@students.latrobe.edu.au](mailto:n.stepan@students.latrobe.edu.au).**

# Research update

"I can get off this train. When you're "mindful" you realise what your thought train is and then you can decide to get off of it, if it's not constructive or helpful or healthy." ESSENCE participant.

Mindfulness is sparking interest in medical research, with new evidence suggesting there are advantages for people living with neurodegenerative diseases.

Parkinson's Victoria funded the following research study - **Impact of a Mindfulness-based Program amongst People Living with Parkinson's Disease** - to examine benefits of a mindfulness and lifestyle program (ESSENCE) for people living with Parkinson's.

## ESSENCE Project update

Q: What is mindfulness?

A: John Kabat-Zinn (2005) defines mindfulness as "the awareness that emerges through paying attention on purpose, in the present moment and non-judgmentally."

Mindfulness has been part of a number of lifestyle interventions, one of which is ESSENCE; a model, developed by Dr Craig Hassed from Monash University.

ESSENCE is an acronym (for and the name of) a 6 component, holistic approach to health and well-being, encompassing **E**ducation, **S**tress management, **S**pirituality, **E**xercise, **N**utrition, **C**onnectedness and **E**nvironment. Researcher Brooke Emily Vandenberg provides an update on the recent ESSENCE project.

"Dr Hassed's study used a randomised design to ascertain whether attendance at a 6-week ESSENCE program impacted positively upon health and well-being related to Parkinson's. The researchers also conducted a series of interviews with participants to better understand their experience of the program.

A typical ESSENCE Session is 120 minutes in length and involves:

- Discussion on an ESSENCE topic, such as the importance of physical exercise
- Group discussion of challenges, such as how to improve exercise patterns

- Goal setting in relation to exercise
- Mindfulness meditation activity
- Mindfulness-based cognitive activity: reflection and discussion

A total of 73 participants completed the program across four groups in Melbourne. Small groups encouraged discussion about personal experiences using ESSENCE strategies and the realities of living with Parkinson's, and participants remarked on the supportive environment and the beneficial way in which social connectedness was encouraged.

**From the researchers:** "We are grateful to everyone who participated in the ESSENCE program. As with other studies in this domain we needed to invest a great deal of energy in recruiting participants. We had a lot of assistance from an Advisory Board comprising both people living with Parkinson's, experts and members of Parkinson's Victoria.

We attended events like **A Walk in the Park** and made a series of visits to local Parkinson's support groups in order to recruit participants and the whole process has been eye-opening for our research team.

As we listened to the stories of frustrations felt and achievements made by people living with Parkinson's, we saw a genuine appreciation for the potential benefits of holistic and socially empowering group programs, like ESSENCE, for the management of Parkinson's".

**The researchers and Parkinson's Victoria look forward to sharing results of the research project in a forthcoming edition of Signpost.**

**Reference: Kabat-Zinn J. Full catastrophe living—using the wisdom of your body and mind to face stress, pain, and illness. 3rd eds. New York: Bantam Dell 2005.**

**ESSENCE Project Team: Professor Grant Russell (SAPCRU), Dr Jenny Advocat (SAPCRU), Dr Craig Hassed (Dept. General Practice, Monash University), Dr Joanne Enticott (SAPCRU), Ms Jennifer Hester (SAPCRU/Sch. Primary Health Care, Monash University), Ms Brooke Vandenberg (SAPCRU).**

## Advertisement

 **easywear**<sup>®</sup>  
australia

specialising in adaptive clothing for assisted & independent dressing needs

EASYWEAR AUSTRALIA PTY LTD ITF EASYWEAR AUSTRALIA TRUST ABN 98282 516 126

## SPECIAL SATIN SHEETS

for people with Parkinson's

Fully fitted sheets designed in three panels with centre panel in satin and two end panels (head and foot) in cotton/polyester. This combination allows greater ease of movement in the middle section of the bed, whilst the top and bottom portions allow for grip whilst turning. Fully elasticised edges help maintain its position on the mattress. Machine washable.



To order call Easywear Australia on 08 9445 2333  
or email us [info@easywearaustralia.com.au](mailto:info@easywearaustralia.com.au)

75 Guthrie St, Osborne Park WA 6017 T: 08 9445 2333 F: 08 9445 2311  
E: [info@easywearaustralia.com.au](mailto:info@easywearaustralia.com.au) W: [www.easywearaustralia.com.au](http://www.easywearaustralia.com.au)